ADVOCACY IN ACTION

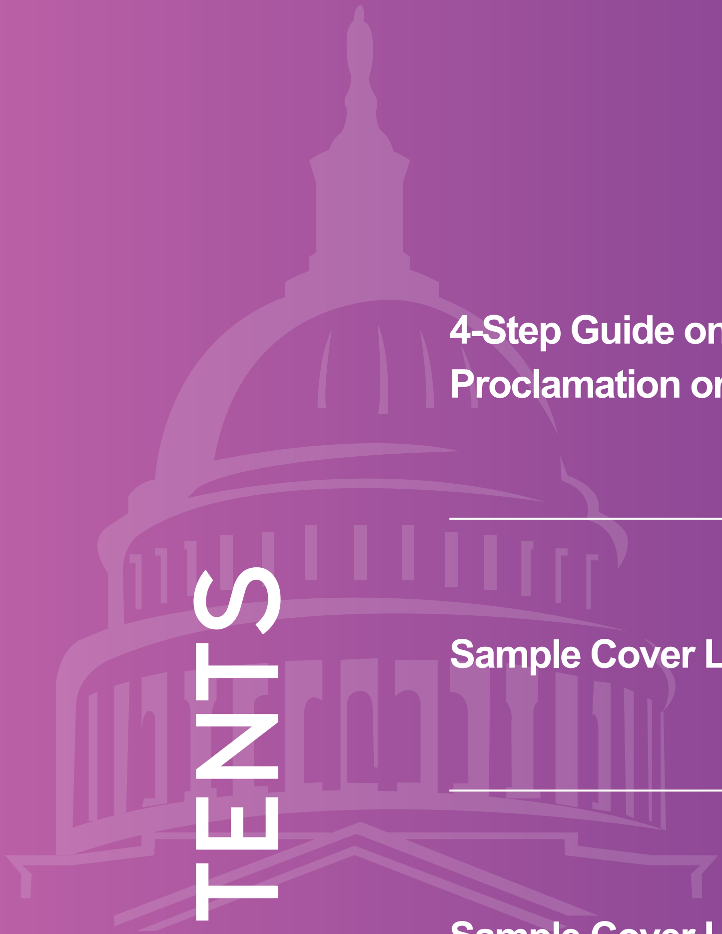
Prader-Willi Syndrome Association | USA

Prader-Willi Syndrome (PWS) Awareness Month

Proclamation Toolkit

Created by PWSA | USA's Advocacy Team

TABLE OF CONTENTS



4-Step Guide on How to Request a Proclamation or Resolution 2

Sample Cover Letter - EXAMPLE 1 3

Sample Cover Letter - EXAMPLE 2 4

PWS Awareness Month Designation by Congress in 2010 5-7

Proclamation Success Stories 8-9

PWS Awareness Month Toolkit 10

4-Step Guide on How to Request a Proclamation or Resolution

PWS Awareness Day (May 15th) / Month (May)

What is a Proclamation?

A proclamation is an official designation of an event. Proclamations are a great way to educate the public about a PWS and bring attention to our cause. It's also an effective tool for gaining public recognition of your cause and/or event because it carries the full support of a key government official in your state or community.

STEP 1: Contact your State or Local Government Office

Governors, county executives, mayors, state legislatures, municipalities, counties, cities or towns can issue proclamations. For city proclamations, a mayor, city manager, or city marshal may be the person to sign. For counties, it will most likely be the county commissioners. You do not have to have both the city and county proclamations; you can decide which entity in your community would reach more people. Determine whether you would like to request a proclamation from your city, county or state and locate the website for this entity.

STEP 2: Draft your Proclamation

For those of you looking to request a PWS specific proclamation, please visit pages 5-7 of this guide to see the PWS Awareness Month designation by Congress in 2010 for reference.

STEP 3: Follow the Guidelines for Submitting a Proclamation Request

Each city, county, and state will have their own guidelines and procedures for signing proclamations. The easiest way to research your city, county, or state's guidelines is to look on its website and search for the term "proclamation." Some of the larger cities and counties will have proclamation guidelines listed. Smaller cities and counties may provide contact information on the website to call or email for proclamation information.

