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EVENT**

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Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

HOT STOVE DINNER
Clint Hurdle



Key Royale Club

Anna Maria Island, FL & *Virtual*
March 20, 2021

Island Treasure Reception 5:00 p.m. until 6:00 p.m.
6:00 p.m. General Registration

Presented By:  *Leaving Legacies Foundation*

*STRICT COVID-19 PROTOCOLS WILL BE ENFORCED IN ACCORDANCE WITH HOLMES BEACH GUIDELINES INCLUDING:
MASKS TO BE WORN AT ALL TIMES EXCEPT WHEN EATING OR DRINKING AND SEATED AT A TABLE. TEMPERATURE WILL BE TAKEN AT REGISTRATION AND SOCIAL DISTANCING WILL BE PRACTICED WHEN APPROPRIATE.

**Book your hotel room now at Compass by Margaritaville,
the preferred hotel of the Hot Stove event.**



Pioneers in PWS

MAJOR ADVANCEMENT FOR PERSONS WITH PWS - GROWTH HORMONE RESEARCH AND THERAPY

We always admire professionals who have found a special place in their heart to study, research, educate, and care for persons with PWS and their families.

This week, we're featuring the many doctors who have focused their studies on Growth Hormone (GH) therapy in treating PWS.

Click [HERE](#) to read the next article in our Pioneers in PWS series.



Dr. Phillip Lee



Dr. Moris Angulo



Dr. Aaron Carrel



Dr. Barbara Whitman



Dr. Jennifer Miller

Not Pictured
Dr. David Allen
Dr. Barbara Lippe
Dr. Susan Meyers

Career Opportunities: Join PWSA | USA

Have you been considering a career change? Always wanted to get more involved with the Prader-Willi syndrome community? Yes?

PWSA | USA has an exciting opportunity for you:

- **Community Engagement Specialist**

[Click here to learn more!](#)



Save the Date

New! PWSA | USA Virtual Convention Video

**Coming Soon to an Office or
Home Near You!
[WATCH THE VIDEO HERE!](#)**

PWSA | USA's first-ever **virtual** National Convention will be held **June 22-26, 2021!** Our dedicated staff and convention volunteers are hard at work putting together an exciting lineup of educational, informative and fun sessions for the PWS community.

EXCITING NEWS! We are pleased to announce that for the first time ever, admission to the General Conference is free for all to attend! Registration will open soon!



Learn more about this year's virtual event by downloading the Convention flyer [here](#). Don't forget to share with your loved one's medical and care providers!

To learn more about sponsorship opportunities, click [here](#).

Recognize your loved one or family member with a Lifesaving Hope flyer to be showcased during the 2021 Virtual National Convention! **Learn more** [here](#).

Medical & Scientific Convention: Call for Abstracts

PWSA | USA cordially invites abstract submissions for a presentation of recent research or related scientific or medical topics on the subject of Prader-Willi syndrome for our 36th Biennial Medical & Scientific Conference. To participate in the medical and scientific program, submit a one-page abstract on a relevant topic to the Medical & Scientific Conference Committee for review by April 2nd, 2021. **Learn more** [here](#).

Special Virtual Convention Survey Opportunity!

Share your feedback and help us make this convention the most successful yet! Please help us by completing a brief questionnaire [here](#).

Thank You to Our Convention Sponsors!





Lighthouse Sponsor



Regatta Sponsor

Anchor Sponsors

We'd like to thank the PWSA Arizona and Florida Chapters for making a difference in the PWS community by partnering to provide an amazing educational opportunity for families and professionals.

Upcoming Webinars

NORD - The Rare Sibling Experience

The impact of a rare disease extends beyond the patient and is interwoven into their entire family dynamic. Siblings of rare disease patients often face personal challenges inside and outside of the home. Guidance and nurturing can empower unaffected siblings to be supportive members of the family while maintaining their own unique identities.

Join NORD to hear from child life specialist Kate McGowen and psychologist Dr. David Rintell, who will discuss commonly observed barriers and best practices for fostering healthy sibling relationships. Rare sibling Hannah Raskin-Gross will share her experience growing up with a brother who has a rare disease and how it has shaped her commitment to advocacy. This webinar, moderated by special guest and child life specialist Eden Van Alstine, is intended for patients, advocates, caregivers, students and the general public.

Click [HERE](#) to learn more and register.



