



## Welcoming the New Year as a Community

Welcome to the first Weekly Pulse of 2021! With you, I am looking forward to a fresh new year full of promise and hope!

Though 2020 was challenging, there were many triumphs. As a community, we came together to support each other with hugs and help, to continue pushing towards the future we want for our children and our families.

As an organization, PWSA | USA responded to the pandemic by launching a 24-hour phone hotline to support our community more completely. We introduced improved technologies and enhanced content and program design to ensure greater access and relevance for all families. We worked harder than ever to foster collaboration and strengthen relationships with community partners. With **your** support, we were able to elevate our level of service and to bring hope to more families than ever. Thank you.



Looking ahead to 2021, we look forward to bringing you new health and wellness initiatives, to broadening our emphasis on education, and refocusing our research efforts on practical, nearer-term "applied" research. There is so much good ahead.

I look forward to meeting and interacting with you and your family in the year ahead, and I am always interested in your ideas and feedback for our organization. If you would like to contact me at any time, please feel free to email me at [privard@pwsausa.org](mailto:privard@pwsausa.org).

In gratitude,

Paige Rivard, CEO

## PWSA | USA Announces New Development Director

Melanie McDonald joined the staff of PWSA | USA in January 2021 as **Director of Development**.

Melanie is excited to lead the Fund Development and Marketing Team for PWSA | USA. In this role, she will be responsible for identifying, cultivating, and securing financial support to fulfill our mission and fund new initiatives so that families living with PWS have the information and support needed to help their loved one thrive.

After over 20 years in various nonprofit leadership roles across New England, Melanie is eager to put her skills in Fundraising and Community Engagement to work for PWSA | USA. Melanie has held Director positions at regional and state-wide organizations in the Arts, Economic Development, and in Jewish Life - most recently as the Director of the Jewish Federation of New Hampshire. She is active in her community as a school parent volunteer, a membership committee chair for her synagogue, and as a fundraising advisor to several



nonprofits in the health care and education sectors within her New Hampshire community. Melanie is honored to accept this new role at PWSA | USA where she can focus her passion and enthusiasm for giving back to a community that continues to be so critical to her own family.

Melanie and her husband Chris reside in southern New Hampshire with their two amazing children. Their son Henry (age 9), has already been active as a supportive sibling, helping to raise over \$2,000 in funds for PWS research for his little sister! Their daughter, Josephine (age 2.5) was diagnosed with PWS (UPD) in the NICU at 3 weeks old. The McDonald family is indebted to the PWSA | USA community for the critical support and information they continue to provide and are excited to ensure this resource can be sustained for families well into the future.

## 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.

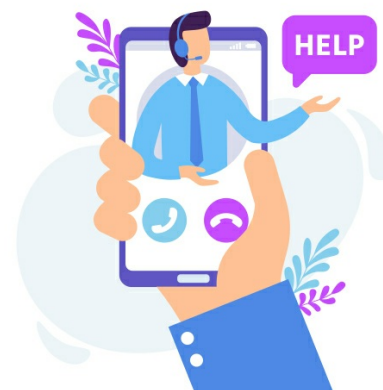
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## Family Support

### PWSA | USA Continues Offering 24-Hour Family Support

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](mailto:info@pwsausa.org).**

## Giving Help, Sharing Hope

In the PWS community, we all care so deeply about one another. And at this time of year especially, we share in the joys and sorrows of our PWS families. Families like the Erdleys.

Amy Erdley is the mother of Sophia who has PWS. Their family is struggling to meet all of the financial demands of Sophia's recent hospitalization. Amy is unable to work, as she won't leave Sophia's side, and her husband is staying home taking care of their other children.

Amy has set up a GoFundMe page during this tremendously difficult time. If you are able, consider making a donation to this very deserving family.

**Give Help, Share Hope.** Visit the GoFundMe page [here](#).

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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!

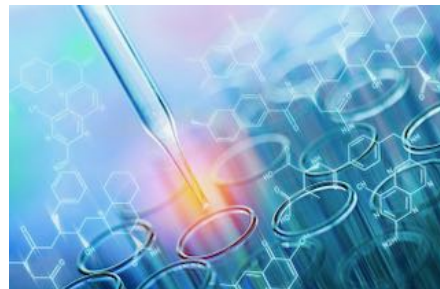
Applications in support of Fall 2021 tuition will open April 1, 2021 and close May 7, 2021. The scholarship offers one-time \$5,000 grants and is available for applicants of all ages and disease groups who are pursuing college, post-graduate degrees, trade school, or class certification courses.