Oftentimes, a cover letter requesting the proclamation is requested or required. We have provided two sample cover letters on pages 3 and 4 written to a city, county, or state's government office in request of a proclamation.

Helpful tips to expedite the process:

- A draft text of the proclamation in the preferred format
- The purpose of the proclamation (PWS Awareness Day or Month)
- The date when the proclamation is needed
- A brief history of your personal story as it relates to PWS
- Your name and best contact information

STEP 4: Make an Event Out of It!

Notify your local paper or media outlets and PWSA | USA about the proclamation. Distribute printed copies to local reporters. Have the proclamation photo enlarged for display at a news conference and/or in a prominent public place. Send copies to local newspapers. As with any media piece, demonstrate its importance to the media's audience by including local statistics.

Sample Cover Letter to Local Officials in Request of a Proclamation - EXAMPLE 1

Note: You may use this sample cover letter when you mail the proposed proclamation wording. If you have already spoken to the proper official, then you should reference that conversation in this letter. Also, please adjust the language of the letter to reflect the details of your request and feel free to add any of your personal story which might be relevant to the request. Be sure to enclose your proclamation draft with your letter.

Honorable [Name]
[Official Title]
[Mailing Address]

[Date]

Dear [Name],

May [insert day/year] is PWS Awareness Month. This month provides an excellent opportunity for our [City / County / State / School] to demonstrate its support for those in our community who are suffering with Prader-Willi syndrome and sheds light on the leading cause of childhood obesity in the US. Moreover, it is a wonderful opportunity to educate the public [or students] on the seriousness of this rare disease and how it effects the lives of over 30 million Americans.

I would be honored if you would sponsor an official proclamation to recognize [insert day/month – May 15 or month of May] as PWS Awareness [Day/Month] in [City / County / State / School]. Your proclamation would lend official recognition to the important work of educating the public on Prader-Willi syndrome, as well as emphasize your personal commitment to raising awareness for rare disease. I have enclosed a sample proclamation from 2010 when Congress declared the month of May PWS Awareness Month in the U.S., which may help your office compose the appropriate proclamation for [City / County / State / School].

If you or your staff have any questions concerning the request or the sample proclamation, please call/email/text me at [telephone number/email address]. I will follow up with your office regarding this request in the next few days. As always, we appreciate your support of PWS Awareness [Day/Month] and thank you for your consideration of this special request.

Sincerely,
[Name]

Enclosure: Sample Proclamation Language

Sample Cover Letter to Local Officials in Request of a Proclamation - EXAMPLE 2 *(Created by GUIDE, Inc.)*

Use this sample cover letter when you mail the proposed proclamation wording. If you have already spoken to the proper official, then you should reference that conversation in this letter. Also, adjust the language of the letter to reflect the details of the event in your community. Be sure to enclose your proclamation draft with your letter.

Honorable [Name]
[Official Title]
[Mailing Address]

[Date]

Dear [Name],

April 2017 is Alcohol Awareness Month. This month provides an excellent opportunity for our [City / County / State / School] to demonstrate its support in preventing underage drinking and to support the numerous people affected by substance abuse issues. Moreover, it is a wonderful opportunity to educate the public [or students] on the seriousness of alcohol abuse and the prevalence of this epidemic in our lives.

[Your organization's name] would be honored if you would sponsor an official proclamation to recognize April 2017 as Alcohol Awareness Month in [City / County / State / School]. Your proclamation would lend official recognition to the important work of educating the public on alcohol abuse, as well as emphasize your personal commitment to raising awareness about the dangers of underage drinking. I have enclosed a sample proclamation which may help your office compose the appropriate proclamation for [City / County / State / School].

[Insert the following paragraph if you are sponsoring a public awareness event.]

[List of organizations] are sponsoring [describe event] on [day] at [time] at [location]. We hope you will attend this special event to present your proclamation. If you are unable to attend, we ask that you or your official representative read the proclamation to our supporters on [day of the event].

