



Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

MEDIA KIT

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WHAT IS PWS?



Insatiable Hunger

Individuals with PWS experience an insatiable hunger, which can lead to overeating and obesity.



Behavioral Issues

PWS is often associated with temper outbursts, obsessive-compulsive tendencies, and anxiety.



Low Muscle Tone

Infants with PWS often have low muscle tone, causing feeding difficulties and delayed milestones.

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WHO WE ARE

OUR HISTORY

The Prader-Willi Syndrome Association | USA (PWSA | USA) is a national nonprofit organization dedicated to supporting individuals and families affected by Prader-Willi syndrome (PWS), a rare genetic disorder. Since our founding in 1975, we have become the leading voice for PWS awareness, support, education, and advocacy across the United States. **In 2025, PWSA | USA is celebrating our 50 year anniversary!**

OUR MISSION

Our mission is to enhance the quality of life for those affected by PWS through support, research, and advocacy. We provide essential resources, raise awareness, and fund research initiatives aimed at understanding PWS and improving treatment options.

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WHAT WE DO

FAMILY SUPPORT

We offer compassionate guidance to families navigating the challenges of living with PWS. Our support includes connecting families with medical professionals, resources, and peer networks to help them manage daily care.

ADVOCACY & AWARENESS

PWSA | USA actively advocates for policies that improve the lives of individuals with PWS. We work closely with lawmakers, healthcare professionals, and the general public to raise awareness and understanding of PWS.

EDUCATION & RESOURCES

We provide a wide range of educational materials, workshops, and training to equip caregivers, educators, and medical professionals with the knowledge needed to support those affected by PWS.

RESEARCH & INNOVATION

We are committed to advancing research on Prader-Willi syndrome. Through funding research initiatives and supporting clinical trials, we strive to move closer to effective treatments.



OUR TEAM & LEADERSHIP



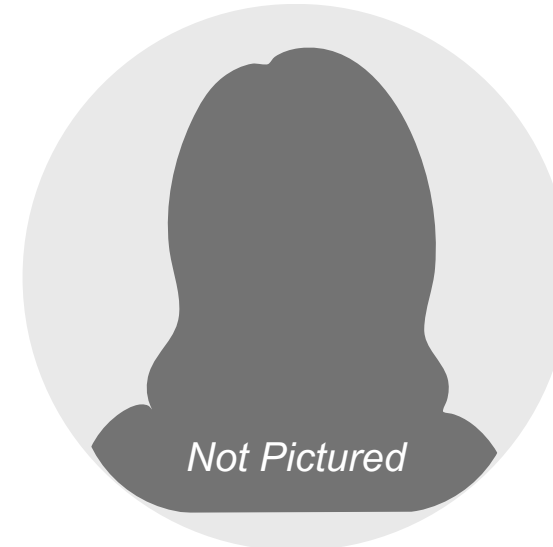
Stacy Ward, MS, BCBA
PWSA | USA CEO



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Board of Directors, Chair



Mitch Cohen, BS, JD
Board of Directors, Vice Chair



Tina Ihlenfeld, MBA
Board of Directors, Treasurer



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Board of Directors, Secretary

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PWSA | USA STAFF

Listed in alphabetical order

Pia Dorson, Fundraising Coach: Special Events
Angela Frazier, Events Coordinator
Anne Fricke, Marketing & Communications Coordinator
Lynn Garrick, MSN, RN, Medical/Research Coordinator
Andrea Hughes, Database Coordinator
Carrie Iljevich, Director of Marketing & Communications
Sarah Kasaby, Information & Referral Specialist
Dorothea Lantz, Director of Community Engagement
Amy Maust, CPA, Director of Accounting

Katie Martinez, Fundraising Coach: Team & Online Events
Melanie Zalman, Director of Development
Kristi Rickenbach, Parent Support Coordinator
Kristen Starkey, Accounting Clerk
Elaine Towle, Advocacy Specialist
Kim Tula, MS, CSW, Senior Family Support Counselor and Trainer
Stacy Ward, MS, BCBA, CEO

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STORIES OF PWS

Click on the images to read/watch these inspiring stories



PWSA | USA'S SPOTLIGHT ON HOPE



Our *Spotlight on Hope* series strives to share and celebrate the successes of our loved ones. No success is too small! Whether they took their first steps, had a great time at the school dance, made a shot in a basketball game, or are working towards a goal, this series celebrates it all. Click the button below to read these stories of hope.

