Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

Vol. 05
February 5, 2021

Free for Families This Year!
PWSA | USA Virtual Convention

PWSA | USA's first-ever **virtual** National Convention will be here soon! 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!

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 1-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.

Rare Disease Month: Show YOUR Stripes, Share Your Story

Rare Disease Month is officially underway! This year, we are creating a community video that celebrates the strength and stripes of our loved ones with PWS. **We need your help to make this project a success!** Send us a **photo** or **10-second Video clip** of your loved one and help us highlight individuals of all ages living their **best life** with PWS!

From first steps to walks across the graduation stage, share your loved one's happiest happenings and help us spread hope and inspiration by emailing **events@pwsausa.org** or by filling out an easy online form **here**.

Webinar Opportunity: Rare Across America

Join PWSA | USA and the Rare Disease Legislative Advocates (RDLA) to learn more about how you can make an impact on federal policy, share your rare disease story, and meet other rare disease advocates.

First Time Advocates Webinar on Tuesday, February 9, 2021 at 2:00 PM Eastern

If you are a first time advocate, we will be offering an additional webinar for you. During this webinar you will hear from a fellow advocate on what to expect during your meetings and ask questions!

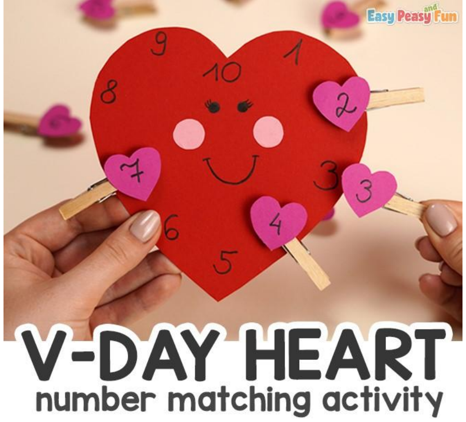
If you have any questions about Rare Across America, the webinars, and/or your meetings, check out www.RareAcrossAmerica.org or contact Katelyn Laws, RDLA Program Coordinator, at klaws@everylifefoundation.org.

Register for both webinars now:
https://everylifefoundation.salsalabs.org/raatrainingwebinar/index.html

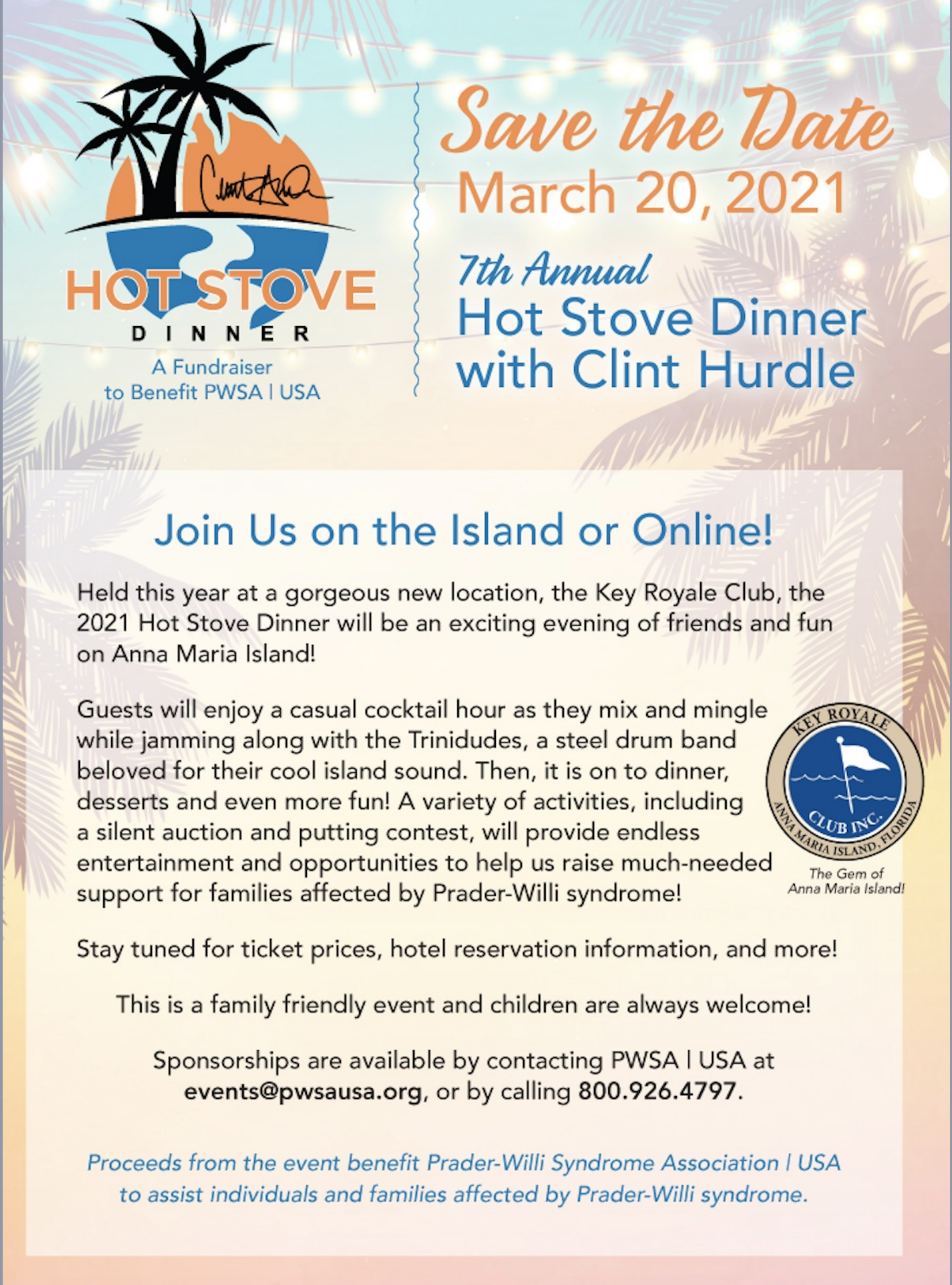
Valentine's Day: Crafting With Cupid

Valentine's Day isn't ALL about chocolate and roses! Here are two super easy crafts to make and share! Check out EasyPeasyandFun.com for more great ideas!

Skip store-bought and make a homemade card instead!
Click **here** for step-by-step instructions.



Make a craft that doubles as a teaching tool!
Click **here** for step-by-step instructions.



HOT STOVE DINNER

A Fundraiser
to Benefit PWSA | USA

Save the Date

March 20, 2021

7th Annual

Hot Stove Dinner
with Clint Hurdle

Join Us on the Island or Online!

Held this year at a gorgeous new location, the Key Royale Club, the 2021 Hot Stove Dinner will be an exciting evening of friends and fun on Anna Maria Island!

