

NM Prader-Willi Syndrome Project

FEBRUARY 2021

Happy February, everyone! While the new Covid-19 vaccines offer hope for our world, we know that we are not out of this pandemic yet. Here are some thoughts from PWSA about the continued support needed for the population we serve:

Supporting Individuals with Prader-Willi Syndrome During the Pandemic

January 21, 2021 PWSA | USA

The pandemic has been a mixed bag for the PWS community. For some individuals, mental health has suffered, isolation has increased, and opportunities for engagement and inclusion have been limited. For others, former anxieties and struggles have been alleviated, and new hobbies and interests have developed. There are fewer opportunities to access food, but also fewer opportunities for activity and movement. Day programs are not currently an option for many, but many did not like their day program and now know it is not necessary to attend. Change of routine can be upsetting for many with PWS, but this population is also accustomed to structured restrictions and is therefore primed for resilience.

Both physical and mental health conditions are prevalent for individuals with PWS, so a great challenge for support persons has been delicately balancing health department restrictions with what is important to and for the supported individual. Perhaps it is physically safer to avoid going to visit relatives, but at what cost to mental and emotional well-being? The limitation on time with family and friends and the lack of being out in the community have certainly been the most detrimental aspects of the pandemic. COVID has disrupted many traditions and events that folks with PWS look forward to every year. It is hard to create a sense of joy and excitement when every day is spent stuck at home. Having staff that are really invested in supporting our individuals remains more than important than ever now that staff are doing far more than ever and for many the only source of outside interaction. Phone calls, cards, letters and packages help remind people that even though there are limits on our movement and gathering, they are still loved and appreciated.

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Please flip over for information about PWSA's First Virtual Conference!!!



Prader-Willi Syndrome Association Announces First Virtual Convention

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Sarasota, Florida: Prader-Willi Syndrome Association | USA (PWSA | USA) is pleased to announce its upcoming 36th National Convention is moving to an **all-new virtual format**. Due to the ongoing health concerns brought forth by the COVID-19 pandemic, the organization will provide members of the Prader-Willi syndrome community with a variety of learning, educational, and support activities online.

The 2021 PWSA | USA Virtual Convention. Hope's on the Horizon, will take place June 22, 23, 24, 25, and 26. The Virtual Convention will include three conferences: Professional Providers, Medical-Scientific, and General. Each conference will feature breakout sessions, workshops, and virtual networking opportunities.

"The National Convention has been one of the most anticipated events in the Prader-Willi syndrome (PWS) communities since its 1979 debut in Minnesota," said PWSA | USA CEO, Paige Rivard. "Since then, thousands of professionals and families have attended the biennial event to connect and to learn from experts who provide attendees with the most up-to-date information and resources for addressing the very complex needs of supporting and caring for an individual diagnosed with PWS. While we will all miss being in-person this year, we look forward to bringing this invaluable resource to more participants than ever before in a way that ensures the highest level of safety and well-being for our community."

Held June 22nd, the Professional Provider Conference provides an opportunity for educational, Social Services, and Residential professional providers to come together to discuss identified and supported best practice and standard of care approaches. Cost is \$25.00 and includes registration for the General Conference. The Medical-Scientific Conference will be held June 23rd – 24th and will bring together scientists, researchers, and medical professionals from different disciplines so they can share ideas and report on progress, helping to meet the ever-present goal to support research that will identify effective treatments for PWS. Cost for that Conference is \$150 and includes registration for the General Conference. **Parents, grandparents, caregivers, and professionals who attend the General Conference will have their choice of multiple learning tracks covering an array of topics that can be tailored to their individual preferences. Registration to the General Conference is free to the PWS community.**

More information about conference schedules and registration information will be shared as it becomes available on the organization's website: www.pwsausa.org

Any questions regarding the 2021 PWSA | USA Virtual Convention may be directed to Jackie Mallow at convention@pwsausa.org or (800) 926-4797.