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Dear Friends,

As we reflect on the successes of 2021 and look ahead to more exciting events and initiatives, I want to take a moment to recognize your dedication to our mission. With your support, PWSA | USA continues to make groundbreaking strides to enhance the quality of life and empower those affected by Prader-Willi syndrome (PWS).

On June 22nd, we kicked off PWSA | USA's first-ever Virtual National Convention! With more than 1,500 people registered from around the world, this year's Convention was our most-attended to date. We want to thank our partnering sponsors, Levo Therapeutics and Soleno Therapeutics, along with all our other amazing sponsors, exhibitors, speakers, staff, and volunteers, who truly made the 2021 National Convention something to be proud of. We are grateful to have reached so many more families this year and offer our General Conference sessions for free. Session recordings can be found by visiting www.pwsausa.org.

On March 20, 2021, surrounded by palm trees, and the sandy beaches of Anna Maria Island and our PWSA family, the 7th Annual Hot Stove Dinner was truly something to celebrate. Thank you to Clint and Karla Hurdle for hosting this amazing event and for being incredible supporters of PWSA | USA. We also want to thank our event partner Leaving Legacies Foundation and all other sponsors for making this year's Hot Stove Dinner a huge success. Make sure you save the date for the 8th Annual Hot Stove Dinner – Saturday, March 26, 2022!

In other good news, PWSA | USA, along with FPWR, were granted a meeting with the U.S. Food & Drug Administration (FDA) on June 17th to share the PWS patient-voice. This 60-minute-long meeting with more than 50 members of the FDA was held to advocate for individuals with PWS and the critical need for treatment options for our community. Find more details at www.pwsausa.org.

I am continuously amazed and humbled by the outpouring of support from our PWS community. Please know that you are making a difference. On behalf of our entire team, thank you.

Sincerely,

Paige Rivard, PWSA | USA CEO

Find information
about our
upcoming
Angel Drive
on Page 9

Hope's on the Horizon 2021 Success!

PWSA | USA's 36th National Convention was one to remember. It was our first-ever Virtual Convention and had the highest attendance of any Convention to date. We were also able to offer FREE General Conference admission thanks to our sponsors Levo Therapeutics and Soleno Therapeutics. The weeklong event was held from June 22, 2021, through June 26, 2021, and although we missed being in-person, this year's event hosted more than 1,500 people from around the world. Convention attendees received the most up-to-date information and research about PWS and had the opportunity to interact with other families during our General Conference virtual sharing sessions.



The morning of June 22, 2021, Lisa Graziano kicked off our Professional Providers' Conference with her Keynote Address, "PWS Behavior Management Strategies and Interventions." Throughout the day, our speakers led sessions for professional providers, including Exercise and Motivation, Medical Issues in PWS, and other informative programs.



On June 23rd and 24th, our Medical & Scientific Conference began with an enlightening keynote speech from Dr. Deepan Singh about behavior problems in Prader-Willi syndrome, and what to expect. This two-day Conference hosted a variety of expert speakers who shared the latest updates on care, treatment, behavior, dietary management, and more.

The final two days of Convention focused on our families. The General Family Conference was a time for attendees to gather, share personal stories, learn how to stay mentally well, and ask our speakers questions specific to their needs. We were grateful to host more than double the number of families compared to past Conventions and to offer this year's General Conference free of charge.

Our Convention Session Recordings are available for public viewing and can be found at www.pwsausa.org.

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“I LOVE the virtual aspect. I learned so much!”

The Convention was great overall. The thing I liked most about the virtual set-up was how easy it was to navigate to the next session of the day using the schedule. I also appreciated that a lot of sessions had significant time for Q & A and there were a lot of questions and additional information.”

“Ellie enjoyed the special box of treats. I love being able to learn from doctors who actually know more about PWS than I do!! Thank you!!”

“I get so bogged down in our own problems with my daughter (and the ripple effects), but the convention helps me lift up my head, see possible solutions, and motivates me intensely to help others.”

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Superhero BINGO Family Fun Night

More than 100 families from our PWS community across the United States joined in on the final eve of our Virtual National Convention to attend a Superhero Bingo Free Family Fun Night, in partnership with Leaving Legacies Foundation. Participants received special kits to get them in the spirit of the event, including superhero capes and masks, comic books, a special toy, and fun photo-props. There was even a special celebrity guest appearance by actor Dean Cain, who played Superman in the '90s hit TV show "Lois and Clark," as well as Wonder Woman, who took time to let participants ask questions. This fun event also featured superhero trivia, a silent auction, a "capture the villain" raffle, and a virtual costume contest for all ages. It was an honor and a pleasure to host this free, fun event for our community, especially during a year in which we would usually be gathering in person.