Guests will enjoy a casual cocktail hour as they mix and mingle while jamming along with the Trinidudes, a steel drum band beloved for their cool island sound. Then, it is on to dinner, desserts and even more fun! A variety of activities, including a silent auction and putting contest, will provide endless entertainment and opportunities to help us raise much-needed support for families affected by Prader-Willi syndrome!

The Gem of Anna Maria Island!

Stay tuned for ticket prices, hotel reservation information, and more!

This is a family friendly event and children are always welcome!

Sponsorships are available by contacting PWSA | USA at **events@pwsausa.org**, or by calling **800.926.4797**.

Proceeds from the event benefit Prader-Willi Syndrome Association | USA to assist individuals and families affected by Prader-Willi syndrome.

Research

Running for Research: A Super Success

An exciting highlight of 2020 was PWSA | USA's partnership with Running for Research, a diverse group of runners dedicated to raising funds for the Prader-Willi Syndrome Research Fund at the University of Florida and

Dr. Jennifer Miller's work to identify effective treatments for children and adults with Prader-Willi syndrome (PWS). Despite the many challenges presented by the COVID-19 pandemic, including the cancellation of in-person races, the collaboration helped the Running for Research group raise more than $128,000, far exceeding their original fundraising goal of $40,000. Funds raised helped fund two studies: Medication to help reduce hair pulling and skin picking, a gut microbiome study of children with PWS. Watch a wrap-up video here.

Maimonides Medical Center: PWS Study

Maimonides Medical Center is seeking volunteers between the ages of 6 and 35 years old diagnosed with Prader-Willi Syndrome (PWS) to participate in a clinical research study to see whether or not the study drug works to reduce the aggressive and self-injurious (such as skin picking) behaviors seen in PWS.

The study requires a 16 week commitment which includes an 8 week double-blinded phase followed by an 8 week open label period. The study is open to qualifying individuals in any state in the U.S. and those outside of the country, however, three mandatory visits require in-person assessments. (Other visits can be conducted virtually via video sessions.) Those individuals currently taking Intuniv are **not** encouraged to participate in this study. During the first 8 weeks of the study, participants have a 50-50 chance of receiving Intuniv or a placebo. All participants will receive Intuniv during the last 8 weeks. Learn more here.

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Prader-Willi Syndrome Association | USA (PWSA | USA) is pleased to offer grant funding for scientific researchers with an interest in improving the lives of those with Prader-Willi syndrome (PWS). PWSA | USA is seeking to fund projects for up to $100,000 and a maximum of a 2 year grant period. Shared grant funding will be allowed at the discretion of the PWSA | USA's Board of Directors.

The current focus of PWSA | USA research is to support projects that have the potential for immediate and high impact for the PWS community, thus we will support research-based translational grants or those showing high promise for translating basic biomedical knowledge to clinical application. The goal is to fast-track better treatment for the syndrome.

Click here for more information.

The Global PWS Registry Needs YOU to Update Your Surveys!

2021 brings new opportunities to learn even more about PWS and improve the health of those living with PWS. De-identified data from the Global PWS Registry is actively being used to help PWS physicians understand medical problems in PWS, provide scientists at the FDA with a better understanding of the needs of the PWS community, and accelerate clinical trials.

The Global PWS Registry is one of the community's most effective tools to inform research and clinical care. There are currently over 2000 families from around the world enrolled in the Registry and our knowledge grows with every survey completed! Up to date entries from each participant are critical to the strength of this powerful community tool! By updating your current surveys and/or completing new surveys, you ensure that the most current information is available to researchers and shared back to the PWS community. Click here to learn more.

Advocacy & Awareness

PWSA | USA "Pioneers in PWS" Historical Series

The leadership in an organization is one of the most important elements to achieving long-lasting success. It is important for this individual to be passionate, knowledgeable and organized. They must be a team builder as well as build and maintain alliances. They must be vigilant in making sure there are the proper resources to maintain and grow the organization. Over the past 45 years, PWSA I USA has had many outstanding executive directors which has allowed them to grow and flourish. Continue reading here.

Marge Wett,
PWSA | USA's First
Executive Director

Outstanding Volunteer Awards: Call for Nominations

PWSA | USA's Outstanding Volunteer Awards recognize our amazing volunteers and the incredible work they do every day. Celebrate these VIPs by nominating someone for one of this year's awards!

Nominations are due **Sunday, February 28**, and winners will be announced in April in honor of Volunteer Recognition Month.

Fill out the nomination form here.

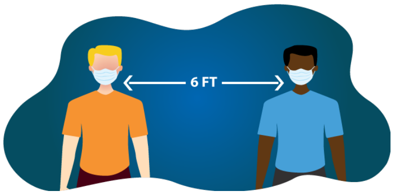
Check out last year's Education Award Winner here.

COVID-19 Community Updates

COVID-19 Vaccine Distribution Plans and Resources by State

Research!America has compiled a list of state-by-state COVID-19 resources and vaccine distribution plans for easy reference. Click here to find information for your state.

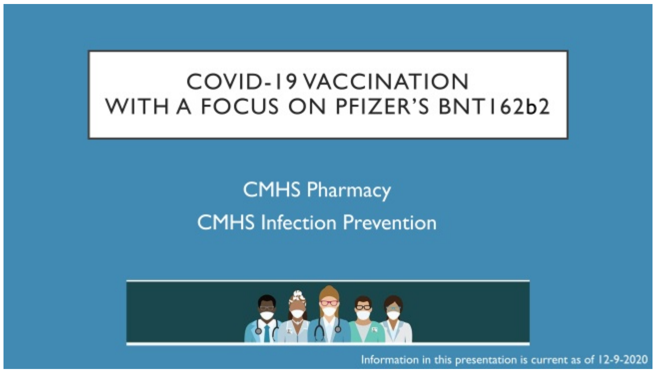
Supporting Individuals with PWS During the Pandemic



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**.

Pfizer COVID - 19 Vaccine Resources

Promising news about COVID-19 vaccines emerge every day. However, exciting as the introduction of these vaccines is, questions about the vaccine approval process, vaccine safety, and vaccine efficacy remain. PWSA | USA is pleased to share an informational presentation created by Community Memorial Health System and a Pfizer-BioNTech COVID-19 Vaccine fact sheet provided by Pfizer. You can download the presentation here and the fact sheet **here**.

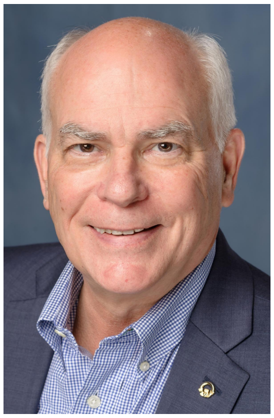


COVID-19 VACCINATION
WITH A FOCUS ON PFIZER'S BNT162b2

CMHS Pharmacy
CMHS Infection Prevention

Information in this presentation is current as of 12-9-2020

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

Family Support

A New Resource from Latham Centers

Latham Centers, Inc. has released a new resource for the PWS community - *Understanding the PWS Mindset and Development of Coping Skills.* The electronic booklet was written by Patrice Carroll, LCSW and edited by Katrina Fryklund, MSPC.

