

PWS COMMUNITY PETITION TO FDA:

Request to File and Priority Review the
NDA for DCCR

July 2024



PRADER-WILLI SYNDROME
ADVOCACY COALITION

Table of Contents

Members of the PWS Advocacy Coalition	1
PWS Community Petition to FDA: Request to File and Priority Review the NDA for DCCR	2-5
Summary of Community Feedback	5-7
Appendix A: Comments from Patients and Family Members Who Do Not Have Personal Experience with DCCR.....	8-111
Appendix B: Comments from Patients and Family Members with DCCR Experience	112-129



Members of the PWS Advocacy Coalition



PRADER-WILLI SYNDROME ADVOCACY COALITION

- **Andrew Gilly**, father to Joseph, age 2 living with PWS, and Co-Chair, Running for Research
- **Kristin Gilly**, mother to Joseph, age 2 living with PWS, and Co-Chair, Running for Research
- **Kelly Guillou**, mom to Clementine, age 14 with PWS, Founder of Running for Research PWS and board member of PWSA Georgia chapter
- **Susan Hedstrom**, Executive Director, Foundation for Prader-Willi Research
- **Noam Josephy, MD MSc MBA**, father to Ilai, age 10 with PWS, and PWS advocate
- **Dorothea C. Lantz**, Director of Community Engagement, Prader-Willi Syndrome Association | USA, mom to Hunter, age 7 with PWS, Patients Rising Senate President Pro Tempore
- **Robert Lutz**, father to Isabel, age 24, with PWS, and PWS Advocate
- **Katie Moureau**, mom to Cade, age 9 with PWS, and PWS Advocate
- **Maria Picone**, mom to 11-year-old with PWS, and Founder/CEO of TREND Community
- **Maggie Senese**, mom to Bridget, age 6 with PWS, and PWS Advocate
- **Theresa Strong, PhD**, mom to a young man with PWS, Founding Member & Director of Research Programs, Foundation for Prader-Willi Research
- **Stacy Ward, MS, BCBA**, Chief Executive Officer, Prader-Willi Syndrome Association | USA
- **Kristin White**, Mother of 7-year-old with Prader-Willi Syndrome, Board Member Foundation for Prader-Willi Research
- **Jennifer Andrews**, mother of 7-year-old daughter with PWS, active PWSA volunteer/parent mentor, MN PWSA Board member, and volunteer grant reviewer for FPWR
- **Jennifer Garzia**, mother to 19-year-old son with PWS, FL PWSA Board member, Patients Rising Patient Senate Committee member
- **Erin Carter, PhD**, mother to 6-year-old daughter with PWS, pediatric clinical psychologist, Ohio Rare Disease Coalition member, member of PWSA Advocacy Group/fly-in team leader

PWS Community Petition to FDA

July 31, 2024

Tiffany Farchione, MD, Director, Division of Psychiatry
Teresa Buracchio, MD, Director, Office of Neuroscience
Center for Drug Evaluation and Research
U.S. Food and Drug Administration
10903 New Hampshire Avenue
Silver Spring, MD 20993-0002

Dear Drs. Farchione and Buracchio,

Petition to request that the FDA file, grant priority review, and review the application for DCCR for people living with Prader-Willi syndrome (PWS)

We, the Prader Will Syndrome (PWS) Advocacy Coalition and the greater PWS community are at a point where our efforts to build a 'research ready' community, including the development of tools for drug development (such as our patient registry, natural history studies, cell and animal models, and clinical network), and investments in research are translating into a pipeline of new potential treatments for PWS. Diazoxide choline (DCCR) is an investigational drug being developed by Soleno Therapeutics, which has been shown to improve symptoms in people with PWS in well-controlled clinical trials. DCCR has the potential to improve hyperphagia, decrease fat mass, and improve challenging PWS-associated behaviors as rated by both clinicians and caregivers.

The voice of the patient is critical to the drug development process. The 21st Century Cures Act requires drug developers to include, and FDA to consider, the patient perspective in making approval decisions for new drugs. The PWS community has been active in documenting the patient perspective and sharing the PWS patient voice with FDA over the last decade. Surveys of parents of those with PWS and individuals with PWS themselves have documented the profound impact of PWS on health and well-being, demonstrating the tremendous unmet need in this population. Treating PWS-associated symptoms including hyperphagia, anxiousness, and temper outbursts are the highest priority for the community. These symptoms make it so patients cannot live alone without significant supervision, cannot have jobs, and have limited friendships. Not surprisingly, there is high tolerance of risk for treatments that would reduce hyperphagia in PWS. These insights into PWS have been shared with FDA through on-site meetings with advocates, a Patient Listening Session (June 2021), and, most recently, through an externally-led Patient Focused Drug Development meeting (June 2023). This meeting showed that hyperphagia, anxiousness, temper outbursts, sleep disorders, obsessive-compulsive behaviors, and intellectual disability have tremendous negative impacts. We described to FDA that these symptoms greatly reduce the ability of the person with PWS to participate in community activities, gain independence, and reach their life goals. Further, we shared the reality that PWS is a life-threatening disease, whether from choking, accidents (e.g., running across a busy street to get food), stomach ruptures, or weight-related health events. This brings us to where we are today. With no approved treatments for any of these aspects of PWS, patients are left with no relief from hyperphagia or the other serious symptoms. This is in stark contrast to the experiences reported by caregivers and those living with PWS who have had access to investigational DCCR.

PWS Community Petition to FDA

During two PWS community town halls (April and May 2021), members of the PWS community highlighted the impact that DCCR had on hyperphagia and other PWS-associated behaviors. For example, parents stated that DCCR treatment allowed participation in activities of daily life not previously possible, such as cooking or traveling. Others described DCCR treatment as changing their children's eating behaviors from eating everything in sight (e.g., entire pound of cashews) to stopping once feeling full (e.g., leaving food on the dinner plate). These direct patient experiences provide a source of hope for the rest of the community that eagerly awaits the opportunity to try DCCR, should it be approved.

We ask that the FDA consider these perspectives from those who, today, have the most to lose by having a potential treatment sidelined if it is not considered for review. People with PWS deserve to have the full data on DCCR reviewed with this patient input in mind. The PWS community is anxious to have the NDA for DCCR filed by the FDA, because any decision to the contrary may amount to a false negative conclusion, denying patients access to a drug that works. Only a full review of the data would give us confidence that this is not the case.

Studies to Evaluate the Efficacy and Safety of DCCR in the Treatment of People with PWS

Development of DCCR in patients with PWS began in 2014 with a Phase 2, single-center study conducted at UC Irvine Medical Center. The study showed improvements in hyperphagia as measured by the Modified Dykens Questionnaire (Mean -4.32, $p=0.006$) and in behavioral and body composition parameters following 10 weeks of open-label treatment. Based on these data, a Phase 3 program was conducted starting in mid-2018. The Phase 3 study, a randomized, double-blind, placebo-controlled study of 127 patients at 29 sites in the US and UK, showed that while the primary analysis did not achieve statistical significance for change from baseline in hyperphagia (as measured by the Hyperphagia Questionnaire for Clinical Trials, HQ-CT) (Mean 1.67, $p=0.198$), the trial was significantly impacted by COVID-19 pandemic and the analyses of hyperphagia excluding the COVID-19 -affected data showed significant improvements in hyperphagia (Mean -3.13, $p=0.037$).

The vast majority of subjects from the double-blind study enrolled in an open-label extension study. In that study, there were highly significant improvements from baseline in hyperphagia after one year of DCCR administration (Mean -9.9, $p<0.0001$) and in the final analysis at 3 years (Mean -10.7, $p<0.0001$), reflecting a more than 50% improvement from baseline in most patients. These long-term changes in hyperphagia were accompanied by improvements in all assessed PWS-associated behaviors, in body composition, in measures of disease severity, and in hormonal and metabolic parameters. Data from the long-term, open-label study of DCCR have also been compared with the Foundation for Prader-Willi Research (FPWR) PATH for PWS (PATH), a contemporaneous natural history study. In this comparison, highly statistically significant improvements in mean change in hyperphagia score compared to the PATH cohort at 6 months (Mean difference 5.9, $p<0.001$) and 12 months (Mean difference -6.2, $p<0.001$) were observed.

Seventy-seven of the 83 patients in the open-label study, at the end of 2022, consented to a four-month double-blind randomized withdrawal period in which half of the patients remained on DCCR and half were randomized to placebo.

PWS Community Petition to FDA

The data showed highly significant worsening of hyperphagia in the placebo group compared to the DCCR group (Mean difference 5.0, $p=0.0022$), and were supported by corresponding differences in changes in mean weight and BMI (weight: Mean 1.6 kg, $p=0.0353$; BMI: Mean 0.6 kg/m², $p=0.034$). In the placebo group compared to the DCCR group, trends towards worsening were observed for all PWS-associated behaviors and clinician-reported impressions of severity and improvement at four months.

The parent molecule of DCCR, diazoxide, has been approved for several decades and while used in a distinct indication, has an estimated 180,000 to 220,000 patient years of safety data showing a well-understood adverse event profile. In patients with PWS, the safety profile has been consistent with that for diazoxide at comparable doses. The most common adverse events have been hypertrichosis, blood glucose increase / hyperglycemia, and peripheral edema. A vast majority of these events have been Grade 1 or 2 and manageable with appropriate monitoring.

Overall, we believe these data support a favorable benefit-risk profile for DCCR.

The PWS Community's Request of FDA

Given the clinical trial results, PWS patients, PWS families, and clinicians strongly encouraged Soleno to submit its NDA for DCCR urgently. On June 28th, Soleno announced that it made its submission. We now ask the FDA to promptly to give people with PWS – who currently have no way to treat hyperphagia and other PWS-associated behaviors – access to DCCR as soon as possible.

FDA has emphasized the importance of the patient voice, especially for rare conditions without FDA-approved treatment options. The patients, families, and clinicians of the PWS community are fully aware of the clinical trial results evaluating the use of DCCR in PWS and are convinced that the results demonstrate meaningful benefit and low risk.

We urge the FDA to consider the significant unmet need to reduce hyperphagia in PWS, allowing PWS individuals and their families to potentially dramatically improve their quality of life and perhaps longevity. We believe that the NDA for DCCR should be filed, designated for Priority Review, and reviewed in its entirety. We, as a community, have reviewed the benefit-risk of DCCR and believe that this option should be available as an option for people with PWS and their doctors as soon as possible.

Since there are no FDA-approved therapies for hyperphagia or other PWS-associated behaviors, DCCR would represent a significant improvement in the treatment of PWS as compared to the current standard of care. Time is of the essence for those living with PWS, so the NDA merits being given a Priority Review at the time of filing. Our coalition conducted a community sign-on petition and survey over the period of approximately one month to collect the opinions of those affected by PWS and this potential of a new therapy to treat PWS. Over 14,250 members of our community endorsed this message, including over 100 individuals living with PWS and over 4,700 family members. This packet contains their feedback, including volumes of comments from those who have not yet personally experienced DCCR (Appendix A) and those who have had experience with DCCR (Appendix B).

We will leave you with a handful of quotes that are representative of the community's response.

PWS Community Petition to FDA

From Those Sharing Their Experience with DCCR

DCCR has helped hands down with leaner body composition and helped my daughter to feel full, something we've wanted to happen from the moment we received her diagnosis of PWS. She can lead a more typical life, not worrying as much about food all the time. This absolutely needs to be a standard of care in the treatment of PWS. - a PWS parent of a participant in the DCCR program

My daughter's anxiety about food significantly decreases when she is on DCCR. Because of that, she has improved her focus in all aspects of her life. Her grades have improved, she has been able to participate in extracurricular activities with no issue, and she has enjoyed some of the independence and freedom that girls her age should. – a PWS parent in the DCCR program

From Those Who Would Like Access to DCCR, Explaining Why

I as the parent/guardian and my son living with PWS and the constant daily struggle we live with is devastating. He actually said to me today I'm so tired of being hungry mommy, I just want it to stop. This forever starvation feeling causes anxiety, outbursts, canceling of plans, not attending get togethers where food will be left out, not going to places with concession stands and never, ever being able to live on his own. – Natalie M., a PWS parent from Ohio

Our daughter had to be placed in a residential year-round PWS school, due to requiring food security, and severe behavioral and emotional outbursts. Families like ours who have done everything to help their affected PWS child are desperate for a med that holds some hope of their child living a more "normal" life. – Jean R. a PWS parent from the United States

There is nothing more heartbreaking than to witness your own child literally beg for food, even though you know and understand that you must constantly say no! Our son is hungry 24/7, yet we are unable to give him more! We live life knowing we cannot go to parties, celebrations, out for meals, due to the fact that we are required to limit his intake of food! – Terry F., a PWS parent from Pennsylvania

Thank you for your consideration of our community input at this seminal moment in PWS drug development. The PWS Advocacy Coalition members offer its PWS patient and caregiver community to FDA as a resource in consideration of these issues, as well as world-leading PWS clinicians and researchers, should the FDA seek expert consultation. We also welcome a meeting to discuss these issues, including patients' needs and preferences.

Sincerely,

*Members of PWS Advocacy Coalition &
14,255 Additional PWS Community Members*

CC: Patrizia Cavazzoni, MD, Director, Center for Drug Evaluation and Research; Peter Stein, MD, Director, Office of New Drugs

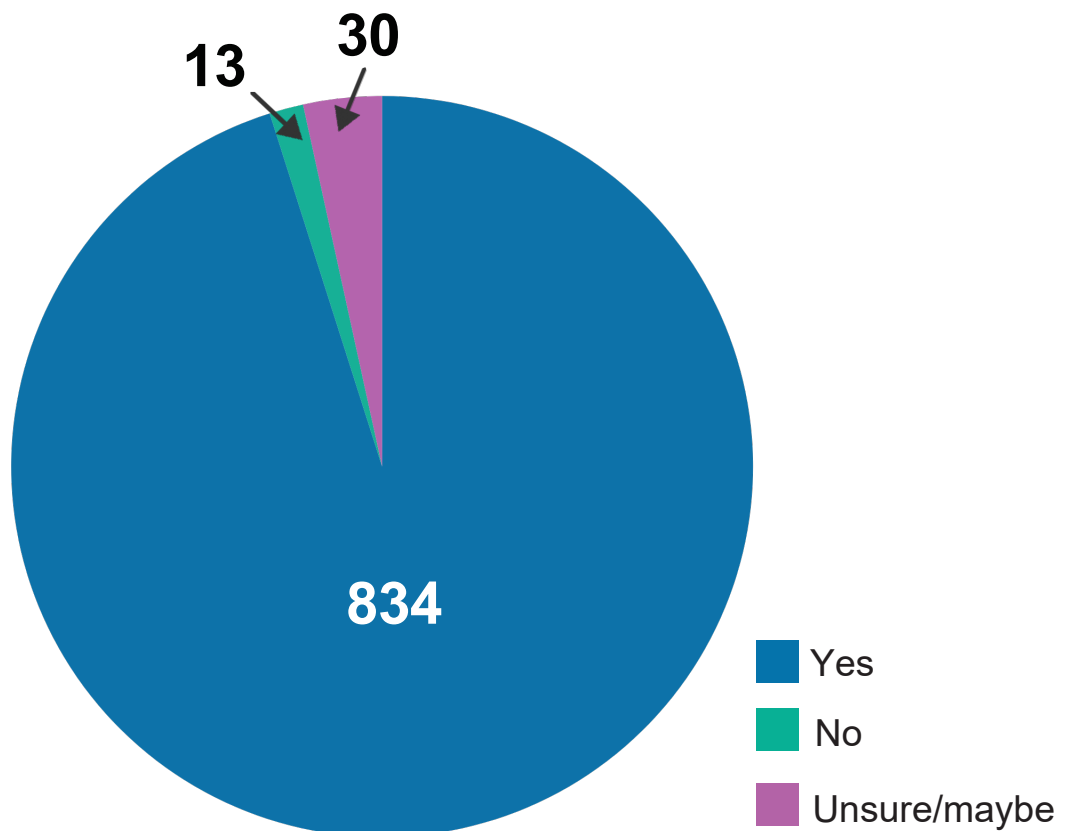
Summary of Community Feedback

14,271 Signatures to the Petition

- 106 Individuals with PWS
- 4720 Family Members
- 8407 Friends, Colleagues, or Other Personal Connections
- 835 Healthcare Providers, Teachers, and Other Specialists
- 47 Researchers
- 156 Other Supporters

Of patients and family members who do not have personal experience with DCCR, 95% responded YES that, based on the data available on the safety and efficacy of DCCR, as well as experiences reported by PWS community members, that they would want the option of taking the medicine.

Want Option to Take DCCR



Summary of Community Feedback

Responses from 49 states plus the District of Columbia

Alabama	Hawaii	Massachusetts	New Mexico	South Dakota
Alaska	Idaho	Michigan	New York	Tennessee
Arizona	Illinois	Minnesota	North Carolina	Texas
Arkansas	Indiana	Mississippi	North Dakota	Utah
California	Iowa	Missouri	Ohio	Vermont
Colorado	Kansas	Montana	Oklahoma	Virginia
Delaware	Kentucky	Nebraska	Oregon	Washington
DC	Louisiana	Nevada	Pennsylvania	West Virginia
Florida	Maine	New Hampshire	Rhode Island	Wisconsin
Georgia	Maryland	New Jersey	South Carolina	Wyoming

Responses from 73+ other countries and territories

Argentina	Denmark	India	North Macedonia	Slovenia
Australia	Dominican Republic	Indonesia	Norway	South Africa
Austria	England	Ireland	Palestine	Spain
Bermuda	Ecuador	Isle of Man	Peru	Sweden
Belgium	Egypt	Israel	Poland	Switzerland
Brazil	Finland	Italy	Portugal	Syria
Brunei Darussalam	France	Latvia	Puerto Rico	Thailand
Bulgaria	French Polynesia	Lebanon	Qatar	Trinidad & Tobago
Canada	Georgia	Lithuania	Romania	Turkey
Chile	Germany	Malaysia	South Korea	United Arab Emirates
China	Greece	Mexico	Saudi Arabia	Ukraine
Colombia	Guam	Morocco	Scotland	Uruguay
Costa Rica	Guatemala	Netherlands	Serbia	Vietnam
Cyprus	Holland	New Zealand	Singapore	
Czech Republic	Hungary	North Korea	Slovakia	

Comments from Patients and Family Members Who Do Not Have Personal Experience with DCCR

NAME	COMMENT
Dora B.	Yes. She certainly needs something. I can't believe she can't.
Fran R.	Yes. These babies deserve a chance!
Carina R.	Yes! It's better to prevent as many of the symptoms before permanent damage is caused. Once weight is gained, it is exceptionally difficult to lose the weight! This drug can help send my child to normal mainstream schools instead of a special needs school because of food supervision, etc. The benefits are major and to start treatment early can only benefit in the long run. It's a chance for an almost normal life. Help us. Please.
Laurie P.	Yes, anything to help would be helpful.
Beata A.	Yes, because we would like our child not to have too strong symptoms of the disease, especially hyperphagia.
Susan A.	Yes, please give it a fair chance.
Rachel A.	Yes. The current data has shown that the drug is safe, effective at certain end points and we need a drug that allows are kids to live a full life.
Toni A.	Yes, as it would help so much and help so many other family's struggling with PWS.
Maryanne A.	Yes. My granddaughter should be able to have the choice to see if this medication can improve her daily life.
Jennifer A.	Yes. It would mean the world to be able to curb the hunger, food seeking and be able to improve muscle tone and weight loss. Anything to make my niece live a happier, healthier, easier life.
Bliss A.	Yes. We should be able to try the drug to see if it helps our son's condition so he can live life and reach his fullest potential. PWS not only effects the individual living with PWS, but it largely impacts the lives of everyone in their family and cause extreme distress and health crisis.
Jennifer A.	Yes. If my child's doctor prescribed the medicine to help her, we would take it. Her improved health would benefit our entire family.
Jane A.	I want what is best for the PWS individual concerned, to give them and their close family the best chance of a more normal life. The PWS diagnosis has been devastating, with little outside help and little hope of anything improving.
Stephane A.	Yes. PWS is a lifelong affliction with no cure, and few alleviative remedies. The symptoms create immense difficulties, challenging the ability of those with it to live even semi-independently. Any drug that can even provide the slightest chance if relief is worth taking.

Appendix A

Christina A.	Yes. Our daughter is 15 years old. She will be graduating from high school in 2027. She looks forward to continuing her education in a college setting. We worry that may not be possible without significant safeguards. One potential tool in keeping her safe while allowing her to have more independence is a medication such as DCCR that helps control the hunger instinct. DCCR trials have been life-changing for many participants. I believe every individual living with PWS should have the right and opportunity to try DCCR if their care team thinks it could positively impact their quality of life. Individuals with PWS deserve access to a potentially improved quality of health and life.
Kriston F.	Yes! So my son can have as much of a normal life as possible!
Tracey A.	Absolutely. We need this drug for our kids.
Sayed A.	Yes, I want my son to be treated with DCCR and for it to be approved as soon as possible so that my son does not develop any serious complications. I have great respect for you.
Alhanouf A.	Yes, it's our hope.. We'll do our best to take it.
Genevieve A.	Yes!! I would want my PWS loved one to have the option to take DCCR. Currently, nothing even comes close to helping with hyperphagia, and, as a small community, there is little interest in the development of other drugs. DCCR would give my loved one a chance at a full life and living life to her fullest potential. Without this option, I know my loved one will suffer. I want my loved one to have any option available to help her and DCCR is that option!
Robert A.	Yes!! I would want my PWS loved one to have the option to take DCCR. Currently, nothing even comes close to helping with hyperphagia, and, as a small community, there is little interest in the development of other drugs. DCCR would give my loved one a chance at a full life and living life to her fullest potential. Without this option, I know my loved one will suffer. I want my loved one to have any option available to help her and DCCR is that option!
Nathan A.	Yes. It is the only known solution to saving our 3-year-old daughter from the debilitating condition of PWS. It gives us hope that she can live an independent life.
Ani A.	Yes; to help control appetite.
Arden A.	Yes, the risks of disease are so severe that this medication is a lifeline.
Roy A.	Yes. I believe this drug is a breakthrough in treating hyperphagia and behavior-related abnormalities associated with PWS.
Herman A.	Yes, for the good of the Child.
Faustino A.	Chance to a normal life, better health.
Ashley A.	YES, I've heard only amazing results from people who have experience with it!!
Yasmin A.	Yes! If our son has access to the drug at the onset of his hyperphagia, we really feel this would be life-changing for him.
Elizabeth A.	Yes yes yes - C is 5 and his behavior is escalating. We are well aware it might not work, but he is a good candidate, and we need to try before he gets much older and patterns and neural pathways are.
Lisa A.	Yes, some hope and help is worth the risk.
Isobelle A.	Yes - it is extremely important we find a cure for the debilitating side effects of hyperphagia.
Denise A.	Yes. Anything to help.
Asli A.	Yes, we would like to start and observe the efficacy of the drug.

Appendix A

Joel A.	Hyperphagia, anxiousness, and temper outbursts.
Adnan A.	Yes, please.
Judy A.	Most definitely! Our son has most symptoms of PWS. Making life manageable for him and us, this medication will be life changing.
Sara A.	Yes, granddaughter has PWS, and this will help her.
MaryAnn A.	Yes, I want my grandchild to be able to live a full and active life. If there is a medical treatment that can reduce the effect of hyperphagia I want him to be able to take it.
Claire A.	Yes. My nephew's parents have been advised by his doctors that it could drastically improve his quality of life.
Samuel A.	Yes. There does not appear to be any medicine available to address hyperphagia, which is the worst part of PWS. Having access to a therapy like DCCR could mean the difference between a life of independence and one where the patient needs constant care and monitoring.
Linda A.	Yes. I would like this drug to be made available to my grandchild. I really believe this could give her a better quality of life.
Heidi A.	Yes! We want the option for our PWS family member.
Andrew A.	Yes! We want the option for our family member to take this medication, please.
Angela A.	It would improve her hunger and behavior so much!
Ellie A.	It would help her quality of health so much!!!
Veronique A.	I want my child to be able to benefit from this medication and have a chance to improve his daily life and become independent.
Amillia A.	Yes, we have been in a few trials and had some success. Would love to help provide the best quality of life for our little one with PWS.
Duke A.	Yes, to improve their quality of life.
Delia A.	My Grandson would definitely benefit from this. He was diagnosed at birth and has had many challenges due to PWS.
Jenna A.	Yes, there is no treatment for some of the hardest symptoms of PWS. DCCR would be the only approved drugs to help someone I know live a full and independent life. DCCR is essential to the individuals and family members whose lives are faced with the horrendous realities of PWS.
Dawn A.	Yes, I believe this would make a great impact on our family's ability to function in normal day to day life activities that are necessary to live without major disruptive challenges to my other non PWS children who become tremendously impacted and are beginning the need to seek their own emotional challenges living with a sibling with PWS, which should not be a stress that they should endure trying to live as a fun kid.
Peggy A.	Yes! Should our Millie develop hyperphagia, we would want her to be able to have access to the drug for hyperphagia.
Emily A.	Yes, I would want my child to have access to this lifesaving medication. This drug could drastically improve the quality of life for those living with PWS and having the option to take it should be available to all individuals and family members affected by PWS.
Tom A.	Yes, so my niece can be independent in adulthood and improve quality of life for her and her parents.
Claire A.	Yes, this medication would greatly improve the quality of life for my cousin's daughter.
Erin A.	Yes. We would use it for all the benefits it provides.
Bryon A.	My nephew who is 6 would tremendously benefit.

Appendix A

Holly A.	Yes definitely. We have heard it will make a huge difference to his quality of life.
Scott A.	Yes, my family would like the option to take this medicine to help my daughter live her best life given all the daily challenges we face as a family living with PWS the stress is unimaginable 24/7
Scott A.	Yes. This will greatly benefit my child with PWS.
Elisabeth A.	My niece has PWS. I have seen first-hand the struggles my brother and sister-in-law have with her condition. Recently is has been very difficult to regulate her hunger and well as her tantrums. They try very hard to help her lead a normal life. I believe this medication could help her significantly. Thank you for your consideration.
Jade A.	Yes, this drug could make it possible for my daughter to have a full and independent life.
Obrejan A.	I want all Chances for that Child.
Amanda A.	Yes, I believe it would greatly improve his wellbeing and make it possible for him to live as close to a normal life as possible
Jonathan A.	Yes, as a parent, I want options for my son when he starts to suffer from hyperphagia.
John A.	Yes, it will help control insatiable hunger PWS children experience.
Hannah A.	Yes, our kids need a treatment to help them live and independent full life.
Maggie A.	Yes. My child hasn't entered hyperphagia and I would love to improve his life so that he doesn't have to experience that awful and cruel part of PWS.
Jason A.	Given the strong anecdotal reports of success and the lack of safety issues with the drug so far, our young daughter should be given the chance to experience the potential benefits of the drug.
Kathleen A.	My family member would like the option of taking this med.
Susan U.	Quality of life
Jennifer A.	Yes. We have reviewed the research and believe that DCCR could be the key to allowing our daughter to live a much more independent and fulfilling life.
Larry A.	Yes! It can change the future of my granddaughter's life
Laura A.	Yes!! It would be life changing for our granddaughter! She could live her life independently!
Drew A.	Yes, it would help her with her quality of life and setting her up for success for her.
Megan A.	Yes, the ability for a better life
Insharah A.	Yes, my son is 4 and already cannot stop eating. He is always distracted by food that hinder his daily life routine. Having access to this medication will be a breakthrough in his lifestyle and also the people around us. Its simply just hard for him to survive in a world that revolves around food.
Eli A.	Option if safe and effective
Lucie T.	Yes, looks very helpful for my son!
Tessa A.	Yes. The evidence is overwhelmingly supportive
Sasha A.	Yes! This drug is well tolerated and helps people with PWS! We have such limited treatment options for a life long and life threatening complex genetic syndrome. This drug has a great safety profile, and even if it doesn't work for everyone with PWS, all people with the syndrome should have the option to take DCCR. Please approve this medication!

Appendix A

Yes, we want to take the drug DCCR because our daughter is 17 years old, with PWS, with morbid obesity weighs 145 kgs, and we know that the drug would help to control this obesity, we urgently need access to the drug.

Caroline A. Yes. No other medication available

Simina A. Yes! Giving a chance to have a different future for my daughter

Alisha A. Absolutely! My Son Is 19 & We Are In Desperate Need Of This Medication!

Elizabeth A. Yes, it will make a life change for my nephew.

Christina A. Absolutely! We respect the FDA's mission and objective to regulate safe and effective drugs/medications to stakeholders and hear our patient voice. The FDA has effectively afforded our family, and thousands of children, the extraordinary effectiveness of one PWS treatment course which has resulted in an exponential shift and success in her early intervention. Knowing that this drug, DCCR, is a promising pathway to the most critical PWS symptom (in our opinion) of ameliorating, and possibly resolving, the unmet needs of satiety. Absolutely, YES! we'd love an option for our child to try this drug and appreciate your consideration for a priority review of DCCR. With great respect, thank you.

yes, my granddaughter would greatly benefit

Julie A. Yes, absolutely! Any chance of giving my son a better life, given there are no other options, why wouldn't I want DCCR as an option? Who wouldn't want this as an option for their child?

Alicia A. Yes, because all the PWS including my son going to have a Bette quality of life.

Chris A. Yes. This would be life changing for my son and our family as a whole. There is no other medication out there that can help my son at the moment.

Cynthia A. We have nothing to lose

Yolanda A. Yes. PWS warriors need all the weapons they can possibly get to fight for as normal a life as possible!

Jhonatan A. Of course, based on the effectiveness of the medication and what it can mean for an improvement in our PWS relatives.

Kate A. Yes - anything available to help with symptoms

Carol A. Yes! All the PWS community needs this help!

Maryann A. Yes, it would greatly improve quality of life.

Richard A. Yes, we need options to help these folks live their best life.

Hayley A. Yes, our daughter is only 8 and does not yet experience hyperphagia but it would mean a lot to us to have an available treatment.

Melanie A. Yes, to overcome quality of life symptoms from the condition.

Kristen A. Yes! Anything to help my daughter thrive

Carson A. Yes, if its helping some families then it's something that should be available to all PWS families

Darbee A. Yes; the chance to help with hyperphagia gives my daughter a real shot at a more typical life. I want that for her.

Brian A. Yes, the possibility of a treatment for any of the symptoms of PWS would be life changing

Catherine A. Yes to have a potential treatment for this cruel condition, or at least some of the symptoms, would be life changing

Appendix A

Janis A.	Yes because of the positive impact it can make in the life of our family member and others with PWS
Alycia A.	Yes, we have not had the option to enroll in a trial for DCCR but we have seen an INCREDIBLE impact this medication has had on kids like my daughter. The medication improved the quality of life for both the parents, children, and all parties who care for the person with PWS. We see my child struggle each day with food seeking and behavioral problems. Currently, there is no other option for us to remedy these painful symptoms. We ask the FDA to consider priority review so our kids and families struggle no more. Please help!
Amy A.	YES! I want my daughter to have a full independent life. Right now that is not her future, but DCCR offers hope of a better life for her.
Balaji A.	Yes, I have been following this trial so long and I think this could change the lives of people with PWS and their caregivers
Jassamayn A.	Yes, my niece would highly benefit from at least trying DCCR for her symptoms from Prader-Willi
Kellie A.	I'm signing this on behalf of all my fellow PWS families in America
Janna A.	Yes!! Addy has so many obstacles to overcome without the effects of hyperphagia. This drug can greatly improve the quality of her life. I beg and plead for help from the FDA to enable her access to this treatment.
Gary A.	Yes, this would increase my child's quality of life.
Danita B.	Yes, all the benefits would tremendously help her live a healthier life.
Brittany B.	Yes! We've heard amazing results and would love the help!
Jaime B.	Yes. To help with symptoms and behaviors associated with PWS
Susan B.	Yes because her life is so hard and self control is not fair to a child
Heather B.	Yes. If there is a treatment to ease the hunger my daughter feels constantly, I would put her on it no questions asked.
Kristin B.	Yes, if it can help my daughter with her hyperphagia, I am will to give it a try. Anything to help her live a more normal life.
Kristi B.	Yes we would like the option to try DCCR, any chance to improve his quality of life would be life changing and we would love the opportunity.
Keith B.	Yes, it would benefit her
Beatrice B.	Yes. Anything to positively impact the syndrome.
Nazeli B.	Yes - to help my nephew have as normal of a childhood and able to curb his appetite
Margaret B.	Yes I want my daughter to have the option to take DCCR. Our individuals with PWS need a better life!
Ashley B.	Yes! Our daughter has had severe food seeking behaviors since she was 2 and it greatly impacts her life and our families life. We would love to have to have the opportunity to have a dad to DCCR as it would be life changing for us all!
Delores B.	Yes, this would be a game changer for Our daughter.
Vinuthna B.	Yes, This medicine will help a person with PWS disability to live a better life
Boglarka B.	Yes, both
Estela B.	Yes, to stop hyperphagia

Appendix A

Stephanie B.	Yes, there is interest. While already participating in volunteer, sports and other community activities, possibly having a medication that could lower supervision levels and increase independence would be greatly welcome.
Chase B.	Yes, if it gives my child the best shot at living a normal life, I want the option.
Jamie B.	Yes!!! This is life changing for my baby, and it needs to be available for when he needs it. I cannot explain the stress as a young parent I have knowing this monster is looming over us for his future. No only is it huge for older kids and people, but for my mental health knowing the cure is out there would be life changing!!!!
Lucia B.	Yes indeed, If it's proven that It can alleviate PWS symptoms
Barbara B.	Yes whatever it takes to help my granddaughter
Kristena B.	Yes to help with this awful disease
Joan B.	Yes - it could help improve her life.
Anna G.	Yes please anything that would help my daughter
Matt B.	Yes. At least eager to begin trials on it. It would make a big difference for her if it worked.
Laura B.	We want options & interventions to improve outcomes and help Audrey reach her potential
Denise B.	Yes as it would offer an opportunity for treatment during nutritional phase 3 of PWS.
Philip B.	Yes it will help with their quality of life
Asha B.	Yes. My daughter already is searching for food at young age and its€™s only going to get worse. Would be a godsend to have a medicine that helps her hunger.
Molly B.	I would love to hear more research to become more educated on what DCCR is and the benefits of it and if there were positives that are proven to work I would love to have at least the option to have access for my child to have the option of taking the drug/medicine
Bailey B.	We will be first in line to take DCCR. We believe that this drug works. Catherine is an incredible kid and we know DCCR can help unlock her full potential. Our community has the right to try this safe, effective drug.
PJ B.	Yes it sounds the most promising of the options out there, and with more information, I'd love to be able to explore the option to make my kiddo's life easier and less impacted by this condition.
Cynthia B.	I would definitely consider the option of taking the medication to get improve quality of life
Kyle B.	Yes shows promising results in helping to manage symptoms of PWS.
Shandra B.	Yes. I would like to learn more about how it might help my daughter.
Carrie B.	ABSOLUTELY YES. It is the ONLY hope we have for our little girl to live a normal life.
Abigail B.	Yes, any opportunity for a better quality of life would be a gift.
Caklum B.	Yes, it would greatly help to improve quality of life
Linda B.	Yes, we would want the option of it Improves the quality of life of our Lebanon
Taylor B.	Yes. It would greatly improve quality of life.
Callum B.	It will greatly improve his quality of life.

Appendix A

Doreen B.	Yes. We know what lies ahead of this medication is not approved and we have heard so many positive testimonies of how amazing this drug has been for people who have taken it. And considering its safety profile it would be nice to have access to something to try for the hyperphagia.
Theresa B.	Yes. If we can curb hyperphagia what a game changer for health life longevity
Macarena B.	Yes, so that she can have a better life
Alvaro B.	For a better life for her
Maria B.	Yes, we want to avoid hyperphagia
Caitlyn B.	Yes due to hyperphagia
Ashley B.	Yes due to the hyperphagia
Kathleen B.	Yes it sounds like a promising drug to help with symptoms of PWS
Karen B.	Yes please to make our granddaughter benefit from this
Jenna B.	Yes, we would love for our family member to have access to DCCR. There is no treatment for some of the hardest symptoms of PWS. DCCR would be the only approved drugs to help them to live a full and independent life. DCCR is essential to the individuals and family members whose lives are faced with the horrendous realities of PWS.
Becky B.	Yes. If it is providing any benefit whatsoever.
Dan B.	I want her to have the best life possible
Derricka B.	Yes to better the health
Shaterraca B.	Yes we've been searching just like other families for years
Mercedes B.	YES!! To help my child live a fulfilling life. To not have to suffer with feeling hunger 24/7. To be happy
Stephen B.	Yes! It seems effective!
Allison B.	Yes! I would hope and pray that DCCR is available for my daughter when she needs it so she doesn't have to experience the hardship of hyperphagia and live more of a normal life.
Braden B.	Yes. Based on study results to date we would be interested in access to this drug.
Huber B.	Yes if possible. Hyperphagia is yet beginning...
Morgan B.	Yes! PWS has devastating symptoms that severely diminish quality of life for individuals. Caregivers, family members, and friends also feel the affects of these terrible symptoms. Any chance at improving symptoms and quality of life is 100% worth it, even if there are some risks involved. This medication could give us our lives back, and give our child the chance at having more of a life, more opportunities, and more freedoms.
Carley B.	Hyperphagia is truly a terrible condition and affects all aspects of the individuals wellbeing as well as the family. This medication would be truly life changing for individuals with PWS and their families
Linda B.	Yes. This is a life threatening disorder.
David B.	Yes - we would want anything to curb hyperphagia as that is the one thing preventing our son from living an independent life as an adult. Access to the drug has the potential to be life changing.
Stacy B.	YES! We would allow our child to take it based on the research and the life-changing benefits it has had for those who have had access to it.