[READ MORE SPOTLIGHT ON HOPE STORIES](#)

MARKETING ANALYTICS

FOLLOWERS

	14,548
	2,272
	1,226
	2,218
	1,179

PWSAUSA.ORG

Monthly Visitors	12,383
Avg. Monthly Page Views	31,810
Avg. Engagement Time	1:43

BLOG

Avg. New Monthly Posts	14
Avg. Monthly Post Views	3,161
Avg. Monthly Readers	275



PODCAST LISTENERS

New episode shared across all Podcast streaming platforms every Tuesday

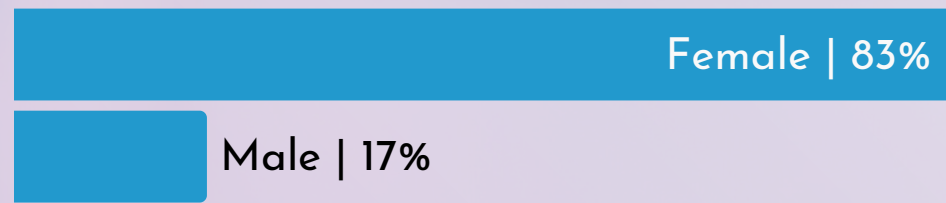
3,292 Total Episode Downloads
265 downloads on top episode
On average, 160 listens per episode