If you or your staff have any questions concerning the request, the sample proclamation or Alcohol Awareness Month, please call me at [telephone number]. I will follow up with your office regarding this request in the next few days. As always, we appreciate your support of Alcohol Awareness Month. Thank you for your consideration of this special request.

Sincerely,
[Name]

Enclosure: Sample Proclamation Language

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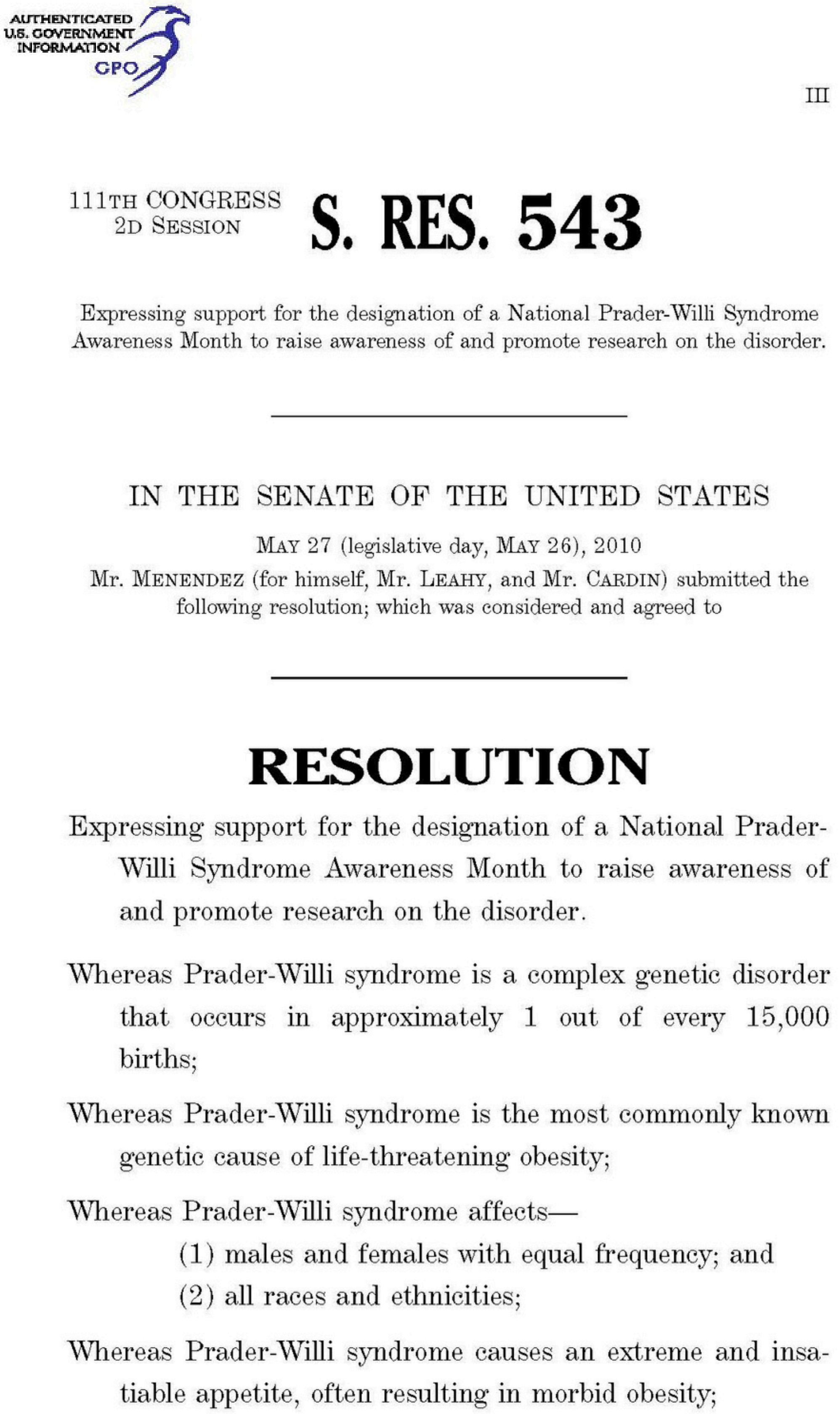
PWS Awareness Month Designation by Congress in 2010



AUTHENTICATED
U.S. GOVERNMENT
INFORMATION
GPO

III

111TH CONGRESS
2D SESSION

S. RES. 543

Expressing support for the designation of a National Prader-Willi Syndrome Awareness Month to raise awareness of and promote research on the disorder.