Appendix A

David B.	Yes. We desperately want for our child to receive help.
Helen B.	Yes, absolutely. This would change our world.
Jelld B.	The boy needs this medicine. He is now 5 years old and it would help him a lot.
Maria F.	Yes, because they not have any options. The medicine to them is a New hope, not only to PWS members, family/friends too.,
Marie B.	Yes so she would not suffer with hyperphagia
Stephen B.	Yes, do Paisley will never experience the pain of hyperphagia.
Anne B.	Yes. My granddaughter is 6 years old and is showing signs of hyperphagia, picking and sleep disorders. It would be wonderful if she could live the rest of her life without these problems.
Alexandra B.	Yes; we don't want her to suffer with hyperplasia.
Samantha B.	Yes; we don't want her to suffer with hyperplasia.
Ellen L.	Yes, to avoid her from suffering with hyperphagia.
Juan B.	Yes it will be important
Catherine B.	We absolutely want and need the option to have DCCR. Behaviors, food seeking, and other issues that have already begun affecting our young lady may positively be affected by the medication and she, and our family, deserve the best possible life available to her.
Bishrawa P.	Yes, if in future as my child grows up with hyperphagia, which I worry most, I will want to use DCCR to prevent or control associated problems.
Emilia B.	Yes, given the low risk and high possible benefit our family member would very much like the option to take DCCR.
Sara B.	My son is 4 years old and has a high interest in food. It would be a blessing to have a drug readily available for when the hyperphagia does hit.
Tom B.	Yes anything that will help with the quality of life should be explored
Earl B.	Would be amazing to help them get a full recovery
Vicky B.	Yes. We need options and we have none
Kealy B.	Yes, to reduce behaviors and anxiety related to food and to afford them the opportunity to live a full life with independence.
Irene B.	Yes, my family is interested for my niece
Patricia B.	Yes. My granddaughter has hyperphagia
Michael B.	Yes. The current level of demonstrated efficacy and understood risk greatly outweighs the emotional and financial (public and private) costs of current life experience.
Stephanie B.	Yes. PWS and hyperplasia as well as behavioral and emotional issues have been a struggle for my niece her whole life. I worry about what this means for her current safety, independence and ability to reach goals.
Clare B.	Yes! The cruel Hyperphagia aspect of PWS prevents an independently lived life and is painful and distressing. With DCCR the PWS community can be independent. We desperately pray for this new drug to come to the UK
Terry B.	Yes, we would want the option of giving Logan this medicine to give him a chance at a happy future.
Kathy B.	Yes. DCC
Jennifer B.	Yes. I believe DCCR could help my daughter with hyperphagia.

Appendix A

Brad B.	Yes. Anything that would help control hunger and facilitate weight loss would be tremendous.
Sherie B.	Yes! We need help managing these symptoms! They rule my child and the rest of my families life! Hyperphagia and anxiety about food impacts everything we do.
Traci B.	Yes, if it will benefit my sweet son. Please help him. Thank you
Victor A.	Yes. We are open to try anything to minimize the effects of PWS in an individual .
Jillian B.	I absolutely would have my daughter take this medication. It is life saving and right now we don't have a cure for PWS ..this would help my daughter so much
Rebecca B.	Yes, it has already been proven to be safe and effective for other dx. And has shown positive effects for those with PWS that have had access to it
Elizabeth B.	Yes, anything that can help my child live a full life is a drug worth trying
Jill and John B.	Anything would help!
Wendy B.	Yes, especially if it helps with the hyperphagia which is a daily struggle.
Samantha B.	Yes if it could be helpful to my child.
Ashley B.	Yes, absolutely. This would be life changing for the entire family and dramatically improve Callan's (PWS) quality of life in so many ways.
Matthew B.	Yes. Without a doubt. Based off its trials/results it would change our lives.
Norma B.	Yes! There have been no drugs approved to help my granddaughter and she deserves the chance to lead as good of life as possible
Jeffrey B.	Yes, given the low risk and evidence of benefits we eagerly look forward to having DCCR as an option for current and future PWS-related symptoms.
Nicky B.	Yes, given the low risk and high possible benefit our family member would very much like the option to take DCCR.
Adam B.	Yes, given the low risk and high possible benefit our family member would very much like the option to take DCCR.
Ferdinand B.	yes to prevent hunger all day
Mary B.	Yes, PWS is a syndrome that is extremely difficult to manage . My son does work and because the rest of the world can control their eating behaviors, he is exposed to food in the workplace which is hard for him to ignore. A medicine that could curb his urges to eat and help with his body mass would change his life forever, and ours. The fear a parent of a PWS adult is , what happens when we are no longer here to watch his every movement? If there is a medicine that could help control the symptoms of PWS, I for one would be very grateful to have it in my son's life.
Sarah B.	Yes they should have every chance to take some thing that could improve their life
Richard B.	yes if DCCR will help mitigate the symptoms of PWS
Mary B.	Yes. It is hopeful
Sarah B.	Yes once my daughter is 4 we are hoping it is ready for her to start taking
Jared B.	Yes , I believe this is the best way forward for our kids to live the best life
Marylin B.	We would like the opportunity for access, and for the Canadian FDA to approve its use and access.

Appendix A

- Natalie B.** Yes. DCCR shows promise as a treatment for PWS, with potential benefits for hyperphagia, body composition, and other symptoms. Our community deserves access to treatments that may help.
- Laura B.** Yes, absolutely!! My granddaughter would be helped in so many ways. It is shocking that PWS has been ignored regarding research for treatments to help them live a safer, healthier, happier independent life. They desperately need help from the daily challenges PWS causes. PWS endangers the individual who lives with all the complications caused by trying to live with the health, emotional problems and safety measures that are a part of everyday life! The family members must all be diligent in keeping their loved one safe regarding all the problems that are part of their daily lives. Our family member is so deserving at a chance to live the life she deserves. Please do the right thing and approve this drug.
- Carol B.** Yes. All possible options should be available for this debilitating condition
- Steven B.** Yes, everything we've read and seen it's a life changing medicine. These poor babies have enough trouble and the struggle with uncontrollable hunger is one of the saddest things I've ever heard or seen. We would love to give our daughter the best chance at a normal life.
- Monica B.** Yes. My granddaughter has PWS
- Ashley B.** Yes I have witnessed it to be life changing for people with PWS and I want my little girl to not have to feel hungry all the time when she hits that age
- Beverly B.** Absolutely, anything to help our precious children live their best lives, or for those who follow. I think individuals with PWS would agree completely
- Gary B.** this syndrome has such an effect on not only the PWS person but family and community as well. Any drug that has promise to aid in the multi symptoms should be given serious consideration.
- Kelly B.** Yes, the treatment would change our family member's life and hopefully prevent symptoms
- James B.** The treatment would change how they live and hopefully prevent symptoms.
- Cindy B.** Yes, please anything to help...
- Jenny B.** We would definitely want our daughter to have access to this medication! The benefits far outweigh the risks in her case. Prolonging the period of waiting for this is prolonging her risks and our family's equilibrium.
- Miranda B.** Yes we really do! Hopefully also soon in the Netherlands
- Lee B.** Absolutely! Gives us such hope
- Jake B.** Yes - in a disease process where interventions are limited and where the disease progression is somewhat dubious, simply having additional therapeutic options is important
- Jane B.** Yes to the option, enhance quality of life
- Kathryn B.** Yes we want the option. I will dramatically help change my grandson's life.
- Ashley B.** Yes! If it would to help my son and his future and the help with his friends and their future.
- Allison B.** I would love the opportunity for my son to take DCCR to help manage his symptoms resulting from having PWS. DCCR's potential impact on our PWS community and the future success and independence for our PWS kids would be life changing.
- Carol B.** Yes as a newborn would like the opportunity for him to fully develop

Appendix A

Marion B.	Yes. We would want every opportunity for our children to have a better life
Katherine B.	Yes, we want access to this life saving drug so my son can live a comfortable life without dealing with all the difficulties involved with PWS.
Etienne B.	Yes for quality of life and prevention of PWS related issues
Diana B.	Yes because they deserve a chance
Brett B.	Yes! Research has validated the life changing effects DCCR has had on individuals with PWS
Leigh B.	Yes. Anything that can give my daughter a chance at a more normal, regulated, safe and fulfilling life is something I will never stop fighting for. Even if the impact is minimal and the chance of improvement is rare, it's worth it to our community, without a single hesitation. It is unacceptable that there isn't a single treatment for these symptoms and it is far past time to change that.
Patricia B.	Yes. It's worth trying
Vicky B.	Yes, anything that might help this debilitating disease
Jennifer B.	If it is shown to be safe and effective, yes, to help alleviate the hunger, etc. for my son.
Janet B.	Yes! Even if it only helps some it's still a blessing !!
Brady B.	Yes, this would help him a lot.
Michelle B.	Yes. As far as we've read and researched, it had been proven to be safe and effective and we would be willing to try anything that would help any person living with PWS
Francis B.	Yes, these people need all the help they can get with this fight
Casey B.	I would like to give him any chance at a so called normal life. PWS is hard and anything that allows it to not be as hard I am all for!
Elizabeth B.	To give him a better chance of a better life.
Elizabeth B.	Yes I believe it could help my child in many ways
Bev M.	Yes , I worked as a CNA in a hospital & saw the horrible results of from the overeating can do.
Maxine B.	Absolutely. I will do anything to prevent my son Carlo from suffering from the debilitating symptoms of PWS. If it is possible I will be travelling to the US for the medication before it becomes available in Australia.
Marcin B.	Yes, I would like to try taking DCCR by my daughter. Basing on my basic dietetical knowledge I do not have bad feeling about choline compounds. In these times our loves have no other solution than growth hormone to decrease negative effects of PWS. I have had observed DCCR research since some time and I am live in hope that this drug could change our life.
Christina B.	Yes. My daughter is only 4 and has not entered hyperphagia yet. When the time comes, we absolutely want the option to try a treatment under the guidance of her medical professionals.
Charla B.	Yes the child parents would like for him to try
Corey B.	Yes, it is very important for our child's future
Nancy B.	Anything that could help our baby Charlie would be welcome.
Susan B.	Yes. We want our grandson to avoid the worst of the Prader Willi symptoms

Appendix A

- Julie B.** Yes we should be given the option as a treatment choice. Our kids and family members with this potentially life threatening disease deserve to be given an option for treatment if appropriate. Our rare communities are always the ones impacted by so little research due to the cost complete and commercialization. In the end every life is important.
- Jessie B.** Yes, as this drug shows effectiveness at relieving incessant hunger and food seeking behaviors and the associated anxieties and temper related to hunger, it would mean a huge positive change in the quality of my sisters life, as well as mine and my aging parents. We are all suffering because of PWS.
- Megan B.** Yes as it was drastically increase my nieces quality of life
- Doreen B.** Yes. The lack of choices available to manage our adults with PWS leaves many in group homes, which is not acceptable.
- John B.** YES!!! Our daughter is constantly hungry, steals food whenever and wherever she can find it, picks through trash to find food. She has severe behavioral and emotional outbursts surrounding food and not being able to do what other kids her age get to do. It is a miserable and daily traumatic experience for our daughter and every family member in our household. Anyone who has not experienced living with a PWS individual has no comprehension of the living hell PWS families endure, and there is no help available because we have tried.
- Felipe C.** We urgently need treatment to reduce the serious symptoms our son presents. His anxiety overwhelms him and he self-harms. For this reason and more difficulties that we experience daily, we need appropriate treatments.
- Shari B.** Yes, Any help is appreciated
- Tammy B.** Yes! Help is needed. Our son is 31 years old. He is not on growth hormones as it severely increased his scoliosis as a young boy. Low muscle tone, poor balance and obesity keep him from exercising enough to lose weight. We were told when he was diagnosed that life expectancy was early 20s. We have worked hard to protect him from food and he is still with us. His quality of life could be vastly improved with weight loss and not constantly seeking food.
- Elizabeth B.** Absolutely, yes!!! My daughter's behaviors are extremely challenging and limit her ability to participate in her daily life. Please approve this drug so Violet has a chance to experience what others have experienced with DCCR!
- Liliana C.** Because it is something that would undoubtedly help hyperphagia, especially in our children like PWS.
- Natalia C.** For a better quality of life and hope for my daughter
- Jennifer C.** Absolutely. Anything to help him. Or at least try.
- Silvia C.** May it improve your quality of life.
- Katty C.** Absolutely. It is a good option for all people with PWS.
- Ayana C.** The benefits that comes with it.
- Paula C.** Yes, could change his life and is very difficult to access
- Mingbo C.** Yes. We have seen the statistics of the result and we are hoping thus can treat hyperphagia for our son in the future
- Diego C.** For my son, so he can have a better life.
- Jamie C.** Absolutely! We are begging for the opportunity for our daughter to have access to this medication.

Appendix A

David C.	Yes, my granddaughter needs access to this medicine to potentially improve her quality of life.
Tammy C.	Yes. She is young enough that with the medication she and the family will never have to deal with the stress of living with all the effects of PWS. It will be a daily part of her life.
Gregory C.	Yes. The results seem extremely positive particularly for children
Maureen C.	Yes in order to improve science and data for PWS
Cristabelle C.	Absolutely we want and NEED access to this drug! My son is an infant but we know what is to come with him having Prader Willi Syndrome. We understand that there are risks to any drug but the future without this drug is bleak and would severely limit and affect my sons quality of life as well as our families! Please help change the trajectory of the syndrome for all people afflicted with PWS and for their loved ones who care and live with them. The PWS population is living in dire conditions! A ravaging feeling of hunger everyday is unacceptable if there is a drug out there that can help this awful symptom. Please have some compassion for humans living with Prader Willi Syndrome!!!!
Debra C.	Yes. As Thomas gets older, it will be harder to control his hyperphagia. With a younger sister, who can eat anything, the challenges for Thomas will be more difficult.
Myriam C.	Si requiero medicamento/ x saciedad
Elizabeth C.	Yes with FDA approval.
Laura C.	Yes it would be life changing
Arlene C.	yes, if it helps
Rosie C.	Yes, improvements to hyperphagia = improvement to quality of life for PWS family member and family.
Jose C.	Yes of course. We wish a help for our Delfina
Aldo C.	Hope
Paula C.	Yes. It would give him a better quality of life
Shelley C.	Our niece, Allison Covey, would sign her daughter, Scarlett Arnold up for a drug to address hunger.
Kimberly C.	Yes. Our sweet girl deserves a chance to live without hunger
Danielle C.	Yes. A major part of PWS is hyperphagia and I would like my child to be able to have access to medication that can be life saving.
Luis C.	Yes. Improvement of quality of life is our main battle. Being in constant hunger (where you cannot perform on your daily basis due to the constant hunger) is an extremely cruel symptoms. As a parent telling your child that cannot have any more food is cruel. Being in constant watch because it can happen that eats so much and so fast that can burst their stomach transforms in a constant state of anxiety. The improvement for our kids is also the improvement of the rest of our families.
Maureen C.	Yes. Anything to help my niece lead a better life us what we are reaching for
Vivian C.	Yes. Having an option to improve the quality life for our son is so important. The right to decide should be with the patient and parents.
Susan C.	Yes my nephew deserves the chance for a better life.
Deborah C.	Yes! The benefits sound wonderful and would help my daughter so much

Appendix A

David C.	My son doesn't have hyperphagia but it's coming soon. I'm really confident with medicine and research and I think France are late. I know that hyperphagia is a very important symptom and I want the best for my young son Benjamin CARTA
Wendy C.	Yes we would like the drug
Stephanie C.	Yes. My daughter struggles. She struggles with outbursts. She struggles with comprehension. She struggles socially.
Brian C.	We would absolutely like access to DCCR for our son. Even a modest improvement in hyperphagia would make a massive improvement in his life and that of his family. most of his behavioral issues revolve around food and food-seeking activities. also any improvements that may result in body composition and lipid profiles would help him to live a healthier life with fewer long term medical problems. The safety profile of DCCR appears to be quite good and there are no other drug options available to Prader-Willi patients that offer any of these benefits.
Claire C.	Yes, I want access to DCCR for my daughter with PWS. The risk of hyperphagia is one of the biggest obstacles to her living a full and independent life. DCCR could be life changing for her and our family.
Deborah C.	I want the best possible life for my granddaughter
Conor C.	DCCR as a hyperphagia treatment could be the key to PWS individuals living independent lives, how our community needs access to DCCR to treat hyperphagia, how our community currently has nothing to treat hyperphagia and DCCR could change that.
Kellyann C.	Yes to help the child have a better quality of life
Lynn C.	Yes-they feel this medicine is their only hope right now. Thank you.
Carlos C.	To help my daughter
Antonia C.	Yes would make a huge difference to quality of life and be the difference between life and death in some instances!
Arianne C.	Yes definitely. The older that Savannah gets, the more difficult it is for our family to keep her safe and healthy. Education is one of the most difficult to navigate, as the symptoms of PWS grow more intense with age. Our family has had to transition our child to home school because our local district didn't take her hyperphagia seriously and she was continuously exposed to life threatening risk associated with food.
Fillebeen C.	Yes because of improvement of hyperplasia, more independence and better life for my little one!
Joanne C.	To improve quality of life
HsiaoYi C.	Yes. Our children need access to the drug to help them live to their true potential.
Adam C.	Yes. Hyperphagia has not fully manifested in my son yet but he will benefit from all options.
Allison C.	It would be up to my nephew's parents to decide that, but if it gives the chance of him living life with PWS a little easier I believe they would try it.
Katherine C.	Yes, it is very hard for them and for us as a family every day.
Jose C.	Yes, to reduce hyperphagia and probably the anxiety for lack of food
Bethany C.	Absolutely! Our daughter has so much potential but many roadblocks because of PWS. If there are treatments available to break down even one of those barriers, we want that for her, so she can live her absolute best life.

Appendix A

Susan C.	Yes. Our granddaughter was helped by this drug during a trial. She no longer has access to it.
Calvin C.	Yes it seems to be working
Rochelle C.	I think any and all available medications should be available for families to choose how to treat this life threatening and suppressing syndrome.
Carol C.	Yes, because it could help give them relief of constant hunger!
Tatyana C.	Yes. The studies have shown positive effects and I think it would help our daughter.
Joseph C.	I would definitely love having the option to see if it can help
Amanda C.	Yes, it would be great to have this med help with hyperphagia!
Tracy C.	Yes when it's indicated for her, we would want the option
Alexander C.	YES! It would provide valuable developmental scaffolding for my family
Jill C.	Yes, DCCR would help change my grand niece's life.
Suzanne C.	Yes, if it could help Audra it would give hope to my cousin Tracy and her husband Dylan.
Jeanette C.	I'm for it if it helps all PWS patients.
Clare C.	Yes, my nephew would take it.
Abby C.	Yes! Anything to alleviate the symptoms!
Malene C.	Yes! If DCCR can improve the quality of my kids life just a little, I would never hesitate.
Manisha C.	Yes, we would be open to trying this medication for my child when it is appropriate for his age as it is very helpful for people with PWS.
Olivia C.	Yes because I believe it will help this individual not have to experience hyperphagia
Katarzyna C.	Yes I Hope DCCR will make his live easier on future.
Caitlin C.	Yes!!!! We need something to help us with hyperphagia and to date this has been our only hope! Please do not delay, as this is something many families need. If you were in our shoes, you would want every option available for your loved ones!
Valerie C.	Yes, my son is in the hyperphagia phase of PWS so food seeking and the possibility of choking or overeating leading to death is always on our mind
Michael C. Meneses C.	Yes, anything that will help with quality of life and longevity is needed. We want treatment for better metabolic control of the disease
Amy C.	Yes, to provide a better quality of life to children and adults diagnosed with PWS.
Jim C.	Yes. The management of hyperphagia and all the side benefits would significantly improve the independence and quality of life of affected individuals.
Vicki C.	Yes, a chance to live a full life with fewer symptoms.
Angela C.	Yes, because our daughter is at the point where it's becoming a life or death situation for her. She weighs 321 pounds and the hunger drive had become insane. This is our only hope in saving our daughter life.
Danielle C.	It's my great-nephew. His parents and family want this for him.
Marcel C.	I think DCCR is a good choice for the future
Hannah C.	Yes absolutely! DCCR is our only hope for Grace to live a normal life!
Heather C.	Yes. The data looks hopeful.
Rachel C.	Yes, there is a need in it community for access to medications that may help with PWS symptoms.

Appendix A

Humphrey C.	Yes - hyperphagia is terrifying, anything that might be able to assist our family to manage it would be very welcome. It doesn't just impact the person with PWS but also siblings and other loved ones. It is so cruel.
Justine C.	Yes, we would. We want him to have the best, longest and most normal life possible. This will help.
Heather C.	It will be a life changer for our PWS grandson.
Matt C.	Yes, we have heard numerous first hand accounts of the positive impact it has had in the lives of those with PWS
JayLee C.	We absolutely want access to DCCR as a treatment option, in the future, for our son. Given, there are little to no treatment options for the countless effects of PWS; any FDA approved treatment options mean hope for our son's future.
Sherril C.	Yes please, my grandson is just turned three and we are so worried about his future. Hearing great things about his trial and praying Dr miller will put our grandson on it.
Erin C.	Yes! Anything to help our child with hyperphagia would help tremendously.
Sarah C.	Yes, knowing what we know about the safety and efficacy of the drug, we want my nephew to have the option of taking it to curb his obsession with food, even if it's just a little bit.
Jessica C.	Yes, to improve their quality of life
Michele C.	Yes as it would help her quality of life as she gets older
Peter C.	Quality of life enhancement
Patricia C.	Yes, it is imperative that Vivian has the opportunity to live a normal life.
Susan C.	Yes my grandson has PWS and any medicine that has the potential in helping to make his live better and to succeed is worth a try! Please help these kids and adults before it's too late!
Rageeni C.	Yes, to increase quality of life.
Sue C.	Yes, we desperately want our daughter to have access to this medication. Our daughter needs your help and we ask to please consider reviewing this medication as it can potentially save her life and allow us all to live a better quality of life. Our children deserve the chance to life a happier, fuller and healthier life.
Andrew C.	Yes. The data and testimonials from the trial make it clear that PWS patients need this drug!
Lisa C.	Yes - my adult son is thriving other than his weight/hyperphagia - he drives, works in community job and is awesome. He currently weighs 400 lbs and is 6 foot 5. He needs all the help he can get.
Brayden C.	Yes, it is supposed to help with Hyperphagia and I'd like my niece to not have to deal with that.
Katelin C.	Yes, it seems to help with a lot of the potential problems that will make raising a child with PWS hard, and it seems to help with the chance of independent living
Katherine C.	yes. I am a mother to a smart, funny, beautiful boy who is thriving in the same preschool his siblings attended. I fear the day hyperphagia begins and his life changes. He has all the potential in the world right now and this will stay true in the absence of hyperphagia. I am also a physician and have reviewed all the data. The reality with him NOT getting DCCR means living in a residential facility. With DCCR and less hyperphagia, he can have a meaningful life. No one in this community cares about tiny or theoretical risks. We need solutions.

Appendix A

William C.	Yes. Studies suggest that DCCR could significantly improve the life and potential for those impacted by PWS
Lauren C.	Yes, for him to be able to thrive and get the care he needs and deserves
Margaret C.	Yea, to control hyperphagia, anxiety and to live a full life.
Luke C.	Yes to improve there quality
Rochelle C.	yes, help with temper outbursts would be awesome. I am in constant fear of something happening in a public setting with police intervention. I have twins with PWS so I have sneaking & watching weight times 2.
Kathy C.	Yes. This appears to help with behavior, the meltdowns are more than just a normal toddler meltdown. It also helps with hunger. I can't imagine never feeling full, but our PWS kids feel this all day, every day. There are so many things our PWS kids go through. They need help, they need this medication to help them live a normal life!
Dorothy C.	Yes. This medication could have a significantly positive impact on my child's quality of life.
Rachel C.	Yes, I have heard of life changing results.
Connie C.	We are blessed with 2 little boys with PWS. We would love for our boys to experience more of a normal life with this medication. They are such blessings to our family and deserve to live as normal life as possible.
Gabrielle C.	Yes. We desire the opportunity to give both of our boys DCCR. We have adopted two little boys who have PWS. We know that without this drug they have little hope to live a normal life. We would love the opportunity to give them both a fair chance at trying DCCR with the great results that the clinical trials have seen.
Joshua C.	Yes. We have two sons that have PWS and this medicine would greatly make a positive impact on their quality of life.
Lorena C.	Yes, we would try anything to help our son with the scariest symptom of PWS- hyperphagia
Christine C.	Yes, Desperately seeking something that would lessen my daughter's hyperphagia which impacts her ability to find and keep a job and thrive in our community, and stresses our family life so much
Samuel G.	Yes, we would try it for sure if it can help our daughter with PWS's worst symptoms.
Cheryl C.	Any promising therapies would offer hope in dealing with this condition, our granddaughter has
Allison C.	Desperately wanting this girl my 9yr old daughter w PWS
June C.	Yes, we want and need the option. We request the FDA fully review ALL data available on DCCR.
Denise C.	based on studies and testimonies of families that have access to the drug that it would be beneficial for all individuals with PWS to have access to
Angella C.	Yes. If anything would make life even a little bit better to live with PWS then we would want access to it.
Angella C.	In a current study already
Kevin C.	Yes. It will increase their quality of life.
Susan C.	Yes. My cousins granddaughter has PWS and her parents want access to this drug.
Bas C.	Yes. This seems to be a medicine that would make our life and that of our daughter a lot easier

Appendix A

Katie C.	Yes! She needs access to the best medication.
April C.	Yes. Should this medication become available and my daughter show a need for this particular medication, I would absolutely want the option to have this medication prescribed for my daughter.
Marsha C.	Yes! I would be interested to see how it can help with body fat, trying to reduce hunger, calories and weight as well as behaviors
Linda C.	Yes - it would be life changing, even life saving.
Sophie C.	I really want this for my brother
Paul C.	We need this drug! My son has PWS and suffers from all of the symptoms associated with PWS. DCCR would be a game changer for him and our family's ability to lead a more normal life. And gives him the chance to extend his time on this earth with all who love him.
Sharon C.	Yes. My son can successfully hold down a part-time job at a clothing retailer, but consistently gains weight because of the amount of food found in a normal break room. In addition, most instances of behavior issues at his house are related to food restriction. Reducing his urge to eat would help so much.
Joyce C.	Yes - Anything that could possibly help this child is needed!
Ashley C.	Yes! This would be wonderful for my bud to have!!!
Sally C.	Yes we would trial DCCR to help our 6 year old son with hyperphagia. This is impacting our lives tremendously for our son, his siblings and us as a family unit.
Sarah C.	Yes. Our 6yr old daughter is thriving right now. But with the natural progression of PWS this will soon quickly change. Having DCCR available asap will allow her to continue to thrive & live life full.
Sarah C.	Yes, to let the hyperphagia no longer control their/our lives
Marni C.	Yes, we hold out hope. In fact we are desperate for the outlook for our son's future to be different than what is known or expected for this syndrome
Persephane C.	Yes. The alternative is way too risky, scary, and harmful. This could save her life!
David C.	Yes! My granddaughter has PWS and is obsessed with food to the point that she will go to any means possible to eat anything she can get her hands on. Her parents have to lock the refrigerator and pantry where food is kept and still she will try to unlock it break in to those areas. She has been known to enter visitor's cars and eat anything edible. She has been known to go through the trash can to find food. Her parents give her daily growth hormone injections as the only presently available treatment, but still she gains weight and her health is thereby threatened. I have an acquaintance whose son became morbidly obese and ultimately died because of PWS. Please, please, please give this one and only drug option for these people, consideration that these suffering patients and families deserve and so desperately need.
Debra C.	Yes. It appears this drug may offer some relief, especially from constant hunger that would be such a blessing to her current situation. She has never had anything like this to help her in her daily struggle with PWS.

Appendix A

Lori C.	We would definitely want the opportunity to try this. It would create a better, more typical life for our daughter. She would no longer feel like she was starving every day. Every aspect of her life would not be controlled by food. She would have a more promising future and have the same opportunities as her peers. Her quality of life would greatly improve. Please give this drug consideration
Eva C.	Yes, much needed for hyperphagia
Sean C.	Yes. My sons quality of life would be greatly improved!
Catrina C.	Yes I would want the option for my child as she struggles with diverticulitis and it is hard to find foods for her and with this it will help provide more options for her that aren't considered in her diet range
Lisa C.	Yes we would want the option
William C.	Yes, it's needed for development
Lenue C.	Yes, because this medicine will permit to my son to have a normal life, to save his life. I don't understand why we cannot save ours child if it's possible, please let's be humans and let us save our PWS suffering.
Neil C.	Yes they believe that it has passed multiple tests through the FDA and believe it can be life-changing
Stacey C.	Yes. help with hyperphagia and obesity as well as behavioral issues
Maddie C.	Yes, the family wants the option and would change their daughter's life for the better.
Linda C.	Yes...she needs with her PWS
ĐœĐ, Ñ Đ.	Yes because we have hope that will help
Ana D.	Yes. Its Will be amazing to the behaviors
Courtney A.	Yes, to alleviate the symptoms of PWS and alleviate the pressure from his parents and siblings
Aimee O.	Yes! The potential risks are worth the potential rewards. We have no options today, this is an option.
Raymond D.	Yes, in the future. My son is now 3 months old and I hope for effective treatments in his future
Mitsi D.	I would like to have the option in the future. My son is only 3 months old now.
Helene D.	Yes. If there is a medication that could help him control his behavior even 1% then it would be worth taking
Lisa D.	We would definitely want to take the medication. This is a very difficult way to live.
Jose D.	Yes, because DCCR will help a lot to my brother.
Rajat D.	Yes we would as it would lower the symptoms associated with the condition. Currently there is no other medical option
Sagolane D.	To improve the care and life of PWS
Isabelle D.	Yes, we think every little help we can get to improve life of people touched by PWS is important.

Appendix A

- Joanna D.** Yes. My son died at age 20 and I would have tried any safe options that could have prevented that. I currently work with the PWS community in New Zealand and know from the families I work with that there are 2 key areas in which treatments are needed the most - hyperphagia and challenging behavior/mental health. Alleviating some of the symptoms which impact people living with PWS and their families the most would be life transforming.
- Ana D.** Yes, We believe that medication can bring good benefits with hyperphagia, behavior and improved social relationships.
- Kaitlyn D.** Absolutely. We have been waiting for this for 3 years now.
- Peyton D.** Yes we would because this could really benefit my sister. I know how hard it is for her and really think this will be good for the PWS patients.
- Meghan D.** Yes! It's the only hope for a normal life!
- Zachary D.** Yes, absolutely! The results that have been shared with us are remarkable and we want to give our Addison the best chance possible at a normal life. She battles so much already and to finally have a tool that works would be so huge for her future!
- Brenda D.** Yes. When my daughter is older and at the stage of hyperphagia, I would feel so much relief if she had access to and the option of taking this drug/medication to alleviate her hyperphagia symptom. I believe it would give her a much better quality of life and would allow her more opportunities in life also.
- Anna D.** Yes, my daughter is 1 year old, but by the time she starts experiencing insatiable hunger I want to make sure that there are drugs/medicine available for her.
- Julia D.** Yes! I want my baby to live a happy and fulfilling life
- Alexis D.** Yes! PWS individuals need access to as many treatment options as possible. This condition is so unique from case to case. For this reason, if DCCR is useful for 1 in ever 5 or 5 in every 5 patients, it should be available and accessible.
- Deborah D.** Yes, If this medicine has any chance to help these individuals with hyperphagia, it is completely worth it!
- Brittany D.** Yes, my niece deserves a chance to live, her parents have done every single thing imaginable to keep their daughter in the best shape and health that they can. Please!! Help her!!
- Kayla D.** Yes. It is extremely important to my daughter and this community to have access to this drug
- Anne G.** Yes. I understand that the DCCR can give a chance to person with PWS to live with autonomy.
- Rick D.** Yes, I hope it will make life easier
- Katia B.** I like to improve the quality of life of my 19 years old daughter.
- Douglas D.** Yes, Trying to help our family member have better quality of life
- Meagan D.** Yes. I would want any person with PWS to have access to a medication that could improve their quality of like and DCCR would do that.
- Christina F.** YES! I don't want my son to experience hyperphagia - it's torture.
- Brandon H.** Yes! Anything we are willing to try to help our precious daughter.
- Nia H.** Yes! Our life is so hard day to day. If we had any opportunity for a drug to help with her challenges one day we would take it in a heart beat
- Lisa D.** Yes, it would help my son with his PWS

Appendix A

Dominique D.	Yes. Hyperphagia, anxiety and OCD associated with PWS have debilitating effects on our child, and keep him from participating in most community events. At the age of 17, he still needs constant supervision. We are looking for a better quality of life for him through treatments such as DCCR.
Debbie D.	Yes we would. I wouldn't want to deny my son any chance of living a better life with PWS. There have been so many positives from DCCR trials that we need to also have this opportunity
Veronique D.	Yes without a doubt. Hyperphagia has a big impact and I talked to my sons doctor in the US about DCCR.
Mallory D.	Yes. Those suffering from PWS deserve every right to try a new medication to help relieve some of its symptoms and I would love to see more trials performed in aide of this.
Josee D.	Yes, I want to help my son live as independently as possible. He has severe food allergies. It would help a lot if he were no longer hyperphagic.
Julie D.	Yes. Quality of life
Linda D.	Yes, it will make a high difference in our PRW child and the life of our family, I will help with the debilitating issues facing our family.
Royce D.	Yes. This could make a difference for the whole family and their wellbeing
Frank D.	I will help with his hyperphagia, anxiousness, and temper outbursts
Brian D.	Yes. My daughter has PWS and would greatly benefit from it if she were able to take it.
Paula D.	I have identical twins with PWS. I would try anything that was proven to help their PWS characteristics. Life is difficult.
Geraldine C.	YES My daughter has hyperphagia This is a horrible syndrome that causes daily suffering for my daughter.
Judy D.	Yes. It appears that the trials of this drug in the PWS community have proven to be effective to curb unhealthy/life-threatening characteristics of PWS.
Crystal D.	Yes. It would greatly help with hyperphagia.
Macy D.	Yes to give my niece a chance of living an independent life.
Ana D.	I would! I've read all the documents and results of people with PWS taking it and I would definitely try this drug/medicine on my daughter.
Amanda P.	Yes. My child is in hyperphagia and this drug could provide him the relief he so desperately needs to be able to function and engage in society.
Jan T.	yes, if the drug is available and applicable to my granddaughters PWS, then I advocate for the drug to be passed by the FDA.
Sasha D.	Yes, I believe my nephew would benefit extremely from it.
Shannon D.	Yes. The treatment could prevent symptoms and change all of our lives.
Daivik D.	Yes, I want medicine
Hannah D.	Yes, it will likely improve my family members quality of life
Julie D.	It has been revolutionary for so many families. It's the first treatment that has given us so much hope
Zdenek D.	Better and happier life for my son.
Dana D.	Yes. This drug offers a positive outcome
Ruth D.	Yes please. Anything to help our family, researchers and other families.

Appendix A

David D.	Yes. Over 50 years and still no approved treatment.
Pia D.	Yes. We have no other treatments, besides growth hormone. DCCR is a game changer for our daughter, our entire family, and the whole PWS community.
Allison S.	Yes, anything to help our son
Robin D.	Yes. Give them a chance.
Janie D.	Yes, being a grandmother who watches my beautiful granddaughter who has PWS the effects of PWS on my granddaughter of constant hunger having to lock down all access to food including trash, dog food, food in all homes she visits is challenging but family friends do this to protect granddaughter. The constant having to know where my granddaughter is at all times as she is always food seeking and will hide with any food or medications she may find then panic mode kicks in while we search for her. It's a challenge to shop with her so we try not to take her to stores, all holidays are challenging due to food is always a big part of holidays, everywhere we go with her you have to be on alert for any foods, medicines that are mistaken for FOODS. It's heart breaking as she is starving as she never feels full, the behavior outburst is a constant problem there is more!! Please approve and give our warriors a chance to live hunger free and a chance of living a more fulfilling life.
Peggy D.	As a grandmother of a PWS child it's not my decision but I feel the drug should be available as an option for anyone with PWS
Amanda D.	Absolutely. The risk benefit analysis clearly points to taking DCCR. It's much more likely that it would improve Win's life (and our family's).
Jaclyn D.	Absolutely! This drug has the potential to change my daughter and family's life.
Terrie D.	Yes we are willing to make to different in his life!
Romain D.	Yes because it's apparently the only one treatment for this disease
Alaina D.	Yes, if it can help our daughter then I want to be able to utilize it and give her the option.
Brittany D.	Yes, the results are very promising.
Kris D.	Yes they would benefit greatly
Kelly D.	Yes to give my grandson a chance at a better life
Destiny D.	Yes we love the opportunity to get treatment for PWS for my son it would help so much
Jessica D.	Yes. This would be huge for the PWS community. Anything to help elevate the hunger.
Martine D.	Yes, it will help my daughter.
Holly D.	Yes. We would like her to have as normal a life as possible.
Kathleen D.	Yes. Want and need this drug and all PWS drugs to help our daughter
Cherise D.	Yes my son should have the opportunity to take DCCR to reduce his fat mass.

Appendix A

- Anna D.** Considering the available data on the safety and efficacy of DCCR, alongside the firsthand experiences shared within the PWS community, I wholeheartedly support the option for my son, as well as other PWS individuals, to access this medication. Hunger pains and the limitations they impose can significantly impede my son's ability to thrive and reach his full potential. Therefore, the prospect of alleviating this burden and offering him a chance at a more fulfilling life is paramount. By providing him with the opportunity to manage his condition more effectively, I believe DCCR could empower him to lead a life with greater freedom and possibilities. Moreover, the impact extends beyond my son alone; access to this drug and the ability to manage the most challenging aspects of this syndrome would also enhance the quality of life for our entire family, including my son's younger sibling who does not have PWS.
- Rebecca D.** Absolutely. It is a life saving, life changing drug that will enable my child to live her life to the fullest. We currently struggle with anxiety as well as increased food interest and focus. It is challenging and we hope one day we can access this drug for our daughter.
- Sandra D.** I believe so. I am not that close to
- Sharon D.** Yes! I feel it would do quite a lot to improve the quality of life of my son.
- Olivia D.** Yes!!! Definitely.
- Sarah E.** Yes, our son suffers from Hyperphagia and many other PWS related behaviors, keeping him from living a full life and having any independence
- Catherine E.** Yes, would want the pros and cons of taking it
- Tayla E.** Yes, my daughter experiences many symptoms listed
- Melissa E.** Yes, to live well!
- Penny E.** Yes to help with eating issues
- Jean E.** I would like my granddaughter to have access to this medication. It would be so helpful to her.
- April E.** Yes, anything to help with symptoms
- Paniagua E.** I want the medicine, thank you
- Nina E.** Yes we definitely would like the option because we've spoken with families on the trial who have been positively impacted by the drug. It seems to be our only hope for the future right now.
- Candace E.** Yes, I would love for my daughter to have the opportunity to not be starving all the time and alleviate behaviors associated with the hyperphagia.
- Lin E.** Yes. This gives everyone hope.
- Wanda E.** Yes. To try to help with this disease
- Renee E.** This would be amazing for my 7 years old PWS daughter who hasn't had access to this. And would love her to get a chance in the future so she will live a long lifetime
- Kirsten E.** Yes, we need all available options to choose from to manage the most significant symptoms of PWS as our daughter gets older.
- Tara E.** It would be life changing
- Bianca E.** I would definitely like my daughter to have access to this medicine as the hyperphagia has caused us to have to lock up our pantry and fridge as well as hide what we eat from her in order for her not to be triggered. This puts a huge stressor on our family and leads to more isolation for the person with PWS.