Latham Centers, Inc. is internationally renowned for its

expertise and success in working with individuals with PWS, a rare genetic disorder with no known cure.

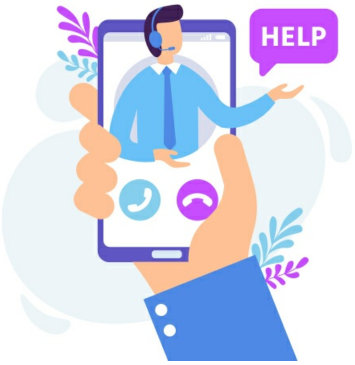
Download the booklet here.

EveryLife to grant more #RAREis Scholarships - 2021

The **#RAREis** Scholarship Fund was established in 2020 to help young adults with rare diseases to pursue their dreams through education. Thanks to the support of Horizon Therapeutics, $185,000 in scholarships were granted last year to 37 rare disease patients, representing 31 disease groups and 23 states!

Applications in support of Fall 2021 tuition will open April 1, 2021 and close May 7, 2021. The scholarship offers one-time $5,000 grants and is available for applicants of all ages and disease groups who are pursuing college, post-graduate degrees, trade school, or class certification courses. So…what's your dream? Make it happen with the #RAREis Scholarship Fund. **Please visit RareScholarship.org or email lcundiff@everylifefoundation.org to learn more.**

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.

Save the Date

36th PWSA | USA Virtual Convention | June 22 - 26

Check back here each week for more information and Convention updates!

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

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

Schedule of Events

- Professional Providers Conference; June 22, 11:00 AM to 7:00 PM EST
- Medical & Scientific Conference; June 23 & 24, 11:00 AM to 5:40 PM EST
- General Conference; June 25 & 26, 11:00 AM to 5:15 PM EST

To learn more about sponsorship opportunities, click here.

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Thank You to Our Convention Sponsors!

SOLENO THERAPEUTICS

Lighthouse Sponsor

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Regatta Sponsor

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.

Susanne's brother, George Royer, is currently in the hospital with pneumonia, possibly COVID-19, and other health complications. George was born with Prader-Willi syndrome, and has lived in a PWS residential group home in Maine for a number of years. Because of George's current health issues, the home needs to make major renovations to accommodate his housing needs when he is released from the hospital. George's family has set up a GoFundMe page to help raise funds to cover the cost of these renovations. If you'd like to make a donation to help with these renovations, please visit the link below.

Give Help, Share Hope. Visit the GoFundMe page here.

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.

We Appreciate Our Corporate Sponsors

Prader-Willi
Homes
A MyPath Company

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! www.pwsausa.org

Prader-Willi
SYNDROME ASSOCIATION | USA
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Vol. 06
February 12, 2021

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From first steps to walks across the graduation stage, share your loved one's happiest happenings and help us spread hope and inspiration by emailing **events@pwsausa.org** or by filling out an easy online form here.

Wear Your Rare this Rare Disease Month!

Want a fun way to raise PWS awareness and celebrate Rare Disease Day? Check out these awesome t-shirts, hoodies, onesies, masks, ball caps, and more! All proceeds benefit PWSA | USA, so the more you buy, the more funds you help raise to support the Prader-Willi syndrome community! Special thank you to PWS parent and volunteer, Christina Argo, for hosting this fundraiser!

Get Your Rare Gear Here!

Share Your Rare on Facebook!

Share your rare on Facebook this month with PWSA | USA's profile pic frame! Here's how:

- Click your profile photo on Facebook
- Select “Update Profile Picture”
- Select “Add Frame”
- Search "PWSA Rare Disease Day 2021"

Try it now!

Official Hashtags!

Don’t forget to use our official hashtags for the month:

#ShareYourRare
#ShowYourStripes
#ILoveSomeoneRare
#RoarForTheRare
#RareDiseaseDay2021
#RareIs ____________(Fill in what Rare is to YOU)

Download Your #Selfie Print Out Here

Make a donation in honor of your loved one this Rare Disease Day!

Raise for Rare

Upcoming Webinars

Drug Development and Clinical Trials 101

Please join PWSA | USA and the following pharmaceutical companies: Saniona, Soleno Therapeutics, Levo Therapeutics, and Harmony Biosciences for an educational journey through the drug development and clinical trials process.

With specialists from these 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. 60-minute presentation followed by 30-minute Q&A.

Date: Saturday, February 20, 2021
Time: 11:00 AM to 12:30 PM EST

Register in advance for this webinar here. After registering, you will receive a confirmation email containing information about joining the webinar.

Rare Disease Day 101

Join us to learn more about Rare Disease Day and how YOU can raise awareness among the general public and decision-makers about rare diseases and the impact PWS has on your lives. Presented by Stacy Ward, PWSA | USA Family Support Director, and Kristi Rickenbach, PWSA | USA Parent Support Coordinator.

Date: Feb 24, 2021 01:00 PM
Time: 1:00 PM to 2:00 PM EST

Register in advance of the webinar here. After registering, you will receive a confirmation email containing information about joining the webinar.

Kristi Rickenbach

Stacy Ward, MS

About the presenters:

Kristi Rickenbach is the President of the PWSA Minnesota chapter, a parent mentor, the PWSA | USA General Conference Coordinator, is a former member of the PWSA | USA Board of Directors, is involved in several committees, and currently serves as the Parent Support Coordinator at PWSA | USA.

Stacy Ward has a master's degree in Psychology/Applied Behavior Analysis and a certification in Special Education Advocacy from the William and Mary College of Law Pele Clinic. Stacy has been actively involved in public policy advocacy as a member of the New York Rare Action Network and EveryLife Foundation Community Congress, and has participated in Rare Across America, Rare Disease Week on Capitol Hill, and other legislative advocacy events.

Career Opportunity: 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!

Click here to learn more!

Advocacy & Awareness

Advocacy Alert: Prioritizing Students with Disabilities

Tell your US Representative and Senator to prioritize students with disabilities by providing an infusion of funds to IDEA!

Under current regulations, funds provided to states and districts for education may be spent on special education but no specific funding is allocated to support students with disabilities during the pandemic. Students with disabilities have been especially impacted by the pandemic and it is imperative funding is allocated for special education to ensure **all** students receive a free, appropriate public education, as required by law. Senators Murphy (D-CT), VanHollen (D-MD), and Hassan (D-NH) have proposed that $12 billion of the next COVID-19 stimulus package specifically fund IDEA; $11 billion to Park B (K-12), $500 million to Park C (infant and toddlers), and $400 million to Part B (preschool).

To contact your Representative and Senators click here.

Outstanding Volunteer Awards: Call for Nominations

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Check out last year's Family Support Award Winner here.