IN THE SENATE OF THE UNITED STATES

MAY 27 (legislative day, MAY 26), 2010

Mr. MENENDEZ (for himself, Mr. LEAHY, and Mr. CARDIN) submitted the following resolution; which was considered and agreed to

RESOLUTION

Expressing support for the designation of a National Prader-Willi Syndrome Awareness Month to raise awareness of and promote research on the disorder.

Whereas Prader-Willi syndrome is a complex genetic disorder that occurs in approximately 1 out of every 15,000 births;

Whereas Prader-Willi syndrome is the most commonly known genetic cause of life-threatening obesity;

Whereas Prader-Willi syndrome affects—

(1) males and females with equal frequency; and

(2) all races and ethnicities;

Whereas Prader-Willi syndrome causes an extreme and insatiable appetite, often resulting in morbid obesity;

Whereas morbid obesity is the major cause of death for individuals with the Prader-Willi syndrome;

Whereas Prader-Willi syndrome causes cognitive and learning disabilities and behavioral difficulties, including obsessive-compulsive disorder and difficulty controlling emotions;

Whereas the hunger, metabolic, and behavioral characteristics of Prader-Willi syndrome force affected individuals to require constant and lifelong supervision in a controlled environment;

Whereas studies have shown that individuals with Prader-Willi syndrome have a high morbidity and mortality rate;

Whereas there is no known cure for Prader-Willi syndrome;

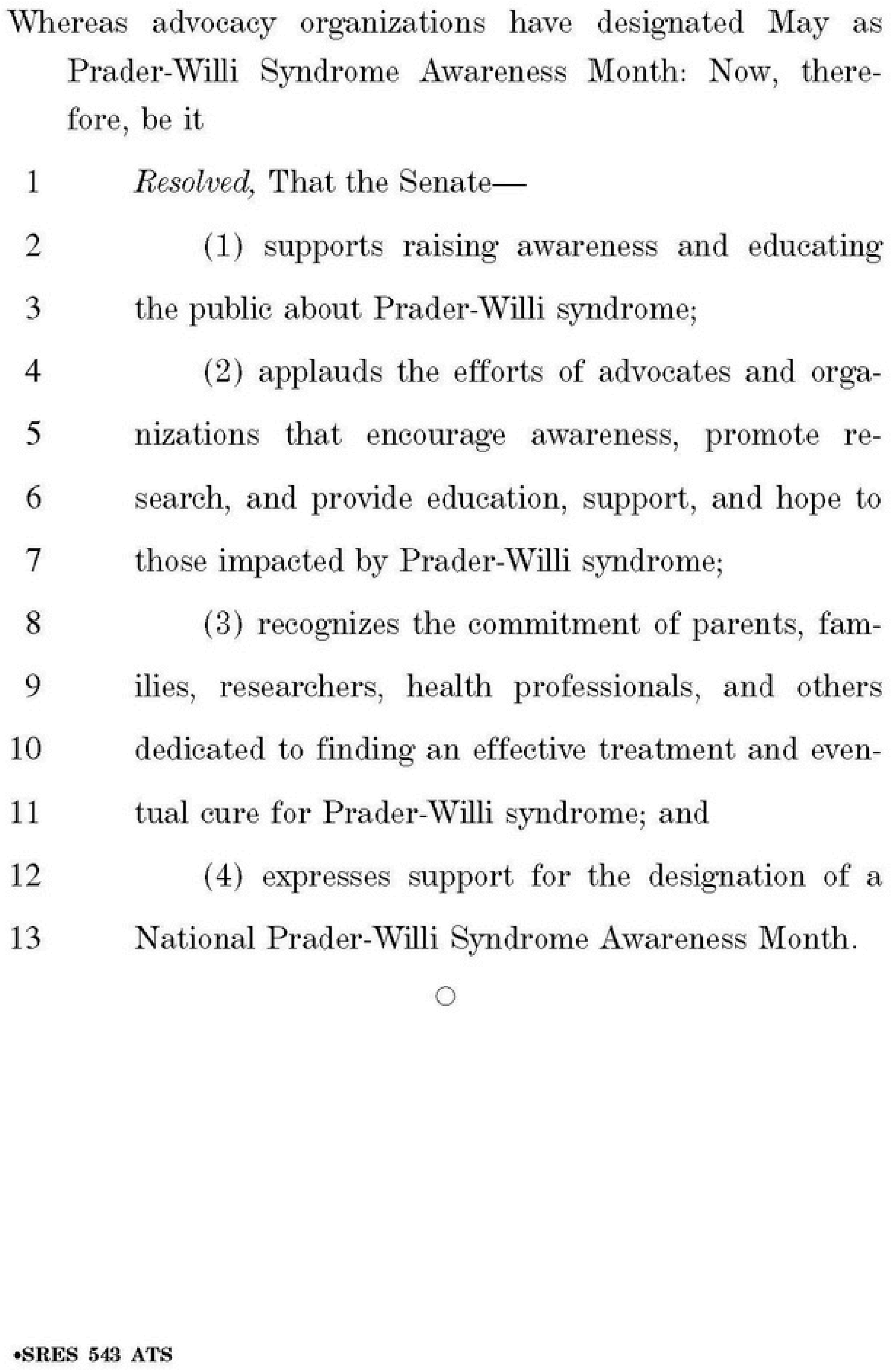
Whereas early diagnosis of Prader-Willi syndrome allows families to access treatment, intervention services, and support from health professionals, advocacy organizations, and other families who are dealing with the syndrome;