So...what's your dream? Make it happen with the #RAREis Scholarship Fund.

## Research

### PWSA | USA Call 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 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.

### Respiratory Syncytial Virus (RSV) in Infants with PWS

Respiratory illness in persons with Prader-Willi syndrome (PWS) can be extraordinarily complicated and the course of the illness is often more serious than it is for others. Pronounced hypotonia in PWS is a significant risk factor for respiratory illness with severe complications.

In a recently released study by Dr.'s Miller and Thornton, parents of children with PWS were surveyed regarding their experience with Respiratory Syncytial Virus (RSV), a common respiratory illness in early childhood.

Read more [here](#).

## COVID-19 Community Updates

### NORD Webinar: Vaccine Updates

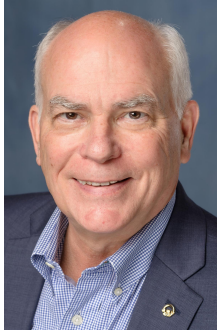
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# Statement from Members of the Clinical Advisory Board (CAB) Regarding People with PWS and COVID-19 Immunization

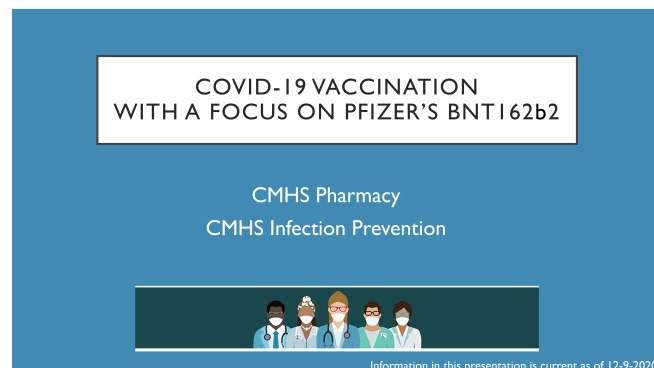


Daniel J. Driscoll, MD, PhD, FAAP, FFACMG; Chair, Prader-Willi Syndrome Association | USA; Clinical Advisory Board Chair, International Prader-Willi Syndrome Organization Clinical & Scientific Advisory Board

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](#).

## 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](#).



## Advocacy & Awareness

### Prader-Willi Syndrome Association | USA and the Foundation for Prader-Willi Research Partner for Telehealth Needs Assessment

Prader-Willi Syndrome Association | USA (PWSA | USA) and the Foundation for Prader-Willi Research (FPWR) have partnered to conduct a study to measure interest in telehealth as a way of increasing access to care from Prader-Willi syndrome specialists. In addition, the project aims to better understand the demographic makeup of the Prader-Willi syndrome (PWS) parent and caregiver population, to measure stress associated with traveling for healthcare, and to measure the well-being of children with PWS.



At this time, the survey and research is limited to families residing in the United States. International families interested in participating in future studies are encouraged to contact Paige Rivard at [privard@pwsausa.org](mailto:privard@pwsausa.org).

[Read more here.](#)

## Running for Research

PWSA | USA has partnered 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). Since its founding in 2018, the group has nearly tripled in the number of runners and now includes runners of all ages and abilities, from across the world, running local and virtual races in support of the cause.



Members of Running for Research come from a variety of backgrounds but are united in their determination to help find treatments for the most debilitating aspects of PWS. With your support, we can create a future for children with PWS that is happier and healthier than ever before.

[Click here to learn more.](#)



ALL TOGETHER  
"RUNNING FOR RESEARCH"  
TO FUND PRADER-WILLIS  
SYNDROME RESEARCH



### All together "Running for research" to fund Prader-Willi syndrome research

Lallemand issued a press release announcing their involvement with "Running for Research".

[Read more here.](#)

Thank you to Lallemand Health Solutions, Torbert Produce, Levo Therapeutics, Soleno Therapeutics, and Prader-Willi Homes for their sponsorships!