THANK YOU TO OUR SPONSOR



Advocacy Efforts

On June 17, 2021, representatives from PWSA | USA, FPWR and experts in the field of Prader-Willi syndrome research met with the FDA's Center for Drug Evaluation and Research to discuss issues related to PWS clinical trials.

The purpose of this meeting was to promote dialogue between PWSA | USA, FPWR and members of the PWS patient community to ensure that the FDA has a full understanding of the unique challenges of PWS. PWSA | USA and FPWR shared information on the dire unmet medical need, the community's tolerance for risk and uncertainty of benefit as it relates to new treatments, and the impact of the COVID-19 pandemic on PWS clinical trials.

We also discussed the PWS community's perception as to what constitutes meaningful changes in addressing hyperphagia and other behavioral aspects of PWS, the unique challenges of performing clinical trials in the PWS population, and considering those concerns, discussed how to efficiently advance new medical products that may be safe and effective for PWS. On June 30, 2021, PWSA | USA and FPWR joined together for a public webinar to present a recap of the Patient Listening Session meeting with the FDA.

A written recap summary was also released to the public on July 23, 2021, outlining key presentation points and reactions from FDA representatives in attendance. More details about the Patient Listening Session meeting can be found at www.pwsausa.org.



**PWSA | USA
AND FPWR
granted meeting
with the
FDA**

PWS Joint Advocacy Initiative



FDA Advisory Committee to Review LEVO's Carbetocin as a Treatment for PWS

levō

We are excited to share that Levo's New Drug Application (NDA) for carbetocin as a treatment for PWS will be discussed at a public meeting of the Psychopharmacologic Drugs Advisory Committee to be held November 4, 2021. This is a major step forward on this drug's path through the approval process. It is also a chance for the PWS community to show our support of this potential new treatment. Here's some information and details about how we can work together to support this critical next step:

- The meeting will take place virtually through an online teleconference on November 4, 2021, from 10 a.m. to 4 p.m. Eastern Time.
- Electronic comments may be submitted on or before November 3, 2021. Visit <https://www.regulations.gov> to submit your comments [Docket No. FDA-2021-N-0860]. Comments received on or before October 21, 2021, will be provided to the Advisory Committee. Comments received after that date will be taken into consideration by FDA.

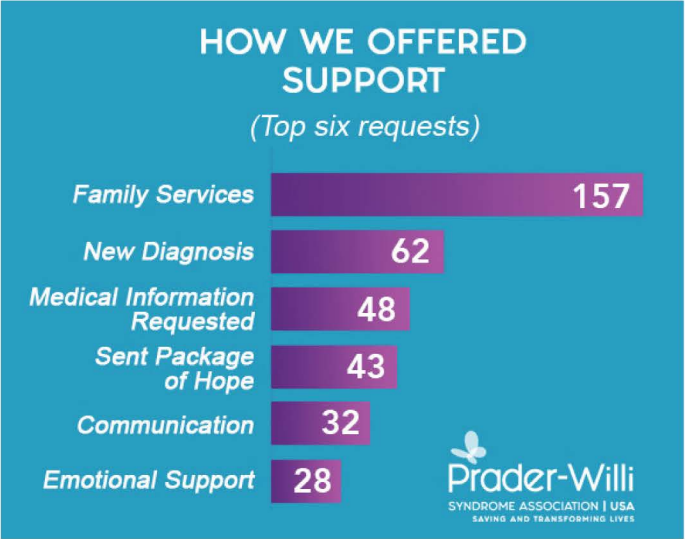
Family Support 2021

Thanks to the generosity of our community, PWSA | USA raised more than \$70,000 to provide funding for our Family Support Program. We received support from 570 donors, 26% more than last year, and 15% of these individuals raised money through peer-led Facebook fundraisers. Our five-person Family Support Team provides help and hope to the PWS community on a national scale.

Through personal stories and pictures shared by our PWS families, we were able to showcase the incredible work our team does daily. Whether it is a compassionate call of support after your child's diagnosis, or a resource-filled consultation when your loved one is entering a new phase of development, PWSA | USA is here for you and your family 24 hours a day, 7 days a week, 365 days a year.