PWS United Podcast launched in August 2024

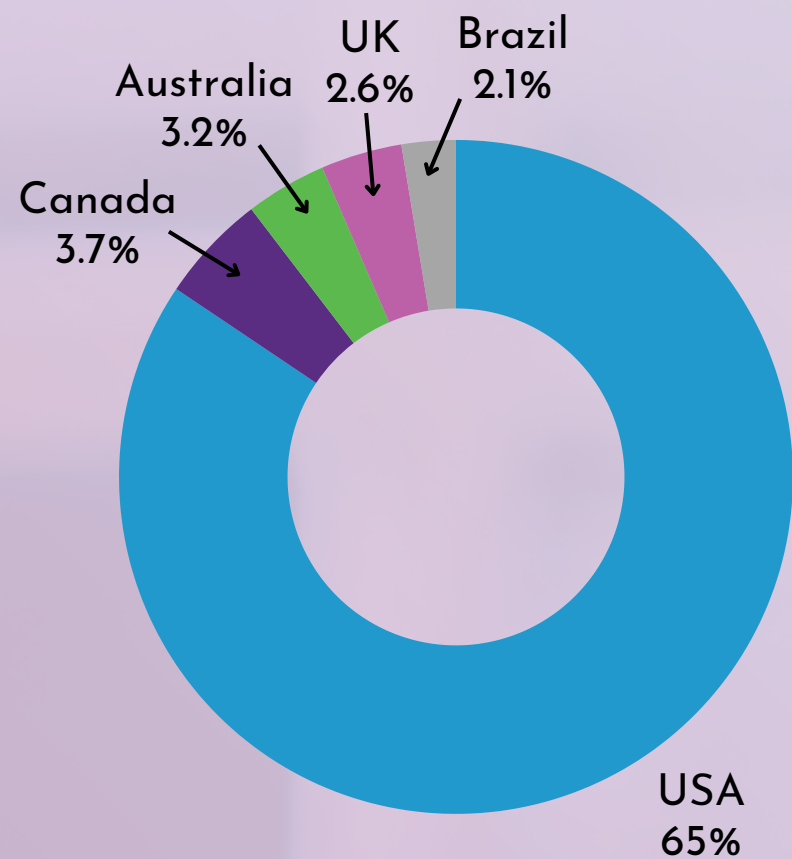
MARKETING ANALYTICS - DEMOGRAPHICS

SOCIAL MEDIA FOLLOWERS

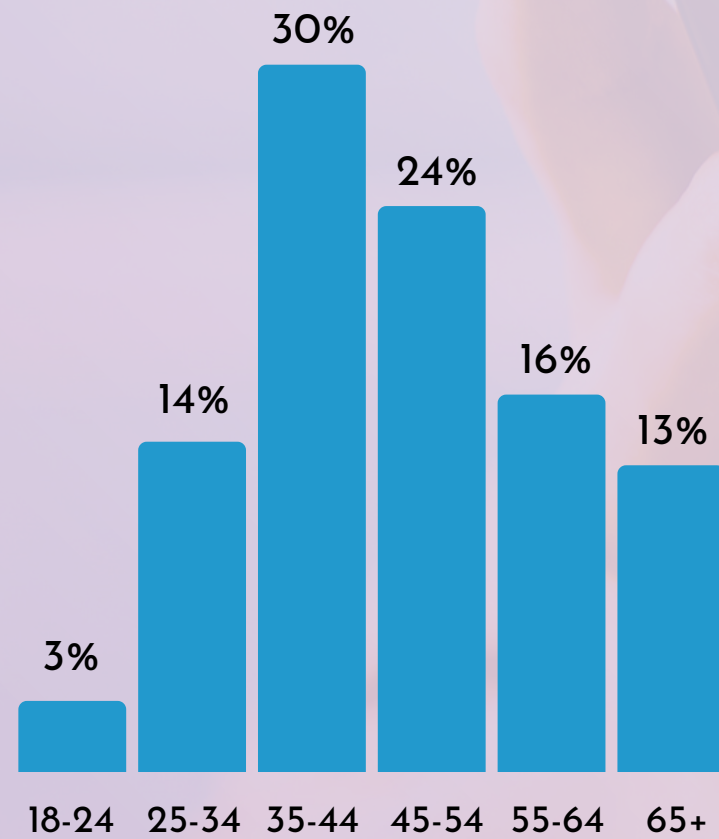
Gender



Countries (Top 5)