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Hope's on the Horizon
PWSA | USA VIRTUAL NATIONAL CONVENTION 2021

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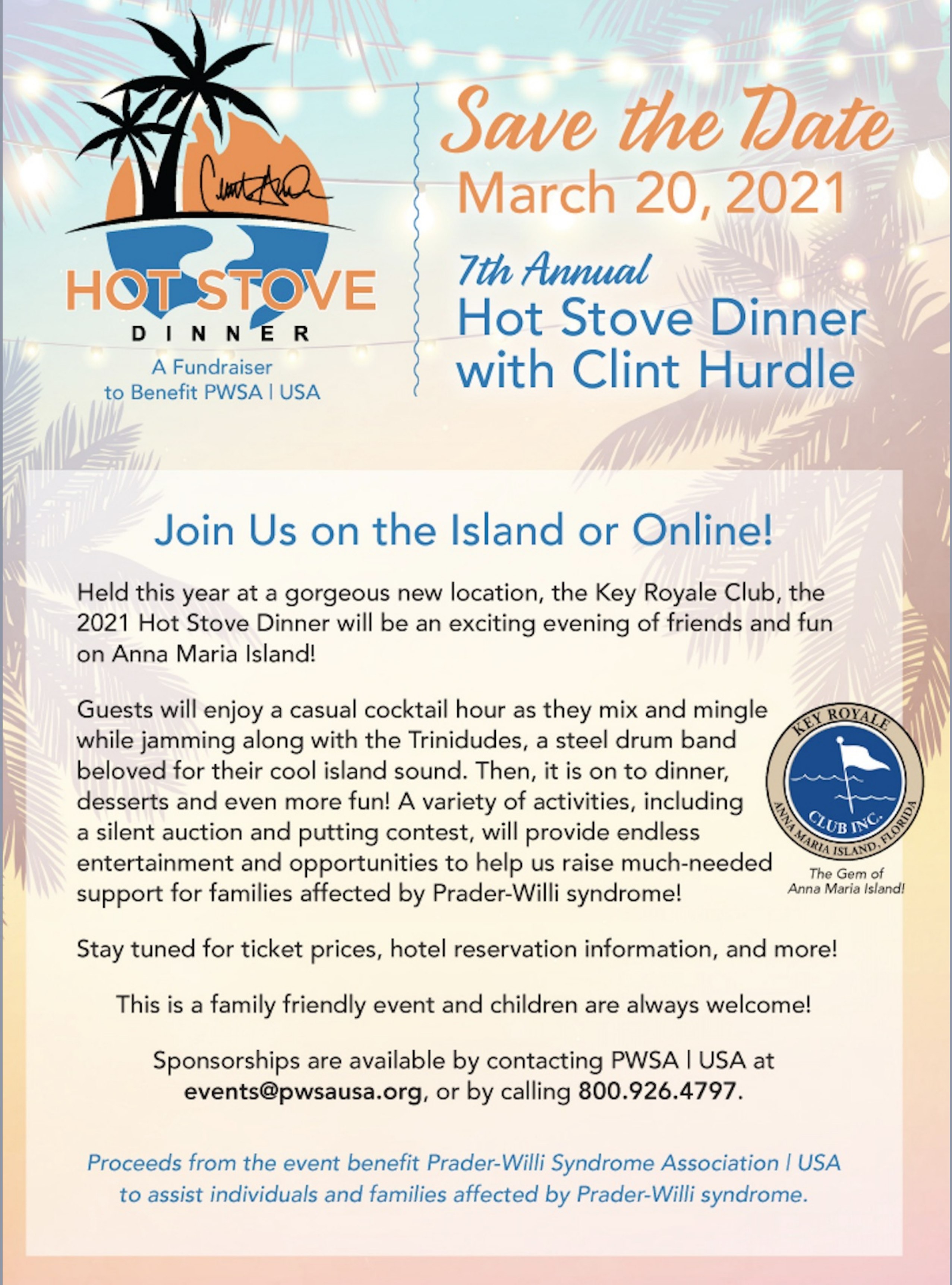

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KEY ROYALE CLUB INC.
ANNA MARIA ISLAND, FLORIDA
The Gem of Anna Maria Island!

Stay tuned for ticket prices, hotel reservation information, and more!

This is a family friendly event and children are always welcome!

Sponsorships are available by contacting PWSA | USA at **events@pwsausa.org**, or by calling **800.926.4797**.

Proceeds from the event benefit Prader-Willi Syndrome Association | USA to assist individuals and families affected by Prader-Willi syndrome.

Research

Harmony Biosciences Announces New Trial Sites

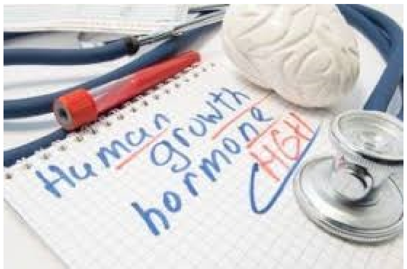
Harmony Biosciences Holdings, Inc., a pharmaceutical company dedicated to developing and commercializing innovative therapies for patients living with rare neurological disorders who have unmet medical needs, is sponsoring a phase 2 study to evaluate the safety and efficacy of Pitolisant in patients with Prader-Willi syndrome. Harmony Biosciences has announced two new trial sites:

Nemours Alfred I duPont Hospital for Children
Wilmington, Delaware, United States, 19803
Contact: Kimberly Renner; Kimberly.Renner@nemours.org
Principal Investigator: Aaron Chidekel, MD

Rady Children's Hospital - San Diego
San Diego, California, United States, 92123
Contact: Janelle Celso; jcelso@rchsd.org; P: 858-576-1700, ext. 220011
Principal Investigator: Rakesh Bhattacharjee, MD

Learn more about the recruiting sites **here**.

Time for a General Approval: GH in Adults with PWS



Growth hormone (GH) deficiency and other hormone deficiencies are common due to hypothalamic dysfunction. In children with PWS GH treatment has been widely demonstrated to improve body composition, normalize height and improve psychomotor development. In adults with PWS, GH's main effects are to maintain normal body structure and metabolism. The positive effects of GH treatment on body composition, physical fitness and beneficial effects on cardiovascular risk markers, behavior and quality of life in adults with PWS are also well established from several studies.

GH treatment is approved for treatment of children with PWS in many countries, but until recently not as a treatment in young adults in the transition period or for adults in general. In this commentary we want to draw attention to the uneven global use of GH treatment, specifically in adults with PWS, and advocate for GH treatment to be approved internationally, not just for children, but also for adults with PWS and based only on the diagnosis of genetically confirmed PWS. Continue reading here.

Maimonides Medical Center: PWS Study

Maimonides Medical Center is seeking volunteers between the ages of 6 and 35 years old diagnosed with Prader-Willi Syndrome (PWS) to participate in a clinical research study to see whether or not the study drug works to reduce the aggressive and self-injurious (such as skin picking) behaviors seen in PWS.