Whereas recently discovered treatments, including the use of human growth hormone, are improving the quality of life for individuals with the syndrome and offer new hope to families, but many difficult symptoms associated with Prader-Willi syndrome remain untreated;

Whereas increased research into Prader-Willi syndrome—

(1) may lead to a better understanding of the disorder, more effective treatments, and an eventual cure for Prader-Willi syndrome; and

(2) is likely to lead to a better understanding of common public health concerns, including childhood obesity and mental health; and



Whereas advocacy organizations have designated May as Prader-Willi Syndrome Awareness Month: Now, therefore, be it

Resolved, That the Senate—

(1) supports raising awareness and educating the public about Prader-Willi syndrome;

(2) applauds the efforts of advocates and organizations that encourage awareness, promote research, and provide education, support, and hope to those impacted by Prader-Willi syndrome;

(3) recognizes the commitment of parents, families, researchers, health professionals, and others dedicated to finding an effective treatment and eventual cure for Prader-Willi syndrome; and

(4) expresses support for the designation of a National Prader-Willi Syndrome Awareness Month.

○

CLICK HERE TO DOWNLOAD THE PDF

Proclamation Success Stories

Advice from Families in the Prader-Willi Syndrome Community

Sheri and Lyra

“Connecting with an elected official in your state is very important. They may not even know about Prader-Willi syndrome, or that a resident/residents in their state have this diagnosis. They are very busy with their matters of interest to get through when the session is open, that it might be hard to see past their own agendas. Educating and advocating is an ongoing part of who I am as a parent, and something I think is very important. It is the only way to get the word out that we need help and support.

I had initially contacted Senator Patricia Rucker, who is our county's elected official, about lighting the capital up for rare disease day. She came back offering a resolution. Until being honored on the senate floor on rare disease day, we have felt little support from the state of West Virginia. As most states do not know about PWS, they do not recognize it as a diagnosis in the state for programs like Medicaid Waiver or other state programs. Programs that are very important to the financial support for the families and also the financial support for the future of the child with Prader-Willi syndrome.