Appendix A

Lola E.	Yes. Jax is a sweet young boy and our family feels he would benefit greatly if given the opportunity to live a more normal life
Rodney E.	Yes we would like our daughter to have the medicine. It would improve her quality of life.
Amanda E.	My child should have every opportunity available to live life full! I strongly agree that this drug be available as soon as possible!
Ahmed E.	Yes we would like to take the drug to improve the life quality of my daughter
Lisbeth E.	Yes! To have improved life quality is very important for my grandson and our whole family. my
Philip E.	This would improve quality of life.
Angela E.	Yes! We would love for our son Donald to live as close to a normal life as possible! This would be the topping on the cake!
Valerie E.	Yes. I'm supporting my family who would like this option for their son.
Katherine E.	Yes Anna has made significant strides in the last year but will always face the challenges of PWS. Medication could help her everyday and could give her a better outcome in her life.
Gabriela E.	Improve your quality of life
Ivana E.	Yes. Like all parents, we want to help our child.
Nicole E.	Yes if I had the choice, however I am the aunt
Michele E.	Yes, to regulate symptoms associated with condition
Melissa E.	Yes. This would allow a better quality of life for my son.
Cassandra E.	Living in daily fear of how hyperphagia controls your child's life, that's not living. That's surviving. We don't want to live this way. We need a treatment
David E.	There is no current treatment for hyperphagia . Without medication to provide relief my daughter will always suffer. I want to make sure she has all the tools to succeed without having to deal with the effects of hyperphagia
John E.	As far as we read and researched appears to be safe and effective and we would want our child to try it.
Kelly E.	Yes! Anything to help these babes live an easier life. My nephew and grandson have PWS. This is something we are very passionate about.
Kelly E.	Yes. From everything we have read and researched, DCCR appears to be safe and effective. We would be willing to try anything that might offer any help to anyone in the PWS community
MaryEllen E.	I'm doing what I need to do to help my nephew .
Jennifer E.	Yes, it offers promising benefits of symptom management that can greatly improve quality of life
Wendy F.	Yes. My granddaughter has PWS and the outburst are heartbreaking. It would be a blessing to see her have the option of living a life where her anxiety and lifestyle doesn't focus on food. Rather for her to see food as provision not obsession.
Carina F.	Yes - I strongly believe my nephew (aged 6) will benefit from DCCR to help with his hyperphagia and thus, his behavior.
Albert F.	I pray to my lord every night that my great-granddaughter gets the medication she needs.

Appendix A

- Robert F.** Given the compelling data suggesting a potentially significant benefit for individuals with PWS, I truly hope that my adorable niece Olivia can have the opportunity to access this seemingly game-changer medicine. Please act fast!
- Wendy F.** Yes please. This life changing drug could make a huge difference for my young nephew..
- Alison F.** Yes his mother believes it will help him
- Sarah F.** Yes if experiments proved it is safe for the kid
- Sarah F.** Yes. I have talked to PWS parents and kids with PWS who had taken DCCR and saw significant improvement while taking the drug, then a drastic decline after. It helped all around, the constant hunger affects school and family life. Those had improved while taking DCCR.
- Aspen F.** For the survey, Olivia has not yet had access to DCCR. We want the option to take the drug because it would represent a huge improvement in our lives. We struggle daily with social skills, educational deficits, food obsession and fixation and other symptoms. We are up to speed on the safety of the drug and have been following its development. Our doctors are also waiting to be able to prescribe the drug for us. We desperately need to try DCCR to help alleviate some of the many debilitating symptoms of PWS.
- Emily F.** Our daughter has PWS. We have been waiting for this drug, and we desperately want the option of taking it. This could significantly improve the quality of our lives. We believe this is a safe drug for us to try, our doctors have been waiting for approval so that we can get access to it. We've been involved with PWSA and spoken to parents of children who have taken DCCR, with very positive results. We urgently need the option to try it out for ourselves to alleviate some of the multiple debilitating aspects of PWS that we have to live with every day. At times, the stress of PWS on our family has seemed insurmountable. The sibling of our child with PWS has experienced PTSD due to the effect of PWS on our lives. We urgently need to be able to try DCCR.
- Ronald F.** I would very much want my granddaughter to have access to this drug which will hopefully slow her to live a more typical life with the constant feeling of being hungry.
- Lori F.** I am praying my granddaughter can live a normal life, without food seeking and craving. This medicine is the answer to prayers. PLEASE approve this drug for her and the others with PWS, their families and caregivers.
- Roberto F.** We want the option to test the medication
- Rebecca F.** Yes, she is constantly hungry, overweight and has anxiety related to food
- Maria F.** Yes, we would
- Sara F.** Yes. I would try anything to intercept hyperphagia for my son.
- Stephen F.** Our family would like the opportunity to taking this medication. My son is on 4 different medications to help control behaviors, but none of them focus on the root cause. If DCCR is able to suppress the hunger, it would open up the ability to reduce other medications, and allow more freedom to live his own life.
- Terence F.** Yes. It is important to have a medication available that could be effective in treating hyperphagia.
- Nancy F.** Options are a great comfort
- Anna F.** Absolutely Yes. This is a chance for my daughter to never feel such hyperphagia are others older people with PWS that can dramatically change her quality of life and probably her development.

Appendix A

Wojciech F.	Yes, this would be a chance for my little daughter to never feel hyperphagia. Also, others people with PWS could dramatically improve their quality of life.
Agata F.	Yes. DCCR therapy has proven very effective therapy which significantly reduces hunger and difficult behavior related to PWS. I believe that my niece will really benefit from this therapy. We really need this treatment for our loved ones.
Katarzyna F.	My brother's daughter, my niece, needs DCCR, it is not easily available in Poland. I know how much they care about this and how much it will help her quality of life.
Santana F.	Yes, he would benefit greatly from it.
Leticia F.	Yes, it will help the PWS family member and other living PWS individuals in a better quality of life.
Gina F.	Yes, my cousin needs this to help her quality of life
June F.	Yes! Relief from the hyperphagia & some peace for my son and our household
Alana F.	Yes, I have heard great things.
John F.	Yes. I think it has benefits that aren't seen elsewhere on the market and could help some of his most severe symptoms
Terry F.	We would like everyone in the PWS community have access to this very promising treatment! There is nothing more heartbreaking than to witness your own child literally beg for food, even though you know and understand that you must constantly say no! Our son is hungry 24/7, yet we are unable to give him more! We live life knowing we cannot go to parties, celebrations, out for meals, due to the fact that we are required to limit his intake of food!
Gerald F.	Yes. It would better her quality of life and help normalize her daily functions.
Elizabeth F.	Would better her quality of life and help normalize her daily functions
Rose F.	Yes for better quality of life
Robert F.	YES. THIS DRUG WOULD GIVE HOPE TO A CLOSE TO NORMAL LIFE.
Kerri F.	Yes!! I'm desperate for something to help my child. His weight is now affecting his function in things that most children his age have no trouble doing. It's discouraging and scary. He needs help and I feel like this drug would help him!
Carrie F.	Yes! We would like to try all things that have a chance in giving our girl the chance of living the most successful life possible
Bart F.	Yes, I feel like having the ability to get ahead of the cravings and the mental aspect would be a great benefit for my daughter
Peggy F.	Yes. It would change our lives!!!
Donna F.	We would want the option of our daughter taking DCCR if it would benefit her.
Jonivieve L.	Yes. Everyone deserves a chance with their quality of life
Saverine F.	My son actually taking growing hormone (genotonorm5.3), and L-thyroxine but he is often searching for food and we can't do nothing about it, to help him maybe someday taking medicine can help.
Megan F.	Yes, our son has PWS and want to be able to treat his symptoms
Tavis F.	Yes, Owen currently does not get any treatment for hyperphagia
Joan F.	Yes! I have heard this is life-changing, and restores dignity to the lives of those with PWS.
John F.	Yes, both the quality of life and long-term health benefits far outweigh the observed risks, especially compared to the harsh status quo of living with PWS without DCCR

Appendix A

William F.	Yes, I have heard it can be beneficial and improve the life of those with PWS.
Emily F.	YES. We have heard how life changing it has been for patients receiving this drug
Charles F.	The risk to our loved one is very low. The benefit is massive in both quality of life and long term health
Burton F.	Yes it has been strongly recommended to us
Gail F.	Yes, as we have personally heard from a friend whose child was in the clinical study how helpful and life changing it was for their child with PWS. We see our loved one struggling with PWS challenges of anxiety, food obsession and feel it would help provide relief and make daily living challenges so much easier.
Alicia F.	Yes, I believe if it has shown to be effective I would like my daughter to be able to take it. She struggles with multiple issues related to her diagnosis that the drug has been shown in trials to be effective for treating.
Anne F.	Yes, it sounds like an incredible treatment option.
Haven S.	Yes, DCCR could provide much needed relief for many families, and offers hope to people living with PWS and their families
Lisa F.	Yes, to live a full and happy life
Vernon F.	Yes. It has been shown to be effective in most
Samantha F.	Yes! Anything to stop the horrible hunger
Christine F.	I'm glad an would love for this to become available my son is a big boy an if it helps that would be wonderful
Jennifer F.	Yes if it helps improve the life of a PWS patient
Maria F.	I would love for my daughter to take this medication, since it is the only remedy with positive results for hyperphagia!!!
Shane F.	Yes. Recent studies have shown promise in DCCR.
Leslie F.	Absolutely, hands down, YES we'd want the option for our son to take DCCR. The benefits far outweigh the risks, which we have thoroughly considered. Simply, we want our son who lives with PWS to effectively live his happiest life.
Corey F.	Yes! Everyone we have talked with that was able to take part in the trials made nothing short of improvement, if not dramatic change. Our kids risk so much more everyday, the risk/reward of a medication to help them is not worse than death, which without intervening, is already almost guaranteed.
Tim F.	Yes, we'd like to explore all options for the best outcome possible
Laura F.	My nephew needs the option. This is the best step. p
McKenzie F.	I love for my daughter to be granted access to something that could give her a better quality of life.
Michelle F.	Trying to get some much needed help
Pearl F.	Yes if age-appropriate and considered safe.
Judy F.	Yes. My child suffers every day and should not have to live like this.
Kahla F.	Yes she needs to live a normal life
Paula F.	Yes, we would like to try this to help my child
Martyna F.	Yes, Wed love to try
Nelson G.	We are afraid as a family that our son who is bedridden, we take great care of his diet, will still gain weight, it is frustrating.

Appendix A

Lory G.	Yes. It would mean that my daughter could have less difficulty in the future when the hyperphagia phase begins.
Diana G.	Yes, assistance with hyperphagia is a must ! She needs to be able to live independently .
Letisia G.	Yes!!! I want more than anything to give my daughter a chance to live without the constant hunger and behaviors. This would be life changing!
Bonnie G.	Yes, there is a lack of effective drugs to treat PWS and additional help would be welcome.
Tammy G.	Yes, we need something. Currently, we have nothing but a cocktail of meds combatting different characteristics of the syndrome.
Norma G.	Yes this would be amazing for my granddaughter to have this opportunity. Her cousin is 22 and also has PWS and is severely obese.
Mariella G.	Yes, it would be a life changing event, for me and my kid.
Li-Kim G.	Yes, so that my PWS child can have better life quality
Carmen G.	Yes, we need to improve de life of my son who has PWS
Maria G.	I think it will bring a better life
Carlos G.	The patient's parents want to have the opportunity for new options for the patient's treatment and improvement.
Marcela R.	Yes, we consider it could reduce hyperphagia and as a result decrease anxiety for the lack of food.
Christy G.	Yes. Having access to this drug would potentially increase the quality of life not just for our daughter, but our family unit as well. The struggles of someone with PWS significantly impacts not just the individual, but caregivers, siblings and other family members.
Shila G.	Absolutely, yes!! My grand daughter has early symptoms of hyperphagia. DCCR will be a life saver for her. Please approve the drug. It will be such a help to these kids with PWS.
Eugenia G.	Yes, if it helps my daughter live a normal life.
Katherine G.	Yes - I am satisfied on the basis of the safety data that we would trial this drug. There are quite simply no viable treatment alternatives, so this drug represents the best chance our loved ones with PWS have of a life less impacted by hyperphagia.
Maritza G.	Yes. Any relief of symptoms due to PWS is a plus and benefit.
Arpine G.	Yes having access to this medication can help my nephew with his PWS diagnosis and symptoms. As a rare disease there aren't many options that can help and we would definitely use this medication to help give him a close to normal life as possible. Please
Stephanie G.	Yes, every opportunity should be available to those in need.
Bethany G.	Yes. When my nephew is older, I dream of a day he can have hope that there is a medicine to help him face his hyperphagia battle. His family works tirelessly to help give him an amazing life, and medicine coupled with his strict diet, can help optimize outcomes for him.
Brittany G.	Yes! Given the efficacy and safety profile of this drug we hope to offer it to our son someday so that he can have a chance at an independent life
Zachary G.	Yes, we believe the benefits of this medicine outweigh the reported risks. Any medicine that will help curb appetite and help deter food seeking will drastically improve our way of life.

Appendix A

Carole G.	I am eager for my grandson to explore options available for a life long better health option. My son and his wife would definitely want him to be a part of throw trial. As a Registered Nurse with blood cancer as my specialty, every day I see trials and fabulous opportunities for life with new medications. I want longevity for this sweet little boy and this drug offers extended life for him. Thank you!!!
Nicolas G.	Yes, when my daughter will need medicine to fight hyperphagia, we will take the risks in order for her to have a more happy and independent life.
Susan G.	Yes, the drug has proven to be safe and effective. There is no drug approved for hyperphagia in individuals with PWS, so if this drug can help my child or even others with PWS, it is needed urgently for our community. These individuals deserve to live a life of happiness, and the drug is safe and effective.
Lisa G.	Yes. To help with dysphagia for our granddaughter who has this.
Richard G.	Part of finding a cure is research and new drugs
Ronnie G.	Yes, we would like our family member to live a normal life like the rest of us.
Pranjali G.	Taking medicine
Angie G.	Yes, there have been many positive results & should be made available to the PWS community.
Mary G.	My nephew has PWS. I think he would be willing to try the medication.
Isabella G.	Yes, my cousin's daughter is quite young, so they haven't yet had to face the challenges and symptoms described by older patients, but I know some of these symptoms (especially Hyperphagia) are beginning to show. If this medication can in any way help normalize their lives or lessen the burden of PWS, I'd like them to have access to try it.
Brooke G.	Absolutely!! Anything that enhances and potentially normalizes his quality of life would be a substantial win!!
Tiffany G.	Yes. The efficacy and improvement in quality of life for those who have had access to this drug will be life changing for so many individuals with PWS and their care takers.
Joanna T.	Yes, it would give us hope to improve our functioning.
Sandra H.	si, realmente es my importante para nosotros que elnio reciba e medicamento
Erin G.	Yes, his parents would like him to have access.
Lynn G.	As a loving grandparent I want my grandson to have the benefit of taking DCCR
Amy G.	I have been impacted by PWS two of my nephews have it. And I want the best for them and any chance that any of this could possibly help them they should have access to
Bradford G.	Yes, because we believe it would greatly impact the quality of life for our two little nephews and many others as well.
Mary G.	Yes, so my granddaughter can experience her full potential in life. She is very bright, connects well with everyone, is a lovely engaging toddler, almost 3 years old. She will be a wonderful contributor to society.
Branson G.	Yes of course if it can increase the quality of their life.
Kristin G.	Yes, we have to have a drug address all of these symptoms. This will effect my child's whole life. As parents, we want to ensure my son has every opportunity especially when it comes to drugs that can reduce his symptoms of PWS now and in the future.
Josiah R.	Yes. I want my granddaughter to have access to DCCR in order to reduce the severe difficulties of a life with hyperphagia
Jose R.	I would like my niece to try it out

Appendix A

Sandra G.	yes, my daughter lives with significant behavioral and food seeking problems that have greatly affected her quality of life
Maria G.	If it is beneficial we would do treatment with DCCR
Amy G.	Yes! This would eliminate so many struggles for my child and our family!
Kevin G.	Yes, absolutely! This could prove to be a life changing drug for persons with PWS
Trevor G.	Yes. Low muscle tone and hyperphagia are already problems my son is struggling with. DCCR has shown exceptional results in helping to alleviate these problems.
Mary G.	100% we want the option to give our child the best opportunity to live her life to the fullest. Without a drug like this she is doomed to forever need constant supervision as her insatiable hunger will prevent her from gaining any independence as she grows older and her quality of life will be a fraction of what it could be. This is a VERY exciting drug with an excellent safety profile.
Ashley G.	Yes. I want to give my daughter the best life possible with her disorder.
Jeannie G.	Yes!. Being chronically hungry is a cruel torture no one should have to suffer.
Victoria G.	I want to cure him
Jacqueline G.	Yes, we would be willing to try most anything to help with the most challenging aspects of PWS that this drug may address.
Nicholas G.	We would welcome the opportunity to improve the effects of PWS. Behavior related struggles are a very difficult effect of PWS for a family to deal with. They have a profound effect on daily life and we would live to try something that may help with that.
Charles G.	Yes it's proven effective and the PWS community is being hurt by not approving it.
Michael G.	Yes, her mother asked that I sign the petition.
Cathie G.	Yes -- to offset growing up with all the dangers associated with PWS.
Becky G.	Yes- I would do anything to help my child with hyperphagia
Barbara G.	Of course. Thanks to it, a person with PWS could be at least a little independent
Peggy G.	Yes showing good results for those in study
Amy G.	Yes; the fear of hyperphagia onset is causing much anxiety in our family and fear for our son's future and how we will be able to manage caring for him without this drug. Please help our son and those other living with PWS to live their best lives without so many challenges
Kristian G.	Yes, of course. We'd love her to have access to any potential treatment.
Patricia G.	Yes, I am the aunt of a person affected with PWS and also a scientist (biochemist and doctor in biological sciences). I have reviewed in detail the information available on DCCR and attended the Third International Symposium on PWS organized by the Colombian PWS Association in 2023. I verified that the results with this medication are promising and would be a huge contribution to improving the quality of life of people affected with PWS, for whom there are currently no specific medications
Hilda G.	Yes, it is always better to have some help for my son.
Magdalena G.	Yes, to have a normal life that allows autonomy to my daughter.
Zenaida G.	Yes to address hyperphagia
Arturo G.	Yes we do. We do believe a monitored tool to control hyperphagia will have a significant positive impact in the quality of living of our son
Sandra G.	Yes to help my child with this illness

Appendix A

Michelle G.	Yes we would. There is no other treatment for hyperphagia on the market. This drug would be game changing for our son and community.
Colleen G.	YES. There are so few options for us now. This gives me a bit of hope that I may have the resources when needed
Florian G.	Yes, because the results are very, very encouraging
Rolf G.	We heard from friends how better life would be for our grand-son
Barbara G.	Yes. Dr Miller, my grandson's doctor said the drug was life changing. Every child should have the same expectation for a bright normal future.
Joni G.	Yes! The daily struggle is so difficult for our son and this could be a game changer for all PWS individuals.
Emily G.	Yes - I have seen the positive impact this drug has had on many of the PWS community. At present there is no alternative available. I would like my child to have the best chance for an independent life
Rocelia G.	Yes we would like to see whether the medication would be beneficial in decreasing his hyperphagia and associated difficulties including weight gain, poor muscle tone, and behavioral challenges to promote a better future for my loved one.
Inva G.	Yes , for the safety of our
Tammy G.	Yes. I would love for my daughter to have a chance at a somewhat better life. She is always hungry, always anxious, has no friends & can't even get into a group home because of behaviors. Her life is miserable & our whole family is affected. Parents fight & blame each other, sisters get beat on & called names, belongings get destroyed. Please, please, please do something before it is too late for our daughter & our family!!
Caitlin G.	Yes! There has been such good outcomes for a lot of people with PWS, I just want my baby to be able to live the best life she can and it's already hard without medication.
Olivia G.	Yes. I feel that as caregivers we struggle with limited options in medications to help our loved ones.
Theresa G.	Yes, I would love for my loved one to have any opportunity to improve her life
Jemma G.	Yes if it improves well being
Penni G.	Yes! Anything to curb hunger and the anxiety that comes with it. We would like to have the option to try it.
Jackie G.	Yes I believe it will greatly improve the quality of life for my grandson with PWS
Karen G.	Promising results may make life easier
Lisa G.	Yes. Having the option for my son to take DCCR could mean he feels less anxious about food, and less anxious overall. DCCR could potentially increase his ability to be more independent in the community and in his life. I want this opportunity for my son.
Theresa G.	Yes; we are most interested in having access to any and all drugs and services/interventions that may help our loved one to live a healthier and happier life.
Evette G.	She deserves a better opportunity and this drug will give her those.
Dylan G.	As parents, we desperately need access to effectively treatments for this challenging diagnosis.
Alexis G.	Yes, it would be incredibly life changing for my daughter as well as all PWS patients who are struggling with the many challenges they face daily.
Susan G.	Yes. I would like my son to have access to treatment that would greatly improve his quality of life.
Barbara G.	Yes to try to have a better life

Appendix A

- Nancy G.** Yes! My son's biggest and most impactful part of PWS is hyperphagia. We try everything to help him with eating but the urge is too strong. We need a medication that helps this urge, like DCCR to be available. I worry daily about his health, weight gain and other medical issues that come with PWS. It affects all of our family but DCCR would help so much!
- Jane G.** Yes, sufficient evidence exists to support the use of the drug to improve quality of life for people with PWS
- Kenna G.** Yes! I believe that the benefits would outweigh any potential negative side effects! We need treatment options!
- Linda G.** Let's give every child with PWS a chance for a happier life.
- Elvira G.** Yes we would like the option
- Theresa G.** I would want doctor to tell me if this could improve my son's quality of life. If yes I would want access to the drug.
- Erika G.** yes, we believe this would be such an amazing thing for my little brother. we have hope and we're choosing to hold onto that. If there's something out there can help and ease PWS for him we want it.
- Helena G.** We need this treatment for my cousin to have a chance for a better life without feeling of irresistible hunger and severe problems with behavior in the future. I want her to feel that she is a regular girl and she can reach the sky if she wants to.
- Sarah G.** Yes, absolutely. As our daughter gets older, PWS has become a major hurdle in her/our life. The PWS community has been searching for help to make those affected by PWS able to sustain a higher quality of life and possible independence as adults. The benefits of access to a medication like this would have far-reaching benefits beyond the basic treatment of hyperphagia.
- Penny G.** Yes. Given the severe impact that hyperphagia has on a person with PWS and their family the large reward out weighs the small risk.
- Marcia G.** Yes. As a grandparent to support the parent of the PW child
- Athena G.** Yes, any opportunity to have a medication available to help should be given. I whole heartedly support DCCR to be given to my family member to have a better quality of life.
- Jackson G.** Yes, it would be very vital for her to have access to this.
- Kelly G.** I would definitely want the opportunity to try DCCR. My daughter suffers from both PWS and T1D so hyperphagia is extremely serious and potentially deadly for her. As such, any medication that could mitigate hyperphagia would be worth trying.
- Janet G.** We absolutely would want access to DCCR. Our Daughter has done amazingly well and worked incredibly hard, however the hyperphagia is getting stronger. She is living a life of measuring food and skipping social situations to not have to fight with her own body to enjoy the fun but not the food. She is a junior in high school and an honor student who will not be able to go to college or to live independently ... ever... because she needs support as it comes to managing food. If her hunger would abate she would be set free to live an amazing, productive, and independent life. She has done her part for 16 years with a life of zero days off from strict food management, daily exercise, and a commitment to choose to do all she can to be healthy. It is heart breaking to watch PWS winning. She needs DCCR and she needs it now. Our family needs relief. We understand possible side effects but compared to a significantly limited future and the health issues of disease progression, it would definitely be a benefit that outweighs the side effect.

Appendix A

Kayla G.	Yes, we know the impact it would make
Megann G.	DCCR gives my family member a chance to live without the feeling of constant starvation, 24/7 supervision with food, and the chance to potentially live independently. All of which right now is not possible. The doors it would open for individuals with PWS would fundamentally change their lives.
Ashley G.	Yes, I want her to be able to feel confident living in her own.
Cathy G.	Yes of course. We deal with terrible tantrums related to food and his need for food and sweets
Omar G.	Yes it would help improve behavioral and hunger issues
Fadila H.	Yes. This drug candidate shows promises in improving the lives of those living with PWS, and could impact subsequently the family members in a positive way.
Catie H.	YES!!! It would change her life!!!!
Brenda H.	Yes, it could potentially be a life saver in regards to helping behavior related to PWS
Penny H.	Yes! Seems very promising
Erin H.	Yes, any treatment that could improve my child's quality of life we would try
Vincent H.	Yes, having the option available vs the devastation of no treatment for the symptoms of hyperphagia
Rebecca H.	Yes, it seems to be very beneficial for most and we would love the option of trying it to treat the devastating hyperphagia that those with Prader Willi Syndrome struggle with.
Jennifer H.	Yes, it would greatly benefit my nieces wellbeing
Frances H.	Yes. Our nephew has struggled so much and for so long with food seeking and other PWS behaviors described in this petition. I feel this drug would change his life for the better!
Justin H.	PWS is an awful disease that has tried to destroy my cousin's life. She has overcome and is active and succeeding, but with amazing difficulty. I would love to see her have the option for a drug that would actually allow her to exist without constant hunger. I cannot imagine having to live with the burden of never being full. Despite the incredible dedication of her mother and friends to help her fight temptation and eat healthy, weight gain has been a battle she has not been able to win.
Shereen H.	Yes or please share updates.
Deanna H.	Yes. To help my nephew not feel hungry all the time.
Megan H.	DCCR could offer our son the ability to have a significantly improved quality of life.
Kebra H.	Yes! My daughter has enough challenges to face. She only can have help from growth hormone but with DCCR we can stop or slow her hunger issues when they come. If we only had to focus on the potential issues with behavior and psychosis then it wouldn't be overwhelming. My baby might be able to be independent in life and do more than avoid the world. If you want to live like a PWS family try to avoid all forms of food in this world then you will see how limited our babies are.
Michele H.	Yes. If this medication can have a positive affect in her overall life experience, we are hopeful for this as a cure for some of the VERY difficult day to day feelings, behaviors, and emotions individuals with PWS endure.
Ivana H.	Yes , it is hope for a better life.
Amber H.	At this point we are willing to try anything to make this hell of a journey easier for our little boy

Appendix A

Elizabeth H.	Yes, because Liam is almost 5 and already his hunger sensation is not accurate and his life is severely impacted when around food. To be able to have access to a medication that changes that for him would be truly life saving.
Shawn H.	Yes. I want my son with PWS to have the best quality life possible.
Susan H.	Yes. Prader-Willi syndrome is not the more common obesity problem seen and is uncontrollable by the person afflicted with it.
Heather H.	Yes, as a mother of a young child with PWS it's terrifying to see what our future could look like. It's been 20 years since growth hormone was approved. As a member of this community I've seen where DCCR has completely changed families lives for the better because DCCR has helped their loved one with PWS so much.
Ashley H.	Yes. PWS is an extremely debilitating condition for the person with the diagnosis as well as their family. It has been highly impactful on my child's siblings growth and development as well. My child wants relief (begs for relief) from the symptoms and impact of his syndrome which have increased with puberty. He desires a future that is not so limited by his condition. This medication may be able to provide this.
Rachel A.	When age appropriate
Steve H.	Yes. Due to lack of other treatment options.
Gina H.	Yes! I've only heard great things regarding DCCR. There are zero other options outside of the growth hormone. So yes we want to take it.
Vicki H.	Yes she is an infant and we want all the odds in her favor n pray the med would help her I think any person living with PWS should have anything available to make their quality of life better
Debbie H.	Yes. Her hyperphagia disrupts her life, learning, sleeping and coping with life. She needs help now. Please make this available to our loved ones with PWS.
Courtney H.	Yes. This drug had the potential and the hope to change our daughters life and our families lives. It's hard to be hopeful in rare situations. This drug gives our family a sliver of hope for a bright, independent future.
William H.	Absolutely, I want to provide my child with PWS, or anyone else's child with an opportunity that might provide some relief from any or all of the PWS symptoms.
John H.	Yes I believe it will help.
Becky H.	Yes, we are desperately trying to find medications to offset the continual hunger and the behavior battles that we endure 24 seven we desperately need assistance and anything that could take a little of the pain of this disorder off of our child and our family after 14 years of suffering, this alone is greatly needed please help
Jameson H.	I would want my nephew to have access to this treatment to help manage an already difficult diagnosis. Treatment for these symptoms can offer a brighter and more normal future for individuals with PWS. I would want my nephew the have the chance for that future.
Amy H.	Yes! We need options!
Anna H.	YES!!! We need a medicine to help treat the PWS symptoms, so it would be great if FDA will give it a go.
Jennifer H.	Yes, potentially after reviewing more information on the drug. Thank you.
Sally H.	Yes. I would like this drug to be made accessible for my daughter to try and assist with some of the symptoms of PWS.
Jamie H.	We love him with all our hearts. Why not live as normal of a life as possible

Appendix A

Nadine H.	If it's something that will improve an individual's life and ability to have more freedom with no or minor adverse side-effects of course we would love to have that option.
Mckenzie H.	Absolutely! We believe this medicine can help our daughter live a full life!
Jodi H.	Yes, being a parent of someone with PWS and knowing and seeing the challenges my child currently faces and the challenges she will see in the future, a drug that has the potential to alleviate some of the challenges especially the food challenges is definitely something I'd like to be considered and have an option as part of her treatment regime. Please consider what it would be like to be hungry all the time, if there was something that could potentially overcome that feeling wouldn't you want it to be an option?
Tonya H.	Yes it would be so beneficial for my nephew
Olivia H.	YES! My life is impacted by two little boys with PWS that would have much greater hope of a normal life with this medication.
Isabella H.	Yes. The opportunity to take this medicine will be greatly appreciated and would hopefully better their lives.
Cheri H.	Yes, we are running out of time
Kinga H.	Yes, we world like to be ale to take the medicine, it would make the life of my child with PWS easier.
Sharon H.	Yes definitely
John H.	Yes, it will improve my sons quality of life.
Max H.	I am the older brother of Rafael Heaton who is 7 years old has PWS. I think it would make a very positive impact on Rafa, and our family if Rafa had access to DCCR. For example, the other day my brother tried to eat a food he is not allowed to eat, he got in trouble and had a massive meltdown. If he had access to DCCR, he wouldn't have had either of these problems.
Morgan H.	Absolutely!! We are begging for a chance at getting this life changing medicine. The experience I have living with PWS is awful for my young adult daughter. She hates having this burden her life and the opportunity to live like her typical age group. This medication would allow her to have independence, something she is craving for. But she knows the addiction she has to food prohibits that. She is otherwise high functioning but the addiction to food causes severe anxiety for her. It's a terrible way to live. Having a medication available that would change this and not having it available NOW is torture!!! Anybody would want this for their child and I'm not understanding why it can't be a priority to pass this through. We are begging. Please consider making this a priority ASAP. Our kids and adults deserve this.
Janalee H.	Yes - due to the hyperphagia and the obesity.
Allen H.	Yes, my son can gain over 10 pounds in a week if his access to food isn't controlled. His drive to eat is the most important thing on his mind. And his anxiety level is very high because of the desire to eat.
Megan H.	Yes. The symptoms of PWS are debilitating. A medication to treat symptoms is desperately needed!
Marie H.	Yes of course, according a medical prescription. Hyperphagia is so difficult to contain
Mary H.	yes. effectively managing hyperphagia would be life giving
Olivia H.	Yes, our child PWS develop severe hyperphagia due to PWS and autism

Appendix A

Karla H.	Do you want my nephew to take the medication so that he has a better quality of life and can fully develop
Gaudencio H.	Yes to help combat the symptoms of Hyperphagia
Valerie H.	Yes, as it has shown promising results.
Kathy H.	Yes, I would love for anybody living with PWS to get all treatment for PWS
Sally H.	Research found how important DCCR is for Prader Willi patients and vital is for them to have access
Jose O.	Yes, hyperphagia is the main issue to stop that triggers all the other problems of children with PWS
Laura H.	Yes I want that my daughter have a better life
Elizabeth H.	Yes, anything that will help him thrive and live a full life with his brothers.
Dorte H.	Yes, it could be life-changing for us as a family
Zach H.	Yes, we are willing to try any treatment options that have the ability improve our sons health and quality of life while living with this life-altering condition
Amy H.	Yes. My grandchild struggles with food seeking, being overweight.
Reece H.	Yes, we would love for our family member to have access to DCCR. There is no treatment for some of the hardest symptoms of PWS. DCCR would be the only approved drugs to help them to live a full and independent life. DCCR is essential to the individuals and family members whose lives are faced with the horrendous realities of PWS.
Trish H.	Yes absolutely! My daughter has a debilitating condition that affects every part of her life, currently there no treatment to help her live life without constant hunger and anxiety, if I was given the choice to give her a medication that would help her to not have to live everyday if her life thinking about food, you better believe Id try it! Safety is important to me as well but I believe DCCR has great result and trust worthy track record of safety.
Michelle H.	Yes looking to help my loved one live an easier life with PWS
Jennifer H.	Yes, absolutely. A medicine to treat hyperphagia is critical to enable our daughter to live an independent life. The data for DCCR has shown that the drug is effective and safe for the treatment of PWS and its most debilitating symptoms.
Austin H.	Yes, DCCR it revolutionary and can completely transform my sisters life. DCCR in testing has been proven to reverse some of the effect of Prader-Willie Syndrome. My sister deserves a life as normal as possible.
Brian H.	Yes. A medicine/treatment for hyperphagia is critical to enable our daughter to have the opportunity for an independent life. Based on study data, DCCR has shown to be safe and effective.
Amy H.	Yes, because it will vastly improve her quality of life.
Stephanie H.	Yes, for hyperphagia and food anxiety.
Laura L.	Yes! This medicine would allow Nico to live independently, thinking also long term, and improve his quality of life, avoiding even possible high risks.
Sandra H.	Absolutely! To alleviate the debilitating symptoms of PWS

Appendix A

Denise H.	Yes - amazing results with controlled diet for our child.
Madigan H.	Yes, limited side effects noted in research and positive outcomes with well controlled diet
Kara H.	Yes. It has a good safety profile and seems effective for hyperphagia which would transform our lives.
Jenna H.	Yes - for a chance to live a longer and healthier life
Dixie H.	There has to be hope
Dayla H.	Yes to help my daughter with her constant hunger
Ken H.	Yes, to live a normal and healthy life.
Patricia H.	Yes, to live a normal, healthy and happy life.
Michelle H.	Yes, to be able to live a more normal and happy life.
Amy H.	Yes! We believe data supports effective use of DCCR.
Serina E.	Quality of life
Miriam H.	Yes, the benefits of this medication can have live-changing beneficial effects for my son. Hardships that he struggles with daily can be minimized, allowing him greater opportunities life has to offer, which are currently out of his reach.
Kevin H.	Yes, anything to help with hyperphagia
Miranda H.	Yes. We will want this medication for our son as soon as he needs it. And in order for that to happen it needs to be FDA approved.
Luke H.	I would want my nephew to be able to have access to it. He hasn't experienced Hyperphagia yet because he's so young, but the medication could allow him to never experience it.
Dylan H.	I want it to be available for when my son needs it
Shari H.	Yes for the improved quality of life for patients and families
Shamia H.	Yes, we would want, it provides a much needed option as my niece grows up. This will give her a chance to experience life with less challenges.
Cheri H.	Yes to using the medicine. PWS is a difficult syndrome to manage and any help would be welcomed.
Joshua H.	Yes, hyperphagia is what I most dread for my son Jame's future.
Nathaniel H.	Yes, with the hope it's a life changing drug
Martin H.	I believe my great niece's family would be very interested in finding help to avoid the symptoms to extent possible
Kathy H.	Yes! The hyperplasia my granddaughter has is heartbreaking. Please help us help her and kids like her.
Nathan H.	Yes! We have been looking forward to new treatments for PWS, especially for hyperphagia and behavioral issues. We are passionate about doing our part to help advance treatment options for our daughter and all people living with PWS.
Kaitlyn H.	Yes, this drug could be life changing for my Neice
John H.	My daughter's hyperphagia controls our lives. Every day is structured around meal times and snacks as much as possible. A drug or treatment that could help her and her family live more normal lives and most likely help her manage behavior swings around food as well.
Robin H.	Yes. Helping my daughter live a productive uncomplicated life without PWS symptoms has always been the goal.

Appendix A

Lynn H.	Based on data I have seen, I believe access to use of DCCR would provide a much needed significant improvement to my grandson's quality of life, and to others with PWS as well.
Jared H.	Yes, I've heard so much positive responses to this new treatment option, I very much hope that this will be made available to my son.
Gloria H.	Yes. Hope for the future.
Judy H.	Yes, the parent feels it will help.
Ya H.	Yes we would like to give our kid a try for anything possible to treat their syndrome.
Clement H.	Save her
Melinda H.	Yes if this treatment can help
Pamela H.	Yes! If this could help improve my son's quality of life and independence, I would love the opportunity. Could you imagine living your feeling hungry all the time?
David H.	Viable option recommended by patient's specialist
Montana H.	Yes definitely
Sally H.	Would like the opportunity to have this offered to my grandson to help him live his best life
Natalie H.	Yes we would. We want our daughter to live a "normal" life without being controlled all the time. We want her to be happy and independent some day what means not to be surveyed all the time. To be happy with her body, to have true friends, to avoid being a angry monster when getting in a new food situation.
Anastasia H.	Yes, we would love for our family member to have access to DCCR. There is no treatment for some of the hardest symptoms of PWS. DCCR would be the only approved drugs to help them to live a full and independent life. DCCR is essential to the individuals and family members whose lives are faced with the horrendous realities of PWS.
Haley A.	Yes I do
Aida H.	Yes. It has shown tremendous advantages and help to people living with PWS
Ramona H.	Yes. There aren't any other medications that benefit a person living with PWS. We need access to what is available.
Karen H.	Having the option is crucial
Jeanie H.	Yes, this medicine could be life changing to anyone with PWS.
Shadan H.	Yes. The choice should be available
Shanlee H.	Yes, I want my child to have the best possible life available
Blanca I.	Yes I would totally be in favor of my son trying it. Obviously when he hits the appropriate age and most importantly his safety. PWS already is scary and mysterious for us and not sure what to expect. This just gives me and my family a lot of hope for our loved one for the future.
Nancy I.	Help my son overcome any symptoms related to hyperphagia and be able to live and independent life if possible
Daisy I.	To better their future
Alvaro I.	Yes. A better life for my niece
Sara I.	Yes this member of my family would want to take the medicine. It would improve her life, physically and socially
Paliukh I.	to improve the quality of my daughter's life in the future
Agustan I.	Yes, we hope it could be life changing for them
Sara I.	Yes, but I am the grandparent of twins with PWS. Their parents would make that decision.