# Save the Date

## 36th PWSA | USA National Convention | June 23 - 26



### Breaking News: We're going virtual!

Based on community feedback and out of an abundance of caution for the health and safety of the Prader-Willi syndrome community, the 2021 National Convention will be virtual! We are thrilled at this opportunity to bring information, resources, and connection to more families than ever before.

Stay tuned for more information and Convention updates!

*Thank you to our Regatta Sponsor, Novo Nordisk!*



## Get Involved and Stay Connected

You Shop. Amazon Gives.



If you or your loved ones are shopping online this holiday season, be sure to use [smile.amazon.com](https://smile.amazon.com), and **AmazonSmile donates to Prader-Willi Syndrome Association | USA** at no cost to you!

[Try it now!](#)

## Follow 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.



**Dedicate Your Birthday to PWSA | USA!**

Facebook Fundraisers are a fun and easy way to raise support and awareness for PWSA | USA and the PWS community! Set your goal to raise a little or raise a lot...every fundraiser helps! **Since 2018, the PWS community has raised \$200,730** to support PWSA | USA!

**If you've already created a Facebook Fundraiser in support of PWSA | USA, THANK YOU! Together we are showing the world the lives of children and adults with PWS need not be defined by their diagnosis!**

### Ready to Get Started?

To add a donate button to your Facebook post, click "Support Nonprofit," type in "Prader-Willi Syndrome Association," then click on our name when it pops up.

Click [HERE](#) to start a fundraiser campaign on Facebook. You can use the default text and picture, or you can customize them to share your unique story. When you're all set up, you can easily share the campaign with your Facebook friends!

## Volunteer Opportunities

Check back next week for more volunteer opportunities!

## We Appreciate Our Corporate Sponsors



*The information provided in The Weekly Pulse 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.*

PWSA | USA | [Website](#)

[Donate Today](#)





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Read the full press release [here](#).



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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 Advocacy Award Winner [here](#).

## PWSA | USA Announces Calls for Letters of Interest

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.



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Click [here](#) for more information.

# The Global PWS Registry Needs YOU to Update Your Surveys!



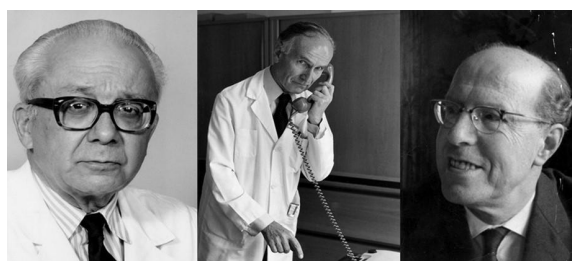
2021 brings new opportunities to learn even more about PWS and improve the health of those living with PWS. De-identified data from the Global PWS Registry is actively being used to help PWS physicians understand medical problems in PWS, provide scientists at the FDA with a better understanding of the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

PWSA | USA is pleased to introduce its new "Pioneers in PWS – Past and Present" series. In this series, we will highlight the individuals who have been leaders in the growth of PWSA | USA as well as who have furthered our advancement in knowledge and research of PWS.



Andrea Prader, Alexis Labhart, Heinrich Willi

2020 was a year we will never forget. However, we can't forget to acknowledge and celebrate the fact that it was the year that PWSA | USA celebrated its 45<sup>th</sup> anniversary. Read the series intro [here](#).

Did you know that when the syndrome was first identified in 1956, it was called Prader-Labhart-Willi Syndrome (PLWS)? Read more about it [here](#)!

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[Read more here.](#)

## Family Support

### Psychological Wellbeing of Siblings of Children with PWS



Dr. Laura Bennett Murphy, together with Emma and Jane Thronton, have released a new video describing their findings on the psychological wellbeing of siblings of children with PWS based on qualitative research and support groups.

