Coming this PWS Awareness Month - Giving HOPE has never been easier! 💗

This month, PWSA | USA will unveil an exciting surprise for our community on our social media pages! If you haven't done so already, make sure you follow us on Facebook (@PWSAUSA) and tell your family and friends to do the same. This month, PWSA | USA will reveal all of the details (and puzzle pieces) about this brand-new initiative. We will share our "reveal date" soon and can't WAIT to show you what's in store!
Show your PWS pride during the month of May, and all year long, with our NEW Ask Me... About PWS, Hope defined, PWS is RARE but HOPE is NOT items, including shirts, sweatshirts, water bottles, coffee mugs, hats, onesies, and so much more.

**SHOP HERE TODAY!**

There are many ways you can help raise awareness for Prader-Willi syndrome during the month of May and all year long! We have highlighted 15 easy ways to take action, including reaching out to your elected officials, becoming a volunteer or parent mentor, and hosting your own Wear Jeans for Rare Jeans fundraiser!

**LEARN MORE HERE**

If you know someone who regularly shares their story in a blog, provides helpful information on their social media pages, hosts an inspirational podcast, or even

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**SAVE THE DATE**

**Upcoming Events >>**

"No Gimmes for Jimmy" Annual Charity Golf Outing
When: Friday, May 6, 2022
Show Your Support Here >>

Texas Prader-Willi Association Bi-Annual Statewide Conference
When: May 14, 2022
Learn More Here >>

PWANY 30th Annual Conference
When: May 20 - May 21, 2022
Learn More Here >>
organizes events to support the PWS community - we want to shine a light on them! Simply click on the button below, fill out the form, and submit an image if you have one to share.

SHARE YOUR SPOTLIGHT STORY HERE

11th Annual IPWSO Conference 2022
When: July 6 - 10, 2022
Learn More Here >>

PWS Awareness Month Yard Sign
Download PWSA | USA’s PWS Awareness Month yard sign by clicking the button below. You can then send the PDF file to your local printer!

DOWNLOAD HERE

EVENTS
"We are extremely thankful for such great attendance and energy throughout the Volunteer Summit, and are already working to implement some of the amazing ideas shared during the event. We look forward to collaborating more with our volunteers in the future. If you are interested in becoming a PWSA | USA volunteer, reach out to us at volunteer@pwsausa.org."

Paige Rivard, MBA | CEO

The Find Your Voice: Advocating for PWS Health Care webinar series recordings are now available for viewing! Thank you to those who attended
these informative sessions, and to our amazing speakers who offered their expertise in various health care subjects. Find the webinar recordings and handouts by clicking the button below.

WATCH THE RECORDINGS HERE

A Special Thank You to Joe Gill for Supporting PWSA | USA!

Joe Gill (22), sibling to Gavin (16) who is living with PWS, set out to raise $16,000 for PWSA | USA as part of his race in the Boston Marathon. Joe has far exceeded that goal, raising nearly $38,000 to date! We are sincerely appreciative for Joe's determination to help raise funds and awareness for PWS. Donations to "Gavin's Run" will be accepted through June 2022 and can be made here.

Congratulations to Joe on a great marathon race!
ADVOCACY

WATCH: April 27th Advocacy in Action Webinar with the Federal Food & Drug Administration
Join us for our May 25, 2022 Advocacy in Action Webinar at 8:00 p.m. EST

Topic: We The Patients, a preview to RDLA in Washington, D.C.

Speaker: Rachel Derby, Executive Director of Policy and Advocacy for Patients Rising Now

REGISTER IN ADVANCE HERE

PWSA | USA Staff Featured in Arc of New Jersey Family Institute Podcast Series "Tell Us About"

PWSA | USA CEO Paige Rivard and Community Engagement Coordinator Dorothea Lantz were recently featured on The Arc of New Jersey Family Institute's Podcast series Tell Us About.

They discussed Prader-Willi Syndrome (PWS) and the different resources available for families who have a child with PWS. We encourage you to listen to this informative conversation by clicking the button below.

LISTEN HERE
Early Intervention: IDEA Part C

In this informative article, PWSA | USA’s Director of Family Support Stacy Ward gives an in-depth description of Part C (Early Intervention) of the Individuals with Disabilities Education Act (IDEA) and how it can impact your loved one living with PWS.

READ MORE HERE

May 6, 2022 kicks off National Nurses Week!

We want to take this opportunity to share a big thank you to PWSA | USA’s Medical/Research Coordinator Lynn Garrick, RN for all that you do for our community!

CBDV Study for Prader-Willi Syndrome
CBDV Treatment Research Study for Children with Prader-Willi Syndrome (PWS)

Recruitment is open for a research study examining the effects of a cannabis compound (CBDV) on irritability, repetitive/rigid behaviors, and hyperphagia in children and young adults with PWS.

CBDV is not psychoactive (does not cause a "high").

Who: Children and young adults ages 5-30 with PWS.

What: This is a 12-week trial; 2 on-site visits.

Where: Albert Einstein College of Medicine-Montefiore Medical Center, NYC.

How: Email: Spectrum@montefiore.org or call Bonnie Taylor, PhD at 718-839-7530

DOWNLOAD THE FLYER HERE
If you or any member of your family is a member of the military (active, inactive, retired, reserves), PWSA | USA wants to hear from you! Please click the button below, then fill out and submit the information in the form. If you have any questions, please contact us at info@pwsausa.org. Thank you!