Appendix A

Sara I.	Yes, if needed, I would like DCCR to be available to my daughter with PWS
Iryna I.	yes, we would like to use any options to improve the condition.
Alexa I.	Definitely. This impacts quality of life in a significant manner.
Ashton I.	Yes, when my family member is older, this medication will make a huge difference in their quality of life.
Stephanie I.	Yes!! There are currently NO options to treat hyperphagia. Once my son gets to that phase it means everything to us that we have a way to help him.
Raju J.	Yes. We would like to.
Erin J.	Yes- this is could greatly affect the quality of life of my nephew
Austin J.	Yes so he can live a more normal life
Brandy J.	Yes, this medication could prevent our family member from ever experiencing hyperphagia.
Santosh J.	Yes, I would be willing to enroll my son for medication available at our place of living. After careful evaluation of the situation and discussing with caregivers and care takers, I believe the pros overpower the cons. So I am very positive for a bright future of my son
Sheena J.	Yes. Almost anything would be better than living in a state of hunger.
Vahab J.	Yes. Our daughter needs the best chance to have as normal of a life as possible. In an era where we have access to vast information, technology to validate tests/findings, we can't let red tape hinder progress for these life alter drugs.
Brian J.	Yes, we would definitely like access to a DCCR medication. The extensive track record of safety should allow parents to request DCCR on a compassionate basis, or better yet, through approval. Thank you.
Michelle J.	Yes to control Insatiable appetite
Joyce J.	Yes!! My granddaughter deserves treatment! HELP PLEASE!
Catalina J.	Yes, because it would help it will help with the most debilitating symptom of PWS and allow him to live an independent life, no strict restrictions to food and participate freely in all social activities.
Allyson J.	Yes. Weighing the low risk and potential of high reward to alleviate some of my daughter's worst symptoms of PWS and increase her quality of life and ours as her family, we would love the option of taking DCCR.
Brittany J.	Yes. Our son deserves the chance to improve the symptoms associated with his PWS!!
George J.	Yes, strong efficacy/safety profile
Craig J.	We are desperate for something that will alleviate the suffering of our son from constant hunger, and for something to help him and our family manage very difficult behaviors. This is the first ray of hope we have had for 17 years. I do not wish to be ungrateful or disrespectful, but the delays at this point seem at best unnecessary and at worst inexplicably cruel. Please put an end to our waiting and my child's suffering.
Mark J.	Yes, the potential benefits are to great to say no
Ronda J.	Yes. Currently, there are no treatments to combat our daughter's persistent hyperphagia and resulting extremely difficult behaviors. DCCR has the potential to improve these symptoms and improve the quality of life not just for our daughter but for our whole family. a
Allyson J.	I would like to have this option for my niece since there is no medications she can take now

Appendix A

John J.	Yes. Our God daughter has PWS and we support any options that might help her and others with this disease.
Rachel J.	Yes, it would possibly help my nephew with outbursts
Cindy J.	Yes I need my son to be able to have to the option to take the medicine and keep from gaining more weight
Victoria J.	Yes so she can live a live without constantly wanting food
Nikole J.	Yes, we would love to have our daughter on DCCR to help with symptoms of PWS.
Miranda J.	Absolutely! We want our son to live a happy, independent life!
Libby J.	Yes 100% yes ... To be given the opportunity to try DCCR to reduce the effects of hyperphagia would make a huge difference to our daughters life but also for her siblings and us as her parents. PWS is a cruel and non relenting condition. To give her some symptom relief would be so beneficial on so many levels. We live in Australia with a small population so we need the help of the FDA so we can then lobby our TGA to approve DCCR so that we too could access a potential life changing drug.
Cynthia J.	Yes only hope available right now
Jessica J.	Yes she would like to take it
Johnnie J.	Yes, I would try anything to make my son's life better.
Annette J.	Yes, we believe this drug could help Jackson live a more normal life. It could help control the feeling of always being hungry and also help with feelings of anxiety. Please give the PWS community the option of taking this medication for hope of a better life.
Rachel J.	Yes, we have run out of options and hope. DCCR is all we have left.
Ashley J.	Yes. My cousin's child suffers from PWS and she has spoken about this drug with the hope that it can help.
Denver J.	As an extended family member, I've learned of the challenges faced by my loved ones due to their grandson's battle with Prader-Willi Syndrome (PWS). It's heartbreaking to know that Jackson must endure the lifelong challenges posed by this condition with no cure in sight. The hope of effective treatments like DCCR (Diazoxide Choline Controlled-Release) provides a ray of hope in an otherwise difficult situation. I stand in solidarity with my family in urging the FDA to prioritize the review process for DCCR, recognizing the urgent need for treatments that can offer relief and improve the quality of life for individuals like their cherished Jackson.
John J.	Yes, we would want our family member to have the option of taking this drug for help with the symptoms of PWS. I believe it could help Jackson live a more independent life and be able to participate in more activities with his family and friends.
Robin J.	Yes, any opportunity my daughter has to live a life free from hyperphagia is an opportunity we would love to have.
Ashley J.	Absolutely- we want the option for our Sophie for hyperphagia
Keith J.	Yes anything to provide hope for a long life
Marina J.	Yes of course! I would want the opportunity to see if it makes a difference in my son's daily life. He deserves the possibility of a better quality of life.
Alicia J.	Yes! I have heard very positive feedback from those who have had access to the drug. As there are no other approved medications for PWS, aside from growth hormone, I would love to have DCCR as an option.

Appendix A

Nicole J.	Yes, to elevate the hyperphagia and the behavior that goes along with it is worth the risks of this drug.
Tashia J.	All persons deserves to live a fulfilled life without limitation
Dona J.	Would love for my grandson to take it. My daughter is very hopeful that it will help him have a better life.
Sarah J.	Yes. If will help the PWS community in any way it would be wonderful of this were available.
Lisa E.	Need for family member with hyperphagia symptoms
Jen J.	Yes, without this drug her life will be stifled or even worse. At this point an experimental drug is better than not having an option.
Ben J.	I'm watching my niece not have the same childhood as other kids her age. She needs this drug to help her. Please help her and other kids have the better life they deserve
Jessica J.	Yes, DCCR treats an unmet medical need for those with PWS. It is life changing.
Jennifer J.	Definitely we would want to have the option for our child to take DCCR. It could potentially mean living a full and independent life! They would be able to pursue their dreams and as parents, we could worry less about what their future will hold.
Peter J.	Yes with regard to the option of taking the drug once it becomes approved .
Noam J.	Yes! the data are very compelling, with minimal risk to our kids
Ramã J.	Yes, because several studies support its effectiveness
Gordon O.	Benefits outweigh risk
Julie H.	My daughter starts sneaking food when it's not time to eat at all. It becomes urgent to control your impulses.
Catherine J.	Yes! I have a PWS son and this is amazing!
Katrina K.	We would like to Help our children
Brian K.	Absolutely! We dream of a future for our son that is full life and opportunity. We believe DCCR can help us all achieve this.
Dennis K.	Yes, to counter hyperphagia and mood swings
Samantha K.	Absolutely. We have zero options now. As a parents we deserve to choose whether or not to give something to our child. This has been shown to work and be very low risk. We are praying for this drug
Mohamad K.	I agree in order to improve the quality of life
Tanya K.	We would absolutely want this option if the time became necessary to implement a treatment for hyperphagia.
Hana K.	Improve quality of life
Gavin K.	Yes - my daughter is struggling to keep her weight in check and has weight related health issues.
Elizabeth K.	Yes, anything that can help my son thrive in this world and let him live life to its fullest, I want him to have full access to DCCR knowing it's benefits.
Christine K.	Yes, our little guy deserves to have the opportunity to have some symptoms of this disease alleviated with the hope of leading a more independent life.
Nicholas K.	Yes, the PWS community needs more weapons in their battle with PWS. There currently are not enough tools in their arsenal and it can be very straining on families

Appendix A

Randi K.	Yes, I want my family member to be able to function in society and have the best chance at assimilating.
Diane K.	Absolutely! Anything to help with the never ending feeling of not feeling full
Lindsey K.	Yes - I have followed this drug and its effectiveness within our community more then not. Every drug out on the market for the world works differently to the individual. It's not going to work for everyone but it worked for most or at least improvement . This drug needs to be available in the US then it will trickle down to most if not all over countries . Please consider this drug for review and pass it . Our kids need this . It's the answer to so many problems that can change our lives. You have the power to make our community live the life they deserve. This drug will also eliminate the need of other resources in the future which in then returns to less gov funding needed to be used . I understand you have a duty and responsibility to make safe decisions. But as you can see with the results this is affective and is the answer for most of our kids . Than
Mitchell K.	Yes - it would help out so much!
Barbara K.	Yes! We haven't been able to get in any of the trials due to lack of space or geographical distance. We need something for her hyperphagia!!
Samuel K.	Yes. Any medicine that could benefit my daughter needs to be available.
Charlotte K.	Yes. I believe this could vastly improve my 9-year-old daughter's current and future quality of life.
Kory K.	Absolutely, yes. It will be life changing for our son
Josephine K.	Yes. My son is living with PWS and we want to give him the opportunity to live a more typical life around food. DCCR could help with a major aspect of PWS of hyperphagia. This could potentially drastically improve his life.
Susan K.	Yes - we will try anything that might help take the "edge" off of food for him.
Sean K.	Yes. Anything that can curb his food seeking would be beneficial
Tessa K.	Absolutely. The results are incredible and there is nothing by else. I would do anything to help this devastating aspect of PWS
Jessica K.	Yes, I believe it is safe and can help to better the life of my daughter
Doreen K.	If it can help my granddaughter I want that option
Lesley K.	Yes- data suggests it improves health outcomes for this life threatening condition.
Scott K.	Yes; the situation is very difficult. If anything had the potential to help, it would be worth trying.
William K.	Yes, my 37 year old son has Prader Willi. The resulting hyperphagia and behavioral issues are debilitating for him and my family. There is now no treatment. This medicine my be lifesaving. Please, please, please grant priority review.
Amanda K.	Yes, it sounds very promising and my son desperately needs some help with hyperphagia and anxiety
Lynnette K.	Yes we would like the opportunity to try anything that would help
Jala K.	Yes since there are very limited options
Amber K.	Yes, this medicine could change her life. She is only 13 but gained 27 pounds this past year from stealing food. We desperately need this help.
Annet K.	We would like to, because we already see the beginning of hyperphagia.
Danica K.	Yes. Needed to keep her healthy!

Appendix A

Kyungmin K.	Yes. It is a battle everyday to control my sister who has PWS. It is very difficult to keep her away from overeating. She's not able to have a normal life (i.e. having friends, going to work (for at least things she could do), or even taking a walk by herself) as she is always tempted to reach out for food.
Amy K.	100% we believe in science and medication and the vast improvement of quality in life that DCCR brings with decreasing the effects of hyperphagia. Our 2 year old is already asking for more food and throws tantrums around, we need a treatment so all of us can live some semblance of a normal, non suffering life.
Ashley K.	Yes we would be very interested in using it in our 8 year old with PWS
Lisa K.	Yes. Hyperphagia and fat collection are huge issues as well as behaviors. It's bad because now he realizes these things too and it making Sebbie very sad.
Renee T.	My son is 13 years old and anything that would be supportive of him. Would be great.
Christy K.	Yes for quality of life
Helen K.	Yes, since there isn't an effective drugs to help hyperphagia, I would love to have it available for my grandniece!
Jessica K.	Yes. It is safe.
Ashley K.	yes! Everyone should always have access to all available medical care choices.
Melissa K.	Yes! This medication could help our daughter and all her PWS friends live life full!!
Brandon K.	I 100% want my child to have access to DCCR, as it has been shown to be effective AND safe, and there is no approved medication to help with these PWS issues!
Michael K.	Yes, b/c I want to give my child the best chance at a higher quality of life and this option would be worth it for us.
Jordan K.	Yes. I think it would definitely show positive changes in his life as well as others with PWS
Mana K.	Yes. It's extremely important to our family for the kids to have access to more opportunities in their future.
Rebecca K.	Yes he needs help with his ever present day
Katherine C.	Yes! This is the only hope my son has to not experience hyperphagia when he gets older.
Martin K.	Yes. Any improvement is good.
Thomas K.	Yes. If it helps him than he will take it
Paige K.	Yes. It would greatly improve the quality of his life.
Izabela K.	Yes, we would love to have access to this medicine because our son is starting to eat more and more and wants to eat more and more often. In fact, the situation is getting more and more difficult because we also have older children and it is becoming more and more difficult for them to live with it. We would like to live as normally as possible, without hiding what we eat and closing the kitchen.
Lori K.	100% Yes! Right now there are no options for us to treat this syndrome. We are managing while we have no solutions. Living a life that PWS kiddos have to live is cruel and unfair. This drug will give them a chance to be "normal" which is all any parent wants for their child.
Jan K.	yes, Because it seems to do no harm and actually works very well in a proportion of people with extreme hunger
Ted K.	Yes, if it works it will be a big change in his and our life

Appendix A

Florence K.	Yes, because it doesn't seem to do any harm and actually works very well for some people with extreme hunger
Keriann K.	Yes, to give her a chance at help
Gregory K.	Yes, we would
Stacy K.	Yes. Hyperphagia can kill my daughter. If there's a drug that can reduce or stop that behavior, it could save her life.
Holly K.	Yes, 100%. Our daughter is showing the first signs of Hyperphagia and it is terrifying and already life changing. I would give absolutely anything to make sure she can live a happy and independent life without the constant feeling of hunger and the anxiety that can bring on her and our entire family.
Lisa K.	Yes! I have been following the DCCR trials for years and I am absolutely convinced that patients such as my son should be allowed to try this potentially life-changing medication.
Jon K.	Yes, DCCR has been proven to be effective. My son, Thomas, struggles with hunger on a daily basis and is beginning to show signs of hyperphagia.
Mary K.	Yes. All possibilities need to be explored.
Noa K.	Yes, it could really help
Dianne K.	Yes, our family member has progressed in this challenging disease. Anything that can help our children should take president for a better quality of life.
Stephanie K.	Yes, once it is approved
Jennifer K.	This medication has shown to be very promising for individuals with PWS who have had access to it. With very few treatments available for individuals with PWS, it is critical to allow access to this medication to as many individuals as possible.
Hannah K.	Yes, my nephew is still very young and it would save him from the future trauma he will undoubtedly experience without this drug.
Theodore K.	Yes, to help him live a more normal lifestyle
Jayne K.	Yes, it could prevent him from ever having to deal with hyperphagia or other issues related to uncontrollable over eating.
Anna K.	Yes, this is our great hope for a better life for our son. I really hope that the drug will be approved.
Jonathan K.	We most certainly want the opportunity to take the medicine to help my nephew grow stronger
Darla K.	Yes. There are currently no medications for PWS
Abhishek K.	Yes, we reviewed the data and its positive response to be on DCCR. Yes, we would like this medicine available for our son when he will be eligible.
Jason K.	Yes, the double blind study in 2023 showed promise for subjects with severe baseline hyperphagia and this population of PWS patients while rare has lacked updated research and treatment plans to provide them with a better lifestyle in 2024. Thank you very much for allowing us to voice our passion!
Annie K.	Yes, to help with quality of life for our child & our family
Barbara K.	Yes - this disease is so devastating that anything that would help would be great.
Cecilia K.	Yes, the drug could improve the daily life of our family member with PWS

Appendix A

Malea K.	Yes - it would be life changing- as in, allow them to participate in life.
Maria M.	Yes to assist in their life challenges
Jarg L.	Yes, we would appreciate if our family member could have access to new treatment.
Lorena L.	Yes, it is very important that she receive medication since she is very overweight and it is increasingly difficult for her to move and it is essential that she have treatment that helps her improve.
Maria L.	All our hopes are on this
Pat B.	Yes. My daughter dreams of the day when her PWS is more under control.
Arthur L.	Yes because results are very good as we can read in different talks / articles.
Sara L.	yes, that would grant a stable and healthy future to my niece to ensure less comorbid effects PWS.
Rebecca L.	Yes. I've watched my 15 yr old nephew struggle all his life with being constantly hungry! Even though his parents are extremely regimented with his meal and snack times and healthy foods, he still is always hungry. It would be amazing for him to have the option to take this medication!
Jerry L.	Yes. As his uncle I obviously want my nephew to have a life that is not a constant battle for him.
Ashley L.	Yes. It would be life changing for him
Bailee L.	My cousin could potentially benefit from this medication. Anything to make life easier on him! I believe that this could be a huge opportunity for him to feel much more comfortable on a day-to-day basis.
Danielle G.	Yes. Getting older and harder to control PWS patient's outburst Cousin to patient
Daniel L.	Yes because it has been demonstrated that it can help people with PWS
Tania G.	Yes, because several studies support its effectiveness
William L.	Yes so she wouldn't suffer the pain of hyperphagia.
Jane L.	Absolutely yes. I have raised my biological grandchild since birth who is now 17 and is left to live forever hungry ... the anxiety she endures with the constant hunger. If there was an opportunity to save her from the nonstop hunger ..
Nicole L.	Absolutely! It would greatly improve my niece's quality of life. She would have the chance to live her life as the rest of us do.
Lisa L.	Yes, anything to help lessen the hyperphagia
Charles L.	Daughter's son has PWS and is willing to have my grandson try the drug.
Sandra L.	Yes. What parent wouldn't for their child with a rare disease.
Jennie L.	Yes, our son is always hungry and needs help!
Stephany L.	Yes. My son's appetite has increased and along with it comes frustration and upset.
Karen L.	Yes! We are willing to try anything to help extend the life of my 32 year old sister
Amy L.	Yes based on what I hear from those doing research
Sandra L.	Yes, I believe it would help with a difficult condition that hinders most PWS patients
Dorothea L.	YES! There is no approved treatment for hyperphagia and my son is already exhibiting signs!
Veronique L.	Yes, to help him live a less stressful life and a more secure one.
Mathieu L.	Yes to help my Family member getting access to treatment
Jim L.	Yes- to improve the conditions to get/have a better life
Tina L.	Yes, his hunger is out of control which leads into physical aggression

Appendix A

Lindsey L.	Yes, we would like the option to have access to this medication as soon as possible.
Danielle L.	Yes please!! Nothing we've tried has helped and it seems to be getting worse :(
Carol L.	Yes for my young grandchild who has PWS.
Michael L.	It would help them greatly the remainder of there life not having to deal with all of the symptoms from PWS
Angela L.	Yes because it provides so many good benefits. It would allow us to live like a normal family instead of having to run away from events that offer food.
Katherine L.	Yes, I have heard it is life changing for the patients receiving it.
Laurianne V.	Yes we want to tryptophane for us daughter
Joseph L.	Yes. The research listed shows that this medication will significantly improve the qualify of live for those living with PWS.
Brandon L.	Yes! We need to have this medication available for our daughter so she can live a typical life and not suffer from hyperphagia.
Melissa L.	Yes, this drug would allow my daughter to live a full, independent life.
Gemma L.	Yes! I feel the studies show enough positive results with little negatives.
Marie A.	They need something!
Olivia L.	Yes, it would provide an option to help her symptoms
Didier L.	control of satiety and improvement of comfort of life
Sourisack L.	Give better chance to my Child to have a happy life
Jennifer L.	Yes. Our family would love to have access to a medication that could help our daughter. There are currently no treatments for the symptoms of PWS and we would love to have access to one.
Lea L.	Yes, my nephew is at the age where he has extreme hyperphagia and he is gaining weight very frequently. We are working very hard to reduce his weight
Natalya L.	Yes! We are so looking for ward to the opportunity for our son to take this drug. He is 6yo and we are seeing his anxiety around food increase day by day. It has been our dream since we first heard of DCCR that it would be available to him when hyperphagia comes and hyperphagia is right around the corner for our family, which feels very scary. Please prioritize reviewing DCCR so our son has a chance at minimizing any time in his life experiencing hyperphagia!
Allyson L.	Yes, drug therapies should be available as an option to all families who wish to participate.
Matthew L.	Yes, we are interested in anything that will help our son grow up with a more typical lifestyle
Joanne L.	Yes. Advance the cause
Shelby L.	Yes. We would love to improve the quality of life for her now, and for her future
Darla L.	Yes. I want my child and all of the PWS kids to have access to this drug to help the kids have a better life and hopefully, live their lives full. I have cried many tears over the last several years and prayed to God for a drug/cure for PWS. The challenges of PWS affect everyone in the family. It's devastating as a parent to watch your child struggle and not be able to fix it. Please approve DCCR for the PWS kids.

Appendix A

Emilie L.	Yes, overeating is a very difficult symptom for children to manage and generates many frustrations and crises. This medication could both soothe the feeling of hunger but also all the tensions surrounding this symptom.
Katharina L.	Yes. It has the potential to even save his live as it would reduce or eliminate high risks associated with PWS
Tobias L.	Yes. This would allow him to have the opportunity to live independently without restriction of access to food and allow him to participate in activities with others of his age and his family.
Krysten L.	yes, it will give my child the opportunity to live without hunger and thrive to her best potential.
Lucas L.	Yes. Anything that can help
Krysten L.	Yes. If this drug shows vast improvement of the quality of life for people living with PWS, we want that opportunity for our child.
Eileen L.	Yes, I would want my nephew to have access to this medication. If he can get help with hyperphagia, behavioral and emotional challenges this would be an amazing thing. I want him to have as happy and healthy of a life as possible.
Jennifer L.	Yes, I believe this would help my son.
John L.	Yes to support and help my son whom has PWS
Fiona L.	Yes, because food is a real problem in the life of a PWS person. Indeed, the frustration create a lot of crises which are difficult for the family who lived with a PWS person. Furthermore, when the child with a PWS grow up, the parents have more difficulties to keep an eye on what the PWS child eat every days.
Kristin L.	Yes. Need medication for hyperphagia
Melinda L.	Yes!! My daughter was diagnosed around the age six. Started the growth hormones a few years after which I had to fight and travel 2 hours from home. she is currently 12 over weight and very little support. I truly need help.
LI LI.	YES, TO HELP THE PATIENT TO CONTROL HIS HUNGER & TO BE ABLE TO LEAD AS NORMAL A LIFE AS POSSIBLE
Camille L.	Yes if it will further the safety
Brigitte L.	Yes, I think so
Paula L.	Yes we currently have no medications to help with hyperplasia and would love to have medication available
Kelly L.	Yes, I think it is vital to his development and to his social-emotional well-being, as well as his physical health.
Joshua L.	Yes, willing to try anything to give her a better life
Linda L.	Yes, based on the present result this mediation will reduce the hyperphagia and behavior issues associated with it.
Mary L.	I think her parents would appreciate having access to medication that would make their daughter more comfortable.
Abigail L.	Yes. As soon as possible. Hyperphagia significantly reduces my son and our family's quality of life.
Helga L.	yes, we're hoping this medicine will normalize her hyperphagia
Jennifer L.	Yes! If we can lessen the burden of the horrific challenges that PWS creates we would LOVE the opportunity and access to DCCR.

Appendix A

- Nguyen L.** Yes, I do. They are very lovely children but disadvantaged in their own lives. So I want my child to have the best opportunities and be able to take control of his life
- Tricia L.** Yes, as my daughter grows older her obsession with food and constant anxiety around food has worsened. We would consider any medication that would help her.
- Deborah L.** He's young, starting at the beginning of his life would be detrimental in him having a normal life
- Kallie L.** Yes, we would like to try anything that might help him.
- Meghana L.** Yes, as we are open to exploring all new treatment options
- AnnaMaria L.** Yes, we would want access and would work closely to monitor all effects with our care team.
- Pamela L.** Yes. Whatever there is to improve their quality of life I would do it. lives
- Nicole L.** As a licensed pharmacist with firsthand experience in pharmaceuticals, and as a parent of a child diagnosed with PWS, I strongly advocate for the expedited review of DCCR due to its potential to address the unmet medical needs of individuals living with this rare genetic disorder. DCCR has demonstrated promising safety and efficacy data in clinical trials, and as such, I believe it is imperative that it be made available as a treatment option for PWS patients as soon as possible. Given the debilitating nature of PWS and its associated complications, including hyperphagia, obesity, and behavioral issues, there is an urgent need for innovative therapies like DCCR to improve the quality of life for affected individuals and their families. My husband and I, both pharmacists, have thoroughly reviewed the available data on DCCR and firmly believe in its potential to make a meaningful difference in the lives of patients with PWS. In light of the urgency and severity of the challenges faced by individuals with PWS, I respectfully request that the FDA prioritize the review of DCCR and expedite the approval process to ensure timely access to this important therapeutic option. Thank you for giving our son the best possible chance at a normal life.
- Rene L.** As a father, pharmacist, and advocate for my son Jackson, who bravely battles Prader-Willi Syndrome (PWS), I am deeply invested in the search for effective treatments. Witnessing Jackson's daily struggles with PWS and knowing there is currently no cure weighs heavily on my heart. The hope of treatments like DCCR (Diazoxide Choline Controlled-Release) provides a beacon of light amidst this darkness. Its potential to alleviate symptoms and improve Jackson's quality of life is immeasurable. I implore the FDA to prioritize the review process for DCCR, recognizing the urgent need for treatments that can offer relief and the possibility of a brighter future for Jackson and others living with PWS.
- Hannah L.** Yes! Anything to help this little kiddo.
- Amy L.** Yes it would improve his quality of live
- Janis L.** Yes. My grandson has no social life. He cannot live alone or go out on his own because constant hunger creates intense stress, and the urge to eat is overwhelming.
- Pilar L.** Yes, it is the only drug which can help improving hyperphagia
- David L.** Yes. . We are supporting this new drug
- Israel L.** We need the medication because it will improve her life quality and help with social and physical condition. Thanks

Appendix A

Glenda S.	Yes! Our little niece deserves to be given the opportunity to be a thriving and contributing member of our world.
Robien L.	Yes to help her
Paula L.	Yes. He would be willing to try anything that may give him relief and live a more normal life.
Catherine L.	Yes, if it will improve quality of life
Rebecca L.	Yes anything to help with his hunger and the meltdowns
Stacey L.	Yes. Anything to help my daughter
Eric L.	Absolutely! It would provide a chance to live a more normal life
Jen L.	Yes, anything that would improve the lives of children living with PWS hyperphagia
Kristie L.	We would love to participate in anything that helps our community
Neyra L.	We love to trial this medication for our daughter Mia. We've been waiting for someone to contact us regarding any kind of trials for far too long now. We won't lose hope!
Ying L.	Yes, if it is approved by FDA, we would love to have access to DCCR!
Adeline L.	Hyperphagia
Cerdan L.	Yes, everything that can improve the life of my child need to be known and use.
Kathryn L.	Yes, this medication would help with the anxiety my child has with food
Margarita L.	Yes. We would love to try and see if it would help our girl as much as other PWS people
Brian L.	Yes, based on the information provided through research and testimony, I believe all individuals with PWS should have access to DCCR
Jeanette L.	To help her live a normal life, not be hungry all the time.
Henrik L.	Yes his behavior effect our life quality.
Edan L.	<p>Yes! Our daughter is 31 yrs old and has had PWS since birth. There in not ONE Dr in the State of NM that works with PWS. She did have a diagnosis until she was ten and that was after taking her to every specialist we could find. An Endocrinologist in Albuquerque finally ordered a DNA Fish Methylation test & low & behold, + PWS. As an RN, I had been working in the NICU and while holding a feed & grow, I got a hold of the Smiths book of human malformations. Never read that book when you're pregnant, and I was 8 mos pregnant with our son. This book is where I found PWS, and since no one in NM could diagnose it, we raised her by the guidelines in the book. We've been active in 4 different Clinical Trials. One of the trials had to be stopped due to blood clots. One at UC Irvine and 3 at Rady's with Dr Lynne Bird. We would absolutely LOVE to be in your Clinical Trial!! We are uncredited to all specialists in NM. We pay an extra \$470/month just so Sarah can have PPO coverage to go to Mayo & Rady's. It's been a 31 year long medical journey. She's on CPAP & Modafinil for her Sleep /Wake cycle. We are really hoping to be put on your Clinical Trial as Sarah never rcvd HGH, she had a short stay in Pittsburgh before it was shut down. The Rady's Team is amazing. I truly hope you consider Sarah. We would be happy to travel anywhere in order to get this. It's one medication that she's never been tried on. Thank you so much for your kind consideration..</p>
Debra E.	Yes, game changer!

Appendix A

Robert L.	I believe that the trial results thus far regarding DCCR clearly show it can be safe and effective in reducing hunger in PWS. My daughter (who has PWS) and her peers are desperate for a treatment for their hyperphagia and all the anxiety and life challenges it creates. The FDA should as quickly as possible review the data for DCCR.
Brenda L.	Yes it is medically necessary
Kamilla M.	Yes, because it shows promising results
Lasse M.	Yes. It gives us hope it will help our daughter.
Lisa M.	I think Options on medications would be great!!
Maria C.	In order to control the symptoms, we need all the options available
Christine I.	Yes, it will make a huge difference in my family members quality of life.
Larry I.	Yes. It could be a life changing drug
Kyrie I.	Yes. Right now she is too young but the results of trials are very promising.
Keely I.	Yes! We have been looking forward to new treatments for PWS, especially for hyperphagia and behavioral issues. We are passionate about doing our part to help advance treatment options for our daughter and all people living with PWS.
Christine M.	Yes. We believe it is effective for many symptoms of PWS of which my child has many.
Catherine M.	Yes- access to options is a need. The need for Pharmacological control of the eating compulsion is desperate.
Camellia M.	yes, it would be a lifechanging treatment that could hopefully prevent harmful symptoms of PWS
Clifford M.	The treatment will change our lives and hopefully prevent symptoms.
Jennifer M.	Yes. Controlling hunger is our number one priority.
Olivier M.	Yes, I have been told by the parents they needed support to request the authorization of this new medication.t
Pierre M.	Yes. Need to try to enhance research
Essam M.	Yes, we would like to try it, as access to PWS medicine in the region is incredibly hard.
Bohdanna M.	to improve the quality of my daughter's life in the future
Michael M.	Yes, I think it will greatly benefit my cousin
Jenny M.	Yes, my family member would like the opportunity to explore this option for the wellbeing of her child.
Silvia M.	Yes, my daughter is always struggling with hunger
Mario M.	Yes, my son is two years old and this medicine would benefit him greatly and allow him the opportunity to thrive and have a fulfilling independent life. Thank you and God bless you
Tara M.	Yes I believe it will benefit him.
Andrea M.	Yes I have two nephews with PWS who want to take DCCR and who's life could greatly benefit from it
Karen M.	2 of my nephews have PWS and I would love to see if this medication could help them.
Sally M.	Yes, my family member would like the option to take this drug. The potential benefits far outweigh the difficulties and health consequences caused by Prader Willi Syndrome.
Anthony M.	Yes. We have always looked for medicinal therapies capable of improving quality of life.

Appendix A

Heather M.	Definitely. It has the possibility of reducing her hunger AND the anxiety that drives many of her behaviors.
Justin M.	Definitely. It has the possibility of reducing her hunger and the anxiety that drives many of her behaviors.
Jeremy M.	Yes - I would like to see my sister explore all options that allow her to live her life more independently.
Concetta M.	Yes. To help my daughter live an independent life
Matthew M.	Yes, because this is her best chance at alleviating the symptoms of PWS.
Rodolfo R.	Yes, with the aim of avoiding/minimizing hyperphagia in the near future
Jill M.	Yes! The promise of life quality currently unavailable for our daughter
James M.	This seems like an excellent option for my daughter!
Pascale M.	Yes . I will for sure try the drug so my child can have a chance to live normally and have also the chance to go to school without thinking every second of when he will be the next meal! This drug mean a better future for our children
Ana M.	Yes, for a better life and opportunities to make if painful
Stephen M.	Yes if needed, currently under 2, may need in next year or so.
Teresa M.	Yes, I want for her an improvement in her life
Nancy A.	Mom expresses interest
Elisa M.	Yes, anything that can improve my niece's well being and help others is a blessing
Ines M.	Yes, we believe it will significantly improve our family's quality of life and our daughter's independency
Rana M.	Yes, at a later stage when my daughter is older and experiencing more complex symptoms of PWS
Maria M.	It reduces the severity of the disease
Joseph M.	Reduced disease severity and improved quality of life
Veronica M.	FDA approval is absolutely necessary and the possibility for all PWS members to have a better quality of life.
Claudia M.	Yes, to Allow ease the integration in the society
Alisha M.	Yes, we have an almost 2 year old who has started consuming food at a quicker rate than we're used to and therefore we would like to plan for the potential challenges ahead to give our girl her best chance at life
Trisha M.	Yes, we would try anything that would make life more manageable
Debbie M.	Yes, in the future
Katie M.	Yes if it will help with the debilitating symptoms
Mariela M.	yes of course. We are interested as a family in being able to have the medication.
Pateicia M.	Yes, it will alleviate the symptoms for my daughter living w
Samuel M.	Yes, to help alleviate the debilitating symptoms of Prader-Willi syndrome
Antonio M.	Yes because that would help kids with the urge of being hungry and improve their health
Mauricio M.	Yes he is 3 years old
Erika G.	Of course yes, since any medication that helps my daughter improve neurologically is quite helpful.
Fatima S.	To help with the debilitating symptoms of Prader Willi Syndrome

Appendix A

Petra A.	Yes. There has to be some way found to relieve the suffering of our loved ones with PWS.
Andrea M.	Yes, this would significantly improve my loved one's daily life
Holly M.	Yes we are desperate for drugs to help with PWS traits
Susana M.	Yes, if testing is near us.
Rita M.	Yes, I want every opportunity to help my daughter and I've heard great things about this.
Jodi M.	Yes. It can be effective in helping my niece
Amanda M.	Yes, this would greatly be able to help cousin.
Kristine M.	Yes, we would try anything deemed safe
Gerardo T.	Si, para ayudar a su vida y a su salud de mi hijo
Melissa M.	Yes! I have seen the struggles of others in the PWS community without any options for treatment. I have heard the testimony of some who saw wonderful results with DCCR. I would like my daughter to have options for her future and the chance at an independent life.
Elisabeth M.	Yes absolutely. My son's independence is severely limited due to hyperphagia. We are desperate for a medication to curb his appetite and hyperphagia so he can live a more normal adult life.
Holly M.	Yes because it would improve my daughter's chances at having an actual childhood where she isn't solely focused on food and when she can eat next, leaving her to enjoy kid things like bike riding more. Currently she is 4 years old and I've already had to watch her for food seeking and at times wanting food instead of playing with her older and younger siblings. This medication would increase her ability to just be a kid.
Cynthia M.	Yes as it could help to improve the overall health of those with PWS.
Chris M.	Definitely would like the option.
Robert M.	Yes - it helps with some of the symptoms he is experiencing
Harriette M.	Yes, to ease bad behaviors
Gerald M.	To obtain the benefits of this medication
Mary M.	Yes. Hyperphagia, aggression/destruction, excess weight "our PWS person's like would be substantially improved with effective treatment.
Andrew M.	Yes, my family member with PWS hopes to one day have access to this drug. hyperphagia is the main symptom responsible for lack of independence in adulthood for those living with PWS. A drug that could treat hyperphagia, would mean a hope for a better tomorrow for those with PWS.
Natasha M.	Yes please. Having a child with PWS and is constantly hungry is tiring for both my child and family. This medication will help my child not suffer anymore.
Lynn M.	Yes we feel it would be very beneficial
Carol M.	Yes to help her
Terrence M.	DCCR is a treatment for hyperphagia which is a key symptom of PWS. This medication can improve the life of people living with PWS.
Julia M.	Yes! We are in full support of developments in the PES world that can aide in improving our child's quality of life.
Marsha M.	Yes, we could use extra help with her appetite and weight
Jane M.	We have seen how it helps those affected with PWS.
Barbara M.	Yes it will improve his quality of life and give him a chance at an independent life
Grace M.	yes We hope it will help

Appendix A

ReBecca M.	Yes. If it can change my daughter's life then she deserves to have the chance of getting it.
Kim M.	Yes, to improve quality of life and functionality going forward.
David M.	Yes. I fully support all approved methods to treat PWS.
Deven M.	I believe is those in my family that are educated on the benefits of this drug are in favor of this, I am as well. Leave no stone unturned to assist with living with PWS.
Brian M.	Yes, as it would help to mitigate or reduce some of the effects of PWS
Melanie M.	Yes. Preventing or diminishing the plague of hyperphagia is well worth any side effect or risk
Mandy M.	Yes, please! If my precious niece had access to this medication it would mean so much to her well-being, and our family would be so thankful!
Dolores M.	Absolutely yes. We want our granddaughter to be able to live as normal a life as possible. We just love this little girl so much this of course we want the best for her.
Joseph M.	Yes. I feel it's so incredibly important that our granddaughter be able to experience a lifetime of happiness without the constant agony of hyperphagia. No person, much less a child, should have to live with this. Every effort should be made by the FDA to support those inflicted with PWS.
Nicole M.	Yes, of needed I'd want this drug to be an option for my loved one
Mitchell M.	Yes, the evidence shows that the medicine will be very helpful to those with PWS.
Ashley M.	Yes. Our daughter will not experience hyperphagia if we have access to DCCR for her.
Matthew M.	I cannot express enough how much I WOULD indeed want access to DCCR. It will change my daughter's life.
Barbara M.	I want my family member to have the best life possible.
Kathryn M.	We need help for our kids and with the safety profile so fat I would absolutely give it to my daughter.
Lauren M.	Yes!! I would want my PWS daughter to have the option to take DCCR. Currently there is nothing that even comes close to helping with hyperphagia and, as a small community, not a lot of interest in the development. DCCR would give her a chance at a real life and living life to her fullest potential. Without this option, I know my loved one will suffer. Like any parent, I want to give my child any option at succeeding.
Natalie M.	Yes, I as the parent/guardian and my son living with PWS and the constant daily struggle we live with is devastating. He actually said to me today I'm so tired of being hungry mommy, I just want it to stop. This forever starvation feeling causes anxiety, outbursts, canceling of plans, not attending get togethers where food will be left out, not going to places with concession stands and never, ever being able to live on his own.
Bobbie M.	Absolutely, yes! My daughter has PWS and is 26 years old. She was diagnosed at 17-months-old. While she did have typical PWS manifestations her whole life, it wasn't until the last 3 or 4 years that her weight skyrocketed. She is currently 5'1" and 260 pounds. Her PWS manifestations have become much more severe in the last 10 months, with increased food seeking, weight gain, aggression and negative behaviors, decreased cognition, increased urine and stool incontinence among other things. DCCR is desperately needed! Her quality of life is poor and her mortality is approaching. We need this drug desperately! Please help our often overlooked community!