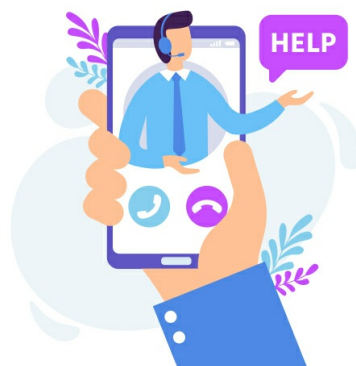
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## Radius Planning Pivotal Trial of Cannabidiol RAD011



Radius Health has acquired the development and commercialization rights to a synthetic oral cannabidiol therapy known as RAD011, formally an INSYS formulation. The plan is to start recruitment for a pivotal Phase 2/3 clinical trial in Prader-Willi syndrome (PWS) in the second half of 2021 following discussions with the U.S. Food and Drug Administration (FDA). Read more [here](#).

## US FDA Accepts Regulatory Submission from Pfizer and OPKO for Review of Somatrogen to Treat Pediatric Patients with Growth Hormone Deficiency

The US Food and Drug Administration (FDA) has accepted for filing the initial Biologics License Application (BLA) for somatrogen, a long-acting human growth hormone that is intended to be administered once-weekly for the treatment of pediatric patients with growth hormone deficiency (GHD). Read the press release [here](#). Please note: Families interested in learning more about somatrogen should consult with their endocrinologists.



## Preliminary Efficacy of a Remote Play-Based Intervention for Children with Prader-Willi Syndrome



Prader-Willi Syndrome (PWS) is characterized by decreased social and emotional functioning. Due to the low base-rate of children with PWS, developing behavioral interventions for individuals with PWS is faced with the challenge of enrolling enough local participants for adequate study of behavioral intervention efficacy. However, these types of studies are greatly needed in PWS and telehealth methodology may be useful in addressing this challenge. This article is a follow-up to a previous feasibility study (Dimitropoulos et al., 2017) and reports on the preliminary efficacy of a telehealth intervention delivered to 15 children, ages 6–12, with PWS. Overall, children demonstrated significantly improved cognitive and affective processes in pretend play and general cognitive flexibility following the 6-week remote intervention. These findings are limited by the lack of control group and small sample size which should be considered when interpreting results. Overall, these preliminary findings point to the potential role pretend play can serve as a means of enacting cognitive and behavioral change via telehealth. Read the full study [here](#).

## COVID-19 Community Updates

### NORD Webinar: Vaccine Updates

January 15 at 2:00 PM



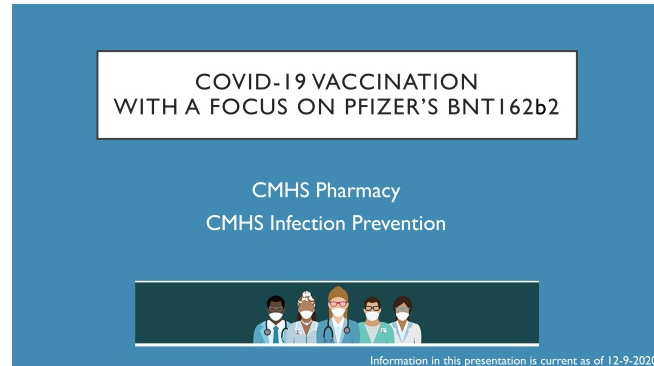
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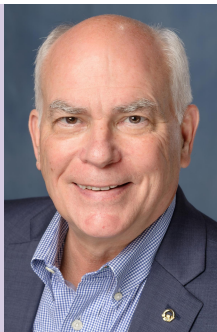
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Daniel J. Driscoll, MD, PhD, FAAP,  
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## Save the Date

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

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



## 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

## Thank You to Our Convention Sponsors!



Lighthouse Sponsor



Regatta Sponsor

## Get Involved and Stay Connected

You Shop. Amazon Gives.



If you or your loved ones are shopping online this holiday season, be sure to use [smile.amazon.com](https://smile.amazon.com), and **AmazonSmile donates to Prader-Willi Syndrome Association | USA** at no cost to you!

[Try it now!](#)

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## 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](mailto:privard@pwsausa.org).

## We Appreciate Our Corporate Sponsors



Prader-Willi  
Homes

A MyPath Company

**Important Note:** 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](http://www.pwsausa.org)





## PWSA | USA Virtual Convention Survey

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. Now we need your feedback to ensure this convention is the most successful yet. Please help us by completing a brief questionnaire [here](#).