Kate McGowen



Hannah Raskin-Gross



Dr. David Rintell

Drug Development and Clinical Trials 101

PRESENTED BY
Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

Saturday, March 27, 2021

1:00 PM – 2:30 PM EST

Please join PWSA | USA and the following pharmaceutical companies:
Saniona, Soleno Therapeutics, Levo Therapeutics and Harmony Biosciences



Have you ever wondered how drug development works, or wanted to better understand the clinical trial process? Register for this **free webinar**, and learn all about the drug development and clinical trials process in this informative and accessible forum.

With specialists from four pharmaceutical companies, attendees can expect to gain insight on the different ways clinical trial researchers are working to bring the patient perspective to the drug development process. A 30-minute Q&A will follow the hour-long presentation.

Date: Saturday, March 27, 2021

Time: 1:00 PM - 2:30 PM EST

Register in advance for this webinar [here](#). After registering, you will receive a confirmation email containing information about joining the webinar. Read about our presenters [here](#).

Presenters:



Dean S. Carson, Ph.D.
VP of Scientific Affairs
Saniona



Kristen Yen, MS
VP of Clinical Operations
Soleno Therapeutics



Jessica Ernest



Michele Roy

Research

Saniona Receives U.S. FDA Orphan Drug Designation for Tesomet in Prader-Willi Syndrome

PRESS RELEASE
March 3, 2021



Saniona (OMX: SANION), a clinical stage biopharmaceutical company focused on rare diseases, today announced that the U.S. Food and Drug Administration (FDA) has granted orphan drug designation to Tesomet for the treatment of Prader-Willi syndrome (PWS). Saniona is preparing to initiate a Phase 2b study of Tesomet in PWS in the first half of this year.

Read more [HERE](#).

Announcement from Radius Health



Radius Health has announced the addition of synthetic Cannabidiol (CBD) Oral Solution to their development pipeline, with plans to advance in Prader-Willi syndrome.

Read more [HERE](#).

Purdue University Recruiting for New PWS Study



The Purdue University Neurodevelopmental Family Lab is now recruiting! Black parents and caregivers of children with Prader-Willi syndrome under the age of 12 are invited to participate in a study of [how families cope with stress caused by the COVID-19 pandemic](#) (IRB-2020-517 - "Family Adaptation to COVID-19"). Participation lasts seven weeks and includes (1) completing web- and smartphone-based surveys and (2) sharing videos of you spending time with your child. To be eligible, families must live in the United States, live at least part-time with their child, speak primarily English at home, and must be willing and able to download a free smartphone app to complete surveys. Families are compensated up to \$120 in Amazon gift cards over the course of the study. To learn more, please contact Taylor at the Neurodevelopmental Family Lab at nddfamilylab@purdue.edu and mention COVID-19 in your email.

If you are interested in other research projects you or your family may be eligible to participate in through the Neurodevelopmental Family Lab, please click [here](#).

Family Support

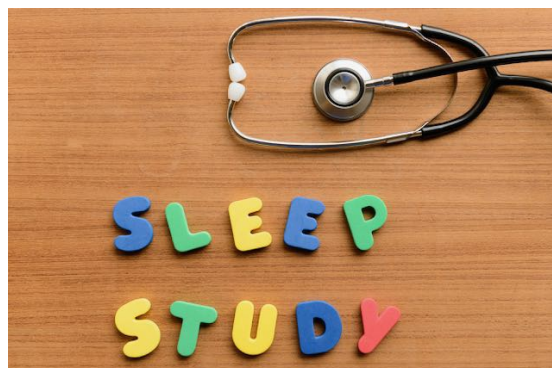
Narcolepsy as a Characteristic of Prader-Willi

Syndrome

Althea Shelton, MD and Jessica Duis, MD, MS

Use of growth hormone requires a baseline sleep study prior to use and one at 8-10 weeks after initiation. Beyond this, when we see a child or adult in clinic who is having excessive daytime sleepiness and/or worsening behavioral concerns among other symptoms (e.g., headaches or bedwetting), we consider a work up that includes a sleep study.

Read more [HERE](#).



We Need Your Help Updating Our Provider Directory

Attention parents and caregivers: We need your help! PWSA | USA is compiling a list of psychiatrists and psychologists who work with patients with Prader-Willi syndrome.

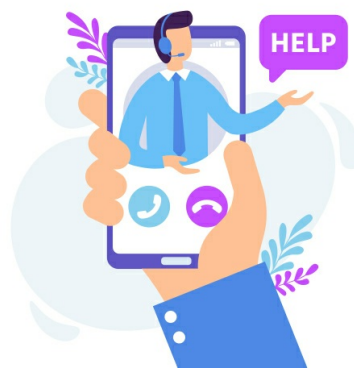
Please send the name, phone number and address for the psychiatrist and/or psychologist on your loved one's team to support@pwsausa.org. Thank you!