- Bobbie M.** Yes we would! My daughter is 26 years old and has PWS by deletion. She is 5'1" and 268 pounds. We have always been careful with her food and caloric intake, however, she has gained over 100 pounds in the past 4 years. This is partially due to psychiatric medications necessary to treat the progressive behavior problems that are common with PWS. I am desperate for a medical intervention that will help her improve. She can barely roll over in bed, struggles to get dressed and put on shoes and socks, can no longer reach her private areas to wash, dry or wipe herself. She has incontinence issues, and is too large for even the largest incontinence briefs, so her therapeutic mattress has been ruined. The entire PWS community needs a big boost in available treatment options for its loved ones. Mortality is a very real concern with this syndrome, and without access to medicinal trials and options, that fear only grows. I am so sickened to see so many people losing their lives too this condition because of the struggles with addressing weight and behavior issues!
- Steve M.** Very much so. Our little Gracie has such Hyperphagia & irritable behavior outbursts causing issues with family, friends & at school. Thank you so much.
- Lisa M.** Yes! There has not been success alleviating her symptoms without this medication.
- Julia M.** Yes because they need options for treatment as there are currently none
- Christopher M.** Yes. Their care providers are advocating usage.
- Erin M.** Yes, we should all have the option to live our best lives and not be held back by access
- Ruth M.** Yes, my family member would like the option of taking this drug as we have heard that it can be life changing
- Robert M.** absolutely. my understanding of DCCR is that it has shown promise in treating the hyperphagia that is the hallmark of Prader-Willi Syndrome. Anything which would help treat that horrible symptom would be an incredible blessing to all who deal with PWS.
- Delanie M.** YES! Currently there is NOTHING to help with the hyperphagia in the PWS population. It was be the first breakthrough for PWS individuals to possibly help them live an independent life.
- Carolyn M.** Yes! The last section has a text box asking to explain if you want access to DCCR- You can copy paste this if you want: Yes, there is no treatment for some of the hardest symptoms of PWS. DCCR would be the only approved drugs to help my niece live a full and independent life. DCCR is essential to the individuals and family members whose lives are faced with the horrendous realities of PWS.
- Mike M.** Yes, the more options the better
- Curtis M.** Yes, there is no treatment for some of the hardest symptoms of PWS. DCCR would be the only approved drugs to help my daughter live a full and independent life. DCCR is essential to the individuals and family members whose lives are faced with the horrendous realities of PWS.
- Breanna M.** Yes, there is no treatment for some of the hardest symptoms of PWS. DCCR would be the only approved drugs to help my daughter live a full and independent life. DCCR is essential to the individuals and family members whose lives are faced with the horrendous realities of PWS.

Appendix A

Trevor M.	Yes. My wife and I have spoken to parents whose children have been on the trials. We've met with the researchers and PWS doctors. We know this drug can have a significant, important impact and that the downside risks are limited. Given the dramatic impact of hyperphagia on any life, we'd want all possible options for our daughter to help mitigate it.
James M.	Yes! This for an infant that I suffering, with no energy and little hope for longevity and a huge burden on the family that would require constant care and support.
Calvin M.	Yes, whatever is safe and can help her as soon as possible.
Richard M.	Yes. It would give her the ability to live a more stable life.
Morgan M.	Yes! Access to this medicine has a HUGE impact on their quality of life
Kathleen M.	YES. Treatment options are too limited! My nephew is suffering.
Dennis M.	My grandson doesn't have hyperphagia yet, but if he does develop that, I would like DCCR to be available for him
Kim M.	My grandson does not yet have hyperphagia, but if he ever gets it, I would live for this to be available for him.
Cristin M.	Yes we want the option. There are not other medications available. It could improve the quality of life not for her but the whole family. If you do not live with someone that has Prader Willi Syndrome then you will never know or truly understand the strain that it can put on a marriage or the relationship between siblings. This is a much needed treatment in the Prader Willi world.
Deborah M.	Yes! To have the chance to relieve the torture of hyperphagia and the associated behaviors would truly be incredible for my 33 year old son.
Elizabeth M.	Yes. This drug looks to have wonderful potential to mitigate some of the devastating health impacts our loved ones with PWS face everyday.
David M.	We would at least like the opportunity
Cathy M.	Yes the 3 year old could use it very much
Brittanie M.	Yes we would if it is able to help curb those hunger needs. She will have better control of her emotions.
Melissa M.	Yes, giving my daughter the option to a therapy that improves her quality of life, is something we should have the option to provide for her.
Albert M.	Yes, it would assist with the condition greatly.
Daisy M.	Yes, anything to help our loved ones and their parents alleviate their symptoms
Ashley M.	Yes it would help me feel not hungry all the time
Kimberly M.	Something is better than nothing and right now not having any treatment available that can help with the immensely challenging hyperphagia, greatly impacts the quality of life for both my daughter with PWS and myself as her sole Care Provider
Elizabeth M.	Yes!!! His Doctor believes this is the most advanced drug for PWS and that it would be life changing!
Marjorie M.	Yes, in hopes that the medicine would improve his quality of life.
Meredith M.	Yes, they feel along with their Dr. this is his best chance at a cure.

Appendix A

- Steven M.** Yes, we would love for our family member to have access to DCCR. There is no treatment for some of the hardest symptoms of PWS. DCCR would be the only approved drugs to help them to live a full and independent life. DCCR is essential to the individuals and family members whose lives are faced with the horrendous realities of PWS.
- Ronda M.** Yes, we would love for our family member to have access to DCCR. There is NO treatment for some of the hardest symptoms of PWS. DCCR would be the only approved drug to help them live a full and independent life. DCCR is ESSENTIAL to the individuals and family members whose lives are faced with the horrendous realities of PWS.
- Bradley M.** Yes, we would love for our family member to have access to DCCR. There is no treatment for some of the hardest symptoms of PWS. DCCR would be the only approved drugs to help them to live a full and independent life. DCCR is essential to the individuals and family members whose lives are faced with the horrendous realities of PWS.
- Rachel M.** Yes, we would love for our sweet Sophie to have access to DCCR. There is no treatment for some of the hardest symptoms of PWS. DCCR would be the only approved drugs to help them to live a full and independent life. DCCR is essential to the individuals and family members whose lives are faced with the horrendous realities of PWS.
- Juliane M.** Yes, because of the promising symptoms relief results
- Moises M.** Certainly, if there is a solution we should pursue it.
- Hanni J.** Yes, due to the reduction in hyperphagia and OCD that currently tremendously impact our son's life
- Aileen M.** Because it is safe, because it has been shown to ease symptoms, because it is a life altering opportunity for individuals living with PWS. Withholding and dragging out approval of this safe and effective drug would be likened to purposely forcing those with PWS to suffer terrible symptoms they could otherwise have treatment for.
- Erin M.** Yes!!!! My son and all his fellow PWS friends deserve a full life. A life of independence and so much more!
- Diego M.** helps the development of the affected
- Marcia M.** Yes, my granddaughter is at the age now that all she does is ask when her next meal is or is it snack time yet. She constantly thinks of food and it breaks my heart. This drug needs to be approved so that all children with PWS can live a better life. The future of these children deserve a chance to live a normal lifestyle and the parents of these children need a break mentally and physically and emotionally.
- Melinda M.** Yes willing to try anything for outbursts
- Brenda M.** Willing to try anything to get help.
- Michele M.** Yes, I feel it would be helpful w/ his hyperphagia
- Michelle M.** Yes, certainly if it could be helpful.
- Paul M.** Yes, I want him to have every benefit possible for improvement.

Appendix A

- Lindsay M.** My daughter is four and while she has not yet reached the hyperphagia stage of the syndrome, her life is already impacted significantly by a hyper interest and fixation with food. My daughter is amazing-- she is so incredibly kind, she is joyful, she loves to learn. She already has to overcome so much to show up in the world this way. I want her to have every opportunity to keep being her and for her to enrich the lives of those around her. It is devastating to think her brain will one day make that nearly impossible. She deserves all the options she can get.
- Baptiste M.** Yes can't be worst than not taking anything
- Heather M.** Yes, my 13 year old daughter suffers from behavior outburst, OCD like behaviors, anxiety regarding food. She cannot be left alone. This drug would give her a chance at a more typical life, with independence, friendship and would greatly improve the quality of life of her brother and parents.
- Teddy M.** My daughter, Palin Meyer is 13 years old and had lived with PWS since birth. Since birth she has attained a quality of life we never thought imaginable. This drug would create an ability for her feel like she is not always behind the 8-ball. It could give her independence and a life without fear of hyperphagia, and anxiety just to make a few things. Our family has waited for this drug since Palins birth and with the help of the FDA you could make her dreams a reality. Thank you for your time in reading this excerpt and the opportunity for us to share our story. Teddy Meyer - St. Augustine, FL
- Desire M.** Yes, the extent to which our whole family life has been controlled by my daughter's hyperphagia. It has compromised the future of my daughter and us as parents. If we could just manage her eating, it would make a world of a difference to an exhausted family
- Jessica M.** Yes, to improve the quality of their lives and give them the ability to live their lives safely and with dignity.
- Elzbieta M.** Absolutely Yes. Based on very strong data from clinical trials along with very good safety profile, I believe that my granddaughter will really benefit from DCCR therapy and she will have a chance for better, fulfilling live with really reduced hunger feeling and lead behavioral problems that can really improve her functioning. We really need this treatment for our loved ones.
- Grzegorz M.** Yes, we do! DCCR data has proven significant improvement in critical PWS symptoms like hyperphagia and behavioral issues. I want my granddaughter to have a chance for better life without feeling constant hunger. We need this treatment and whole PWS community need this.
- Anna M.** Yes, yes, yes! As my daughter is only 4 months I truly believe that thanks to DCCR therapy that has proved very good safety profile and high effectiveness for many challenges that people living with PWS have to live, my daughter has a chance to live a better life and not to feel so overwhelming symptoms which can extremely improve her quality of live. I truly believe in DCCR therapy and I'm full of hope that this breakthrough therapy will be available for all people living with PWS asap.
- Maja M.** I want my sister to have a chance to be treated with DCCR. I want her to have a chance to reduce her hunger ok the future and improve her quality of life. I don't want her to feel excluded at school, during family gatherings etc. Please, we need this treatment for her. It breaks my heart when I think how she can suffer in the future because of PWS symptoms. I want her to be happy girl.

Appendix A

Samantha M.	Yes, there is no medications to help the symptoms of PWS. Our community desperately needs help getting medications approved to give kids like mine a better chance at living a normal life.
Laura M.	Yes, the data demonstrate efficacy.
David M.	Yes would like the option for my child to use DCCR. Benefits outweigh risks and there are no other approved options.
Everett M.	Yes, we desperately need options for some of the worst symptoms of PWS
Heidi M.	We would love to have this drug as an option for our daughter for her future struggles.
Brett M.	Yes! We want to give him every opportunity to live a normal life
Deana M.	Yes, anyone would want someone who has any syndrome to have access to any drug that would help.
Lindy M.	Yes. It would help to promote a healthier future.
Susan M.	High anxiety and temper outbursts
Patricia M.	I definitely want this medicine made available for my beautiful niece. She deserves to live as normal and self sufficient a life as possible. This medication could make all the difference for Prader-Willi sufferers.
Kaitlin M.	Likely if needed in the future
Lee M.	Absolutely as looks promising and will try whatever helps
Sheri M.	YES! We need to try and see if this will work for my child. We have no other choice. We need hope, and we need trial /error. It starts with approving one medication.
Cara M.	Yes, it would greatly improve life.
Margaret M.	Yes, it could make a huge difference in quality of life
Michelle M.	Yes. It is not the business of the government to gatekeep the potential life-saving measures for those with PWS.
Kayla M.	Yes, to help with living with the effects of PWS
Cheryl M.	Yes. The management of hyperphagia and all the side benefits would significantly improve the independence and quality of life of affected individuals.
Daylene M.	Yes. The management of hyperphagia and all the side benefits would significantly improve the independence and quality of life of affected individuals.
Drew M.	Yes. The management of hyperphagia and all the side benefits would significantly improve the independence and quality of life of affected individuals.
Bryce M.	Yes. The management of hyperphagia and all the side benefits would significantly improve the independence and quality of life of affected individuals.
Kim M.	Yes, I would want my family member to have the chance at a life changing or medication that improve his quality of life.
Cory M.	Yes! Absolutely! PWS is a complex genetic syndrome that impacts my daughter profoundly on a daily basis. Any medication that can help her a better life is something I want her to have access to.
Walaa M.	Yes, I want the option to take medication
Sameem M.	Yes, with no other cure for hyperphagia, I am willing to give my son this medicine.

Appendix A

Cainan M.	Based upon the information about the data collected on DCCR, I would love to have the option of taking this medication. As a 19 year old male who lives with PWS and who struggles with excessive hunger and increased hunger cravings, I have been hoping that the FDA would approve a special drug that would significantly help alleviate these struggles so that I can feel better, and I don't have to be worried about needing extra food anymore because I have a special medication that actually works efficiently to reduce my appetite and boost my energy. I also know that my parents and my brother would also really want this medication to be approved by the FDA and they would be very happy to know that I would be able to take this medication. I hope that the FDA approved this drug not only for my sake, but for everyone else who struggles with PWS.
Heather M.	We would want our son to take DCCR to improve his PWS symptoms.
Joe M.	Yes. Any chance to lessen the food seeking
Kiara M.	Yes, it would improve his quality of life and he would be able to integrate with society easier
Luis M.	Yes. This medicine has the potential to allow my son to have a more normal life
Eduardo M.	Giving him the opportunity to participate in the society
Angela M.	Yes! It will allow our son to have opportunities for independence! also to participate in everyday activities and be part of our society without restrictions.
Anna M.	Yes our 14 year old has all the symptoms of PWS and it affects every aspect of her daily living and our household. We need an intervention.
Carolina M.	Yes, this person thinks it is life changing
Susan M.	Yes, as Vivi is at a point, 6 years of age, where the onset of insatiable appetite, tantrums are looming in the near future.
Evan M.	Yes- she is only 6 months old and this treatment could change her life.
Rebecca M.	Yes. It would improve quality of life
Diego M.	Yes, to control hyperphagia
Mai M.	Yes , we look forward to the life quality that the drug might provide us
Omar M.	Yes please, life is getting harder everyday with our daughter Hana, with DCCR results during all trials, we really need this, we need hope and future for our daughter
Isabel M.	Yes because it has proven to help with food anxiety among other things.
Maureen M.	Yes I want my daughter have a good live and I know this medication help with the hyperphagia.
Lourdes M.	Yes, I would like for my son to have this option to better help him when the time comes. I've heard and seen how It's painful and frustrating for them to go through hyperphagia and would love the option to have a chance of helping him through it or even avoid it.
Vanessa M.	Yes, if it can help my family member with hyperphagia
Ryan M.	Yes definitely! I've only heard good things from the parents involved with the initial studies
Stephanie M.	Yes, this will allow those with PWS to live full and independent lives, which is currently not possible due to hyperphagia

Appendix A

Annamarie M.	Yes. Her parents are extremely concerned about her future quality of life and this drug could make a huge difference to her.
Alli M.	In the future when hyperphagia becomes more of an obstacle, yes, I would love the option to treat my son with medication that would serve him in living a better quality of life, without becoming a slave to food. So many living with PWS would benefit from such a drug, and we as mothers, family members, friends, etc., of those living with PWS will do all we can to make this happen.
Ashley M.	I would love for my son to not be hungry all the time.
Jorgen M.	Yes, it will be GREAT if my granddaughter can have this drug, to get a more normal life
Yosef M.	Unequivocally Yes! We trust the PWS community and our medical providers that all highly recommend DCCR. We need this medicine as soon as possible to give our daughter a chance at a more productive and independent life!
Elizabeth M.	Yes, very promising results from clinical trials
Ashley M.	The data speaks volumes: DCCR has demonstrated significant improvements in hyperphagia and other PWS-related symptoms. Patients and caregivers have reported life-changing experiences, from regained control over eating habits to newfound independence in daily activities.
Michele I.	Yes. Could benefit.
Michele M.	Yes, could be lifechanging.
Anna M.	Yes, I hope this can be a ground breaking innovation for better quality of live for my grandchild.
Cade M.	Yes My brother is my best friend and I need him not to think about food all the time or eat himself to death.
Ryder M.	Yes, it is safe and I know it will help my brother
Asher M.	Yes. He's my big brother and needs something.
Paul M.	Yes. It is 100% safe and has shown to work for many.
Katie M.	yes. it has a great safety profile. so great it is used in infants
Grant M.	yes. it's safe and I dint want my brother to be hungry all the time
Ann M.	Yes, to improve quality of life
Sierra M.	I have twin boys that suffer from PWS and I want to give them the life that they deserve and the ability to live a fulfilling life without the worries of dying so early from this illness. From what I've heard about DCCR and the research sounds like this is the key to making that happen for them and other people suffering from this illness.
Robert M.	The data shows that the medicine can reduce hyperphagia and OCD. Therefore I wish this medicine to be available for my PWS family member.
Marissa R.	Yes! If a medication made a difference in your life for the better, wouldn't you want to take it?
Christina M.	Yes we would be interested for our daughter and her well-being. This drug has the ability to change her life.
Dennis M.	When the PCW family member (6 months old) would benefit from taking DCCR.
Mary M.	Yes, My daughter is overweight and her hyperphagia is so bad she would benefit greatly.
Marcello M.	Yes. We want a treatment for hyperphagia for our daughter. She deserves to live life full.

Appendix A

Kevin M.	Yes. The results reported by families who took part in the trial significantly increase my confidence that DCCR would be greatly beneficial for my son
Jeanne M.	Yes. My adult son has so many independent skills, and the hyperplasia overrides it all. It's a fight he cannot win.
Joshua M.	Yes. If it shows a positive effect on an individual with PWS after 30 plus years of dealing with this condition I see this drug being a huge advantage to the caregiver.
Jonathan M.	Yes. We heard it works!
Murielle M.	My nephew is 16-months old and is followed closely to allow him to develop normally intellectually and physically. He isn't having hyperphagia symptoms yet but we want him to have a treatment available when he will need it so that he can have a normal life. Every child deserves that chance.
Rosalinda M.	Yes, already seeing the beginnings of some of the problems that will only get worse is heartbreaking.
Ronique M.	Yes! Yes! Yes! There are so few treatment options for people living with this condition. We are all desperate for a solution. This condition impacts every aspect of life and it's not fair that people with this genetic condition should have to suffer through life when there are more options available
Sandi M.	Yes, I believe, given the study information, it would improve our family member's quality of life.
Jeanmarie M.	Symptoms of hyperphagia are in the near future for our 2 year old granddaughter. We have met other PWS children with this devastating disease who have been struggling with the horrors of hyperphagia. The foundation for PWS research has worked tirelessly to raise funds to continue to study this rare disease. Approval of DCCR for our entire population would significantly improve our daily lives and the lives of children affected by PWS
Diogo M.	Yes! Alternatives are not effective and any hope is better than no hope.
Charlotte N.	Yes. It would help my cousin greatly.
Barbara N.	Yes I would like the option to try this medication.
Raina N.	Yes, access to anything that would help her live a better life is critical
Rebekah N.	Yes, we would be interested in speaking with our team of doctors about this opportunity for our son.
Omaira N.	Yes. Based in the studies, I think DCCR could help a lot
Julie N.	Yes, my granddaughter's parents want this option for their daughter who has been diagnosed with PWS available as she gets older and struggles with these hunger issues.
Haleigh N.	Yes. My daughter currently receives many interventions just to live a life of quality. She has already started showing food related behaviors, and I know as it progresses it will start to impair her growth. It is also important for parents and caregivers to have hope for the future of their children.
Marwa N.	Yes, we would love the option. To this medicine
Rhys N.	Yes, we need something that helps alleviate the effects of PWS for our loved ones. Right now there is nothing...

Appendix A

Brooke N.	Yes!! Hyperphagia is very dangerous on its own and can cause a lot of physical and mental problems with the individual and caregivers. This would be very helpful tool to help manage this condition.
Bernadette N.	Yes I would like my loved one to have the option of taking the drug
Diane N.	Yes, to help with hyperphagia, anxiety and behaviors.
Chelsea N.	Yes it would be a life changing drug to be able to have this drug readily available to my nephew
Annastasia N.	yes. My sister has PWS and autism and was on a previous drug trial that decreased her anxiety, decreased weight, increased muscle mass, and increased attention span to have a meaningful conversation for loved ones.
Natalie N.	Yes we would definitely want the option to be able to have access to DCCR. We are not in a position to participate in clinical trials due to our location but we would have if we could. We are grateful to those who have to help prove the efficacy of this drug and we strongly believe that the testimonies of those who have taken DCCR and experienced any benefits should be taken into account above all else. Our families are under severe stress on a permanent basis and there are no alternative solutions. PWS affects entire families and it is difficult to overstate how important a drug like DCCR is to us. We know best
Maggi N.	Yes based on the amazing results we've read about so far
Johnna N.	Yes! This drug holds so much promise of improving the life quality of my daughter. A future for her that we have only dreamed of where there is no more hunger and a quality of life where she could be independent.
Emily N.	Yes, my family member is a perfect candidate and this medication would change her life! Please help her gain access to this medication so she can have a better quality of life! We love her and she deserves the best life possible!
Daniel N.	Yes, my sister has been struggling with the negative effects of Prader-Willi, more severely recently in her life. This medication would change her life and the lives of those who care for her.
Jeanne D.	Yes. Looking for whatever means possible to help our little Gabi.
Ann N.	Yes please help us have an option of hyperphagia treatment for PWS kids
Thu T.	Yes, We hope to have access to medicine
Jennifer N.	Yes, this will allow him to feel full when he gets to the point of hyperphagia.
Kathleen N.	Yes it would make tremendous impact on quality of life for my loved one.
Julia N.	Yes, this drug has shown clinically significant evidence that it minimizes hyperphagia amongst other symptoms.
Alyssa N.	Yes. Hyperphagia is currently our biggest hurdle in our daughter potentially living an independent life. Access to this treatment would be HUGE for her quality of life.
Trishae N.	Yes. We want that little girl to have as normal of a life as she can get with such a rare syndrome
Kerstin N.	Yes, hopes are high that it will help my sweet cousin in her early age development
Sandra N.	Yes- to help with quality of life
Melissa N.	Yes, it could be life changing to decrease hyperphagia and help people living with PWS to improve emotion regulation.

Appendix A

Melbourne N.	Yes. No other treatment available for a major PWS symptom.
Rebecca N.	Yes. It shows great promise to improve my son's, and our, quality of life.
Renee N.	Yes. I believe it would give him a better quality of life.
Annaliese N.	It would make a huge difference in my family member's quality of life.
Sherry N.	Yes. Obesity due to hyperphagia is making my daughter sick
Sharon N.	Yes, although our grandson is 2 right now, we know that he most likely will experience hyperphagia as part of PWS. We want to make every effort to improve his quality of life.
Andrea N.	Yes, I would love for Kirk not to feel hungry
Marie N.	Yes. It would be life-changing, now and in the future. It would allow for a normal life.
Minna N.	Yes. The endless hunger effects your life so fully, you make bad decision because of it, you are never satisfied, you can eat very bad things, glue, paint, dirt etc.
Karen N.	Yes, if it helps it could increase the quality of life PWS patients
Jody N.	Yes, want to take advantage of every possible option.
Amy D.	Yes to help him with his daily struggles with PWS
Marianne O.	This drug is needed to combat the insatiable hunger that patients with PWS experience
Marianne O.	This is the only way our sweet little Grace will be able to live a normal life
Kristyn C.	Yes if it will help our daughter
Adriana C.	Of course I want to try this drug that can help my daughter to have a better life
Chris O.	Yes, to help manage the challenging symptoms associated with hyperphagia and other PWS symptoms.
Andreas O.	Yes, because the earlier she receives it the more chances she'll have
Abigail O.	Yes, there are no medications for hyperphagia and we would take it if it were available based on all the data and resorts of decreased appetite.
Kay O.	Yes - Based on the study and subsequent results my family would love the opportunity to take this drug. If there is a drug that would improve the quality of my cousins life. He lives in a constant state of hyperphagia and his quality of life is impacted greatly. This drug would significantly improve his health, life, and relationships. It will allow him to be more independent and support accounts for simple decisions like – what's for breakfast.
Betty O.	Yes, because it's the first time scientists have discovered a method to assist individuals who have PWS in handling their issue of constant hunger.
Jared O.	Yes, any treatment with any level of effectiveness would be extremely helpful. DCCR far exceeds this bar and is our HOPE for a better future.
Luca O.	Yes, DCCR has been shown to improve symptoms with PWS.
Huma O.	Yes, we would love the option no matter of cost as the benefits shown are priceless with minimal to no side effects.
Bianca O.	She would like to have the option to have the medication. With access to this medication it will help her with her PWS and make her day-to-day life better.
Michael O.	Yes this would benefit her and her family.
Linda O.	For my granddaughter to have a normal life
Joanne O.	Yes, it could be life changing for my child

Appendix A

Nikki O.	Yes. We need treatments for the devastating symptoms of PWS. Improving our lives one health and quality of life as well as those that care for them is what is most important
Joyce O.	Our kids and adults need this drug !
Samantha O.	Yes. My son has not hit the phase in which hyperplasia presents itself. However when/if he does, we would like to have a treatment option. Currently there is not one. As a parent of a child with PWS, this is a scary though. As you know, PWS comes with a multitude of behavior issues, some of which, this medication my also help. My son deserves a chance to live a happy, fulfilling life where he doesn't suffer with these constant problems.
Beatriz O.	Yes, we need to advance on treatments for our loved ones and improve their quality of life.
Kristi O.	Absolutely. Across to this drug would be life changing for my daughter.
Glenn O.	YES. This drug would be a game changer for my daughter.
Judith O.	Yes, my daughter is already suffering with hyperphagia. We don't want to lose her. I hope someday soon this drug will be available in all countries.
Olga O.	Yes, currently my grandchild has very low muscle tone and is being fed through a feeding tube. We are still unsure of what mental delays she may have. The sooner she can receive medication to improve her living condition the better quality of life she will have. Her parents will also experience fewer stresses as a family.
Eileen O.	Yes, to help her live a normal life.
Devon O.	Absolutely! My daughter is 16 and struggles daily with hyperplasia and losing weight. No matter how much she works out and eats healthy. It's incredibly difficult!
Heather O.	Yes! This drug is proven safe, and if it can possibly help my son, I feel We should have the availability to have access to it, to better the life of our child.
Teri O.	Yes I believe any intervention which can help the quality of life is important.
Suzanne O.	Yes. She needs it to have a normal life
Kathy O.	Yes. Anything that may help is better than no options.
Carolina O.	Hello, we would like to access DCCR. since my nephew needs the medicine urgently
Ellen O.	Yes, the results show better life quality
Eduardo P.	I would love my daughter could take this drug, she has hyperphagia and is a must for her. I know this could help her to have a better life.
Elga P.	Oh yes, it will help her to live a better life and to improved quality of life.
Yuri P.	Yes, I think it would help him.
Laurel P.	Would want the option of taking medication.
Sheri P.	Yes, as it has shown to be effective.
Brandy P.	Yes I would want to option to give this medicine to my son. There are no other medical options for our medical rate community. We need this medication available as soon as possible.
Victor P.	Yes, we would. We've heard so many great things about the DC CR and would love for child and opportunity.
Mariana P.	Yes. It's the best medicine since GH, approved 20 years ago. Our community deserves that. Our kids deserve a better life

Appendix A

Kathleen P.	Yes, this is a rare disease with so many complications, of course I would want my niece to have access to any and all treatments.
Sulema P.	Yes we would be open to it. We need this as an option for people living with PWS.
Cheryl P.	PWS has many challenges and struggles for all involved, and the families
Jedidiah P.	Yes my nephews would have a greater chance at leading a normal life with this!
Lorri P.	Yes. The medicine will greatly impact our grandson's life. They are currently living with no hope of relief from food seeking. The medicine has been proven to help.
David P.	Yes. To improve behavior
Leland P.	Yes, having my daughter take DCCR could be a positive benefit for her many challenges and limitations because of Prader-Willi Syndrome
Brian P.	Yes this medicine shows potential to help people treating PWS, which could be life changing both for the individual as well as the family members
Andrea P.	Yes, there is no other medicine that can help
Bruce P.	Yes, this would potentially greatly improve quality of life.
Carla P.	Yes we would like the option to take this medication for all PWS options are needed. Help is needed
Helen P.	Yes. I know that within the community it has provided people trialing DCCR a positive change of health and lifestyle. Without any treatments for the challenges of PWS our community faces a life limiting condition and risk of early death and poor health.
Simone M.	Yes because of better quality of life for my daughter with PWS
Allison P.	Yes, absolutely we want the option!
Lynsey P.	Increased quality of life, behavioral control, peace of mind, a chance at a normal life.
Suzanne P.	Yes, we would like to try anything/everything possible to help my dear niece live a normal life.
Panayiota P.	YES, to improve my child's quality of life
Laura P.	Yes, I think that having the option to take this medication will provide a tremendous impact on the quality of life for my son, Jake.
Jared P.	Yes, there a few medications available for us. Hyperphagia is a debilitating condition. I live with many conditions associated with my PWS if this were something that could be mitigated that would be life changing.
Loren P.	Yes-to improve the life of people dealing with PWS
Catalina P.	We want more help for hyperphagia problems
Cynthia Y.	Advancement through trial.
Rorri P.	Yes but doctor miller wants rorri to be at 250 lbs before starting the drug
Deborah P.	Yes PWs would benefit with healthcare
Sarah P.	Yes. We would do anything if it meant a better quality of life.
Joseph P.	Yes- we need this option for a better life
Raquel P.	Yes! My brother has almost no quality of life!! If this can give him some of that then yes!!!
Tammie P.	Our children deserve Ronan e a quality of life available through DCCR
Cathie P.	Yes it could be life changing
Dulce P.	Yes! If all research leads to a better life for my niece with DCCR.
Rachel A.	Yes, he would.

Appendix A

Marilyn P.	According to Her Parents Yes
Jerry P.	Alternative is far worse without making the effort to sustain Life.
Katrina P.	Yes in the future when my child gets old enough
Lauryn P.	Absolutely to improve his quality of life
Susan P.	Yes, the pain of watching my granddaughter being so obsessed with food due to hunger
Roxanne P.	yes, due to not losing adequate weight, hard to maintain weight loss, hard to loose fat, and etc.
Trevor P.	Yes. This person is in the beginning stages of hyperphagia, and this medicine could help his significantly
Mark P.	Yes. We feel that the experts and our industry have put a ton of effort and energy into developing and testing this medication. They feel they are achieving good results from this. I would like to have access to it.
Nicole P.	Yes. We need a treatment for hyperphagia.
Susi P.	Perhaps. It seems to be getting g some good results so yes, would like to try. Toni is still not walking at age, 21 months. He is non-communicative and we worry about his future with food-seeking and other behaviors associated with the syndrome.
Jack P.	Yes because it would help him with what he has
Tina P.	Yes I All the studies so far showed that it was successful in treating the patients PWS
Amy P.	Yes-my daughters weight has significantly increased over the years even with strict food control. Efforts to lose weight have been unsuccessful on our own
Linh P.	I really look forward to using this medicine to treat PWS syndrome for our children
Linh P.	I want to use medicine for PWS patients
Brooke P.	Absolutely! As a parent, not having any options for treatment for our son is a helpless, terrifying feeling. We want to be able to do anything possible to help him live a full, independent life. Those with PWS deserve viable options for treatments for the most debilitating aspects of PWS.
Maria P.	It would be an excellent opportunity since he has been living under diet and deprivation for 36 years, not being able to handle money despite having the capacity to do so.
Dominique P.	My granddaughter has PWS syndrome. If this can help her have a better quality of life. We must not stop the research, thank you
Shamus P.	Yes. If we could help with the hyperphagia and body weight my son could live so much more freely
Angie P.	Yes, we believe it will be helpful in our child's development
Cherippe P.	Yes This medication seems to provide tons of benefits to a person living with PWS.
Hope P.	Yes. This will help her live a life close to normal. Without this, she could be in pain and live in confusion. She deserves a better way.
Walter P.	Yes, we don't have other options
Jean P.	Yes, to have a better live quality.
Margaret G.	Yes, definitely. I believe that any drug that can improve the quality of life of a PWS individual, is worth the research and investment.
Alin P.	This medicine can save my son, please let Be humans and permit us to save our son live if it's possible.
Caroline P.	Yes. Data shows it would vastly improve their quality of life and ability to become independent citizens with potential, rather than needing lifelong support

Appendix A

Joanne P.	Yes if it would give them a better quality of life, sure
Ariana P.	Yes- if this drug can help and give PWS individuals improve their lives and longevity then please offer this life changing drug
Shera P.	Yes, he desperately needs it as there are not other options available.
Thomas P.	Yes. I believe this could help my nephew
Bill J.	To control hunger and behavior
Ashley S.	Yes if needed
Jennifer P.	Yes, I would love it for my daughter anything to safely help her.
Nicole P.	Absolutely! We all believe that the risks are worth the relief from severe symptoms of PWS
Carl P.	Absolutely, we believe in the science and believe in our doctors who support this drug
Marissa P.	Absolutely, yes. The drug is safe and side effects are minimal. The positive change this would make in her life would far outweigh any minor side effects.
Alison P.	Yes- it's been our biggest hope
Mario P.	Yes. I think we should use every tool available to help people living with PWS
Maarten P.	Yes, because I think it helps a lot in raising the child. It takes away a lot of stress for the child and the parents
Kathleen P.	Yes, my daughter fights hunger everyday. She should have the option to take a medication that helps her combat hunger.
Zachary P.	Yes, this could give my son so much. The thought of him struggling with hunger breaks me inside.
Joanne P.	It helps with hunger and behavior problems
Frank P.	Helps with hunger and behavior issues
Warren P.	yes. Other children on the drug had wonderful results. I can't understand why that opportunity for a full life is not given to all. If there is the slightest chance that this could be a benefit I don't understand why this should not be a slam dunk. This is not a dangerous drug. Please help our kids.
Kimberly P.	Yes! My daughter has no freedoms and is in constant danger if she is not monitored 24 7. Can't socialize with peers. Can't go to programs or classes or dances or anything social because of the food and her inability to control food seeking.
Doris P.	Yes, in a heart beat. This medication is going to be a life changing opportunity for all
Omar P.	It will change my grandsons life
Doris P.	Yes, it is life changing not only for the person Witherspoon PWS bueno their caretakers
Amber P.	Yes! My daughters life is controlled by food. Because her life is controlled by food, our whole family suffers. This medication could offer freedom for my daughter to be more independent & fulfilled by life. To interact with her peers & participate in social outings with constant food anxiety.
Nate P.	Yes, we are interested in any treatment for hyperphagia.
Lori P.	Yes. This medication has the potential to allow my son to live independently as a productive citizen.
Glenda P.	My grandson would be perfect to take the medication.
Kara P.	Yes most definitely

Appendix A

Shaquinta P.	My daughter was diagnosed at 3 months old and very often I cry at the thought of hyperphagia creeping in and taking away her freedom. Even though we are a small community we each want our family members to thrive and not live in fear of food. Options are freedom and every person deserves that chance.
Gayla P.	Please make this available to all who need it. Force insurance companies to pay for this.
Jeanine P.	Yes. It seems to have helped so many with behavior and hunger, even if only a little bit, its worth it to be an option. Please.
Catherine P.	Definitely! A game changer!! Will prevent hunger and help with behavior.
Paxton P.	Will help with my hunger
Ana P.	Yes. As I've Heard it could be a life changing medicine for PWS patients. This way we only want to give our beloved ones Their Best chance of having a fulfilling, happy, independent life.
Linda P.	Yes, since my daughter has been plagued with PWS symptoms throughout her life. We're open to trying anything that will help decrease her food cravings, anxiety, muddled thinking and behavior issues.
Terri P.	Yes. Any treatment to help him.
Dolores Q.	Yes but will be guided by the babies progress as she is only one year old now. We are terrified of hyperphagia and want everything possible from the medical community to prepare us for what we might be faced with. The neurological issues are tough to deal with but hyperphagia is cruel. Cruel enough to make even the most religious question whether or not there really is a God
Matthew Q.	We are desperate for Carlo not to suffer with the debilitating symptoms of PWS. Willing to travel to the US for access to DCCR.
Beverly Q.	YES, Absolutely. I am aware of families whose loved one with PWS quality of life has been transformed for the better. Not only the person with PWS but everyone in the family benefits from this positive, life changing drug.
Johana Q.	Yes, I think it will change the future to our PWS kids and families. Please accept DCCR
Sabra Q.	Yes, opportunity to reduce hyperphagia
Jeanne Q.	Yes, to move forward with potentials for treatment or cure
Erin Q.	Yes. Access to DCCR would give us a chance at treating hyperphagia.
Kristalyn Q.	Yes. Micah suffers from severe hunger due to PWS
Robin R.	Yes. We are willing to try DCCR
Grayna R.	Yes. It's a big chance to live as normal as its is possible for my granddaughter
Kata R.	Yes, we are always looking for ways to help improve quality of life in the long term and short term.
Kimberly R.	Yes it has been getting very hard with his food seeking and his weight gain.
Kristi R.	Yes, absolutely. Anything that may make the lives of people with PWS easier and healthier and improve their quality of life should be able to be accessed and trialed. The effects of PWS on the person affected health and quality of life can be devastating.
Robert R.	We are willing to try anything that would give our daughter a normal life.
Diamondra R.	Yes, I want the medicine for my son. It will improve his life, become independent and have a life like others

Appendix A

Catherine R.	Yes, in order to improve the quality of life of our son.
Helen R.	100%. I work in clinical trials and understand that the data shows a statistically significant reduction in hyperphagia. Access to DCCR is the most important thing in my life as it would have a dramatic effect on my son's entire life. It would mean he isn't extremely hungry 24/7, could focus more at school, require much less 1:1 support, have more independence. This list is much longer as the impact to people with PWS and caregivers is huge.
Kayla R.	Absolutely. The data speaks for itself, and it something we absolutely would consider if we had access to it.
Nathaniel R.	Yes - The anxiety around food is debilitating for my daughter, and to lessen that would be life changing.
Daniel R.	Yes based on test results to date & the possibility of living a more independent life style.
Pamela R.	Yes! As it is an avenue to improved lifestyle and longevity!
Maharlika R.	Yes - it shows promising results for my daughter to be able to thrive in the future
Rosa R.	Yes, he struggles and all the family suffers cause he needs to eat all the time
Christina R.	Yes, I would love the option for my child to be able to take DCCR. If there was a chance of her not being so hungry she asks me for snack every 30 minutes, or if she could actually feel full I would take it. If this could help her loose some of her fat mass, it would be amazing! We pray every single day for some kind of relief for our children, and now it is here at the tips of our fingers and we can not have access to it.
Nandini R.	Absolutely - we want our daughter to have the chance to achieve her dreams of becoming an engineer, to build a dog-friendly ambulance and live independently. None of this is possible without treatments like DCCR. She turns 8 next month and hyperphagia typically occurs between the ages of 3 and 8. She is a ticking time bomb and needs treatments approved today.
Juan R.	Yes! It will change her life and everyone around her!
Maria R.	Yes. For a better life
Leah R.	Yes, to improve quality of life.
David R.	Yes. Because she has PWS.
Joel R.	Yes...PWS is something of an orphan, under-served, under-treated and under-funded.
Leslie R.	Yes effects of PWS such as hyperphagia, and other known PWS symptoms.
Aaron R.	Yes I'm sure at this point they would be willing to try anything to help there child
Carole R.	Yes if it would improve quality of life.
Nancy R.	Yes.it sounds very beneficial
Miriam R.	Yes absolutely! A life with PWS is a life filled with continuous risks of death. Any medication that can provide some normality is worth ALL risks.
Amy R.	Yes, it could help him.
Crystal R.	Yes, most definitely
Kelsey R.	Yes- hyperphagia is my daughters main symptom of PWS this would be a life changing drug for her and our family.