FILL OUT THE FORM HERE

It’s Teacher Appreciation Week!

Thank you to all of the amazing teachers in our lives - in the classroom and at home! Find several ways you can share your gratitude when you click on the button below.

LEARN MORE HERE

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!

Donate

Privacy Policy | Unsubscribe
Prader-Willi Syndrome Association | USA
1032 E Brandon Blvd #4744 Brandon, FL 33511
Coming this PWS Awareness Month - Giving HOPE has never been easier!

On Thursday, May 26, 2022, PWSA | USA will unveil an exciting surprise for our community on our social media pages! If you haven't done so already, make sure you follow us on Facebook (@PWSAUSA) and tell your family and friends to do the same. We can't WAIT to show you what's in store!
Here’s How You Can Get Involved
This PWS Awareness Month

PWS Awareness Month Store Items Available!

Shop Here!

Share Your PWS Awareness Spotlight Story!

Save the Date

Upcoming Events >>>

Advocacy in Action: We The Patients, a preview to RDLA in Washington, D.C.

When: May 25, 2022 at 8:00 p.m. EST

Learn More Here >>

Making Hope Happen: An Opportunity to Make a Difference

When: May 31, 2022 at 8:00 p.m. EST

Learn More Here >>

11th Annual IPWSO Conference 2022

When: July 6 - 10, 2022

Learn More Here >>
EVENTS

Other Upcoming Events of Interest

#WeThePatients | Washington, D.C. Fly-In 2022 | June 14-15, 2022 >>

Rare Across America 2022 | August 8 -19, 2022 >>

PWSA | USA Staff Attend TXPWA Conference
"Last weekend, PWSA | USA Medical/Research Coordinator Lynn Garrick and I had the opportunity to attend TXPWA’s 2022 Conference. We thoroughly enjoyed the inspiring speakers, making new connections, and being able to share what we're doing at PWSA | USA’s national organization.

As the world opens back up to travel and gatherings, PWSA | USA looks forward to connecting more frequently in-person with our community and chapters. We are extremely appreciative of all the work our chapters are doing to help spread awareness and assist our community where they're at."

- Paige Rivard, MBA | CEO
A Look into AME Community Services' Minnesota Prader-Willi Group Home

PWSA | USA Alterman Family Support Counselor, Kim Tula, MS, CSW and Medical/Research Coordinator Lynn Garrick, RN give an inside look into the AME Counseling Services Prader-Willi Group Home in Hastings, Minnesota.
CBDV Study for Prader-Willi Syndrome
CBDV Treatment Research Study for Children with Prader-Willi Syndrome (PWS)

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Who: Children and young adults ages 5-30 with PWS.

What: This is a 12-week trial; 2 on-site visits.

Where: Albert Einstein College of Medicine-Montefiore Medical Center, NYC.

How: Email: Spectrum@montefiore.org or call Bonnie Taylor, PhD at 718-839-7530

DOWNLOAD THE FLYER HERE
Changes to PWSA | USA Facebook Groups

PWSA | USA will be combining two of our community Facebook groups. The Parent Mentor and Chapter Leaders Facebook Group will no longer be accessible and instead, will be combined into one group called PWSA | USA Volunteers.

LEARN MORE HERE

If you or any member of your family is a member of the military (active, inactive, retired, reserves), PWSA | USA wants to hear from you! Please click the button below, then fill out and submit the information in the form. If you have any questions, please contact us at info@pwsausa.org. Thank you!

FILL OUT THE FORM HERE

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!

Donate
THE WAIT IS OVER!

We are thrilled to reveal the exciting new initiative that our PWSA | USA team has worked so hard to prepare. In the video below, CEO Paige Rivard shares insight on our new Peer-to-Peer Fundraising platform, PWS Hope United!
Giving hope has never been easier, and you can make it happen! Help us become stronger and more united than ever as a community.

Hope is here to stay ❤️

Making Hope Happen: An Opportunity to Make a Difference

Please join us next Tuesday, May 31st, for our May Community Conversation – Making Hope Happen – where we will share how YOU can become a Hope United Champion and support your loved one living with PWS! Register in advance by clicking the button below.
REGISTER IN ADVANCE HERE

Be one of the first 20 to sign up for a Hope United Fundraiser!

YOU can make HOPE happen!

Be one of the first 20 to create your own Hope United fundraiser and receive a Hope United t-shirt! No matter what your vision is, no idea or dollar amount is too great or too small, and we are here to help every step of the way.

Click the button below to get started!

Questions? Contact us at hopeunited@pwsausa.org.

BECOME A HOPE UNITED FUNDRAISER!

Get Your Hope United Water Bottle TODAY!

Just in time for summer, stay hydrated in style with our brand-new Hope United water bottles!

Here's how you can get yours:
1. Go to store.ZagFundraising.com
2. Enter the PWSA I USA's Seller ID: 98913778
3. Click the SHOP button
4. Email family and friends the shopping link, store.ZagFundraising.com, and the Seller ID. Don’t forget to share on Social Media!
5. Orders will have a nominal shipping fee and orders over $150.00 will receive Free Shipping!
6. Orders will be received in approximately three business days from the order date!

PURCHASE YOUR HOPE UNITED WATER BOTTLE HERE

Find Inspiration from a Few of our Fundraising Stars!

THANK YOU FOR MAKING Hope Happen

Donate