## Hypothermia and Prader-Willi Syndrome

Hypothermia can be a life-threatening condition that some children and adults with Prader-Willi syndrome appear to be more susceptible to than the general population. This condition develops when the body temperature drops too low – to 95 degrees Fahrenheit or lower. Our body attempts to warm itself; but there are situations in which it is not able to do this successfully. When the body temperature drops too low, the heart, nervous system and other organs can't work normally. If left untreated, hypothermia can lead to heart and respiratory failure and in some cases even death. Read more [here](#).



## 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.



GLOBAL  
**PRADER-WILLI SYNDROME**  
REGISTRY

[WWW.PWSREGISTRY.ORG](http://WWW.PWSREGISTRY.ORG)

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

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. Dr. Vanja Holm and Peggy Pipes MRH, RD, were two of those remarkable people and examples of some of the earliest pioneers who exemplified this. Continue reading [here](#).



Dr. Vanja Holm

## 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 Awareness Award Winner [here](#).

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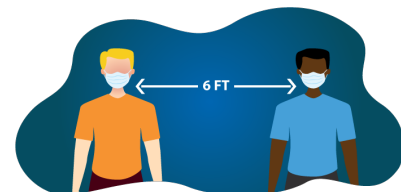
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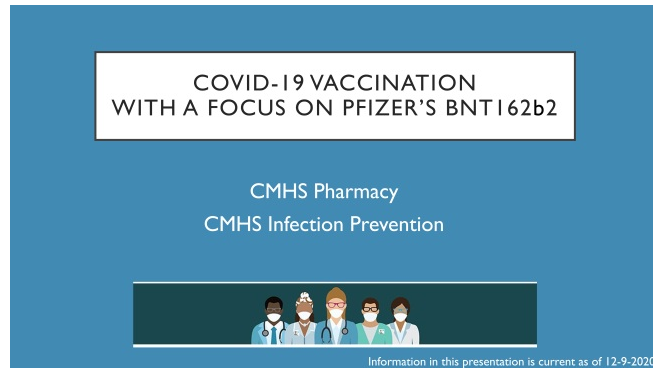
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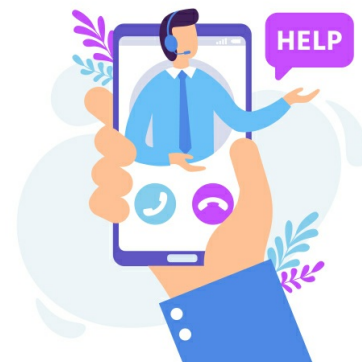
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"We are incredibly thankful to our donors whose generosity make this critical service possible for the PWS community," continued Rivard. "We know our families need extra support during these uncertain times and we are honored to be here for them."

**If you have any questions about PWSA | USA's 24-hour Family Support services, please contact us at [info@pwsausa.org](mailto:info@pwsausa.org).**

## Prader-Willi Association of New York Workshops



Prader-Willi Association of New York is hosting a series of workshops for the PWS community in January. The workshops will run every Monday in January from 7- 8 PM EST on Zoom. The series is free to PWANY members or \$10 per workshop for nonmembers (\$30 for all four workshops). Workshop topics include: Service

Dogs; Nutrition; and COVID-Era Educational and IEP Concerns Forum. For more information, please visit: <https://forms.gle/KKQBiapH1LW5esH6A>

## 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](http://RareScholarship.org) or email [lcundiff@everylifefoundation.org](mailto:lcundiff@everylifefoundation.org) to learn more.**

## Research

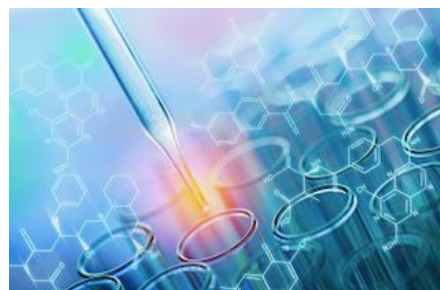
### Longer Use of Oxytocin Helped Boys with PWS

Prader-Willi syndrome (PWS) is characterized by hypothalamic dysfunction, hyperphagia and a typical behavioural phenotype, with characteristics of autism spectrum disorder (ASD) like stubbornness, temper tantrums and compulsivity. It has been suggested that the oxytocin system in patients with PWS is dysfunctional. In ASD, intranasal oxytocin treatment has favourable effects on behaviour. Continue reading [here](#).