Appendix A

Kathy R.	Living with PW is a 24/7/365 job for the parents or caregiver. My 26 year old daughter must have 1 on 1 supervision while awake. She will at times get up during the night to seek food. The constant urge to eat causes anxiety, self harming, low self esteem. If there was something to help with symptoms she would be able to live a better quality life as well as her family. Simple things the average person takes for granted going out to eat, being able to go to a public bathroom alone, feed your pets, and I could go on & on are things she would be able to do.
Aspen R.	Nephew was born with PWS & would benefit from this drug and have an improved quality of life.
Amelia R.	Yes if it will improve my daughters quality of life
Rebecca R.	Yes, very much so! I think DCCR and carbetocin both have presented some of the most promising potential treatment options for our community in a very long time. It is so disheartening to live with the day in and day out difficulties of the extreme hunger of PWS, and all of the other many other issues we deal with each and every day, and not have trials be able to continue because of FDA red tape when there has been so much improvement seen in lives in our community, like happened with carbetocin in the past. I also want to emphasize that individuals with PWS are just that individuals, and there will not be a one size fits all medication for our community. So if DCCR eventually ends up with FDA approval, our community would still like to have other up and coming medication options (carbetocin, etc.) to still be considered, as our community will need more than one single drug to help ALL. Please, PLEASE consider the caregiver voice and others within our community, as our voices so often go unheard.
Sara R.	Yes. Top researchers indicate that this will be the game changing medication for people living with PWS. My loved one is an infant, but we are hoping to secure her future, and this drug will be critical to her independence and quality of life.
Amy R.	Yes. She has PWS.
Kerry R.	Yes, anything to help him live up to his potential
Katie R.	Yes. Hyperphagia
Sandy R.	Yes. Bridget will soon hit hyperphagia
Jane R.	Yes, but in Carbetocin study now.
Simon R.	Yes we would like the option to be able to have access to take the drug. For quality of life and a somewhat normal way of life for children/adults with PWS is the goal.
Eva R.	Yes. Every child/adult deserves the right to live a regular healthy life. It is a moral and scientific obligation to ensure that every person in need of medical help is given that opportunity to live a life that they can have control of.
Lauren R.	Yes! The clinical trials have had outstanding results thus far, and I would love for my family member to be given access to it in the future.
David R.	Yes, because it is a helpful and effective treatment.
Denelle R.	Yes! Everyone deserves a chance at a better life!
Victoria R.	Yeah. To provide a better quality of life and social development for my child
Maegan R.	Yes, we need a life without hunger
Jaymeson R.	Yes!! We desperately need treatments for PWS to help our kids live life full. To give them opportunities to be independent. To live life like everyone else
Suzette R.	Yes, anything that would improve the quality of life for my granddaughter.

Appendix A

Rebekah R.	Yes we want our child to have the opportunity to relieve the hunger and anxiety associated with it, to free them up to live a more normal life
Kristi R.	Yes, I believe with this medication as an option my daughter could live independently
John R.	Yes. This would help with quality of life, which we all deserve
Justice R.	I need this medication so I can live independently. I know if I had this medication I would not be worried to live on my own. Hyperphagia is the only thing keeping me from being able to live alone
Trudy R.	Since my grandson will be 4 in June, he has not yet developed hyperphagia but if he does, we would definitely want access for him.
Edda R.	Yes. Improve quality of life.
Jordan R.	Yes, I would like my brother to have the option to live his best life possible.
Paige R.	Yes. We would love the opportunity to have access to a therapy to help our son!
Melissa R.	Yes!!!! Currently there are no treatments for PWS you take a second and imagine being hungry all the time. Think of how cranky you get when you're hungry. Think about feeling like that all the time and there's nothing you can do about it. Of course we want to make vacation to help our children. We work hard to prepare children to be contributors of society. All of that goes away when someone can function and their behavior start to change because they are constantly feeling hungry. This medication should've been approval along time ago, especially considering that the side effects are very minimal .
Barbara R.	I want to give every opportunity possible for this infant to grow up with as normal and healthy life as possible.
Scott R.	Hoping for all resources that can help an individual.
Lynn R.	Yes, based on anecdotal reports from families in the PWS community.
Barbara R.	Yes, for him to live as long as possible!
Wendy R.	To help with her condition
Juliet R.	Yes, I would love there to be some help available if/ when my granddaughter needs it.
Darlene R.	yes, we have had very little help for our daughter, we will try anything that shows promise.
Debbie R.	Yes. My son is 23 and living at CDC.
Lauren R.	It will help her live a full and independent life.
Olivia R.	Yes! Grace is a beautiful girl who needs this medicine to help her live a better life.
Gabby R.	Because Grace deserves a chance to live a normal life
Hannah R.	Having the option is always better than not even having an option. This may help treat my cousin's hyperphagia and give her a better chance of a normal life.
Yvonne R.	Yes! PWS is a cruel syndrome and drug that can help reduce the more extreme symptom, hyperphagia is a drug we would try. PWS without this symptom would be just about manageable, but with it, it's debilitating and life limiting. Our kids could be so much more if they had a fighting chance
Kathleen R.	Yes, to help the child.
Amelie R.	yes. it will help with her hyperphagia.
Luis R.	Yes, we need hope for our children
Jennifer R.	Yes. Eppie has hit that age where the pleasure food are becoming incessant.

Appendix A

Kim R.	Yes, would love to see my grandchild be able to enjoy a life without feeling hungry all the time.
Matthew R.	Yes, this is the only promising medication for the biggest symptom/effect of the PWS condition.
Dawn R.	Yes!!!! With the benefits that have been shown in DCCR it could help our daughter's quality of life and health.
Evelin R.	I sign this petition because for our children with Prader Willi Syndrome it is too complicated to be able to control hunger all the time and it is enormous suffering for them. In addition, controlling their weight is very important for me to be able to control the additional conditions of this disease. .
Patrick R.	Yes - I believe it will be life changing.
Cameron R.	Yes. We've heard positive results from families that have been on the trials.
Angelo R.	Yes because it will help my grandson
Brenda R.	Yes it will be beneficial for my niece at it will help her in her everyday life.
Nicte R.	Yes, he needs for a better life
Shawn R.	Yes, it could greatly improve my grandson's life.
Eisa R.	Yes, this could be crucial for her future.
Brad R.	Yes, it is a life changing drug that drastically improve quality of life
Jane R.	I want my daughter to have the option of taking DCCR because it would be life changing and improve quality of life.
Alyssia R.	Yes they want the option of taking the medication
Jeffrey R.	yes. heard and read good prospects
Jamie B.	We would love to have the opportunity to take the drug.
Jessica R.	Yes of course! I know that not every drug will work for every person but this community needs options and I know that the drug has had success for some people with PWS. No drug is without risks, but no disease is like Prader-Willi syndrome and we need drugs for hyperphagia to allow our kids to be able to live full lives.
Marisa R.	Yes, it's always better to have more options for treatment and care. Medical science is advancing daily and new medications can offer significant improvements.
Linda R.	Yes, we'd want significant options for our PWS loved one that would give him and his family the best they can be.
Bobbie R.	I believe it would help him and improve his quality of life
Anthony R.	Yes. My son deserves every chance at a happy and healthy life. If this medicine can help even a fraction of people with PWS why wouldn't we offer it. Pretend it was your child for a second and they needed this drug.
Hillary R.	Yes, would you want your child to feel hungry all the time? To have behavioral issues because the only thing they can think of is food. If DCCR can even help a fraction, let's do this! If covid vaccines can be approved in less than a year with tons of issues, why can't you approve a drug that has had good trials and can help a community.
Caitlin R.	Yes, gives me hope for my baby.

Appendix A

Fabienne R.	Yes we absolutely would like to try the drug. We have identical twins with PWS and the impact on all of our lives and daily routines is enormous. We would love to be able to interact and participate more in our community and within our extended family. We find ourselves often excluded because activities are simply not safe for our girls. This is often food or stress related. We would love our girls to have a more relaxed life without the constant burden they carry. If this drug would only help this in any way we would participate
Barbara R.	We would absolutely want the option to try this medicine. PWS is a tough diagnosis for the individual and those who love them. PWS severely limits participation in the community and leads to isolation of the entire family. It would be wonderful to experience a more normal life that could include our son.
Kathie R.	They want the option
Jean R.	YES emphatically! Our daughter had to be placed in a residential year-round PWS school, due to requiring food security, and severe behavioral and emotional outbursts. Families like ours who have done everything to help their affected PWS child are desperate for a med that holds some hope of their child living a more "normal" life.
Tabitha R.	My sister has PWS. It is a horrible starvation syndrome that has affected me my entire life and always will. I have been humiliated from my sister's outbursts, from her trying to eat out of trash, from her stealing food out of other kids lunchboxes, from her punching and kicking me, her teachers, my mom and my dad. Please do something to help her! Nobody I know with special needs siblings has had to endure what I have had endure. Please help my sister, me, my siblings and my family!
Tracy R.	Yes! If this will help my child who struggles daily with PWS, then I absolutely would want it.
Jeison R.	Yes, I consider this medicine like a tool for give more healthy and improve the quality of live of my son.
Heather R.	Yes! His family is in need of hope!
Ana R.	Yes, to reduce appetite and reduce Hyperphagia so giving her better life conditions. Thank you
Cristina R.	Yes, we live with the anxiety of Prader Willi hyperphagia and we would like to have that drug when our Prader Willi child gets older
Ryan R.	Yes Because the benefits outweigh the risks
Lauren R.	Yes, if it help behaviors
Nikkia R.	Yes. We want the option to utilize treatment that can significantly help the quality of life of our family member and to possibly allow for him to live a longer life.
Timothy R.	If it safely relieves extreme food seeking, temper outbursts and behavior problems, it would allow much improved quality of life and potential for independent living.
Elizabeth R.	Yes if it will advance the quality and life expectancy of those with PWS.
Sydney R.	Yes, everyone should have the OPTION.
Deborah R.	yes, if it means a better quality of life.
Sandra R.	Yes...better quality of life
Larry R.	Yes to improve her quality of life.

Appendix A

Anna R.	Yes. Clinical trials are very encouraging, and I want my niece to have the option to take DCCR.
Susan R.	Yes; to better regulate the satiation and emotional well being would be beneficial to each individual and to the whole of society, as it would enable individuals with PWS to connect engage and participate in the fabric of our world
Katie R.	The impact of DCCR seems incredible and we would love to be able to have access to it to help our daughter live a better life
Shaille S.	Yes! Piper deserves the chance!
Micalah S.	Yes we would be very interested in trying to make his quality of life better
Rashied S.	Yes to improve quality of life
Alayne S.	Yes, definitely want my child to have the option.
Hafiz S.	Yes to improve quality of life
Laurie S.	Yes, everyone deserves to live up to the best of their abilities. Lack of these drugs prevents persons with PWS from achieving this. That is not acceptable.
Malika S.	For sure we would like to have the DCCR medicine to save our daughter from dying from excessive hunger and the behavior attached to it. Our life is not normal as it used to be before PWS. We live a very difficult life.
Pauliina S.	Yes please, this would improve our quality of life significantly!
Monica S.	Yes my daughter has all these symptoms
Jeanne A.	Yes, if my children were of age to participate or were eligible for DCCR as a preventative measure to hyperphagia than I would. A treatment for my children with PWS would be life changing not only for my boys, but the quality of life for my other children, family and the entire PWS community. We need the FDA to approve so that this drug can be approved throughout the world.
Julianne A.	Yes, would absolutely want to try anything that could be a potential cure for this diagnosis
Ramon S.	Yes, for the tx of hyperphagia and better quality of life
Mauricio S.	Based on the information available about DCCR, we need to have the option of taking this medication to improve your living condition, that of your family, your caregivers, and society in general.
Anais S.	Yes please son 30 years old will help him
Andy S.	We strongly need this medicine.
Casey S.	Yes! Kids need this
Maria S.	Yes!! This would help our son so much and me as a parent to have a better quality of life in our home.
Katrina S.	yes, my son is almost 300 pounds and is unable to enjoy life, we need help
Marina S.	Yes, but we don't, we live in Brazil
Luis S.	Yes. My daughter have the PWS and would be a dream if we have this opportunity to taking this medicine.
Jordan S.	Yes. It would make a world of a difference for my little cousin
Gabriela S.	Yes, reducing stress and anxiousness is really important for my brother, sometimes he hurts himself or others for food. We want him to be independent and above all happy.
Ricardo R.	YES. SEEMS SAFE AND SEEMS TO WORK. PLUS, NO OTHER OPTION AVAILABLE
Ashley S.	Yes, anything to help the trajectory of this disease

Appendix A

- Ann S.** Yes. When my niece's little boy Enoch show any problem with food, or having what he wants to eat, she and husband start to worry about what might come next.
- Senjuti S.** Yes, I would like to be able to access the medicine when needed
- Denise S.** Yes. To assist with the most threatening components of living with PWS
- Rachel S.** Yes, we want her to be independent when she is an adult and hyperphagia is one of the main things that could limit that
- Ryan S.** Yes. Our daughter has not shown severe signs of hyperphagia but we also know it is coming. We know the desperation of other families and need to do anything to help.
- Angela S.** Yes. The reports on the results of this drug are very encouraging and exciting as a PWS parent. My daughter is not in the full on stages of hyperphagia yet however the threat of hyperphagia is like a time bomb for all parents right from the moment of diagnosis. To have an option of a drug that will help with this symptom would create so much more ease right from diagnosis for everyone affected.
- Angela S.** There is currently no treatment options for the cruel symptom of Hyperphagia in PWS. An option to treat this would mean relief to those already at this point of PWS, but also reassurance to families of younger children diagnosed with PWS as hyperphagia is like a time bomb that families are just waiting to go off.
- Jennifer S.** Yes! Any help with the symptoms of PWS would be a huge plus in our daily lives. We are hopeful for a better future!
- Kristy S.** Yes. The opportunity for him to not struggle to with hunger every day is worth it!
- Cynthia S.** Yes, we believe the drug will have a significant impact on the child's progress in life.
- Ivana S.** Yes they deserve to live more normal life
- Iryna S.** Yes. We would like to have an opportunity to have access to the medicine. Living with the child who has rare syndrome, many of medical providers never heard or dealt with, if there is a chance that it may ease or improve the life we have the right to have an access to the medicine.
- Gerardo S.** Yes. We need help since we cannot stop his weight gain. She is 14 years old, weighs 170 kg, eats well, does not steal food, but continues to gain weight. We need medication to help her start losing weight.
- Sisi S.** Yes. It's only drugs at the phase 3
- Bryan S.** Yes. My niece is 6 months old and will live with this condition her entire life.
- Noelle S.** Absolutely! we are willing and desperate to have Domenica on DCCR to help alleviate some of the symptoms of PWS and give her any and all opportunities to live a more normal and comfortable life.
- Nicholas S.** Yes we would. We know that this drug will give our daughter a chance to live and better life. The trials have been successful and with minimal side effects. That being said we would try it.
- Ivannia S.** Yes. Hyperphagia is a huge problem for anyone loving with PWS. Imagine feeling hungry at all times? Never satisfied. Terrible to see my 7 year old niece have tantrums over wanting more food. Not only that but if food not seriously restricted she easily gains weight and behavioral problems.
- Heather S.** Yes. It should be an option

Appendix A

Danica S.	DCCR would be good because it could help with understanding things in school better. As well as being more independent. For example going to friend's houses, being home alone, and not worrying about food etc.
Kristen R.	Yes! Yes! Yes!
Lynne S.	Yes, it would be incredible (and the feeling of a miracle) if our son could live a life without constantly feeling hunger. This would also impact our families life in such a tremendous way, relieving us of the constant anxiety that we will somehow get access to large quantities of food that could be deadly to him or leave our home to search for food and be harmed.
Joel S.	Yes this drug has the potential to be a positive life altering drug that could greatly enhance my son's life
Donna S.	Yes. We are hopeful for a more typical life, less anxiety and struggles with more happiness.
Lynn S.	Yes when the need arises
Amy S.	Yes, we like to know that our options are widened by this.
Ann S.	Yes... Anything that could help the hunger drive!!
Larysa S.	Yes! There are currently no treatments for hyperphagia and we need options! It's not one size fits all
Adia S.	Yes! DCCR offers stability and a way to manage the worst symptoms of PWS. Please allow us this opportunity.
Danielle S.	Yea. So many good things for our PWS children to grow a better life
Debbie S.	Yes. Everyone should have the right to make the decision for themselves or a loved one
Ines S.	Yes! It's our only hope right now and the results are very encouraging
Vincent S.	yes, the results so far are very encouraging
Alma S.	the results are very encouraging
Lily S.	the results are very encouraging"
Elias S.	The results are very encouraging
Amanda S.	Yes! Please help him manage his symptoms and improve his quality of life!
Shane S.	Yes, if can help. Yes.
Laura S.	Yes - when my child hits hyperphagia, I want him to have access to a treatment that will help.
Debra S.	Yes. Hyperphagia and behavioral outbursts Severely limit the quality of life for my 14-year-old nephew. We are desperate for effective treatment options and would like the opportunity to try DCCR.
Jean S.	Yes, anything that can help her with her condition knowing that food and frustration are true issues in the development of kids with PWS
Benoit S.	My kid with PWS has not developed hyperphagia yet, but we know it will eventually happen. We are also aware that it is one of the most painful symptoms both for patients and caregivers, and - having read carefully the C601/C602 study results on efficacy and safety - I would definitely consider the option of giving my child DCCR.
Alice S.	Yes, only satisfying solution / hope regarding eating disorders involved in PWS
Kaitlyn S.	Yes, it will provide her the opportunity to gain control over some symptoms to allow some relatively normal childhood memories and milestones.
Ethan S.	Yes - Quality of life. Behavioral control.
Anita S.	Yes! It will help behavior control and improve quality of life and

Appendix A

David S.	Yes, controlling eating behaviors would allow our grand daughter a life of more normalcy.
Aubrey S.	Quality of life. Behavioral control
Kathy S.	I would like my nephew to have this opportunity.
Darryl S.	Yes, I believe all PWS patients should have every possible opportunity to live a life free of PWS.
Patricia S.	yes, if it helps make everyday life easier
Nancy S.	Yes. We need to do everything possible to help her live her best life.
Mary S.	Yes. If it would help to be more in control and able to say no to food, I am all for the use of this drug. PWS is heartbreaking for the entire family. yes, we would love to try.
Jamie S.	YES!!!!!! We are desperate for DCCR to be available for our daughter!! Her future depends on it!
Susan S.	Yes, I would want my granddaughter to have access to a drug that would help her live a longer and healthier life.
Robert S.	Any treatment that can end the HELL on earth for these people afflicted with PWS is not only the right thing to do, it is your moral duty and responsibility to approve this proved remedy to improve significantly their overall quality of life. Life, Liberty and the Pursuit of Happiness are ingrained in our society and guaranteed in our Constitution and that is why this needs urgent attention.
Susan S.	Yes. It is excruciating watching my 10 year old grand daughter as she feels like she is starving, imagine telling your child they cannot have anymore food.
Stephany S.	Yes, DCCR shows to be a beneficial treatment option for those with PWS.
Patricia S.	Yes. My granddaughter is greatly affected by her obsession with food and anxiety about food. It affects her socially, emotionally and physically. Not having this obsession would make it possible for her to grow in so many other areas that get pushed aside while she is focusing on food. Young children do not understand having their food intake controlled so tightly. The family, school, and relatives, friends, church, all social interactions are also affected. This problem takes up so much space in her world, it would be such a relief to have something to help.
Kathy S.	Yes. It has been life changing for so many. These individuals with Prader-Willi Syndrome suffer daily. Their bodies are telling them they are starving. It is torture. No one should have to live the way they do.
Teresa S.	yes, if we have the opportunity to control eating and behavior we would try it.
Kathryn S.	Yes, absolutely.
Marianna S.	Yes, as soon as it is available
Jan S.	Yes, for a chance to feel full and not struggle.
Jennifer S.	Yes as A grandmother I do not want my granddaughter to suffer with this symptom
Scott S.	Yes, this would make his life more manageable
Nancy S.	Yes, because they are running out of time
Martha S.	Yes, based on his doctor's advice.

Appendix A

Diane S.	Yes. This drug will change the outcomes for my son and for others living with a syndrome that KILLS our young adults from overeating, obesity, choking from eating too fast, heart and respiratory issues from being overweight. Many individuals run away from home to seek food and are hit by cars, abducted, or are never found. Food - the very thing that we need for sustenance can cause death in our population! This drug addresses the food seeking, and has other benefits as well.
Lon S.	Yes it's the number one reason my son cannot be independent!
Vanessa S.	Yes, it would be extremely beneficial for my loved one to have access to this life changing drug.
Valerie S.	Yes, we are open to participating in any trials that may benefit anyone living with PWS.
Irina S.	To improve my grandson life
Victor S.	Ye because I want my sister to live a normal life like we all do
Jody S.	Yes, for a better future.
Molly S.	Yes, I would love for my sister to not have to experience hyperplasia and have an opportunity to live an independent life.
Victor S.	Yes, we need treatments approved

Maggie S. After looking at the safety and efficacy data of DCCR, as well as hearing patient experience data, I absolutely want my daughter to have the option to take DCCR. We know what the natural history of PWS is. We know what will happen without treatments for hyperphagia. DCCR has the potential to change all that. Without an approved treatment for hyperphagia, my daughter lives with risk of death every single day. I'm not sure there is a risk that could come with a treatment that is worse than death. The safety profile of DCCR is strong. The biggest risks are ones we can handle and manage under the care of her managing physician. My daughter has hopes and dreams for her future. Based on the natural history of PWS, she will never be able to achieve them. PWS will rob her of those hopes and dreams. DCCR has the potential to change that. DCCR could unlock new opportunities for independence. DCCR could unlock the opportunity to become meaningful members of society. DCCR could change PWS as we know it. Patients need treatments for hyperphagia and DCCR is hopefully going to be the first of multiple hyperphagia treatments. All patients living with PWS have potential and DCCR could be the key to unlocking that. The patient experience data has also shown that DCCR can impact more than hyperphagia. Any treatments that can improve the quality of life for PWS patients, while being safe and effective, should be made available to patients. When my daughter was born, we chose to raise her with the mindset that by the time hyperphagia hit, a treatment would be available. We first learned about DCCR when she was 5 weeks old and have held on to hope it would be approved. As each day goes by, she gets closer and closer to hyperphagia beginning and I hope and pray DCCR will be approved by the time it finally hits. We have pushed her to her max. We have set the bar high for her. We know she will go far in life, but she needs this treatment to get her there.

Vic S. DCCR as a hyperphagia treatment could be the key to PWS individuals living independent lives such as my granddaughter. Our community currently has nothing to treat hyperphagia and DCCR could change that.

Nora S. I want my sister to be able to take DCCR so she can live just like how I get to.

Appendix A

Jamie S.	Yes, because his doctor believes it could change his life and cause him to never experience some the most difficult symptoms of PWS
Nilka S.	Yes because we need help and the drug has been shown to work.
Linda S.	Yes, this drug is needed for the safe maintenance and management of weight for my daughter and all those with PWS. It is such a difficult disorder to manage because food is everywhere!!!!
Sharareh S.	Yes. Anything to help with symptoms.
Kerry S.	Clementine and her orients would want this option and any option that could improve her quality of life.
Charles S.	I don't see how allowing access to this medication can in anyway be a bad thing, give the sufferers of this disease a chance for god's sake
Namrata S.	Yes. As hyperphagia is the hallmark symptom of PWS it will be very much helpful for the individual if treated with drug to some extent
Amy S.	Yes we would love to be able to give our son a more normal life
Yan S.	Yes! DCCR is effective in addressing excessive hunger combined with diet management! It is our hope that my kid will live a better quality of life with the help of this medication in the future
Emily S.	Yes, because it offers a real first hope to help alleviate some of the most difficult symptoms of PWS, which currently means our daughter (and our family) are unable to partake in many areas of typical daily life. It would literally offer her, and us such a brighter future.
Veena S.	Yes we would like them to take the approved medications. Choice is made by parents. I am a grandparent .
Alexys S.	Yes, this drug could help my niece live a far more normal and healthy life. It could prolong her life and make sure she lives into a healthy adulthood.
Randy S.	Yes. Availability of DCCR is life saving for those with PWS.
Mystee S.	Yes. I want my grand daughter to have the option to live on her own someday and not have to worry about food seeking leading to a premature death.
Kelly S.	Yes. I live in hope that this medication will help my young daughter live an independent life in the future.
Vonnie S.	Absolutely! My son is 45 and NEVER been able to be independent. With a treat he could enjoy a job, home of his own, go on a date, get married, stuff anybody wants to have. Not live with constant supervision from MOM to keep him safe and healthy.
Roger S.	Yes. It would allow him to live independently instead of with his aging parents. We are worried about his future when we are gone.
Douglas S.	The perpetual hunger and associated behaviors currently have no treatment options. This might offer one.
Robin S.	Yes - to increase the likelihood of quality life and length of life with the possibility of reducing hyperphagia and related behaviors.
Susan S.	Because she is so strong and willful she deserves to live her best life. Mostly, because we love her so much.
Mary S.	Yes to help Quinn's life
Gordon S.	Anything we can do to help these children to have a better life is a must.
Kian I.	Yes family member

Appendix A

Keri S.	Yes! My nephew always feels hungry. It would be amazing if he could have a drug that helps him feel full.
Rory S.	Yes, it would be life changing for my son.
Randy S.	Yes, my nephew suffers from devastating hunger every moment of his life. This medication is needed to help him live a life that does not revolve solely around food.
Kian S.	Family member wants option.
Jessica S.	Yes, my son is 7 years old with PWS. There is no cure for the life threatening symptoms of PWS. DCCR is demonstrating dramatic changes in an upward trend. DCCR is changing the course of life for those with PWS and their families. I want my son to have a chance at a socially significant life with society, as a participant in society.
Allison S.	Yes. I want the option for my son, should it be a medication his doctor would recommend for him.
Christina S.	Yes. If there are improvements in helping reduce symptoms, resulting in a better quality of life, I would want this for my child.
Sandra S.	Yes. I witness the struggles with my Grandson who has PWS
Susan S.	Yes, possibly depending on the concerns with taking it. The PWS family member has stage 3/4 CKD and not sure if DCCR is acceptable for them to take.
Elton S.	For sure, like the only possibility to relieve patient and caregiver
Danielle S.	Yes, my niece deserves every opportunity.
Matt S.	She deserves life as other children have
Fran S.	Yes, we want our sweet little friend to have a chance to have DCCR.
Richard S.	Yes, the family member with PWS is a child and the symptoms of PWS make it difficult for them to have a normal upbringing. Any treatment for their condition is an improvement to their current state.
Kristen S.	Yes, this drug has the potential to positively impact quality and duration of life.
Nancy S.	Anything to help provide a treatment for my 4 year old grandson
Angelo S.	Yes. I believe DCCR would greatly improve my little girl's quality of life. It would help our whole family.
Sierra S.	Yes, it would be an overall helpful option to help with behavioral and the hunger issues.
Rikki S.	Yes. With hunger, associated behaviors, and other things that plague our loved ones this can benefit my son
Katrina S.	Yes. We should have the right to try!
Larry S.	Yes, I have 2 nephews with PWS
Pat S.	Yes, I have 2 nephews with PWS
Jennifer S.	Yes. My son is growing hungrier by the day. It is becoming more difficult to control. We have read the clinical data provided from each study and we are desperate to start giving this medication to our child.
Susan S.	This would be life changing!
Deni S.	Yes, my son is 24 and could have the potential to fully live his life if his PWS behaviors were under control.
Mira S.	Yes absolutely! I want the best possible future for my daughter and mitigating PWS symptoms would be a huge game changer for her
Thomas S.	Yes. To improve quality of life

Appendix A

Melissa S.	Yes...individuals and families should have the option available to help the individual live the best life possible.
Kelly S.	After final approval and all the success that has been demonstrated, yes. We would like the option of having access to this drug to see if it will help our son to be successful and live a long, healthy, and balanced life.
Rachel S.	Yes. My niece has PWS. I am also a pharmacist and have looked into DCCR. I think the benefits outweigh the risk and would recommend giving it to my niece.
Charles S.	Yes! This treatment will change our lives and hopefully prevent symptoms!
Anouk S.	Yes, we would try this to make her life more easy
Monica S.	Yes having the option for treatment of unbearable symptoms
Sarah S.	Yes as I believe it will help greatly
Molly S.	Yes, because, as my granddaughter gets older, it is becoming increasingly hard to live a normal life with PWS. DCCR would be a life saver!!
Mary S.	Yes if his parent requests it
Carolyn S.	Yes! We want all options for him to improve his quality of life.
Fran S.	Yes if it would help control her appetite it would make an immense difference in her daily life and ours.
Erin S.	Yes, access to DCCR could be life changing.
Lindsay S.	Yes, if it would improve the quality of my daughters life including less anxiety, out bursts, food seeking so she could be the fun caring young lady she is.
Nicole S.	Yes, my 1 year old niece would love the opportunity to have access to DCCR
Elizabeth S.	Yes. He hates having this affliction
Scott S.	Yes. There is a significant need for reliable and safe medications to help with food seeking/hunger as well as weight loss.
Gary S.	The option to take the drug could open the door to an improved lifestyle for this child.
Tricia S.	This would give this sweet child, a more normal life. This medication would truly be a life changer for this sweet boy who suffers from this disease. Every person should have access to this medication and be given the ability to live a full and normal life. This child is only four years old and deserves to live in normal life as a child, not having to deal with this disease
Cathy S.	We have waited so long for anything to help my daughter have a better life
Lindsay S.	We would consider the option
Katrina S.	Yes it should be available as an option if the physician thinks a patient could benefit from it
Barbara S.	Yes. There are few to no options for so many of these children and adults with this terrible condition. Any breakthroughs in medicine will be a mojito help to those families dealing with PWS
Joleen D.	Yes, because hyperphagia has been holding Jason back from living his best life for far too long.
Andrew S.	Yes. We would like the option for this therapy
Kelsi S.	YES! This would be life-changing for our daughter.

Appendix A

Renee S.	Yes, we need therapeutics available for our children with PWS and the entire PWS community. Our children deserve the right to eliminate their challenges of insatiable hunger and behavioral outbursts. There are medications in clinical trials that are proving to be helpful and we need our community to be able to access these medications to improve quality of life for our kids and for the entire family.
Deanne S.	Yes as it will potentially increase his and his family's quality of life.
Maria S.	Yes. we need to reduce anxiety and improve his quality of life
Amy S.	A medication that lessened our son's extreme urge to constantly seek out food would be life altering for him as well as for our family as a whole. Please consider looking into this opportunity for families who have loved ones with PWS.
Kwangseok S.	We want the option of taking the medicine if the medicine
Jim S.	Yes, to give my son the chance to live independently.
Kathy S.	Yes, we need help! We have waited 28 years for something to help our son. With help, he could potentially live independently
Jack S.	YES. My brother is 28 and lives with my parents and one day will be under my care. He is very capable, but deals with unrelenting anxiety in part caused by the hyperphagia symptom. Even if this helps him by a small margin, it would greatly improve his life as well as my parents. There is no treatment out there for PWS, and I'm sure all PWS families would agree that treatment is desperately needed.
Elena S.	If DCCR is shown to reduce hyperphagia symptoms and disruptive behaviors, I would take it.
Melissa S.	Absolutely, yes!!! If my daughter would be able to love life without being insatiably hungry like most humans, that would afford her less anxiety, along with more abilities to just be comfortable in her own skin. All she thinks about is food from the moment she wakes up until the moment she goes to bed.
Salina S.	Yes, my son can potentially benefit from this medication
Heidi S.	Our niece with a 3 year old with PWS wishes to start the med as soon as possible, hopefully to mitigate some of the symptoms.
Chris S.	Yes, I believe it would benefit her.
Rachel S.	Yes, anything to help hyperphagia would be a blessing
Mary S.	Yes- we need more interventions that support a healthy, longer life.
Clinton S.	to improve her quality of life and make independence possible
Brownie S.	Yes! Our great niece has the terrible disease
Daniel S.	Yes I would love to give my child something that has some much promising signs to help with their future and to help them out
Jessica S.	Yes my niece would like the opportunity to take this drug.
Bill S.	Yes, with hopes that will help with her diagnosis
Susan S.	Yes. It would be incredibly helpful to help with symptoms.
Sean S.	Yes! It would change our lives.
Casey S.	Yes!!! It would change our lives
Jamie S.	Yes, my nephew's parents have explained that they would want him to be able to try it

Appendix A

- Emma S.** Absolutely, yes! People living with PWS currently do not and cannot live independently. In order for our wonderful nephew to grow up and live an independent life like his brothers, we need research and the development of new treatments. For the first time in his life, there is a strong pipeline of research and one drug on the cusp of seeking FDA approval. I, like many others, am convinced that the results of DCCR clinical trial demonstrate meaningful benefit and low risk. This is a huge opportunity.
- Michael S.** Yes, we need options for our daughter.
- Michelle S.** My Daughter, Audrey, needs to have access to DCCR in order to potential live a more normal life.
- Laurel R.** absolutely - we have been waiting for something like this to come available! It would mean independence for my child!
- Connie S.** My five year old granddaughter Tallulah needs this medication in order to live a good life since she has Prader-Willi syndrome. Please allow all these children and adults to have access to this so can live a wonderful life. PLEASE, PLEASE, PLEASE. I am not only Tallulah's grandmother but I also am a special education teacher in New Jersey. People that have special needs should never be denied any type of medication to live an independent life. Tallulah is on a special diet and we have to watch all food intake with her. This is heartbreaking for any type of drug to ever be denied to anyone. Thank you for your consideration. If you would ever want to see the special needs school I work at you would see what families have to live with, when there is a special needs child or person. Also, the special needs population is growing. We need a society that can function independently and have access always to what they need. Please contact me if you ever need any information or would like to see my school where I work. I can be contacted at my email: Inspireme432@gmail.com
- Mihaela S.** Yes please. Hyperphagia is ruining our life.
- Tomasz S.** Based on available evidence, my niece would qualify and gain great benefits from access to the treatment.
- Benjamin S.** The quality of life is all we seek
- Charlee S.** Yes indeed when the time came I would love for the availability of the drug to help with the symptoms of PWS be lessened and she be able to live a much less stressful life.
- Amy S.** Yes. This has the potential to improve the lives of my children- I have 2 children who have PWS.
- Jared S.** I believe my brother would want to take it. While we push for a positive outlook, PWS symptoms pose an extreme risk to his life.
- Matthew S.** I would like the option of DCCR medication for my child due to the encouraging research supporting its use. Without it, her development may be impeded. This treatment could potentially be beneficial for many individuals affected by PWS.
- Juliette L.** To have a better life
- Wouter S.** Yes, I would like my family member to take the medicine because of the improved quality of life.
- Uffe S.** Yes! If hyperphagia and food obsession can be reduced, we are on board!
- Jasmin S.** Yes, because of hyperphagia and behavioral issues

Appendix A

Jennilea S.	Yes, we would. My son is 9 months old and I am terrified of the day hyperphagia becomes a problem for him and my family. It would help me to know there are treatment options accessible to him, a chance he might not have to live a life controlled by hunger. We have come so far in treatments, but still this major gap keeps me awake at night. Please consider providing this opportunity to patients.
Mia S.	Yes. The hyperphagia and the anxiety surrounding this disease has a hygge negative impact on our Way of living
Janice S.	Yes, to help ease the struggle he goes through daily.
Wesley S.	Yes. For his health.
Cole S.	Yes. His weight is beginning to greatly affect his life.
Patrick S.	Yes as it would help with the insatiable hunger
Kristy S.	Yes my daughter is atypical PWS high functioning and this medicine would be a dream come true for her and many others. She is a state wide trainer for advocacy in the DODD Community. She's worked with several medically research programs at a national level. She has so much to offer but feels so trapped by her syndrome.
Shannon S.	Yes. This symptom creates other issues in our life and the weight gain recently has been hard to control.
Edward S.	Yes, doctor indicated it has the most promise to ensure quality of life and long term health.
Linda S.	Yes. Would love the hyperplasia to stop for my daughter so she can focus on other things in her life other than food
Andrea S.	1000000 percent! It would make independent, enjoyable life attainable for our son.
Michael S.	It is absolutely critical for him to lead a quality life.
Wendy S.	Yes. To help out with behaviors and to improve his quality of life. Also he has horrible EDS
Amy S.	Yes for relief of hyperphagia and a better quality of life
Kathy S.	Yes, my granddaughter has PWS and this drug has shown good results in counter acting the hyperphagia, skin picking, and other symptoms associated with PWS. These children need all the help they can get to live as normal life as possible. Please approve this drug!
Andrew S.	Yes, we want your daughter to have access to this drug to prevent hyperphagia.
Jayne S.	Yes, we would like to try the drug for our daughter.
Megan S.	YES DEFINITELY!!!
Sara S.	Yes. There are no better options that this drug.
Yael S.	Yes so we don't have to worry about the most debilitating symptom of PWS
Katharine S.	Yes. To date no action exists that helps with hunger and anxiety, as well as DCCR looks like it can. Our daughter struggles daily with hunger and anxiety, we would really like her to be able to have some help and some hope
Brenda S.	Yes feel would be a great benefit
Zaki S.	Yes in order to improve the quality of life of my daughter
Wendy S.	Off course. His quality of life would be significantly improves with this medication, it would allow him to lead an independent life, which he not able to do today
Josie S.	Yes, it may help
Joy S.	Yes, this drug could help my daughter to lead a more independent life. She is very restricted now, unable to even attend family events or any event with open food.