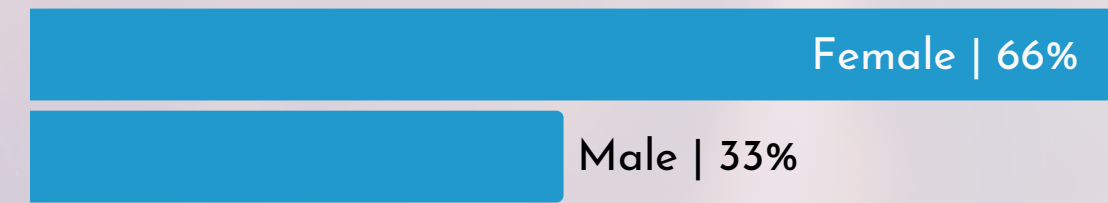


Age

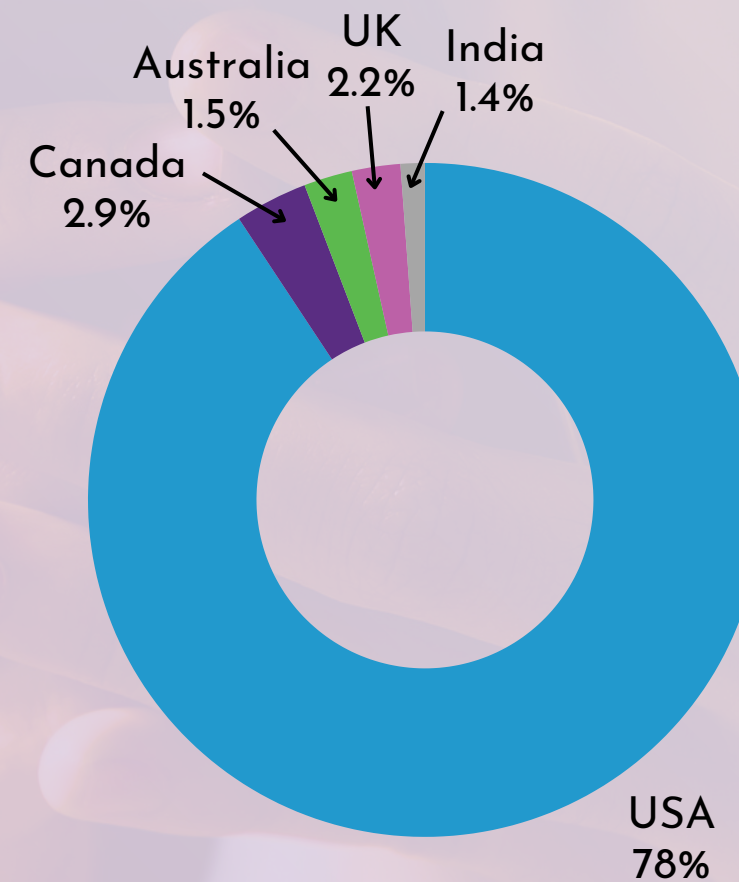


WEBSITE VISITORS

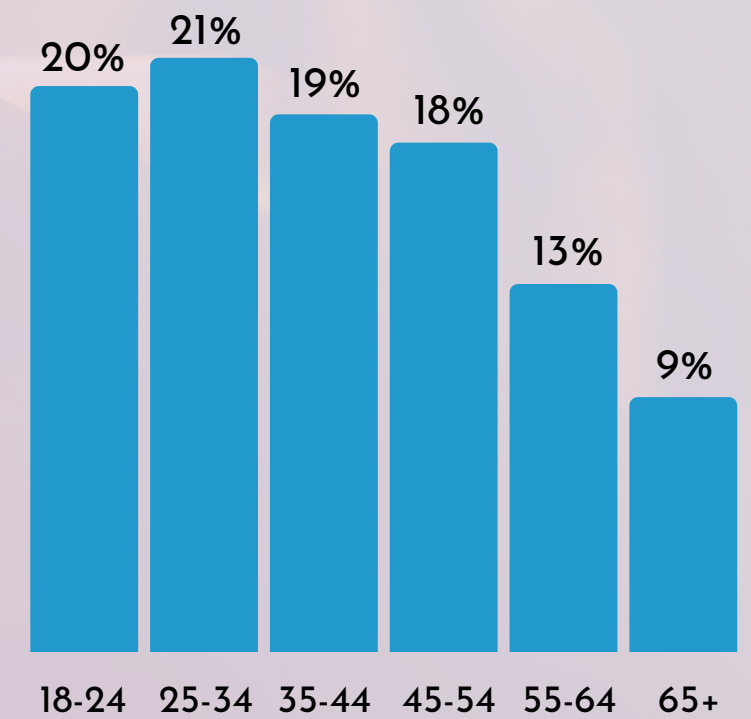
Gender



Countries (Top 5)



Age



SUB-BRANDS OF PWSA | USA



PWSA | USA's Podcast

[LEARN MORE](#)



Peer-to-Peer Fundraising

[LEARN MORE](#)



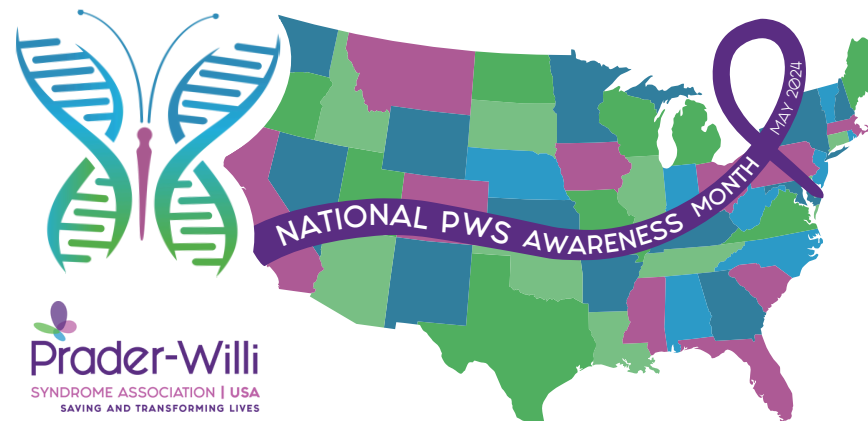
Advocacy Efforts

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Annual Fundraising Drive

[LEARN MORE](#)



PWS Awareness Month (May)

[LEARN MORE](#)



ECHO 4 PWS: Healthcare Provider Series

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PWSA | USA EVENTS

United in HOPE
2025 PWS CONFERENCE



Biennial Conference

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D.C. Fly-In

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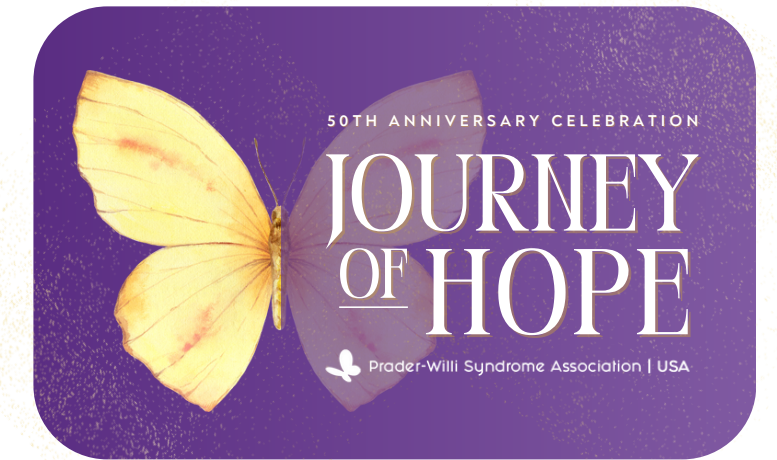
Moms' Retreat