PWSA | USA Family Support Impact April 2021 - September 2021



EVENTS & FUNDRAISERS

THANK YOU FOR SUPPORTING PWSA | USA!



On October 2, 2021, the **12th Annual Hunter Lens Golf Tournament** was held to honor Hunter (23) who is living with PWS and support PWSA | USA

Mattyofit's Miami Endurance Run

On September 25, 2021, Matt ran the Miami Ultra 100 Marathon in honor of his sister, Ana (16), and in support of PWSA | USA



THANK YOU!



On October 22, 2021, **Answers for Audrey Trivia Night** was held in St. Louis, MO in honor of Audrey Spring who is living with PWS and in support of PWSA | USA.

Save the Date
March 26, 2022

8th Annual
Hot Stove Dinner
with Clint Hurdle

HOT STOVE
DINNER
A Fundraiser
to Benefit PWSA | USA

Reserve your Stay
at *Compass by Margaritaville*
on Anna Maria Island, FL

**Limited number of rooms available*

SCAN THE QR CODE TO BOOK YOUR STAY!



Getting Married?

In lieu of gifts, consider asking your guests to make a donation to PWSA | USA.

Your support of our organization will allow us to continue providing support, education, research, advocacy, and HOPE to PWS individuals and families around the world.

To learn more, please reach out to events@pwsausa.org

Fundraising for PWSA | USA is empowering, easy and fun!
Contact events@pwsausa.org to plan your virtual, in-person, or Facebook fundraiser.

STAFF LISTING



Paige Rivard, MBA [NE]
 Chief Executive Officer
 941.487.6724
 privard@pwsausa.org



Melanie McDonald [NH]
 Director of Development
 941.487.6742
 mmcdonald@pwsausa.org



Stacy Ward, MS [NY]
 Director of Family Support
 941.487.6731
 sward@pwsausa.org



Christine Miller [FL]
 Administrative Services
 Coordinator
 941.487.6721
 cmiller@pwsausa.org



Lynn Garrick, RN, BSN [MN]
 Medical/Research Coordinator
 941.487.6741
 lgarrick@pwsausa.org



Carrie Larsen [OH]
 Marketing & Communications
 Specialist
 941.487.6740
 clarsen@pwsausa.org



Spring Velazquez [PA]
 Development Specialist
 941.487.1234
 svelazquez@pwsausa.org



Kim Tula, MS, CSW [WI]
 Family Support Counselor
 941.487.6735
 ktula@pwsausa.org



Kristen Starkey [FL]
 Accounting Clerk
 941.487.6727
 kstarkey@pwsausa.org




Kristi Rickenbach [MN]
 Parent Support Counselor
 941.487.6722
 krickenbach@pwsausa.org



Cheryl Plant [FL]
 Administrative Assistant
 941.487.6720
 cplant@pwsausa.org



Dorothea Lantz [FL]
 Community Engagement
 Specialist
 941.487.6755
 dlantz@pwsausa.org



Sarah Kasaby [NE]
 Information & Referral
 Specialist
 941.487.6725
 skasaby@pwsausa.org



941.312.0400
 www.pwsausa.org



Thank You PWSA | USA Board Members

With deepest appreciation and gratitude to our outgoing Board of Director Members:

Dan Driscoll, Member, Board of Directors 1998-2021

Pete Girard, Member, Board of Directors 2016-2021

Crystal Boser, Member, Board of Directors 2018-2021

For all you have done on behalf of the Prader-Willi syndrome community, for the way you have touched the lives of our children through your dedication, your expertise, and your compassion:
We are forever grateful.

PWSA | USA Board of Directors

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Angel Drive 2021

NO TWO SNOWFLAKES ARE THE SAME, JUST LIKE THOSE LIVING WITH PWS. EACH IS DIFFERENT IN THEIR OWN BEAUTIFUL WAY.



THE 2021 *Angel Drive*
CAMPAIGN KICKS OFF
NOVEMBER 1ST AND WE'RE
COUNTING ON YOU TO BE
OUR PARTNER OF HOPE!



Every year, more than 2,000 individuals and families turn to PWSA | USA to find hope and help when they need it most. Ours is the only organization that provides the comprehensive support, tools, and resources families need to thrive in the face of a rare genetic condition.

PLEASE CONSIDER SUPPORTING PWSA | USA AT
WWW.PWSAUSA.ORG/ANGELDRIVE