Appendix A

Shelby S.	Yes, FDA's expectations for well powered studies on the level of more prevalent conditions is unrealistic and unfair to those suffering. If they can approve ridiculously expensive Alzheimer's medications with zero proven clinical benefit there is no reason they can't approve these medications.
Martin S.	Yes, I want the best for my daughter and a medication would be great
Marzena S.	Yes! My daughter and other kids with PWS deserve a chance to have a safer life. We deserve a chance of not being afraid that food will kill her.
Maria S.	Yes, as this is the only hope for my granddaughter to live the normal life!
Amanda S.	Yes they would want it
Aliza T.	Yes, we would want our niece (and every person with PWS) to have every opportunity to live their fullest life.
Emi T.	Yes, it is a hope to control one of the problems related to PWS.
Beverly T.	Have a more normal life
Kara T.	Yes this medication could provide the help my family member needs
Cody T.	We absolutely need the option! Anything with the possibility of reducing hyperphagia needs to be approved and available!
Krista T.	Yes, I would want my son to take this medicine to help him have a better quality of life.
Greg T.	Yes. Having access to DCCR would permit our loved one with PWS to potentially experience a more normal lifestyle, while reducing the risks of negative health issues related to hyperphagia and its effects on the body.
Saurabh T.	Yes, I would like to try this medicine for my child when it's appropriate for the child's age
Annelise T.	Yes, there is no treatment for some of the hardest symptoms of PWS. DCCR would be the only approved drugs to help my niece live a full and independent life. DCCR is essential to the individuals and family members whose lives are faced with the horrendous realities of PWS.
Karan T.	Yes we would like to use the drug.
Courtney T.	Yes. We want the best life possible for our son.
Deneen T.	Yes, we definitely want the option of this medication for our son to help with the devastating symptoms of his condition
Betsy T.	Yes. My niece's son has PWS and she would like him to have access. He has displayed all the features that DCCR could possibly help.
Georgina T.	So that he can live a more fulfilling life, not be in pain and hungry 24/7 and possibly live an independent life as he won't be able to
Valerie T.	Better living
Grace T.	Yes. The management of hyperphagia and all the side benefits would significantly improve the independence and quality of life of my nephew and others with PWS.
Loranne T.	Yes, my granddaughter has suffered for 19 years with PWS and needs this.
Sarah T.	Yes. If our son suffers with hyperplasia as he gets older we will consider any and all options available to help him with his condition. The results of the study look positive for those living with PWS
Alice T.	Yes She has worked very hard to deal with her hunger
Nelida T.	Hope

Appendix A

	I would like my cousin's daughter to have access to any and all medicines that could possibly help her
Tarjaleena Å.	Yes, we all in our family including the PWS individual want the option of taking the medicine.
Jennifer T.	Yes. We are willing and able to try anything that may help our son's hunger and outbursts and other issues that come along with PWS.
Nicole T.	Yes it would be life changing for our daughter
Christina T.	Yes! This drug has the potential to be LIFE changing and improve the quality of life for all involved in the PWS community
Sandra T.	Some kids were in the trial and it worked
Hope T.	Yes. As a grandmother of a baby, I cannot imagine a more painful life. The developmental delays nor behavioral issues which come with PWS do not make me concerned, those can be worked with and through. It is a terrible thought for anyone to be hungry all the time, which in itself may cause nausea, vomiting, and I believe leads to a lot of the behavioral issues that accompany PWS. Please make this drug available immediately.
Meghan T.	Yes, our 3 year old is struggling with hyperphagia and rapid weight gain and we are desperately in need of help from this medication
Joe T.	Yes. The management of hyperphagia and all the side benefits would significantly improve the independence and quality of life of affected individuals.
Marika T.	Yes, because even it heaps only a small amount, it's still more than nothing.
Jake T.	Yes. As her symptoms become more challenging as she ages this could be significant in giving quality of life for her and her caregivers
Marguerite T.	It must be offered, then you can make the decision at the time if you want to take it or not.
Georgia T.	My niece has PWS. I desperately want to be able to see her live a full and independent life.
Kate T.	To make a great difference to the family living with PWS, making mealtimes more enjoyable and allowing the PWS child to mix with others.
Heather T.	Yes. Prader-Willi has no cure. If DCCR is able to minimize the symptoms/behaviors in PWS and allow these individuals a chance to live a healthier, more normal life, then I would like for my son to have the option to try it.
Randall T.	Yes we need a medicine to help with this.
Misty T.	Yes we would want to take the medicine. Anything that can potentially help. They hyperphagia is getting worse every year that goes by.
Danielle T.	Yes we would love the option to receive it
Isaiah T.	My little Niece needs this Medicine
Danielle T.	Yes we would like him to have the option of taking the medication.
Austen T.	Yes, this would significantly improve the well-being of my family member with PWS.
Aida T.	Yes it would make a world of a difference for my child to have the option of taking the medication.
Natalie T.	Yes! She needs options for treatment as there currently are none.
Joy T.	Yes please. Anything to help her be safer to be in normal environments.
Terri T.	I would like the option and believe all people with PWS should have this option.

Appendix A

Colleen T.	Yes. This could significantly help my son with the challenges that come along with PWS. Please help our children!
Damaris T.	Yes, to help the insatiable hunger phase.
Al T.	Currently there is no other medication out there for PWS. In over 20 years the only treatment has been growth hormone, which helps tremendously, but does not curtail the hunger or the behaviors that come with PWS. The risks of DCCR are minimal, especially when compared to the benefits it offers the PWS community, therefore I would love to see a medication that is approved for such an afflicted community.
Lydia T.	Yes - we are willing to try anything that improves our baby girls' quality of life
Ashley T.	Yes - I am starting to see an increase in hyperphagia and food seeking in my five year old. She even takes other kids food at school. Anything that can help her live a better life is amazing. I know as she gets older the behavior could worsen and hyperphagia increase so I am really hoping this drug is an option for her.
Elaine T.	Yes. We would like to have the opportunity to discuss this with his physicians and make a measured decision about trying it.
Jan T.	Yes, to lead a life that doesn't involve hyperphagia, living as close to normal as possible.
Sarah T.	Yes. This would be immensely helpful!!
Maureen T.	yes we are in need of real help
Tommy T.	Yes, any new treatment options are better than none
Jeff T.	Yes. I believe that if a safe treatment is available to treat the symptoms of PWS, then it should be made available to the people suffering from this.
Caitlin T.	Yes. If this therapy shows promise in enhancing the quality of life for PWS patients by tackling common issues associated with the syndrome, it needs to be made available.
Lynn T.	Yes. Whatever could help and improved my granddaughters condition living with PWS.
Khoa T.	Yes. She is suffering from the syndrome.
Valerie T.	Yes. My son is morbidly obese & needs help urgently.
Lori T.	Yes, I would want to try to improve their quality of life and give them more independence.
Tina T.	Yes, absolutely! We believe in the science and this would completely change the trajectory of our son's and our family's lives.
Cindy T.	Yes, we would like the option
Rebecca T.	Yes, my cousins want to
Cathy T.	Yes, anything that can help with food seeking and behavioral instability is something that would help her live her best life.
Morgan T.	Yes, because she has every right to a normal life
Morgan T.	Yes, I believe that my daughter has the right to live a happy and fulfilling life. This could make a world of a difference in her daily overall function and life activities.
Robin T.	Yes. Because it would better my granddaughter's quality of life and help normalize her daily functions.
George T.	Yes. it would better my granddaughter's quality of life and help normalize her daily functions.
Jeri T.	Yes. It would better my great granddaughter's life and help normalize her daily functions.
Nicholas T.	Yes I feel like this should be readily available for those in need of the medications.
Aurelie T.	Because it's a good way

Appendix A

Brennen T.	Yes, she could use it to function better and have a greater quality of life!
Rachel T.	Yes. PWS is a slow death sentence. Not only that, but it sucks any joy out of the lifespan that is given. While there may still some questions about DCCR, there are none about PWS. We all know that before it does take your life, it brings misery and suffering. If there even a chance that DCCR can help, we are willing to try. And, from what is know , there is more than a chance it could help. The data proves this. Please approve DCCR. A chance is better than nothing, which is what we have now.
Shanna T.	Absolutely!!! I believe my daughter would greatly benefit from this drug if it were available. Our children do not have many options for medicines to help with their condition. This medication gives us hole for her future!!
Jason T.	Yes because we want our child with PWS to have the best chance at a normal life and we feel that with DCCR, she will have the a good chance of living that life.
Amy T.	YES, people of all ages need access to more treatments to help with this rare disease!
Mechell T.	Yes it's my youngest grandchild
Dian T.	Yes to give him the best chance in life
Patty T.	Yes, if it can help please give them the chance .
Ashley T.	Yes, we are desperate for any help to cure the life debilitating symptoms of PWS
Kimberly T.	Yes, when he hits that phase we would be beyond grateful for the availability.
Dian T.	Yes. To stop hunger. It would be invalid
Gayle U.	Most likely
Joane U.	Yes if found safe and effective
Mallary U.	Yes, I want the option. My son just turned 8, he's awesome and his hyperphagia monster is not. I cannot imagine what his options will be when that monster is silenced. Please listen to us. We want change for our children, this would be really wonderful change. Thank you, Mallary U
Lauren U.	Yes. We struggle every day, with behavioral outbursts & insatiable appetite.
Carolina U.	I am interested because I want my son and his family to have a better quality of life.
Laura F.	Siii, si tuviera la hiperfagia y estuviera en el mercado la usaramos sin pensarlo
Milan U.	Yes. My cousin's daughter was born with PWS and any treatment that could potentially help her I support.
Guillermo U.	yes, it could be an improvement for their life
Maria A.	Si, mi hijo pesa : 168 kilos
Kami V.	Yes. I believe it will really help.
Dominique V.	Yes of course! If my daughter needed it would want access to it right away! These children can't wait long when a medication is needed. I see how older PWS adults are and we need to do something NOW for the children
Jennifer V.	Yes, any option is necessary!
Savannah W.	Yes. Any chance at bringing some relief
Ruan W.	Yes. Anything to help my loved one
Niels D.	Yes, better then nothing
Madeleine E.	Yes!! My daughter does not yet have Hyperphagia, but she has behavior issues. We would love to have an option soon to prevent Hyperphagia or address it if it arrives. Living with constant hunger is not a way to live, DCCR is our hope.

Appendix A

Linda L.	Yes. Always hungry is killing
Alex L.	Yes. It could dramatically improve her quality of life.
Pamela M.	Yes, we have to be aware of everything that has to do with food at ALL times. This means tension for all family members. It makes most fun activities like party's, holidays or a day out something difficult. A solution would be impacting not only the person with PWS but their entire surrounding. Also the smallest chance of an independent life is what we all hope for.
Fiora T.	Yes we would to help with her health
David Z.	Yes, hoping for Grant to like a relatively normal life
Adam Z.	Yes, the option should be at the discretion of the caregiver
Brianna V.	Yes! I want my son to take this drug to save his life and the members of our family!
Pamela Z.	Yes, DCCR would be life changing for our grandson and allow him to live the wonderful life he deserves
Rebecca B.	Yes, we want to be able to give our child relief if it is possible from a life of constant hunger. Everyone should have access to try this medication if they wish.
Jean V.	Yes! I believe with appropriate medication my sons quality of life would significantly improve
Brent V.	Yes I think this would greatly help my sons quality of life.
Daniel E.	She should get a chance
Lindsay H.	Yes. We would like our son to be able to live independently when he comes of age. We know that will not be possible without a treatment for hyperphagia and associated behaviors. We would like him to be able to have access as soon as hyperphagia symptoms start so he can have the best quality of life and be an accent to his community.
Danielle V.	We would like to, but we are not residing in the US
Kimberly T.	Yes for sure! We want him to have the best life possible
Mariam V.	Yes. Anything can help our child at this point .
Nancy F.	If it would help you a lot with the issue of hyperphagia
Jackie V.	Yes, absolutely. It would be amazing for my child with Prader-Willi syndrome to have the option to take this medication.
Mandy V.	Yes, I hope my daughter can start this medication as soon as possible. I feel it can make a huge difference in her quality of light.
Moses V.	Yes, we would love to try the trial anything for our son to help him improve
Jose V.	Give a better lifestyle to our children With this horrible sickness
Jose O.	Si, para una mejor calidad de vida
Martijn V.	Yes we want this option because we want to try everything that potentially could improve the quality of life.
Rebecca V.	This medication could give my niece the opportunity to live independently without suffering through hyperphagia.
Subhashini V.	Yes - we are hoping to provide the best care for our family member, especially in advance of the hyperphagia phase.
Adriana V.	Yes, we want her to have the best chances for a healthy life.

Appendix A

Olga V.	Yes, we'd love to have a drug like this one available for us. My son, Alejandro, struggle with anxiousness to the point to hurt himself. We want him to be independent and able to live on his own, without hurting himself or others.
Maria O.	Yes, there are no other treatments for the burden of this disease.
Juliana O.	Yes. As the mom of a PWS kid and physician treating kids with PWS we need a drug for this condition. We have nothing to reduce the burden of this disease.
Lucia O.	Yes. There are no other treatments for the burden of this disease.
Maria M.	Fernanda needs the medication to have more options for improvement
Kate V.	Yes. The management of hyperphagia and all the side benefits would significantly improve the independence and quality of life of affected individuals.
Marilyn V.	Yes we would love the option for my nephew to be able to take the medication. Giving him a chance to live a healthier lifestyle.
Anouk N.	In the future
Victoria V.	If this drug can effectively improve PWS food hunger and emotional problems, as a child's parents, we are very willing to let our child try it.
Brooke V.	Yes we would like our child to have access to this to improve his quality of life!
Jared V.	Yes, I believe DCCR will help my son live a better life.
Claire V.	If it can help my daughter, yes of course! We want her to have a normal life as much as possible in spite of her syndrome.
Karla V.	Yes I want to try to my baby
Ashley V.	Yes- I believe that this drug could be life changing for my niece.
Nina V.	Yes. We want any option that would help our Zoe have access to the best life possible. Please, please allow her to have an easier life. She is an angel
Lesley V.	Give her every chance available to develop normally.
Lorraine V.	Yes, we believe this could make a HUGE difference for our grandson
Kasey V.	Yes. It's our only shot at hope
Joe W.	It helps reduce the severity of disease
Virginia W.	Yes, I'm hoping it will be life changing.
Sarah W.	Yes due to the impact of hyperphagia on the life chances of my PWS son.
Kelli W.	My life is impacted by two little boys who would have much greater hope of a normal life with this medication.
Teresa W.	Yes!! The data shows improvement-full stop! Our children battle every second of the day, any improvement any area would give new life to our children and us as the parents. This drug is needed tremendously!!! Please review, we need help.
Shamekia W.	Absolutely my son faces daily challenges because of the symptoms related to PWS (hyperphagia specifically). It impacts his quality of life, and ability to form relationships with others. As a parent of a child with PWS, I would love the option for him to have access to this drug to give him a chance at living more of a normal life.
Jill W.	Yes, having an option would offer better quality of life.
Natalie W.	Yes, a potential to help alleviate the most debilitating symptom - hunger - would be life changing for people living with PWS.
Bonnie W.	If needed
Alexandria W.	To stop the hunger and anxiety following the hunger

Appendix A

Alexandria W.	We want my sister to had DCCR stop the hunger. She is hungry all the time when it isn't her time to she has angry and violent outbursts that disrupt the entire house hold. We live in a home of lock kitchens and food stealing we live a life of not being about to go to the family picnics or town fair because it all involves food. Almost every activity involves food and we didn't have to think about it before she was here and know this rare disease keeps us locked in our home.
Jonathan W.	Yes. Willing to try anything to improve symptoms
Rosa W.	Yes, since this drug
Tony W.	Yes! DCCR can help my child.
Margaret W.	Yes, I have heard it is life-changing for those who have received it.
Haley W.	Yes. My son was diagnosed later in childhood leading to many issues that could have been prevented with proper diagnosis at birth and we need all the help we can get with weight management and behaviors.
Tricia W.	Yes, our PWS little girl is at the age where hyperphagia will begin soon.
Kathryn W.	My niece's parents and family are aware of the studies done and the availability of the medications would make her quality of life as well as family members so much improved. Quality of life must be of paramount consideration.
Sherri W.	Yes the constant hunger breaks my heart
Chase W.	Anything to make his life better is worth a try.
Sandra W.	Yes, the reason are too many to write.
Paul W.	Yes. We want to do everything possible to assure as happy and fulfilling life as possible for our newborn grandson. DCCR seems to be a promising tool to help him and others with PWS attain a significantly happier, healthier life.
Lori W.	My son is starting to show signs of hyperphagia, and we would love nothing more than to be able to potentially have a medicine to take away his pain. So, yes, we would definitely like to have the option of using this drug.
Danielle W.	Yes!!! Bailey wants so badly to be independent & this could potentially be the game changer that would allow her to do so.
Amy W.	We would very much want the opportunity to access this medicine for our son with PWS. Right now, there is no treatment for so very many of the symptoms of PWS. That includes the hyperphagia that has become synonymous with PWS and drives so many of its other symptoms (anxiety, behavior problems, excessive weight gain, etc.) Those untreated symptoms not only place stress on the life of the person with the PWS diagnosis, but also their families, teachers, caretakers, and classmates. We strongly believe DCCR offers hope of lessening the severity and frequency of symptoms suffered by the PWS community and those who love them based on the data we've seen and the testimonials of those who have had access to the drug. We urge the FDA to please consider this petition and approval for DCCR.
Jennie W.	They would love the opportunity and option to take this medication! They have been waiting for years for this chance, and it would change their lives
Trisha W.	Yes, we'd be willing to give it a try
Tierce W.	Yes, the potential impact of DCCR could be radically beneficial to the child and our family.

Appendix A

- Michael W.** Yes. As a grandfather, I've witnessed firsthand the lifelong struggles that accompany Prader-Willi Syndrome (PWS), a condition for which there is currently no cure. My heart breaks seeing my grandchild face daily challenges, from the relentless hunger to the associated health complications and behavioral issues. The lack of effective treatments only adds to the burden carried by individuals with PWS and their families. DCCR (Diazoxide Choline Controlled-Release) offers a glimmer of hope in this landscape of uncertainty. Its potential to alleviate symptoms and improve quality of life is profound. I implore the FDA to swiftly file, grant priority review, and thoroughly evaluate DCCR's application, recognizing the urgent need for treatments that can provide relief and offer the possibility of a brighter future for individuals living with PWS.
- Dianne W.** YES. As a grandmother deeply invested in the well-being of my only grandchild, Jackson, who bravely battles Prader-Willi Syndrome (PWS), our family has suffers alongside him. From the moment of his diagnosis, our hearts have been heavy with the weight of his struggles, knowing there is currently no cure for this relentless condition. Every day, we witness the challenges he faces, from the constant hunger to the associated health complications and emotional toll it takes on him and our family. The thought of him enduring a lifetime without effective treatments is unbearable. DCCR (Diazoxide Choline Controlled-Release) offers a ray of hope amidst this darkness. Its potential to alleviate symptoms and provide relief is a beacon of light for our family and countless others affected by PWS. I plead with the FDA to expedite the review process, recognizing the urgent need for treatments that can offer respite and the possibility of a brighter future for our beloved grandchild and all those living with PWS.
- Gretchen W.** Yes. It's tough to have a baby who is never not hungry.
- Heidi W.** In the future absolutely
- Daniela W.** Yes. IT would Help my daughter. Nobody wants to be hungry all time.
- William W.** Yes I would want the option of this drug for my family to address one of the most challenging symptoms. It would be life changing for the PWS community.
- Amanda W.** Yes, I would want my child to have the option to receive this drug. I hope for a day where anxiety centered around food for our child (and our family) will be one less thing we have to worry about. The physiological and emotional benefits are immensely needed to improve our child's quality of life and allow for independence in the future.
- Allison W.** Yes!!!! It will help with the symptoms of PWS!!!
- Cindy W.** I believe it would benefit him greatly
- David W.** Yes, anything to potentially improve her life going forward
- Susan W.** Yes it could be life altering
- June W.** Yes, my son struggles with Prader Willi and would benefit having a treatment option.
- Sarah W.** Yes. Anything that helps
- Isabel W.** Yes!! We would like to offer the drug to reduce the appetite when that phase will come
- Ulla W.** It with make big difference for the people who have PWS.
- Jose W.** We have our grandson living with PWS. Hi is only 1 year and 4 months. We have follow DCCR since the very first day. To help him and other patients with PWS and hopefully give them a life with freedom and much more quality
- Wilder W.** Yes, her doctor has recommended it but can't get it.

Appendix A

Denise W.	Yes. We are always looking for medicines that can improve the lives of individuals with PWS
Jennifer W.	Yes to minimize hunger and anxiety
Tara W.	Yes we have heard this drug has been very effective in stopping the constant hunger feeling for other PWS sufferers.
Lynsie W.	Yes, it would be a life changing treatment for our daughter.
Nakeshia W.	Yes, reports have shown this would benefit the PWS community and our children.
Shilo W.	Yes so it could treat her insatiable hunger
Matt W.	Absolutely, yes! People living with PWS currently do not and cannot live independently. In order for our wonderful nephew to grow up and live an independent life like his brothers, we need research and the development of new treatments. For the first time in his life, there is a strong pipeline of research and one drug on the cusp of seeking FDA approval. I, like many others, am convinced that the results of DCCR clinical trial demonstrate meaningful benefit and low risk. This is a huge opportunity. Absolutely, yes! People living with PWS currently do not and cannot live independently. In order for our wonderful nephew to grow up and live an independent life like his brothers, we need research and the development of new treatments. For the first time in his life, there is a strong pipeline of research and one drug on the cusp of seeking FDA approval. I, like many others, am convinced that the results of DCCR clinical trial demonstrate meaningful benefit and low risk. This is a huge opportunity.
Winnie W.	Absolutely, yes. Our daughter deals with food anxiety, tantrums, and obsessive compulsive disorder every single day. It affects every aspect of her life.
Elmer W.	Yes, we are satisfied that DCCR is safe
Cecilia W.	Yes. My cousin's beautiful baby girl was born this year with PWS and their family needs options for their beautiful child as she grows. I believe in science and am strongly encouraged by the evidence presented so far in support DCCR.
Kristin W.	Yes. My son Rafael is 7 years old and living with PWS and I am desperate for something that can help him manage the worst symptoms of his diagnosis as soon as possible.
Jennifer W.	Yes. This is the only thing that feels hopeful to our family.
Bernadette W.	I believe that it is vital that everyone who has PWS has the opportunity to have this medication
Eddie W.	Yes. My grandson with PWS struggles daily with never-ending hunger and tends to get distracted thinking about what he's going to eat at his next meal. He and I have talked about how great it would be for him if he wasn't so hungry all the time, then he could focus more on other interests. He says it's hard to do when he's hungry.
Cynthia W.	We would like our son to take this medication because his response to other interventions has been minimal, and the clinical trials to date show fairly good efficacy, and a high degree of safety. There are very minimal options for the PWS community.
Katrina W.	Yes. It would benefit her.
Constance W.	Yes. Anything that could significantly reduce symptoms would be welcome.
Nathan W.	Yes I would! It would help myself and others a lot!
Deirdre W.	Yes I would - if there is a chance that it will improve my daughter's quality of life - I want to try for her

Appendix A

Marsha W.	Yes. It is her best option and hope to combat the illness/disease.
Chandler W.	Yes, Jackson is currently my nephew and I have witnessed first hand the challenges he has had to face due to hunger and behavioral issues. This drug could be life changing for someone like Jackson.
Jennifer W.	Yes. The dire consequences of life without the benefit of DCCR are overwhelming and terrifying. Every individual with PWS deserves an opportunity to choose this drug as a treatment option.
Marieke W.	Yes! It would make a world of difference in the quality of living.
Dora W.	Yes, I would like this option to help improve my grandson his possibility for a better life and development to reach his independence
Amy W.	Yes. My family member deserves the opportunity to live her life abundantly and satiated, which will allow her to lead an independent life as an adult, and become a contributing member of society.
Jaclyn W.	Yes. It would be a huge benefit for my niece.
Linda W.	Absolutely! As a grandmother, I have witnessed the detrimental effects of my granddaughter experiences with hyperphagia and the stress it causes to her and her caregivers.
Charles W.	yes, my grandson needs an opportunity to get better
Patricia W.	My granddaughter has PWS and is six years old. She hasn't gotten into the hyperphagia stage but is close. Her whole family would like the option to use DCCR for the symptoms we know are coming.
Melissa W.	Anything that will help him have a long and happy life.
Janis W.	My daughter is morbidly obese. She is diabetic. She suffers with copd and congestive heart failure. She is on a ventilator. Losing weight could possibly alleviate these medical problems.
Sally W.	Yes I would want my son to have access to this medication in hopes of preventing him from ever suffering from hyperphagia.
Sara W.	Yes, my brother would appreciate the chance to have access to DCCR to reduce hyperphagia and food-seeking urges that are harmful to his health and well-being.
Clint W.	Yes! This is such a great advance for the PWS community and we should be able to seek all experimental treatments possible
Kelly W.	Yes, the benefits that have been reported would help my son so much in his daily life.
Andrew W.	Yes. The fear of hyperphagia setting in is a fear we live with daily. The opportunity to have a potential drug to mitigate hyperphagia and other complications would be life changing.
Melissa W.	Yes, my daughter is living with this horrific syndrome. This medicine will give her a chance at life.
Ashley W.	Yes if it would give her the chance at a better quality of life.
Richard W.	Yes!! It could help with the day to day activities!! Life in general!!
Jasmine W.	Yes I would be interested in taking the medication my daughter is living with PWS and we are willing to try whatever we can to help her
Jennifer W.	We would love the opportunity to help our daughter improve her life.
Frances W.	yes. We hope this will be a cure so he can live a normal life

- Anne W.** Yes! We want the drug. It is so difficult to go to parties or events because of the food anxiety that my daughter has. She cannot even have fun at events because she wants to be around the food area the whole time. Everything revolves around food for her. She has even gone through the trash to get food. If there is a drug that could help with this, we want the option to try it to at least give my daughter a better quality of life without having to be concerned about food. As her mom, I get anxious about parties because my daughter will throw a fit if we try to take her away from the food areas. Please approve this drug so we have hope for a better life. There is currently nothing else to help with hyperphagia.
- William W.** Yes. My daughter is food seeking and eats food out of the trash if left unattended
- Patricia W.** To help family member overcome issues
- Zac W.** Yes, it would mean the world for my son to have something to help him with his PWS and all the things that come along with PWS.
- Jennifer W.** My beautiful grandson, Greyson Clyde, was born 2/19/24. My son was so excited to have a son of his own. Soon after birth we realized there was something concerning going on. After spending almost his first two weeks of life in the hospital, genetic testing confirmed that Greyson has Prader-Willi Syndrome. This diagnosis has been scary & overwhelming for our family. The scariest thing the doctors told us was that Greyson would likely have a shorter life span due to the medical issues that arise from the hyperphagia (obesity, diabetes, heart issues). Additionally, the thought of Greyson living life with the constant pain of starvation every day for the rest of his life is heartbreaking. The unknown is scary for all of us that love him, especially his parents. Not knowing what effects PWS will have on his behavior, mental health, as well as physical health has been terrifying for Greyson's young, first time parents. They question themselves daily if they are strong enough for this fight, but with one look at Greyson, they know it is worth it. Although there is no cure, DCCR gives us hope that Greyson could have a significantly improved quality of life than what is currently the outlook as there is no treatment like this for patients with PWS. I have so much hope that DCCR will be available to Greyson when his disease progresses into stage 2 in the next couple years.
- Roxane W.** Yes. The possible benefits far outweigh any risks.
- Gloria W.** Yes, it may benefit her
- Carolyn W.** I would like for my son to have the option to take the medicine because the symptoms related to PWS limit his life so significantly and there have been some life threatening situations due to his condition. This also has significantly affected each individual in our family, and our family as a group.
- Yeanna W.** Yes. A much needed medicine to allow my child to have independence
- Louise W.** Yes, it would make a huge difference to his life and hopefully mean he would never have to experience unstoppable hunger
- Sophie W.** Yes- as there is currently no options to assist with the reduction of hyperphagia
- Rebecca W.** Yes! My 6 year old son is already experiencing hyperphagia and this medication would relieve this horrible symptom.

Appendix A

Ashlee W.	Yes, given that there is currently no treatment for PWS, we would love for our son to have access to medicine that was improve his life in every aspect and help him with his daily struggles caused by PWS. It would also make a huge impact on our family, PWS takes a huge toll on the entire family not just the individual. Watching your child struggle and suffer every day is gut wrenching. We need access to a medicine that can help urgently!
Julie W.	Yes!!! DCCR could be the treatment that finally allows for our daughter, Millie, and all those living with PWS to live independent adult lives. Our dream for our daughter's future is that she gets to pick it, and DCCR could allow our daughter, Millie, to live independently, have a fulfilling career, friendships, and relationships, and finally be freed of living in a state of constant hunger pain.
Lisa W.	Yes. The evidence speaks for itself. It has the power help so many people living with the devastating effects PWS.
Debra W.	Absolutely. Having the option of DCCR for my Grandson gives me and my family hope for Logan's future.
Kate W.	Yes, absolutely! the option to have a treatment available is life changing. DCCR would/could change the course of our loved ones lives. It would be a game changer for the whole PWS community
Daniela W.	Yes. my soon has been suffering from the effects of Prader Will for years.
Carly W.	Yes. We believe research is key to everything& following the existing reattach please this is a drug that shows huge potential for our daughter & the PWS community.
Carolyn W.	I want what is best
Brett W.	Anything that will help my brother-in-law live his life to the fullest, we're excited to try!
Reaksm Y.	Yes to improve the life of my son who has PWS
Amanda Y.	Absolutely!!! The study has shown amazing results and the testimonials we have heard are incredible. With no doubts or reservations.
Kathy Y.	Yes, anything that helps
Liu I.	Yes. I want.
Levi Y.	Yes, the parents of my family member living with PWS would like the option for their daughter to receive treatment from this method
Jeane Y.	Yes!! My daughter is 3 years old, but she is constantly thinking about and asking for food. It doesn't matter if she had just eaten, she will ask for her next meal. And throughout the day, she cannot focus on her task at hand, but must ask me repeatedly when her next meal is. I would love the opportunity to offer a therapy to her that would allow her to play, to engage with others, and simply to just be a child without constantly thinking about food and her next meal. I have so much hope for her and her future, but I know we will need an intervention such as DCCR to even have a starting chance.
Breanna Y.	Yes we would love to participate in any current trials for the med
Anne Y.	Yes! It will help him in the years to come as he gets older
Emily Y.	Absolutely! Our child deserves it.
Katherine Y.	Yes! The results of DCCR trials give us so much hope for a more typical life for our daughter

Appendix A

Andrew Y.	Yes. In addition to being a family member of a loved one with PWS, I am also a pediatrician and feel the data presented are compelling
James Y.	When our 13month old daughter reaches the age requirement we would love the option of being able to provide her with DCCR.
Lynne Y.	Yes, any help is good, our grandson is highly affected by PWS
Yenhy Y.	Yes, it would be an option for her to take the medication once it is definitively approved for PWS since we want a better quality of life, both for her and for us as her family. So we are eagerly awaiting positive and favorable responses for this medication, since my daughter turned 5 on May 5. We will be attentive and praying that it reaches our country and whether it is accessible or that social work can grant it is inconvenient. Greetings and thank you very much for this great advance.
Kelly Y.	Yes. We are hoping to find a way to help our daughter live as normal a life as possible, without constantly worrying about food and even her next meal will happen.
Samiha Z.	Yes absolutely! Many cases have seen positive results which is a great sign and I would love for my son to take part in the trial and access the medicine for his overall well-being.
Jordan Z.	Yes I would want to see what it can do to their quality of life.
Stephany Z.	Yes, it has shown improvements and there have been very few other treatment options.
Roos Z.	My girl is 9 months old but it would be great in the future
Lynne Z.	Yes. Seems it would ease her challenges regarding food and the stress/ anxiety and behavioral issues associated with food.
Roksana Z.	Yes, I think that taking this drug could help my son to have a better social life and live more normally
Omar Z.	Yes it would be greatly helpful if there was anything that could help out my younger cousin
Dmitriy Z.	Yes, this is the only option for our child to live normal life
Veronika Z.	Yes. This community desperately needs new approved treatment options that allow them to improve their quality of life and potential outcomes
Kristy Z.	Yes. As long as it wouldn't have any adverse effect. I'd be willing to try anything to help her.
Justyna Z.	Yes, I would like to try taking DCCR by my son. Based on my basic dietetic knowledge I do not have bad feelings about choline compounds. In these times our loved ones have no other solution than growth hormone to decrease negative effects of PWS. I have had observed DCCR research for a while and I really hope that this drug could change our family's life.
Michelle Z.	Absolutely, it would make a world of difference
Marjorie R.	Son is older than a senior, so no
Ereland H.	Probably not just because I already have a lot of medicine that I'm testing right now but I'm here listening for the effects and ways it can help.
Jeannie D.	Our daughter resides in a group home and would not be able to join a study
Jacomijn V.	Not yet, as our child is quite young but maybe at an older age
Sandra H.	Not yet
Haiyen B.	Not yet
Victor I.	Not right now.

Appendix A

Bonner B.	Not my decision as a grandparent
John O.	Not my decision
Frances H.	Not enough information at this point no
Jonalyn M.	Not currently. But yes in the future when she's older.
Shannon H.	Not at this time she is too young
Kimberly W.	Not at this time
Luke C.	Not at this stage as my daughter is only 1 month old and has just been diagnosed with PWS.
Kamal H.	Not at the moment. I would want to see more safety data.
Debra E.	Non lab diagnosis
Jessica C.	No. My brother is 54 years old and is relatively happy and healthy. I'm not sure that this drug would improve his life at this point but I do wish this treatment would've been available when he was younger. His adolescence and young adulthood was a very difficult time for him and for his family. I do think that younger people with PWS should be given the opportunity to improve their lives and health with this new medication.
Deborah F.	No. Health too fragile.
Grace C.	No. He had another clinical trial before.
Jacomijn V.	No, not yet, because of his age
Candice A.	No, not accessible.
Lisset R.	No, he does not need it yet
Auralien C.	No, for the moment my daughter is not affected by hyperphagia, so taking this medication is not necessary. But who knows what the future holds (?), and if it is a real answer to the problem, it is important that others can benefit from it.
Tessa V.	No not yet because of his age
Mel S.	No because as indicated he passed away in the early 1990s.
Linda T.	My son has too many other conditions to risk trying this now. But it might have helped 15 years ago.
Aida C.	I'm not ready for my son to be on the trial drug yet because he's six years old and not able to communicate how he is feeling.
Jane G.	I don't know what DCCR is-- the previous question should have had YES/NO/UNSURE for choices.
Gustavo G.	I don't know the DCCR
Emily W.	I don't think so.
Pamela H.	I don't think so cause my child is on several psych medications now and don't want anything to interfere with the results it's taken us a long road to get to where she's in a good place behavior-wise.
Olivier L.	Depending on options
Dennis J.	Further research
Janice A.	good data, low cost, would like the option to assess possible clinical benefit in our son, if his hyperphagia which is the most disruptive daily symptom of his PWS can be reduced then his daily behavior and quality of life will improve, which will then improve our family's overall quality of life

Appendix A

Laura K.	Have not had access to this, yet
Tina W.	Have to ask the parent. I am a grandparent
Angelica P.	He was not available to take it due to his age
Audrey F.	I am not able to take this kind of decision yet as my nephew is only 2 months old I am not sure as my daughter lives at Latham Centers and will be transitioning to adult care so maybe in the future.
Cecilia M.	I would like more info
Brian G.	I would like to discuss it over with his mother, he is still young and hasn't reached the hyperphagia stage yet.
Alice Y.	I would want it well-researched and available as an option, the decision would be for her parents
Amanda S.	I would want the option to discuss it with my sister-in-law's care team
Alida L.	I'm not yet in this position, but my son is soon ready to experience the most debilitating symptom, hyperphagia. I hope with DCCR he will not be needed to be in that position.
Jessica T.	Maybe if it's proven to be safe for my loved one
Tillie E.	Maybe someday, but not until our child is older
Amanda C.	My brother has passed so he would not need the drug. But I have others I know with PWS who could benefit greatly from this drug
Kelli M.	My cousin has PWS and knows that this drug has minimal side effects and great success. She does not need the drug yet, but will in the future
Jennifer K.	My daughter has had changes in her behavior and body composition recently. Where we were not considered good candidates early in the DCCR studies, she may need something in the near future to help her.
Hannah N.	My daughter was born on April 7th 2024, when she gets a little older of course. She has not started growth hormones yet
Lynda T.	My husband is wary of our son taking any drug.
Janice O.	My Son an DIL are very involved in their daughter's medical needs. I am sure they will make the decision for her based on all available data.
Charles G.	Need more information about risk vs benefit
Laura U.	Need to learn more.
Lillian H.	Not sure, but those who want it should have the opportunity as nothing else is available
Christine R.	Not sure. If my daughter's behavior/anxiety worsens I would.
Cora O.	Note info needed.
Lorryn T.	Only if it was thoroughly tested and safe
Syleste P.	Possibly, but she's already on a growth hormone and two other medications for mood stability.
Stephanie P.	Possibly, depending on the side effects.
MegN C.	Possibly, under the supervision of his specialist.
Robert H.	potentially - pending trial results
Henry T.	Potentially but we would need to understand the risks, my niece has PWS.
Lisa W.	That is up to her parents.
Ellen S.	That will be the parents' decision
Cindy F.	This is my cousins granddaughter who has PWS I wouldn't be able to say

Appendix A

Belinda C.	Unsure as we don't know much about this. Our baby is 2 weeks old and have just been given this diagnosis
Barbara D.	Unsure. Need to review more details about possible risks and side effects.
Victoria B.	We are a family from the country of Chile, we live in the countryside, we are farmers, my son is going to be 12 years old, he already weighs 116 kilos and we were not advised correctly by the Chilean doctors. We are a family that does not have too many financial means, and I am also very worried, because my son no matter how much I take care of him here at home, continues to gain weight, he looks for the opportunity to eat and I am afraid that he will continue to gain even more weight
Michelle D.	We need more treatment options; if we carefully review risks and benefits we should be allowed to make the decision that fits our situation.
Amanda G.	We would need to see some reviews/results and after it's been vigorously tested.
Lucia B.	Yes, because it would improve the quality of my daughter's life.
Jessica B.	yes, because there is no current cure for PWS and no treatment for hyperphagia in patients with PWS
Adam J.	Yes, because there is no current FDA-approved treatment for PWS patients with hyperphagia.
Gail C.	Absolutely, help with controlling hyperphagia would be life-changing.
Adriana R.	Yes, because is heartbreaking to see a child who is hungry and you can't do anything.
Gail T.	Yes. The management of hyperphagia and all the side benefits would significantly improve my grandson's and others with PWS's quality of life.
Alison B.	Yes to prevent hyperphagia and decrease body fat
Augusta G.	Yes. I am confident DCCR would improve the life of my granddaughter Carmen. I am a pharmacist and I had studied profoundly the published studies on DCCR. I know that this drug is of great interest to PWS people.
Lisa C.	Yes, it would greatly improve her life with the ability to stop obsessing over food and other OCD symptoms
Donna S.	Yes to help him with his increasing hunger feelings.
Jamie P.	Dependent upon requirements we absolutely would
Jen H.	Yes, anything that assists with treatment is important!
Theresa S.	Yes, we would like to work with our physicians to see if DCCR would benefit my son
Edward M.	Absolutely want the option of DCCR for my grandson. This could change his life in an amazing positive way.