As I listened to Senator Rucker read the proclamation, I knew that my voice had been heard. I had the attention of her constituents who heard her words. Prader-Willi syndrome was given attention for once in our state. It might not have solved any issues that day, but it could be the start of more conversations in the future - history starts somewhere.

I told Lyra where we were going, and that she was being honored. Every person we passed, she proudly told them, ‘em em me.’ I understood her to be saying ‘honor me.’ She had this energy that I rarely see in her. She wanted to be seen. She wanted PWS to be heard too.

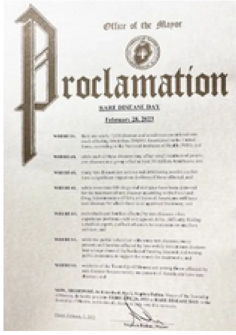
We walked away with an official document from the state of West Virginia, and so much hope. I look forward to the future and what it may bring.”

- Sheri M., mom to Lyra (living with PWS), West Virginia

Valerie and Isla

"When New Mexico Governor Michelle Lujan Grisham officially proclaims that May 15th is Prader-Willi Syndrome Awareness Day in New Mexico, you shout it from the rooftops!! Happy first official PWS Day to my fellow New Mexicans, and thank you Governor Michelle Lujan Grisham and Secretary of State Maggie Toulouse Oliver!"

- Valerie S., mom to Isla (living with PWS), New Mexico


Office of the Mayor

Proclamation

RARE DISEASE DAY

February 28, 2023

Sue and Shealynn

“My motivation for reaching out to my local officials was to raise awareness and bring attention to PWS and all rare diseases that affect so many of our children and families.

I encourage others to do the same because people do want to help, but we can’t receive help without asking and discussing the challenges and needs of our rare community. Raising awareness is essential for PWS and other rare diseases. Awareness can open doors to much needed resources like funding, research, and development of treatments.

As a first step, I created a letter introducing myself, my loved one affected with a rare disease (PWS), and the symptoms and challenges our community faces. I kindly requested their help in raising awareness by illuminating in Rare Disease colors on February 28th, giving a Proclamation or, spotlighting PWS in local newspaper coverage. I also followed up with a call and email.

Our local mayors office contacted us almost right away and offered their full support. We had a meeting with Mayor Dalina and discussed PWS symptoms, the challenges, and our need for awareness. It was a very empowering experience to be the voice for my daughter and so many other individuals living with PWS and any other rare disease.

My inspiration is my daughter Shealynn. I have watched her overcome so many struggles and obstacles due to PWS. I decided to help her fight back through advocacy. I like to call it ‘making noise.’ She is a courageous little girl and she, along with our other PWS friends, deserve an opportunity to live longer, fuller, independent lives.”

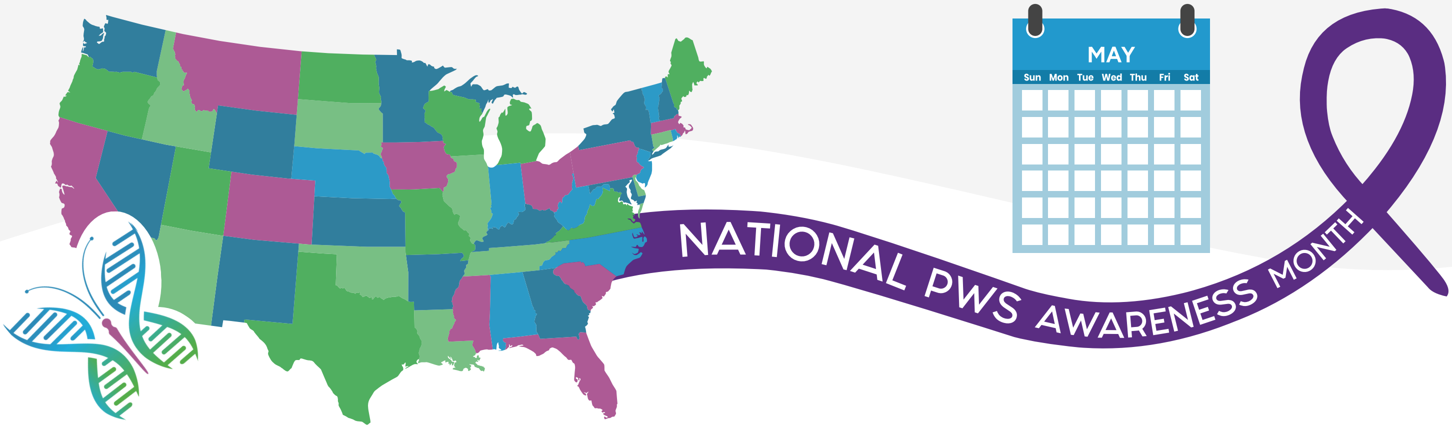
- Sue C., mom to Shealynn (living with PWS), New Jersey