The study requires a 16 week commitment which includes an 8 week double-blinded phase followed by an 8 week open label period. The study is open to qualifying individuals in any state in the U.S. and those outside of the country, however, three mandatory visits require in-person assessments. (Other visits can be conducted virtually via video sessions.) Those individuals currently taking Intuniv are **not** encouraged to participate in this study. During the first 8 weeks of the study, participants have a 50-50 chance of receiving Intuniv or a placebo. All participants will receive Intuniv during the last 8 weeks. Learn more **here**.

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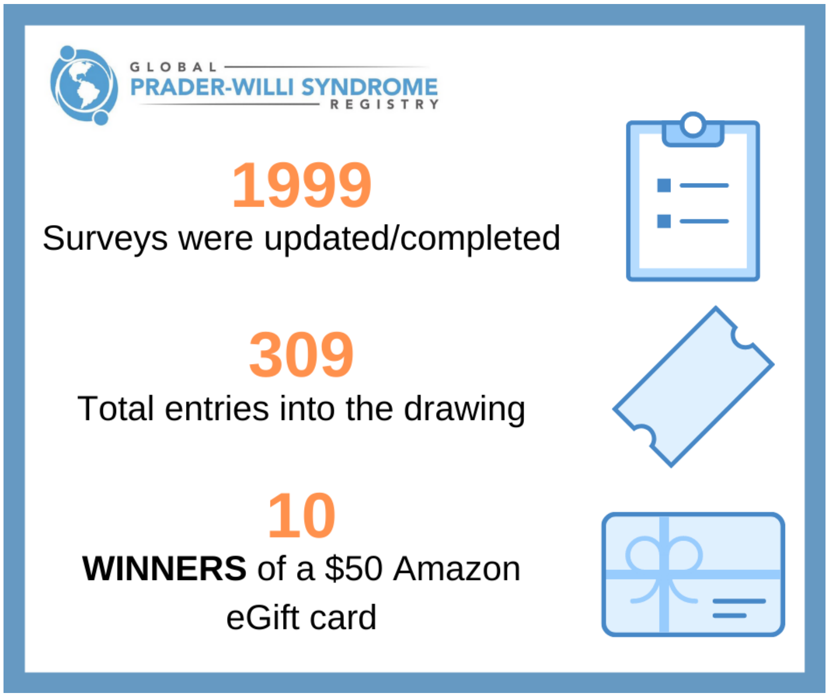
Click here for more information.

The Global PWS Registry Updates

THANK YOU to everyone who updated surveys and completed new surveys in the Global PWS Registry during the January 2021 Registry initiative from January 8-31, 2021!

All winners have been notified by email and Amazon eGift cards have been issued.



GLOBAL PRADER-WILLI SYNDROME REGISTRY

1999
Surveys were updated/completed

309
Total entries into the drawing

10
WINNERS of a $50 Amazon eGift card

Family Support

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!

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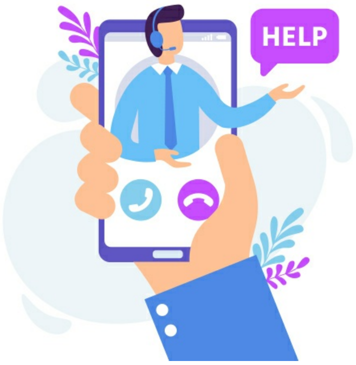
Applications in support of Fall 2021 tuition will open April 1, 2021 and close May 7, 2021. The scholarship offers one-time $5,000 grants and is available for applicants of all ages and disease groups who are pursuing college, post-graduate degrees, trade school, or class certification courses. So…what's your dream? Make it happen with the #RAREis Scholarship Fund. **Please visit RareScholarship.org or email lcundiff@everylifefoundation.org to learn more.**

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

COVID-19 Vaccine Distribution Plans and Resources by State

Research!America has compiled a list of state-by-state COVID-19 resources and vaccine distribution plans for easy reference. Click here to find information for your state.

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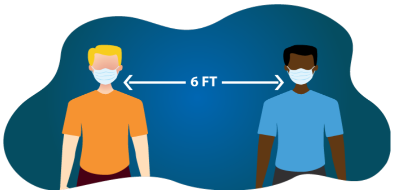
The pandemic has been a mixed bag for the PWS community. For some individuals, mental health has suffered, isolation has increased, and opportunities for engagement and inclusion have been limited. For others, former anxieties and struggles have been alleviated, and new hobbies and interests have developed. Continue reading here.



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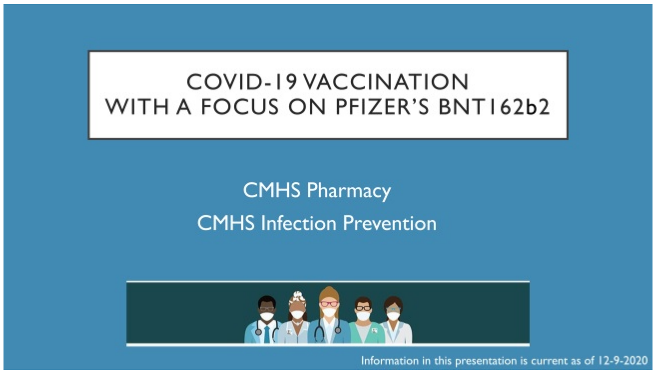

COVID-19 VACCINATION
WITH A FOCUS ON PFIZER'S BNT162b2

CMHS Pharmacy
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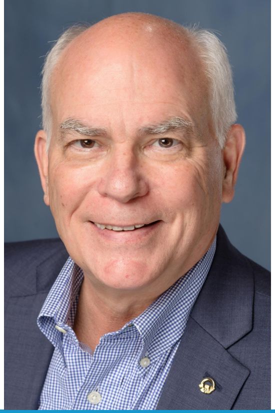
Daniel J. Driscoll, MD, PhD, FAAP, FFACMG; Chair, Prader-Willi



Syndrome Association | USA Clinical Advisory Board; Chair, International Prader-Willi Syndrome Organization Clinical & Scientific Advisory Board

Convention Updates

36th PWSA | USA Virtual Convention | June 22 - 26

Check back here each week for more information and Convention updates!

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

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

Schedule of Events

- Professional Providers Conference; June 22, 11:00 AM to 7:00 PM EST
- Medical & Scientific Conference; June 23 & 24, 11:00 AM to 5:40 PM EST
- General Conference; June 25 & 26, 11:00 AM to 5:15 PM EST

To learn more about sponsorship opportunities, click **here**.

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Thank You to Our Convention Sponsors!

SOLENO THERAPEUTICS

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A MyPath Company

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Regatta Sponsor

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! www.pwsausa.org

Prader-Willi
SYNDROME ASSOCIATION | USA
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Vol. 07
February 19, 2021

Rare Disease Month: Show YOUR Stripes, Share Your Story

Rare Disease Month is officially underway! This year, we are creating a community video that celebrates the strength and stripes of our loved ones with PWS. **We need your help to make this project a success!** Send us a **photo** or **10-second Video clip** of your loved one and help us highlight individuals of all ages living their **best life** with PWS!