Appendix A

Suzanne C. Yes for a better quality of life

Norma G. Yes this is life breaking big game changer for the hyperphagia

Chae N. Yes, we would love to see how it could help our daughter. And improve her quality of life she was born on April 7th, 2024

Makayla W. yes it will help her

Rita H. Yes my granddaughter has that disease

Ashlea G. Weight gain/behavioral issues

Oreste B. Yes my grandson Harry Connerty would love to increase his independence & reduce the intense stress in his & all our lives especially his wonderful parents who we are blessed to have taking care of Harry! This medicine would be a life changer for Harry & the whole family! Harry's Mom & Dad should write a book on diet because they have kept Harry healthy all these years during which everywhere they turn there are issues from food to outbursts to sleep issues to lethargy, I could go on & on! Please understand this is so, so important & all you can do to expedite will be immensely appreciated! Thank You, Grandpa Orry

Michael B. Yes! My nephew Harry would love to increase his independence and reduce the intense stress in his life. This medicine could be a life changer for him and his family.

Emma B. Yes, my grandson Harry would love to increase his independence and reduce the intense stress in his life. This medicine could be a life changer for him and his family.

Amy C. Yes, my nephew Harry would love to increase his independence and reduce the intense stress in his life. This medicine could be a life changer for him and his family.

Emily C. Yes. My nephew would love to increase his independence and reduce the intense stress in his life. This medicine could be a life changer for him and his family.

Jennifer B. Yes, our 18 year old son with Prader Willi would love to have increased independence and less stress in his life. This medicine could be a life changer for him and his family.

Kay L. Yes. My daughter suffers from extremely high BMI. The food drive has gotten so bad that her behaviors to access food are getting unmanageable. She has suffered a pulmonary embolism, enlarged right heart, pulmonary hypertension, hypertension, edema, and many other significant medical conditions. This could be a game changer for our family and many others.

Kelly S. Yes when necessary

Karl H. Yes we certainly would. It could be life changing for our son and the rest of our family.

Virginia J. My niece's son, has PWS and she would like him to be on this medication

Appendix A

Davila Ana C. Yes, We believe that medication can bring good benefits with hyperphagia, behavior, and improved social relationships.

Ryder M. Yes, it is safe and I know it will help my brother

Eli A. Option if safe and effective

Asher M. Yes. He's my big brother and needs something.

Cade M. Yes My brother is my best friend and I need him not to think about food all the time or eat himself to death.

Grant M. yes. it's safe and I didn't want my brother to be hungry all the time

Appendix B: Comments from Patients and Family Members With DCCR Experience

NAME	COMMENTS REGARDING MOST IMPORTANT BENEFIT OF DCCR
Patrick B.	That patients with PWS have a chance at a better life. Especially the children.
Jessica V.	Reduced food obsession, improved satiety, improved BMI, reduced requests for more food, better quality of life
Laurie P.	a step closer to help with excessive need to eat.
Toni A.	To stop the hunger so our babies can live more peacefully and not in constant hunger
Maryanne A.	Relief of never ending hunger
Mychael A.	Curbing appetite and preventing behavioral issues that stem from being hungry
Jennifer A.	Health
Shannon A.	Helped his parents (my brother and sister in law) promote more normalcy for their entire family. The constant focus wasn't *always* on him when he had access to the drug because his behaviors were so much more manageable.
Alhanouf A.	To help enhance PWS patients, and give them a normal healthy happy life ..
Roy A.	Treatment of hyperphagia and treatment of emotional and behavioral changes in children with PWS.
Faustino A.	Not suffer having to accomplish her goals
Shea A.	Treating hyperphagia
Maria A.	Reducing binge eating
Jessica A.	Ability to control one's self more effectively
Pat A.	Help my great niece.
Joel A.	hyperphagia, anxiousness, and temper outbursts
Sara A.	Behavior, metabolic measures and fat mass
Mark A.	Help individuals
Emad A.	We need to have a medicine for our kids to be close to be normal
Pavan A.	Improvement in hyperphagia
Delia A.	The hunger they experience in the diagnosis and all the factors that come with it
Brian A.	Better life.
Kori A.	expansion of daily activities
Jenna A.	Healthy life
Ann A.	Help with hyperphagia
Lilah A.	Helped with behavioural issues and anxiety levels
Lilah A.	Helping with behaviour issues ie: reducing anxiety levels and overall much more compliant and calmer demeanour
Peggy A.	Treating hyperphagia
Jason A.	Control of hyperphagia.
Amanda A.	Getting treatment as early as possible will improve his chance to feel better and learn better
Hoor A.	Help in treating the disease And to live a normal life
Alicia A.	Hyperphagia-related behaviors.
Johanne A.	on aimeraient bien

Appendix B

Matthew A.	Life changing for my niece and the family
Donna A.	Being able to live without the constant hyperphagia that causes stress and physical and mental pain as well as physical health issues.
Dareen A.	It can improve hyperphagia and fat mass
Elena B.	Normal life
Erin B.	Having a clear thought process, feeling full, having non-suicidal thoughts. His behaviors and emotions were under control. We didn't need to lock food up anymore.
Vinuthna B.	Great medicine for people living with PWS
Michael B.	Hyperphagia management
Kelly B.	To help her
Hannah B.	No constant hunger
Linsey B.	The hunger has significantly decreased.
Cristina B.	Cure
Joseph B.	Health benefits to pws
Mike B.	Treatment
Joel B.	Reduced hyperphagia
PJ B.	Reduction in uncontrollable hunger associated with hyperphagia
Brandon B.	Weight loss
Abigail B.	Better quality of life
Callum B.	Helping keep the eight issues under control with PWS
Nataly B.	Calidad de vida de las personas con SPW
Nayhibe B.	Comportamiento e hiperfagia
Maria B.	Better life for my loved one
Robert B.	Relief
Pagliai B.	Hyperphagia
Shaterraca B.	Willing to learn more
Jelld B.	Less feeding off hungry
Anne B.	Control of hyperphagia.
Alexandra B.	We don't want her to suffer from hyperplasia.
Leonardo B.	1 drug for 3 diseases (hyperphagia, fat, behavior)
Alice D.	Hunger and behavior
Tom B.	Help PWS people from over eating ,behavior issues and killing themselves
Ponder B.	Giving my child the opportunity to have a full and maintainable life!
Stephanie B.	It would be for my niece. Addressing the hyperplasia would be the priority.
Clare B.	Slowing/stopping Hyperphagia
Amy B.	To live without hunger, locks and constant supervision over food outside of the home
Patricia B.	Hyperphagia
Kathy B.	The positive behavioral changes. This is a miracle drug that made a significant difference for the entire family.
Sherie B.	Hyperphasia control and anxiety decrease.
Traci B.	Hyperphagia
Victor A.	Better health
Claudia B.	To give relief of symptoms experienced by the child.

Appendix B

Matthew B.	It would improve Callan's entire quality of life. It would change things dramatically. Food is a struggle 24/7.
Nicky B.	Don't know yet. Need to give it a chance.
Ferdinand B.	to avoid hunger
Raquel B.	Improve quality of life.
Laura B.	I was not a participant. But I do know there were significant improvements because of DCCR.
Ashley B.	Behavior concerns
Patricia B.	Symptom control
Elizabeth B.	A better life
Bev M.	Patient has control & can focus on other activities than thinking of food
Marcin B.	I have no big expectations to early phases, but I would expect decrease hyperphagia on next stages. It could decrease other negative effects like for example anxiety or aggressive behaviors which could be based on it in my point of view.
Quoc B.	Minimize the hunger
Anneke B.	Minderen van eetlust
Nancy B.	Mental and physical normal growth.
Susan B.	Reduction of hunger, anxiety and other symptoms listed in above description
Felipe C.	It is difficult for us to be able to explain the causes and consequences of the drug under study, but I have relatives who do know about pharmacological medical advances and they explained to me its benefits and the importance of continuing to advance in phase.
Stacey B.	Opportunity for independence and longevity
Katty C.	Improve the life of the persons with pws.
Ayana C.	Reduced disease severity and improved quality of life of these patients
David C.	Curbing the 24/7 hunger issues.
Linda C.	Behavior adjustments, calmer demeanor, reduction in food seeking and OCD behaviors with food
Belinda C.	Help the symptoms of people living with pws
Russell C.	Distinct improvements in mood and behavior
Suzanne C.	Improved mood & behavior
Maureen C.	To improve live quality of PWS people
Maria R.	Reduce hyperphagia
Amandine C.	Self control of the satiety and anxious behavior. I will be able to come in United States if there is a other trial of DCCR.
Arthur C.	Decreased the food seeking and hunger
Maria C.	improve quality of life
Jose C.	To control her hyperphagia
Marty C.	Help with hunger
Mike C.	Improved quality of life
Macarena C.	The drugs
Luis C.	Control of the hunger sensation.
Sylvain C.	Hyperphagia
David C.	reduce the symptoms of the syndrome

Appendix B

Wendy C.	Hunger and behavior issues
Stephanie C.	It's honestly hard to choose. If it would help in even one area, it would be a blessing. The meltdowns are getting difficult some days though.
Donna C.	Delay of the hunger
Kellyann C.	Better quality of life
Fillebeen C.	Gain of independency, better life...
Megan C.	Decreased hunger, decreased food seeking, and improved body composition.
Gabriel C.	Save children!
Joanne C.	Improved quality of life
Gozde C.	Increase hungry
HsiaoYi C.	Reducing hyperphagia, reducing weight gain
Raj C.	Positive
Chrystena C.	The ability to feel full.
Grace C.	Reduce the appetite
Susan C.	Better behavior. Less picking. Better control of appetite.
Patrick C.	Eating habits, behavior advancements
Micheal C.	Reduction of hyperphagia symptoms
Jill C.	Have not previously participated in the study but having a treatment for hyperphagia in PWS patients is so terribly needed for quality of life and life span.
Joanna C.	The difference it made to my son's behavior and ability to control his emotions. He was far calmer and in control when taking DCCR
Manisha C.	Behavioural health and hyperphagia improvements in patient
Michael C.	Overall quality of life.
Meneses C.	Metabolic control
Angela C.	Helpful in extending his life and keeping him prosperous into adulthood
Hannah C.	Giving Grace a chance to not feel starving and constantly searching for food it's no life for a three-year-old
Humphrey C.	Helping to normalize family life for the whole family, and helping my son live a normal life.
Cynthia C.	They excel when on this and it is highly needed. Please help to make this available!!!
Erin C.	Helping with hyperphagia
Cassidy C.	treating all symptoms that come along with PWS that may affect ADL's
Christy C.	Independence, Friends, a FUTURE!!!
James C.	Reduction of his anxiety and obsessive-compulsive behavior
Kelly C.	Getting the help these kids need to live a long and fulfilling life.
Nicole C.	Treatment of hyperphagia
Olivier C.	Improve life
Chelsea C.	Quality of Life and Behavioral Control
Karen C.	hunger and weight
Jamie C.	It has been life changing for my daughter. It has opened so many doors she otherwise wouldn't have access to.
Zoey C.	It helps me with some of my anxiety and it help me with my food sneaky

Appendix B

Ryan C.	My daughter's anxiety about food significantly decreases when she is on DCCR. Because of that, she has improved her focus in all aspects of her life. Her grades have improved, she has been able to participate in extra curriculars with no issue, and she has enjoyed some of the independence and freedom that girls her age should.
Camden C.	The anxiety went way down and that helped them not want to get ahold of any food available
Angella C.	To help with hyperphagia
John C.	Life quality
Kathleen C.	Food disorder
Elizabeth C.	Better quality of life for my child. Less anxiety over food.
Judy C.	Was not able to participate in the trial based on current guidelines
Sophie C.	To give my brother another chance
Debra C.	Relief or help with from constant hunger.
John C.	Help with eating problems constant hunger
Linda C.	To help her with her diet always feeling hungry
DoëD, Ñ D.	Expecting to make the symptoms of the PWS to be at minimum
Mitsi D.	The life of my son would change
Peyton D.	To help relieve hunger.
Lucy D.	Reduce hyperphagia
Brittany D.	A life changing and saving chance at an even better life.
Rick D.	That it will make it easier to live with PWS
Katia B.	Results in hyperphagia, behaviors and body mass volume.
Leslie L.	Quality of life
Mallory D.	The help of having relief of not ever filling full and the constant want/need to hide and eat food.
Samantha D.	The behavioral effects it has
Ranjana D.	Safe to use
Shannon D.	It decreases hyperphagia and behavioral issues - it's a treatment for symptoms there is no other treatment for.
Jessie D.	Hope
Geri D.	Help minimize the severity of the symptoms of PWS.
Amanda D.	Anxiety reduction
Frederic D.	Stopping the hungry feel and always have the smile
Mary D.	Enable a better life
Lin E.	Hyperphagia control, less anxiety
Tara E.	It is a game changer in the quality of life for my Granddaughter!
Ruth E.	Any relief of the symptoms of Prader-Willi
Bachelier E.	Stop hyperphagia
Ivana E.	Helping with hyperphagia.
Marilyn E.	Help with hunger
Debbie F.	Fullness
Garcia F.	Just keep a child alive
Edward F.	Life style
John F.	To see how this could impact his life in a positive way.

Appendix B

Bouchnita F.	reduce attraction to food
Rebecca F.	Weight loss and behavior
Nancy F.	Information
Katarzyna F.	Access to DCCR will certainly increase the quality of life and reduce the feeling of hunger.
Santana F.	Being able to live a normal life.
Leticia F.	The medication will be a game-changer for individuals living with PWS.
Maureen F.	Behavior modification. It has helped tremendously.
Tracy F.	Major reduction in food related anxiety
Nancy F.	Anything that will help with hunger and tantrums
Kerri F.	Hunger and weight loss
Lacey F.	Benefits for PWS
Anca F.	Great
Deborah F.	To give the PWS individuals hope.
Saverine F.	Peaceful of mind, serenity
Charlyn F.	To help my grandchild and others like her
Samantha F.	Stopping hyperphagia
Laura F.	Helping those with PWS live the closest to normal life.
Tim F.	Increased quality of life
Michelle F.	Helping families and person illness!
Pearl F.	A control over hyperphagia.
Kahla F.	Help her
Sydney G.	Better care
Rubeun G.	The cure
Christy G.	Improved hyperphagia and anxiety
Kerry G.	Less food seeking, weight loss, better overall behavior, less OCD behavior
Michelle G.	Lowered food seeking and lower hunger
Maritza G.	Overall safety of the individual living with PWS.
Stephanie G.	Hyperphagia
Angelique G.	Hyperphagia
Michael G.	Appetite control
Lisa G.	Our granddaughter is too young yet for this medicine, but would like it available for her when she can have it.
Nona G.	Decrease in food seeking
Pranjali G.	To control hyperphagia
Angie G.	The severity of the disease is much less & quality of life is improved.
Chris G.	Long term benefits
Daisy G.	As an extended family member, I've learned of the challenges faced by my loved ones due to their grandson's battle with Prader-Willi Syndrome (PWS). It's heartbreaking to know that Jackson must endure the lifelong challenges posed by this condition with no cure in sight. The hope of effective treatments like DCCR (Diazoxide Choline Controlled-Release) provides a ray of hope in an otherwise difficult situation. I stand in solidarity with my family in urging the FDA to prioritize the review process for DCCR, recognizing the urgent need for treatments that can offer relief and improve the quality of life for individuals like their cherished Jackson.
Branson G.	Stopping the behavioral and Hyperphagia symptoms
Jose R.	Avoid start of cravings

Appendix B

Mary G.	Her behaviors would be minimized and her ability to gain independence would increase- if we could have access to a drug that controls her never-ending hunger.
Therese G.	Maintenance
Cathie G.	Appetite suppression (feeling full to avoid all the dangers associated with food seeking behaviors).
Molly G.	Increased life quality via reduced hunger and bx
Theresa G.	To help reduce her appetite
Karen G.	Not familiar
Evette G.	Better life
Linda G.	Less hunger
Erika G.	All of it, I think just easing his hunger will solve so many other things with that. I like that it's easily used and the benefits that come with just easing his hunger
Sarah G.	The ability to sustain control over hyperphagia and behaviors associated with PWS
Binay G.	It will help them to get a better life
Lim G.	weight
Michele H.	Helping reduce behaviors
John H.	hopefully its a cure
Rema H.	For the last answer just put "reduced disease severity and improved quality of life
Laila H.	reduced disease severity and improved quality of life
Frank H.	Ability to assist the child
Mona H.	Hope her comfort of living
Charlyne H.	Helping my granddaughters hunger
Jennifer H.	To help alleviate the many symptoms of PWS
Ivana H.	In our country there was no opportunity to participate in the study, unfortunately.
Hanane H.	Efficacy
Jaxson H.	Hunger and behavioral
John H.	It can help him.
Kristen H.	Not sure, but his mom relies on it for my nephew
Paul H.	Peace of mind for PWS patient
Sally H.	Curb hunger, improve muscle mass, reduce anxiety
Maryclaire H.	Might help the debilitating symptoms of pws
Olivia H.	Better meal management and weight loss
Elizabeth H.	My brother's daughter is a participant, I'm not sure the answer to this question, but I know he's grateful beyond measure to be a part of this
Jose O.	I think that by not having hyperphagia, children with PWS can live normally in the family dynamic since they can concentrate on everything around them.
Laura H.	Hyperphagia
Dawn H.	Help longterm
Pamela H.	The hunger and behavioral
Trish H.	My daughter did not participate
Laura L.	Mainly it will help debilitating symptoms of PWS
Hã Vã.	Help people living with PWS have a better life
Dayla H.	Hunger control
Chris H.	Decreased food seeking

Appendix B

Ana H.	Improving quality of life
Kim H.	Hunger management and behavioral stability
Katie H.	Pws
Robin H.	Behavior. Weight
Jared H.	Giving my son the hope of focusing on life instead of his constant struggle with food seeking.
Jessica H.	Supporting patient autonomy
Ereland H.	That it can help stop the feeling of starvation
Robert H.	Keep from over eating
Nancy I.	Help my son overcome any symptoms related to hyperphagia and be able to live and independent life if possible
Blanca I.	I believe the most important benefit will be, being able to control any type of obsession or necessity for food. We're not at the stage yet but it sure is scary.
Shelby I.	I believe DCCR would give our family member with PWS the ability to take the edge off of having hyperphagia and give them the ability to relax a little more.
Isabelle D.	To stabilize the weight
Iryna I.	Unfortunately, they didn't take it, but we know about the effectiveness. Hyperphagia is a big problem.
Ammon J.	Signing to help my nephew
Suzi J.	Very important
Catalina J.	it will help with the most debilitating symptom of PWS
Claudia A.	Reduce hyperphagia and aggressive behaviors
Cindy J.	Health of our children
Victoria J.	Helping the stop of hunger
Dennis J.	Better quality of life
Matthew J.	Calming anxiety around hunger.
Gregory J.	improving hyperphagia
Jessica J.	That it help the upsetting behaviors around hunger
Nicole J.	Helping hyperphagia
Tashia J.	Helping the guilty to access a better life
Andrew J.	Helping with hunger
Cathy J.	My granddaughter has participated in this clinical trial, and we have seen great benefits in her quality of life. It has helped her to lead a more typical life around food, and to participate in activities at school/church without massive anxiety.
John J.	My granddaughter has participated in this clinical trial, and we have seen great benefits in her quality of life. It has helped her to lead a more typical life around food, and to participate in activities at school/church without massive anxiety.
Sarah J.	Cure
Marsha J.	It's my great nephew. Progressing almost normal
Josif D.	weight loss
Jullie D.	Reduce overeating
Diede K.	Less hunger
Gavin K.	Weight loss

Appendix B

Gina K.	It would help our sweet cousin.
Christine K.	The possibility of helping hyperplasia for our little guy in the future.
Avgustina K.	Remove hunger
Paula K.	A better future.....it's the unknown now !
Mitchell K.	Better life
Lindsey K.	Decreased appetite, which in turn decreases anxiety/behavioral issues, better social interaction and participation, family mental health & anxiety decreased.
Sean K.	It stopped food seeking behaviors
April K.	Allowing my daughter to live a normal life because the drug helps her control her behaviors. It has allowed her to be able to continue to live with us. It has been a life changing medication.
Jenna K.	Calming behaviors and being able to rationalize behavioral issues better
Brent K.	Emotional stability, less food seeking, and greatly lessened anxiety
Ileen K.	Helping PWS
Yujin K.	Control eating
Hyunsoo K.	Help ensure effectiveness and safety
Sun K.	Validity
Kyungmin K.	We did not participate but know that the results are hopeful.
Christina K.	Quality of life for her is vastly improved
Eungyung K.	Our daughter's future
Sheila K.	Help manage food cravings
Shelley K.	Hopefully the decrease of food wants
Florence K.	Omdat het geen kwaad lijkt te kunnen en bij een deel van de mensen met extreme honger juist erg goed werkt
Gregory K.	Hyperphagia benefits
Darla K.	Help to control symptoms
MELISSA K.	Helping with hyperphagia
Jason K.	Patient access and affordability. Especially for folks of disadvantaged backgrounds who may not have clinical experience, knowledge and access. Additionally, a longitudinal study combined with other relevant interventions could change the trajectory of this condition and provide insight into other related conditions with hyperplasia as the symptom.
Lisa M.	For the last answer just put reduced disease severity and improved quality of life
Pat B.	Appetite control
Sara L.	satiety effect
Tania G.	control of hyperphagia
Sharon L.	To get them better and find a cure.
James L.	The potential to better treat hyperphagia
Katie L.	Our son always leaves food on his plate, doesn't finish everything and he doesn't seek food since taking DCCR. His behaviors have also improved tremendously and he is no longer physical with us. It's been a breath of fresh air to have access to this drug and we want to keep him on it forever!
Vicki L.	This would be the best level of treatment for our granddaughter with PWS. Thank you in advance for making the right decision for these children
Stephanie L.	We did not participate but I would sign her up in a heart beat for anything that would help her!
Erin L.	To help

Appendix B

Laurianne V.	Hyperphagia
Julie L.	Reduction In hyperphagia
Sourisack L.	He won't gain weight and will live like ordinary child
Ariana L.	hyperphagia
Pam L.	To help our loved one
Theresa L.	Helps
Patrick A.	Advancement of treatment options
Matthew L.	Limiting feed seeking behavior which interferes with typical functions
Joanne L.	Treatment options and education of effects.
Sangsoo L.	Validity
Bianco L.	Hyperphagia
Katharina L.	It will help with the most debilitating symptom of PWS
John L.	Stop hunger
Junior L.	Longer and better life
Alida L.	Not to be hungry all the time. Being able to focus on the daily tasks
Melinda L.	To be honest I do know, just want my baby girl to be healthy.
LI LI.	REDUCE/MANAGE THE ANXIETIES OF HUNGER CONTROL & MANAGE OVER-EATING
Brigitte L.	Cannot answer the question, sorry
Sofia L.	Hyperplasia
Dovila L.	Hypertonia and food seeking
Linda L.	Access to more opportunities
Carta L.	Hyperphagia
Nguyen L.	My child hasn't tried it yet, but I really want my child to experience it and have the opportunity
Deborah L.	Behavior and appetite issues
Brittany R.	Life expectancy
Amy L.	Living a full life
Maria L.	improvement in all aspects
Stacy L.	Treatment for hyperphagia
Nakesha L.	Treatment of hyperphagia
David L.	To help with hyperphagia
Catherine L.	Improved quality of life
Eric L.	Controlling the uncontrollable feeling of being hungry
Neyra L.	Weight management. Independent living within PWS limits. Future success in school
Mathieu L.	Hyperphagia
Justine L.	It could help with the biggest challenges of PWS including hyperphagia
Henrik L.	The effect on his food addiction
Kristina D.	Helping my daughter thrive
Maria C.	Giving the opportunity to PWS people to be free of certain symptoms
Sfetcu M.	Health
Catherine M.	The resumption of normal eating patterns to enjoy the company of friends and family.
Essam M.	Hyperphagia control

Appendix B

Silvia M.	Less anxiety
Paola M.	control of hyperphagia
Ana M.	Reduce appetite
JennaLee M.	The overall effect of decreased hunger
Magda M.	Help with living with that disease
Rana M.	Reduced disease severity and increased quality of life
Pateicia M.	I believe it will help alleviate the insatiable hunger that many individuals with PWS live with on a daily basis. It will help reduce the risks of other diseases that come with PWS like obesity, diabetes, hypertension, thyroid disease, insatiable hunger and many others.
Mauricio M.	The drug, maybe could help my grandson
Antonio M.	Yes because that would help kids with the urge of being hungry and improve their health
Erika G.	I have no knowledge about the medication, since my little daughter was recently detected with PWS
Fatima S.	To relieve the debilitating symptoms of Prader-Willi Syndrome
Cynthia M.	Helping with Hyperphagia.
Lisa M.	To have my daughter with PWS have options to lose weight and have control with consuming eating all the time
Patrick M.	It's what child needs!!
Elodie M.	easier protocol
Casal M.	Hyperphagia
James M.	To curb the constant feelings of hunger and normal feelings of pain.
Cathy M.	Control eating. We have all food locked up but she has started going through the trash.
Tracy M.	Longevity of life!
Albert M.	The lessening of appetite
Constanza M.	Very important
Rachel M.	It would be able to help her live a full and independent life!
Diego M.	helps the development of the affected
Marcia M.	To help children feel full and to be able to actually have your children leave the dinner table with food still on their plate.
Shikha M.	Hyperphagia
Desire M.	Helping the over eating and not feeling full as that is the main reason for behaviour outbursts
Rafal M.	Easier life
Lisa M.	It has helped tremendously! Food seeking is minimized and behavior is manageable
Nathan M.	My son's food seeking has been significantly lowered.
Michelle M.	That it would be life-saving and life-lengthening.
Diane M.	It will help her!
Lota M.	She is in a group home six hours from where I live.
Joe M.	Less hyperphagia
Telebas L.	Save children
Frank M.	Health care
Carolina M.	To diminish hunger
Valerie M.	Controlling PWS challenges

Appendix B

Evan M.	Hunger management
Rebecca M.	Improved quality of life
Jennifer M.	Any available to ease PWS manifestations
Anna M.	Reduced hyperphagia and improved body composition
Elizabeth M.	Hyperphagia response
Michele M.	Reduces the likelihood of Hyperphagia, obsessive behaviors, temper outbursts
Tabitha M.	My niece is the most bright girl and she deserves to live the most normal life possible. I want her to be as happy as she can be so being able to function normally will give her the best quality.
Robert M.	The most important benefit is the reduction of hyperphagia and OCD
Elena M.	Controlling hunger
Marcello M.	Being able to live life without constant hunger.
Haleigh N.	A significant decrease in hunger
Marwa N.	Less hunger and outbursts
Brooke N.	People who have come before us have entered into clinical trials and done all the things so we could get to where we are today it's important we keep making the steps forward to do the same
Linnie N.	Improved life
Duy N.	Help our child avoiding obesity
Magdalena N.	Yes. Because we hope it could be life changing
Doreen O.	Would greatly help
Andrea N.	Being able to successfully control Kirk's weight
Amy D.	With his hunger
Suzanne O.	Aidan can function and is more social and calm
Renee O.	Everything
Mary O.	To function with daily life.
Mariam O.	reducing severity of the disease and increase of quality of life
Michael O.	Progress
Martin O.	The life
Alyce O.	To help the FDA approve medical
Amabelly P.	Be healthy
Elga P.	The DCCR will normalize her hyperphagia.
Elodie P.	Hyperphagia
Cheryl P.	PWS families have the right to decide whether or not to try any chance to make their lives better.
Leland P.	hunger control for my daughter
Krysta P.	Getting assistance and medical care
Carla P.	It would help with many health issues caused from over eating
Ewelina P.	Reducing hunger, and improving behaviour
Simone M.	Decrease in hyperphagia
Manciu V.	I'm trying to save lives
Rorri P.	Losing weight and not feeling full no more
Ines P.	Not being Hungry All The Time

Appendix B

Lauryn P.	Improving kids' PWS symptoms would improve how they can provide and access the community better.
Trevor P.	Treatment of hyperphagia
Tina P.	Treating hyperphagia and anxiety
Linh P.	Maybe cure our children's diseases
Thao P.	Maybe cure our children's diseases
Linh P.	Maybe cure our children's diseases
Syleste P.	I need to do more research
Kristina P.	To help his quality of life
Chen P.	Help reduce the desire to swallow
Jean P.	Better life
Joanne P.	Control hunger, and behavior
Delfina P.	Most important for the patient
Alison P.	It gives people with PWS their life back
Shyama P.	Controlling hyperphagia
Terry P.	A normal life for my son
Glenda P.	To make PWS children be more normal
Michael P.	Live a more symptom free life
Belinda P.	Losing fat, gaining Muscle mass, Less anxiety about food, better behavior all around.
Ignacio P.	Changing his life
Kristy P.	Reduced the food seeking- it has changed our lives!!!
Terri P.	Treatment
Dolores Q.	To help children of all ages and the scientific community understand how to treat and manage hyperphagia so that those with PWS can function in society without anxiety brought on by food
Sabra Q.	Hyperphagia, muscle mass
Amy Q.	It is life changing for the patients receiving it
Grayna R.	Don't feel hungry whole time
Rosa R.	Quality life for my nephew and family
Satyaveni R.	Controlling hyperphagia
Nandini R.	She was too young and not yet diagnosed at the time of the trials
Maria R.	A better life
Eduardo R.	Improve life
Aaron R.	Hope for a better quality of life and more opportunities for this child
Crystal R.	The reduced hyperphagia.
Kerry R.	Help control the appetite
Jane R.	Hunger and behavior improvement.
Candice R.	Trying
Simon R.	The ability to contain children/adults with PWS of thoughts and the ongoing drive to consume foods
Kathleen R.	Helping with body mass, helps reduce urge to eat, behavior
Breanna R.	Lessening Hyperphagia
Josie R.	Hyperphagia
Rose R.	Help the children
Nicte R.	Make his life better and easier

Appendix B

Jamie B.	helping with hyperphagia
Nick R.	Able to control symptoms
Barbara R.	Possible alleviation of anxiety and/or behaviors around food.
Kathie R.	Alleviate feeling of hunger after eating
Tasha R.	To just find a cure for it
Jeison R.	Weight loss and behavioral improvement
Heather R.	Helping his constant hunger.
Cristina R.	Hyperphagia
Juan R.	Reduce the hyperphagia
Elizabeth R.	Access to new medicines to include research
Laurie S.	Appetite control which alienates anxiety and meltdowns. This provides quality of life.
Malika S.	Stop hunger and improves behavior
Ivanna S.	Manage hyperphagia
Ramon S.	Hyperphagia
Sthacee S.	Hyperphagia
Shania S.	Getting help PWS people need
Katrina S.	losing weight would allow my son to live a full life, there are so many things he misses out on, and he deserves to be happy
Casey S.	Relieving symptoms for children
Dauvergne S.	Behavior and hyperphagia
Sylvain S.	Less hungry
Luis S.	We lived in Brazil and unfortunately didn't get to participate in the DCCR.
Gabriela S.	reducing anxiousness produced by hyperphagia
Rick S.	Help with hyperphagia
Kristy S.	Curbing feelings of hunger.
Rachel S.	Living a more fulfilling life
Sisi S.	Hyperphagia
Hedy S.	It was life-changing for my son and our entire family! We experienced what it was like to be a 'normal' family. That is until my son received a placebo when the FDA required a double blind withdrawal study. Our life immediately tumbled into chaos. The reason being that going back to what we had been living with was 1000 times worse after experiencing that life could be like. We are still struggling. We beg the FDA to approve this drug. Please give us our son back!
Bryan S.	The ability to live a normal life
Nicholas S.	Helping with hyperphagia
Donna S.	The lessening of food seeking and behavior woes
Jannis S.	The results are very encouraging
Elias S.	Less hunger
Dan S.	Calmer behavior
David S.	Appetite control
John S.	Behavioral control. Quality of life.
Aubrey S.	Quality of life. Behavioral control
Jennifer S.	Calming of food cravings thus behavior outbursts.
John S.	Maintenance of symptoms of PWS

Appendix B

Adam S.	To improve her quality of life by improving hyperphagia
Kathy S.	We have not participated, but know of many who benefited.
Taheerah S.	Better quality of life
Caryn S.	Can go longer when she knows food is coming eventually
Andrew S.	DCCR has a wonderful impact on my daughter's health, allowing her the ability to go greater periods of time without craving food and allowing her to focus on activities and work..
Mike S.	Helping hyperphagia
Victor S.	I want my sister to grow up realizing that there are things in life that are here to help her and I want DCCR to be one of them
Madeleine S.	Didn't seem to affect hunger- slight mood improvement
Darshana S.	Help with controlling hunger.
Namrata S.	To treat hyperphagia is a great relief
Sarah S.	Helping PWS
Douglas S.	The possibility of a healthier lifestyle and less dependence on external control of eating.
Mary S.	A good life, without hungry
Rory S.	Supporting the study and advancement.
Danielle S.	Life.
Dana S.	BMI improvement
Charles S.	Preventing symptoms for my loved one.
Faye S.	Beter leven
Erin S.	Management of symptoms
Lindsay S.	To reduce the desire to over eat if possible
Andrew S.	To help with hyperphagia
Kwangseok S.	Stop eating as soon as possible for oneself.
Emilio S.	It would help my daughter to lead a more typical life.
Gwyn S.	DCCR has helped hands down with leaner body composition and helped Ellie to feel full, something we've wanted to happen from the moment we received her diagnosis of PWS. She can lead a more typical life, not worrying as much about food all the time. This absolutely needs to be a standard of care in the treatment of PWS.
Brownie S.	To help those with this terrible disease live normally!!!
Elena S.	Reduce hunger
Angela S.	Reduced hyperphagia and reduced food anxiety
Michael S.	To make my daughter feel satiety and not constantly hungry.
Connie S.	Tallulah could live an independent life, PLEASE consider this important request for our loved ones.
Patrick S.	Helping with insatiable hunger
Jayne S.	Control of appetite
Whitney S.	Helping with cravings
Ryan S.	Quality of life. Behavioral control
Joy S.	The controlling of hyperphagia and a reduction in temper outbursts and stubbornness
Karin S.	Her quality of life ! Her body composition! It means everything to us to get DCCR approved! We need this medication so very badly for our daughter and all of the people living with PWS
Maria S.	Decrease the hyperphagia.
Lee G.	The patient needs help suppressing his or her appetite

Appendix B

Emi T.	To control problems related to PWS mainly concerning uncontrolled hunger.
Ivona T.	Better and normal life
Melinda T.	More emotional stability
Coleman T.	All of it
Priyanka T.	I want my baby to live long and healthy life, this can prevent obesity and control hypertension but also reduce fat, controlled diet.
Saurabh T.	Hyperphagia and behavioral improvements
Juan T.	Control the hyperphagia and behavior
Georgina T.	Live a dependent life
Curtis T.	Reduced anxiety and food obsession
Anne T.	The reduction in anxiety and food obsession.
Amy T.	Everything! Greatly improved quality of life for our son and our entire family. We often forget PWS is a part of our daily lives.
Lisa T.	My nephew has greatly benefited from the trials and medicine. He's calmer and less anxious about food.
Matt T.	Global change, ie body composition and decreased hyperphagia and decreased anxiety
Lam S.	Cures excessive appetite
Georgia T.	Giving my niece a chance at a full, healthy and independent life.
Marguerite T.	Hard to tell at this moment in time.
Kathleen T.	To help those living with PWS a better life
Isaiah T.	Better Health
Kathleen T.	Helping with some of the symptoms
Nicola T.	Making them not feel hungry
Aida T.	Control hunger and to be able to live a healthy and normal life
Jonathan T.	Living a better life
Janett T.	That it is progressing
Amanda T.	Body composition, better behavior overall, limited food seeking
Amanda T.	Improved quality of life
Henry T.	being able to control diet
Lynn T.	For a better way of life for my granddaughter and improve the quality of living with Pws
Prisma T.	Better future for my daughter
Khoa T.	Reduce any PWS disadvantages
Tina T.	We did not participate but work closely with those who have. The clear reduction in hyperphasia and clear improvement of day to day life for people with PWS.
Brennen T.	It can change an individuals life
Mark T.	End all frantic consumption
Gayle U.	Stopping hunger
Lauren U.	Lessen behaviors & living a "normal" household life for our children & my husband & self.
Laura U.	Health for PWS
Emily E.	Help w/ behavioral issues
Rebecca B.	The most important is the relief from the extreme stress that hunger can put on an individual. To relieve the stress even just a little is life changing.
Phyllis V.	The help with hyperphagia
Maxx S.	I think what would help the most is my parents but also I who are PWS I need a drug that would help my anxiety appetite or could help me order when I am in college

Appendix B

Martin V.	Control de ansiedad alimentaria y masa corporal
Michael V.	Overall assistance with hyperphagia and weight control. That said, my son is still young. Once symptoms appear, we would participate.
Olga V.	Reducing anxiousness produced by hyperphagia
Mary W.	Stop the behaviors of being hungry
Alexandria W.	Hunger to be curbed
Fan W.	Emotional control
Kathryn W.	Improved quality of life
Dianne W.	Relief from the relentless hunger and behavioral issues.
Michael W.	Relief from the unrelenting hunger, behavior issues, health problems.
Tierce W.	The quality of life improvements that come from the absolutely devastating effects of PWS.
Cynthia W.	It would help both boys
Bella W.	improving quality of life
Nakeshia W.	I have heard great benefits including less food seeking, weight management, cognitive support.
Brian W.	General support and confidence booster
Cecilia W.	Increased quality of life for young children and their families
Inge N.	health
Kimberly W.	Side effects
Roy W.	Curbing hung
Sally W.	The prevention of hyperphagia and therefore reducing my son's risk of obesity and its associated health concerns.
Meghan W.	Giving kids a chance to live a normal life.
Ashley W.	Controlling the hyperphagia that will come as he gets older
Deahl W.	Having my child be a child free from hunger
Ashley W.	Eliminating hyperphagia
Hanah W.	As a treatment for hyperphagia, it allows individuals with PWS to live an independent life
Joshua W.	Currently, there is nothing accessible to PWS families to treat hyperphagia, but DCCR could fix that
Jasmine W.	Weight loss and appetite suppressant
Zac W.	Helps reduce the feeling of being starving all of the time.
Carolyn W.	The improvement of hyperphagia and behaviors associated with it.
Kathryn W.	Give kids better life
Helen W.	The option & to be made aware of all this!
Brett W.	Allowing him to achieve a more independent lifestyle, without as much disease complication
Liu I.	Improving child's craving for food
Tammy Y.	Treatment
Anne Y.	For all the reasons you listed. He is only 2 years now, so to have this drug when he gets older will be wonderful
Bi Y.	Helpful for people living with Pws and there families
Sung Y.	Improving bulimia in patients
Samiha Z.	Decreased hyperphagia
Emilie Z.	the possibility of a quality life and future for the son
Dmitriy Z.	Cure constant hunger

Appendix B

Virginia J.	Hyperphagia, reduces it
Suzanne C.	Quality of life
Alison B.	To control hyperphagia
Lisa C.	The control if food obsession
Chae N.	To help better our daughters life, and improve the quality of her life
Kristy P.	It deceases food seeking significantly
Peggy V.	Medication and awareness