## PWSA | USA Announces Calls for Letters of Interest

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.

## Save the Date

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



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

#### 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

### Thank You to Our Convention Sponsors!



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# 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](mailto:privard@pwsausa.org).

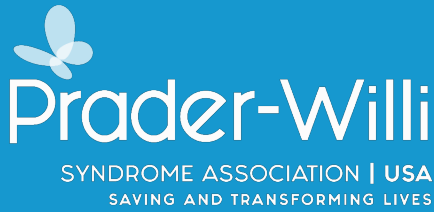
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Prader-Willi  
Homes

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**Important Note:** 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.



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!

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### 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](#).



*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!



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](mailto: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.*

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## Good News Found In Path for PWS: A Family's Story



When our son, Robert, was born almost thirty-one years ago, we had no diagnosis. Seven years later a new blood test confirmed Prader-Willi syndrome. It was not a good day for our family, and from what I understand, it is not a good day for any family (then or now) facing a new diagnosis. I was sure when our son was born that we were going to “fix this.” I wrote in my book *Raising Robert* that denial and I were particularly good friends. Continue reading [here](#).

## Prepping for Cupid: Healthy Valentine's Day Treats

Ah, Valentine's Day...Red hearts, adorable cupids, funny cards, and...treats. While some classrooms have forgone candy, cupcakes, and other sweets for non-food shareables, others have not. If you find your child in a situation where tempting foods are unavoidable, consider bringing one of these fun (and healthy!) goodies to pass!

- [Heart Kabobs 1](#)
- [Heart Kabobs 2](#)
- [Valentine Snacks](#)
- [Chocolate Avocado Pudding](#)
- [Date Caramels](#)
- [Macadamia Truffle Bites](#)



If your child's teacher is open to it, you might try suggesting classmates share nonfood items rather than candy. Even if others will be sharing suckers and such, though, **you** can still forgo food treats by gifting small items like bookmarks, stickers, erasers, and pencils. Need some inspiration? Check out these two helpful articles:

- [26 Nonedible Valentine Ideas for Kids](#)
- [21 Non-Candy Valentines](#)

## Advocacy & Awareness

### PWSA | USA "Pioneers in PWS" Historical Series

You may not know Gene and Fausta Deterling, but they changed your life and the life of your child with PWS. “Curtis has Prader-Willi syndrome.” The Deterlings stared at their doctor in disbelief when they heard those words in 1971. Gene was an engineer and a manager, a problem solver. “Can’t we do something?” That became their mantra – and do something is exactly what they did! There were only four articles on the syndrome published at



that time, no organization of families or professionals, and no Internet. Continue reading [here](#).



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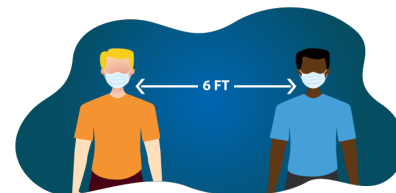
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#### COVID-19 VACCINATION WITH A FOCUS ON PFIZER'S BNT162b2

CMHS Pharmacy  
CMHS Infection Prevention



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

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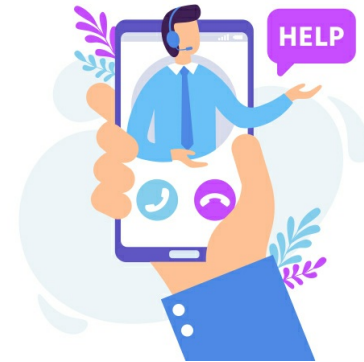
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## Research

### Touchscreen Use Across Early Development Associated with Faster Exogenous, Reduced Endogenous Attention Control

Childhood *screen time* is associated with both attentional difficulties (for television viewing) and benefits (in action video gamers), but few studies have investigated today's pervasive *touchscreen* devices (e.g. smartphones and tablets), which combine salient features, interactive content, and accessibility from toddlerhood (a peak period of cognitive development). Continue reading [here](#).



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Prader-Willi  
Homes

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# Prader-Willi

SYNDROME ASSOCIATION | USA

SAVING AND TRANSFORMING LIVES

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