From first steps to walks across the graduation stage, share your loved one's happiest happenings and help us spread hope and inspiration by emailing **events@pwsausa.org** or by filling out an easy online form here.

Wear Your Rare this Rare Disease Month!

Want a fun way to raise PWS awareness and celebrate Rare Disease Day? Check out these awesome t-shirts, hoodies, onesies, masks, ball caps, and more! All proceeds benefit PWSA | USA, so the more you buy, the more funds you help raise to support the Prader-Willi syndrome community! Special thank you to PWS parent and volunteer, Christina Argo, for hosting this fundraiser!

Get Your Rare Gear Here!

Share Your Rare on Facebook!

Share your rare on Facebook this month with PWSA | USA's profile pic frame! Here's how:

- Click your profile photo on Facebook
- Select “Update Profile Picture”
- Select “Add Frame”
- Search "PWSA Rare Disease Day 2021"

Try it now!

Post a Picture with Our Official Hashtags!

Don’t forget to use our official hashtags during this special month:

#ShareYourRare
#ShowYourStripes
#ILoveSomeoneRare
#RoarForTheRare
#RareDiseaseDay2021
#RareIs ___________(Fill in what Rare is to YOU)

Download Your #Selfie Print Out

Make a donation in honor of your loved one this Rare Disease Day!

Raise for Rare

Upcoming Webinars

Rare Disease Day 101

Join us to learn more about Rare Disease Day and how YOU can raise awareness among the general public and decision-makers about rare diseases and the impact PWS has on your lives. Presented by Stacy Ward, PWSA | USA Family Support Director, and Kristi Rickenbach, PWSA | USA Parent Support Coordinator.

Date: February 24, 2021
Time: 1:00 PM to 2:00 PM EST

Register in advance of the webinar here. After registering, you will receive a confirmation email containing information about joining the webinar.

Kristi Rickenbach

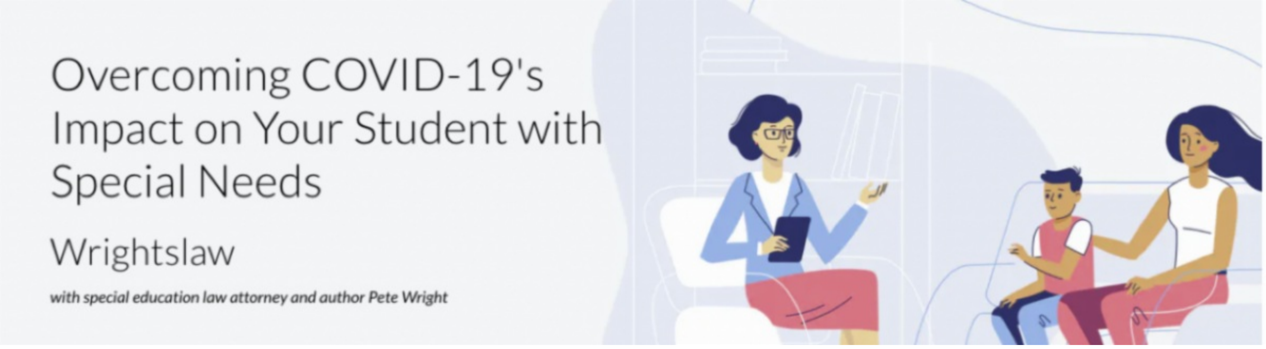
Stacy Ward, MS

About the presenters:

Kristi Rickenbach is the President of the PWSA Minnesota chapter, a parent mentor, the PWSA | USA General Conference Coordinator, is a former member of the PWSA | USA Board of Directors, is involved in several committees, and currently serves as the Parent Support Coordinator at PWSA | USA.

Stacy Ward has a master's degree in Psychology/Applied Behavior Analysis and a certification in Special Education Advocacy from the William and Mary College of Law Pele Clinic. She joined PWSA | USA in 2016 and serves as our Director of Family Support. Stacy has been actively involved in public policy advocacy as a member of the New York Rare Action Network and EveryLife Foundation Community Congress, and has participated in Rare Across America, Rare Disease Week on Capitol Hill, and other legislative advocacy events.

Join Pete Wright & Varsity Tutors - LIVE Training #2



A rare **free** opportunity to learn how to navigate the world of Special Education from special education attorney and founder of Wrightslaw, Pete Wright.

Date: Wednesday, February 24, 2021
Time: 7:00 PM - 8:00 PM EST

About the Class:

In this live class for families navigating the complex world of special education, we'll discuss strategies for making the best of school closures. We'll explore topics like understanding your child's progress and regression, compensatory education, contingency plans, and how to get your student's education back on track.

Learn more about Varsity Tutors and register here.

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 I 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

VP of Clinical Operations
Levo Therapeutics

VP of Regulatory Affairs
Harmony Biosciences

Career Opportunity: 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!

Click here to learn more!

Advocacy & Awareness

Advocacy Alert: Prioritizing Students with Disabilities

Tell your US Representative and Senator to prioritize students with disabilities by providing an infusion of funds to IDEA!

Under current regulations, funds provided to states and districts for education may be spent on special education but no specific funding is allocated to support students with disabilities during the pandemic. Students with disabilities have been especially impacted by the pandemic and it is imperative funding is allocated for special education to ensure **all** students receive a free, appropriate public education, as required by law. Senators Murphy (D-CT), VanHollen (D-MD), and Hassan (D-NH) have proposed that $12 billion of the next COVID-19 stimulus package specifically fund IDEA; $11 billion to Part B (K-12), $500 million to Part C (infant and toddlers), and $400 million to Part B Sec. 619 (preschool).

To contact your Representative and Senators click here.

Outstanding Volunteer Awards: Call for Nominations

PWSA | USA's Outstanding Volunteer Awards recognize our amazing volunteers and the incredible work they do every day. Celebrate these VIPs by nominating someone for one of this year's awards!

Nominations are due **Sunday, February 28**, and winners will be announced in April in honor of Volunteer Recognition Month.

Fill out the nomination form here.

Check out last year's Family Support Award Winner here.

Save the Date

Free for Families: PWSA | USA Virtual Convention

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.

Hope's on the Horizon
PWSA | USA Virtual National Convention 2021

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 1-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!

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Lighthouse Sponsor

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Research

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 7 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.