PWSA | USA Continues 24-Hour Family Support Service

Prader-Willi Syndrome Association | USA will continue to provide 24-hour Family Support services to individuals and families in the Prader-Willi syndrome (PWS) community.

"The past year has been challenging for everyone, and this is especially true for families affected by PWS. In addition to the struggles our community faces on any given day, the global pandemic has brought heightened health and safety concerns, isolation and loneliness, and disrupted routines and schedules," said PWSA | USA CEO, Paige Rivard. "Our organization has experienced a significant increase in requests for help as families learn to navigate a "new normal" and in response we are introducing 24-hour Family Support services."



Families will continue to have round the clock emergency access to information and support for urgent medical and behavior management situations. Emergency support services will be available to the community by calling 800.926.4797. The extended services will be provided by PWSA | USA's knowledgeable and friendly Family Support team.

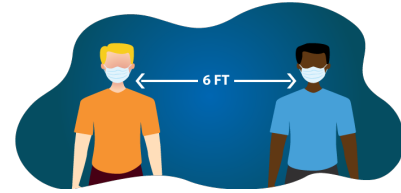
"We are incredibly thankful to our donors whose generosity make this critical service possible for the PWS community," continued Rivard. "We know our families need extra support during these uncertain times and we are honored to be here for them."

If you have any questions about PWSA | USA's 24-hour Family Support services, please contact us at info@pwsausa.org.

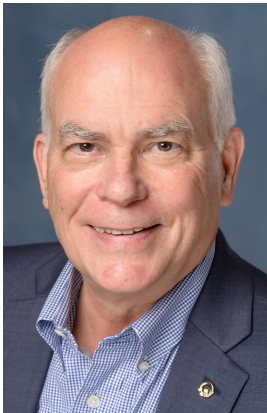
COVID-19 Community Updates

Supporting Individuals with PWS During the Pandemic

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. Continue reading [here](#).



Statement from Members of the Clinical Advisory Board (CAB) Regarding People with PWS and COVID-19 Immunization



PWSA | USA understands that decisions regarding COVID-19 vaccination is a personal/family decision, but advocates for vaccination, particularly among those with Prader-Willi syndrome who are at an increased potential risk for COVID-19 complications (i.e., those individuals with severe obesity, sleep apnea, diabetes and cardiovascular disease). Read more [here](#).

Daniel J. Driscoll, MD, PhD, FAAP, FFACMG; Chair, Prader-Willi Syndrome Association | USA Clinical Advisory Board; Chair, International Prader-Willi Syndrome Organization Clinical & Scientific Advisory Board

Get Involved and Stay Connected

Giving Help, Sharing Hope

In the PWS community, we all care so deeply about one another. "Giving Help, Sharing Hope" is an opportunity to reach out to those in our community at their time of need.

If you or someone you know is in need of help, please send your information and request to info@pwsausa.org.

Give Help, Share Hope.



Find Us On Facebook!

Be sure you're staying connected and receiving all of the latest news and information from PWSA | USA by [liking our Facebook page](#) and following us!

PWSA | USA offers many Facebook groups tailored for various people in the PWS community. Join the [PWSA | USA Birth to Three](#) group, or the [PWSA | USA Dads](#) group. Our Facebook groups are very active, and you'll be able to network and share with other parents and individuals who care deeply about helping those with PWS live the best life possible.



Volunteer Opportunities

Research has been at the core of PWSA | USA's mission for over 40 years. As we start this New Year, we want to set the strategy for the research committee, focusing on applied research. Research that will have a short-term, meaningful impact in the lives of our families. Do you have a background in the sciences or project management? Are you eager to work with others in the scientific community to improve the quality of life of those with PWS? If so, please contact Paige Rivard, privard@pwsausa.org.

Important Message About This Newsletter

The information provided in this email is intended for your general knowledge only and is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your physician or other qualified healthcare provider with any questions regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in this publication.



Prader-Willi

SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

Your gift to PWSA | USA ensures individuals and families living with Prader-Willi syndrome have the connection, guidance, and hope they so desperately need. Thank you!

[Visit Us Online!](http://www.pwsausa.org)
www.pwsausa.org

[Give Now](#)

