FOR IMMEDIATE RELEASE

Empowering Diversity and Inclusion for the PWS Community

June 12, 2024 -- In a significant step towards fostering equity and inclusion within our Prader-Willi syndrome (PWS) community, we are pleased to announce a collaborative initiative aimed at improving the standard of care and support for marginalized individuals living with PWS and their families.

This initiative, undertaken with the active involvement of several community members, seeks to ensure that every person living with PWS, regardless of their background, can access better care and harbor hope for the future. As an initial measure, the community members established a BIPOC (Black, Indigenous, and People of Color) affinity group. This group is dedicated to people of color living with PWS and their caregivers, providing a platform to share experiences, offer mutual support, and develop necessary resources.

We urge all PWS service providers to assist in spreading the word about this vital initiative to families of color within the PWS community. Your support is crucial in reaching those who will benefit most from these efforts. For any questions or further information, please contact the BIPOC organizer group - Charles Conway, Karine Kabundi, and Dini Rao - at bipocpws@gmail.com.

Together, we can make strides towards a more inclusive and equitable future for everyone affected by PWS.

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About PWSA | USA

Prader-Willi Syndrome Association | USA (PWSA | USA) was formed in 1975 to unite parents, professionals, and other interested citizens to enhance the quality of life of those affected by Prader-Willi syndrome. PWSA | USA empowers the PWS community through shared experiences, research, education, advocacy, and support. With chapters in most states, ours is the only national PWS support organization whose sole purpose is to assist individuals with the syndrome, and their families, every step of the way. Our website is full of resources on PWS, and we have a dedicated staff standing by ready to assist families and individuals 24 hours a day, 365 days a year.

About FPWR

The Foundation for Prader-Willi Research was established with one aim in mind: to eliminate the challenges of Prader-Willi syndrome through the advancement of research and therapeutic development. We are uniquely focused on research and developing new therapies. Our devotion to finding new forms of treatment, and ultimately cures, is what drives us. The Foundation for Prader-Willi Research was established in 2003 by a small group of parents who saw the need to foster research that would help their

children with Prader-Willi syndrome lead more healthy and fulfilling lives. Today, FPWR is composed of hundreds of parents, family members, researchers, and others who are interested in addressing the many issues related to PWS. Through our world-class grants program, translational research programs, and the development and support of PWS research tools, FPWR is playing an active role in research in order to develop new treatments for PWS and improve the health and well-being of those with PWS. With the support of the PWS community, FPWR's research programs have grown from funding small pilot studies to encompassing a robust and diverse research portfolio that facilitates and guides the PWS research agenda. We have played an instrumental role in advancing the field of PWS research by supporting innovative research, encouraging collaboration, engaging pharmaceutical companies, and enabling a research-ready community.

About Prader-Willi syndrome (PWS)

Prader-Willi syndrome is a variable and complex genetic disorder resulting from an abnormality on the 15th chromosome. It occurs in males and females equally and in all races. PWS is diagnosed in 1:15,000 to 1:25,000 newborns each year.

Key features include:

- Insatiable Hunger: A distinctive trait of PWS is an unending appetite. This, paired with a slowed metabolism, often leads to significant weight challenges.
- Muscle & Growth: Individuals with Prader-Willi syndrome typically have weak muscle tone and less muscle mass. They also often grow to be shorter than average if they don't receive the right treatment.
- Cognitive Aspects: People with PWS can face learning disabilities, making everyday tasks a little bit tougher.
- Behavioral Challenges: People with Prader-Willi syndrome often face various behavioral challenges. These can include frequent temper tantrums, compulsive skin-picking, stubbornness, and obsessive-compulsive behaviors. Managing these behaviors requires patience and understanding.
- Sleep-Related Issues: Individuals living with PWS often experience sleep-related issues including Excessive Daytime Sleepiness (EDS) and Narcolepsy

About BIPOCPWS *Click the image below to download the flyer*