Harmony Biosciences Announces New Trial Sites

Harmony Biosciences Holdings, Inc., a pharmaceutical company dedicated to developing and commercializing innovative therapies for patients living with rare neurological disorders who have unmet medical needs, is sponsoring a phase 2 study to evaluate the safety and efficacy of Pitolisant in patients with Prader-Willi syndrome. Harmony Biosciences has announced new trial sites:

Ann and Robert H Lurie Children's Hospital
Chicago, Illinois, United States, 60611
Contact: Sarayu Ratnam
Principal Investigator: Priya Khanna, MD

Nemours Alfred I duPont Hospital for Children
Wilmington, Delaware, United States, 19803
Contact: Kimberly Renner; Kimberly.Renner@nemours.org
Principal Investigator: Aaron Chidekel, MD

Rady Children's Hospital - San Diego
San Diego, California, United States, 92123
Contact: Janelle Celso; jcelso@rchsd.org; P: 858-576-1700, ext. 220011
Principal Investigator: Rakesh Bhattacharjee, MD

Learn more about the recruiting sites here.

Maimonides Medical Center: PWS Study

Maimonides Medical Center is seeking volunteers between the ages of 6 and 35 years old diagnosed with Prader-Willi Syndrome (PWS) to participate in a clinical research study to see whether or not the study drug works to reduce the aggressive and self-injurious (such as skin picking) behaviors seen in PWS.

The study requires a 16 week commitment which includes an 8 week double-blinded phase followed by an 8 week open label period. The study is open to qualifying individuals in any state in the U.S. and those outside of the country, however, three mandatory visits require in-person assessments. (Other visits can be conducted virtually via video sessions.) Those individuals currently taking Intuniv are **not** encouraged to participate in this study. During the first 8 weeks of the study, participants have a 50-50 chance of receiving Intuniv or a placebo. All participants will receive Intuniv during the last 8 weeks.

Learn more here.

PWSA | USA Announces Calls for Letters of Intent

Prader-Willi Syndrome Association | USA (PWSA | USA) is pleased to offer grant funding for scientific researchers with an interest in improving the lives of those with Prader-Willi syndrome (PWS). PWSA | USA is seeking to fund projects for up to $100,000 and a maximum of a 2 year grant period. Shared grant funding will be allowed at the discretion of the PWSA | USA's Board of Directors.

The current focus of PWSA | USA research is to support projects that have the potential for immediate and high impact for the PWS community, thus we will support research-based translational grants or those showing high promise for translating basic biomedical knowledge to clinical application. The goal is to fast-track better treatment for the syndrome.

Click here for more information.

Family Support

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!

A New Resource from Latham Centers

Latham Centers, Inc. has released a new resource for the PWS community - *Understanding the PWS Mindset and Development of Coping Skills.* The electronic booklet was written by Patrice Carroll, LCSW and edited by Katrina Fryklund, MSPC.

Latham Centers, Inc. is internationally renowned for its expertise and success in working with individuals with PWS, a rare genetic disorder with no known cure.

Download the booklet here.

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EVERYLIFE FOUNDATION FOR RARE DISEASES

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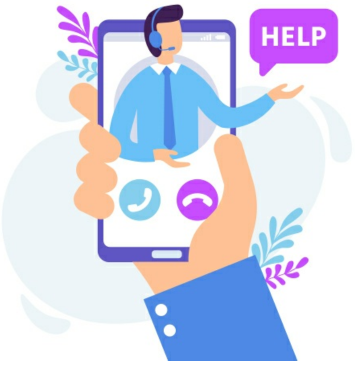

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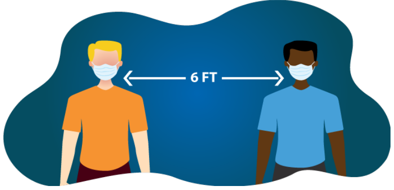

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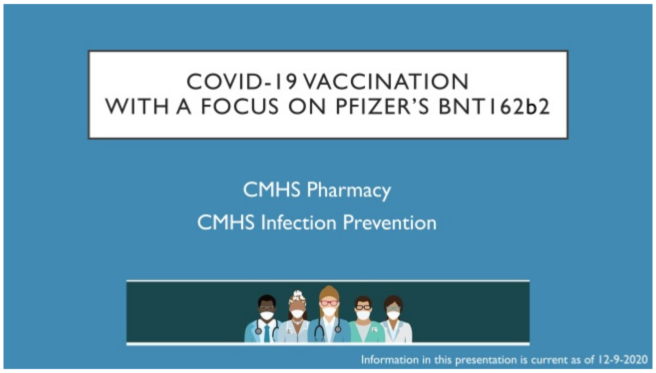

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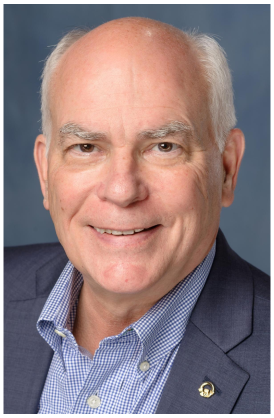

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Important Message About This Newsletter

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!

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

Vol. 08
February 26, 2021

HOT STOVE DINNER
TICKETS NOW AVAILABLE ONLINE!!!

www.stove.givesmart.com

Prader-Willi
SYNDROME ASSOCIATION | USA
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HOT STOVE DINNER

Clint Hurdle

Key Royale Club

Anna Maria Island, FL & *Virtual*

March 20, 2021

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6:00 p.m. General Registration

Presented By: Leaving Legacies Foundation

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Book your hotel room now at Compass by Margaritaville,

the preferred hotel of the Hot Stove event.

COMPASS
BY MARGARITAVILLE
ANNA MARIA SOUND, FL

Rare Disease Day

Make a donation in honor of your loved one this Rare Disease Day!

Give Now

Rare Disease Day takes place on the last day of February each year. The main objective of Rare Disease Day is to raise awareness among the general public and decision-makers about rare diseases and their impact on patients' lives.

Building awareness of rare diseases is so important because 1 in 20 people will live with a rare disease at some point in their life. Despite this, there is no cure for the majority of rare diseases and many go undiagnosed. Rare Disease Day improves knowledge amongst the general public of rare diseases while encouraging researchers and decision-makers to address the needs of those living with rare diseases.

Rare Disease Day at NIH - March 1, 2021

Rare Disease Day at NIH, organized by the **National Institutes of Health** (NIH) and taking place on March 1, will feature panel discussions, patient stories, research updates, TED-style talks, and a presentation by a Nobel laureate recently recognized for her work on a gene editing tool.

The free, virtual event runs from 10:30 a.m. to 5:30 p.m. EST, and is held in observance of Rare Disease Day, which works to raise awareness of the roughly 7,000 known rare diseases, and the hundreds of millions of people believed to be living with them.

Visit this site to register in advance.

Important Upcoming Deadlines

Outstanding Volunteer Awards: Call for Nominations

PWSA | USA's Outstanding Volunteer Awards recognize our amazing volunteers and the incredible work they do every day. Celebrate these VIPs by nominating someone for one of this year's awards!

Nominations are due **Sunday, February 28, 2021**, and winners will be announced in April in honor of Volunteer Recognition Month.

Fill out the nomination form here.

Check out last year's Family Support Award Winner here.