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Residential Providers Conference

[LEARN MORE](#)



50th Celebration: Journey of Hope Gala

[LEARN MORE](#)



2025 EDITORIAL CALENDAR

EMAIL, SOCIAL MEDIA, PODCAST, BLOG SCHEDULE

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
PWS Hope United Fundraiser/event promotion	Resource spotlight social media 2025 International PWS Conference social media	PWS United Podcast episode release Standalone emails sent (event, campaign, program focuses)	Ask Nurse Lynn question/answer blog article	PWSA USA's 50th Anniversary spotlight	PWSA USA Pulse Newsletter (emailed bi-weekly) New Family Support blog article Community-contributed blog article (first Friday of every month)	Spotlight on Hope social media post

PWSA | USA's 2025 editorial calendar is packed with exciting content designed to inform, inspire, and unite the Prader-Willi syndrome community. From social media campaigns and podcast episodes to email updates and blog articles, we're committed to sharing stories, programs, and resources that make a difference.


If you have a program, service, or information you'd like us to help spread the word about, we'd love to collaborate! Reach out to our communications team at communications@pwsausa.org to discuss how we can amplify your message through PWSA | USA's platforms. Let's work together to create greater awareness and support for the PWS community in 2025!

EVENTS, FOCUSES, CAMPAIGNS BY MONTH

JANUARY	FEBRUARY	MARCH	APRIL
PWSA USA Staff Retreat (Jan. 28-Feb. 2) Mental Wellness Month	Diamonds & Denim Event (Feb. 1 Springfield, IL) National Caregivers Day (Feb. 21) Rare Disease Week (Feb. 24-26) Rare Disease Day (Feb. 28)	Developmental Disabilities Awareness Month National Nutrition Month Sleep Awareness Week (March 9-15) Neurodiversity Celebration Week (March 17-23) Clint Hurdle Hot Stove Dinner (March 22 Bradenton, FL)	National Occupational Therapy Month Zahra's Night of Light (April 5 Bedford, NY) National Siblings Day (April 10) National Volunteer Week (April 20-26) PWSA USA's Family Support Campaign
MAY	JUNE	JULY	AUGUST
Prader-Willi Syndrome Awareness Month National Prader-Willi Syndrome Awareness Day (May 15) PWSA USA's Family Support Campaign National Nurses & Teacher Appreciation Weeks (May 5-11)	Scoliosis Awareness Month Family Health & Fitness Day (June 14) International PWS Conference (June 24-28)	National Minority Mental Health Month	Gastroparesis Awareness Month National Make-a-Will Month National Nonprofit Day (Aug. 17) National Grief Awareness Day (Aug. 30) PWS United Podcast Anniversary (Aug. 31)
SEPTEMBER	OCTOBER	NOVEMBER	DECEMBER
Newborn Screening Awareness Month National Service Dog Month Direct Support Professionals Week (September 8-14) World Physical Therapy Day (Sept. 8) World Narcolepsy Day (Sept. 22) PWSA USA's 50th Anniversary Celebration: Journey of Hope Gala (Sept. 26 St. Louis, MO)	National Physical Therapy Month 16th Annual Hunter Lens Golf Tournament (Oct. 4 Lakeville, MA) World Mental Health Day (Oct. 10) Dance Silly for Prader-Willi (Oct. 11 Warren, OH) Cocktails for a Cause (Oct. 18 Troy, NY)	PWSA USA's Angel Drive Campaign National Family Caregivers Month International 15Q Day (Nov. 15) World Prematurity Day (Nov. 17)	PWSA USA's Angel Drive Campaign International Day of Persons with Disabilities (Dec. 3)

LEARN MORE ABOUT OUR WORK

At PWSA | USA, we're here to support, collaborate, and share the stories that matter most to the Prader-Willi syndrome community. Whether you're seeking information, want to help spread awareness, or explore partnership opportunities, we'd love to hear from you. No request is too small - reach out today and let's make a difference together. For media inquiries, please email communications@pwsausa.org or call (941) 312-0400.

 **(941) 312-0400**

 **info@pwsausa.org**

 **www.pwsausa.org**

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