Elaine and James

"As a member of the PWSA | USA Advocacy Workgroup, I am always inspired by the work of others. I decided to follow their examples and try to get a Proclamation for PWS Awareness Month from the Governor’s office in New Hampshire. An acquaintance of mine with another rare disease, guided me through the process and happily, It was incredibly easy. Our state has a staff person in the Governor’s office that handles all Proclamations and there is even a webpage to make your request. The hardest part is the language for the Proclamation but fortunately, there are others in the PWS community who have done this and can help. You can also get language from PWSA | USA directly – that is what I did and it worked perfectly. Once I made my request, I waited several weeks and then followed up with an email – the Proclamation was ready several days later.

I am pleased to shine a little more light on the PWS community here in New Hampshire. My son is an adult so we don’t have things like school events or even IEP meetings to talk about PWS – this is a great opportunity to raise awareness.”

- Elaine T., mom to James (living with PWS), New Hampshire



Click the image to explore PWSA | USA’s **PWS Awareness Month Hub**

15 WAYS TO RAISE AWARENESS

Click Here to Learn More

May 15th is National PWS Awareness Day!

In 2023, U.S. Congressman Paul D. Tonko (D-NY) and Congresswoman Maria Elvira Salazar (R-FL) filed a joint resolution declaring May 15th PWS Awareness Day in the United States of America.

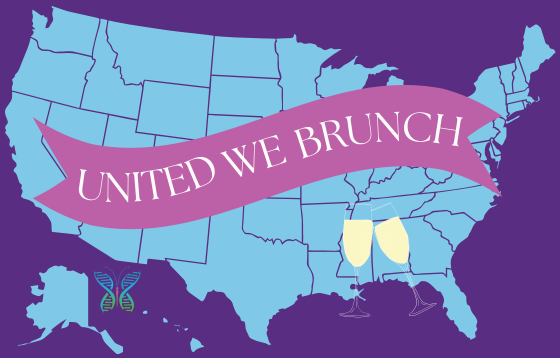
Thank you to our advocates, especially those who shared our PWS Awareness Day ask on Capitol Hill at the September 2022 D.C. Fly-in, for working hard to make this milestone happen. We are hopeful this additional spotlight on our rare disease community will help further and open new doors for the advancement of treatments.

Follow PWSA | USA on social media!

Get everything you need to make an impact this May with our comprehensive PWS Awareness Month Hub. You'll find customizable and pre-made print materials, eye-catching social media graphics, and a list of 15 meaningful ways to raise awareness. Plus, learn how to take part in our exciting new United We Brunch campaign, celebrate creativity in the Rare Aware Art Share gallery, and discover even more ways to get involved. Whether you're hosting an event, sharing resources, or advocating in your community, our hub has everything you need to spread awareness and make a difference!

Host a United We Brunch!

We are excited to introduce the United We Brunch initiative, a nationwide effort designed to bring people together to connect, share experiences, gain resources, and support our community’s needs. United We Brunch is about fostering hope – one brunch, one state, and one family at a time – uniting communities and creating a ripple effect of awareness and compassion across the country. Download the toolkit **HERE**.



CLICK HERE TO GET STARTED!

PWS Facts Toolkit

Share Your Spotlight on Hope Story

Wear Your PWS Pride