PWSA | USA Announces Calls for Letters of Intent

Prader-Willi Syndrome Association | USA (PWSA | USA) is pleased to offer grant funding for scientific researchers with an interest in improving the lives of those with Prader-Willi syndrome (PWS). PWSA | USA is seeking to fund projects for up to $100,000 and a maximum of a two-year grant period. Shared grant funding will be allowed at the discretion of the PWSA | USA's Board of Directors.

The current focus of PWSA | USA research is to support projects that have the potential for immediate and high impact for the PWS community, thus we will support research-based translational grants or those showing high promise for translating basic biomedical knowledge to clinical application. The goal is to fast-track better treatment for the syndrome.

The deadline for Letter of Intent (LOI) submissions is Sunday, February 28, 2021.

Click here for more information.

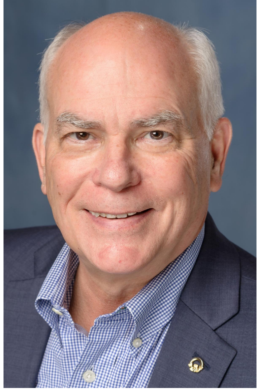
Pioneers in PWS

THE DOCTORS WHO UNLOCKED THE GENETIC CODE OF PRADER-WILLI SYNDROME
Drs. David Ledbetter, Rob Nicholls, Merlin Butler, Dan Driscoll, and Suzanne Cassidy

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.

Drs. David Ledbetter, Rob Nicholls, Merlin Butler, Dan Driscoll, and Suzanne Cassidy were some of those remarkable people and examples of the earliest pioneers who unlocked the genetic code of Prader-Willi syndrome.

Click HERE to read the next article in our Pioneers in PWS series.



Dr. Dan Driscoll

Dr. Merlin Butler

Dr. Suzanne Cassidy

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 TWO exciting opportunities for you:

- **Community Engagement Specialist**
- **Marketing & Communications Specialist**

Click here to learn more!

Save the Date

Free for Families: PWSA | USA Virtual Convention

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!

SOLENO THERAPEUTICS	novo nordisk®
Lighthouse Sponsor	**Regatta Sponsor**

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
VP of Clinical Operations
Levo Therapeutics

Michele Roy
VP of Regulatory Affairs
Harmony Biosciences

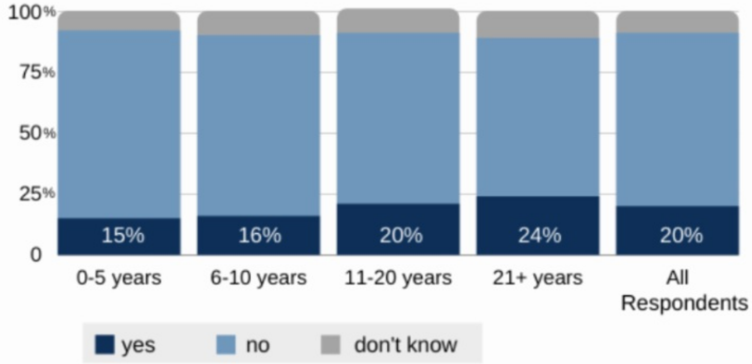
Research

New Data from the Global PWS Registry

THYROID ISSUES IN PWS

GLOBAL PRADER-WILLI SYNDROME REGISTRY
WWW.PWSREGISTRY.ORG

20% of Registry Participants Report a Thyroid Issue

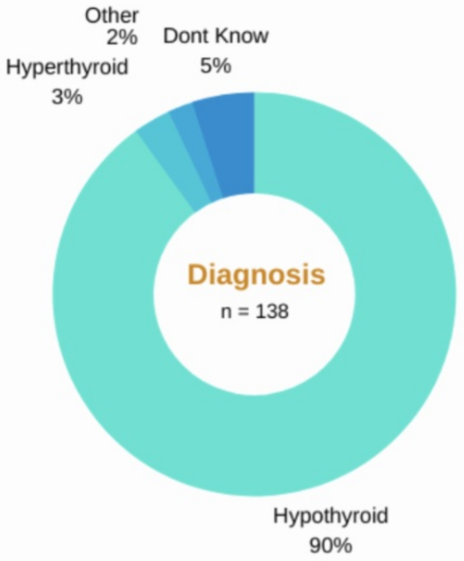


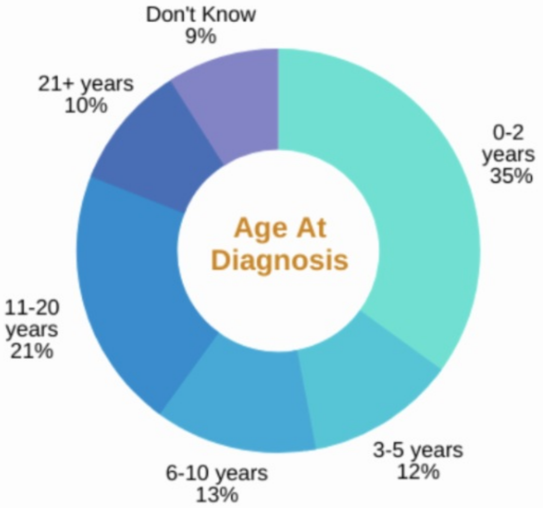
94%

of registry respondents have seen an endocrinologist

n=704

The majority of thyroid issues in PWS are hypothyroidism.





WWW.PWSREGISTRY.ORG FEBRUARY 2021

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

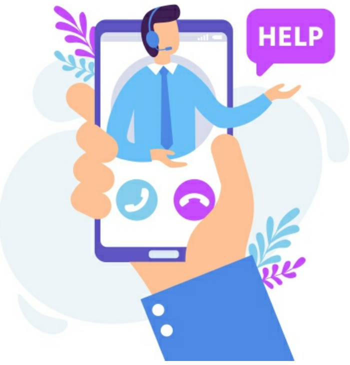
We Need Your Help Updating Our Provider Directory

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."

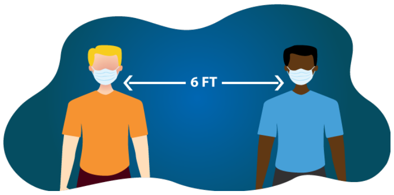
Families will continue to have round the clock emergency access to information and support for urgent medical and behavior management situations. Emergency support services will be available to the community by calling 800.926.4797. The extended services will be provided by PWSA | USA's knowledgeable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

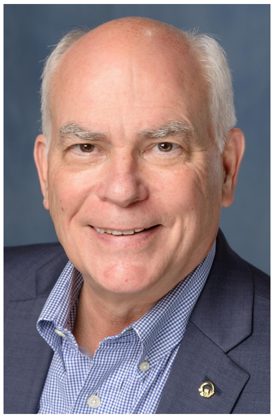
COVID-19 Community Updates

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

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!
www.pwsausa.org

Give Now