Prader-Willi
SYNDROME ASSOCIATION (USA)
SAVING AND TRANSFORMING LIVES

OPPORTUNITY: CORPORATE PARTNERSHIP

PWS & PWSA (USA): The Organization

What is Prader-Willi Syndrome?

Prader-Willi syndrome (PWS) is a complex, non-hereditary genetic disorder characterized by low muscle tone, short stature, incomplete sexual development, cognitive disabilities, problem behaviors, and a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity. Considered a “rare disease,” it is estimated that approximately one in 12,000 to 15,000 people are born with the syndrome. PWS affects both sexes and all races and is one of the most common conditions seen in genetics clinics. It is also the most commonly identified genetic cause of obesity.


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Prader-Willi syndrome is best known for its symptom called “hyperphagia” which means literally “overeating.” For reasons not yet understood, the brain of someone with PWS drives the individual to want to eat as much food as possible all of the time. Persons with PWS feel a constant drive to eat that is never satisfied no matter how much food is eaten. At the same time, metabolism rate slows to about half what it should be. If caloric intake is not significantly reduced and strictly controlled, persons with PWS will quickly gain an enormous amount of weight leading to complications caused by morbid obesity. People with PWS are vulnerable to sudden death due to choking, stomach rupture, or stomach necrosis.

The brain of someone with PWS causes individuals to feel a global sense of anxiety, think oppositionally, have a low tolerance to frustration, be argumentative, and react to disappointment and frustration with tears or anger. Managing the syndrome is a life-long challenge.

Saving and Transforming Lives, Together

We work hand-in-hand with individuals, families, medical and research professionals, education specialists, organizations, and associations to facilitate research, to spread awareness, to advocate, and to educate. By working together, we can do more to Save and Transform Lives of individuals with PWS and their families.

PWSA (USA) FIVE PILLARS OF SUPPORT

AWARENESS
FAMILY SUPPORT
RESEARCH
EDUCATION
ADVOCACY

PRADER-WILLI SYNDROME ASSOCIATION (USA): Who We Are

Founded in 1975, PWSA (USA) has been providing hope and support to individuals with PWS, and their families. Our comprehensive programs are available to assist families every step of the way, providing information and resources for new diagnosis, school assistance, behavior management, guardianship, residential placement, advocacy, and much more. PWSA (USA) is the foremost organization in providing education and resources to medical, scientific, and school professionals, and is a leader in funding PWS research in the United States.

We are Inclusive and Holistic in Our Approach

PWSA (USA) is an organization of individuals, families, and professionals working together to create a collaborative, participative commUNITY wherein individuals with PWS and their families have the resources and support they need to define, create, and live their best lives. PWSA (USA) is a community that welcomes all, one that is committed to ensuring the well-being of the whole person; PWS doesn't just affect one aspect of life, so PWSA (USA) doesn't narrow its focus to just one issue.

Passion into Purpose – Donors & Volunteers

With support from our volunteers and donors, we have created and expanded programs for parents of newly diagnosed children, deployed life-changing family support programs, funded cutting-edge research, and provided training and information to school professionals, residential providers, and healthcare providers from across the country. PWSA (USA) channels its supporters' passion and dedication into substantive, meaningful measures that really do Save and Transform Lives.

What We Offer

Parent Mentoring

- Parent-to-Parent support with a trained parent mentor; special support for parents of a newly diagnosed child
- Extensive age-appropriate materials provided at no cost
- Free packet for physicians which includes a medical overview of PWS (flash drive) and a Growth Hormone booklet.

Crisis Support & Advocacy

- Counseling with trained staff with advanced degrees
- Support for medical, behavioral, legal, school and placement crises
- Information and referral services
- Special education advocacy on behalf of students with PWS including information about IEPs, PWS-specific school strategies, and a resource flash drive for educators.
- Support through our Public Policy Action Center for enhanced services and opportunities for people with PWS and their families.

State Chapters

- Chapters offer local advocacy, resources and family connections. To find a chapter in your state, visit: www.pwsausa.org/links/chapter.htm

Medical and Research Program

- Scientific and Clinical Advisory Boards - all members have extensive PWS experience
- Consultation with PWSA (USA) medical board members available to all physicians
- Scientific conference at national PWSA (USA) convention
- Publishing of Medical Alert booklets and medical handouts that are PWS-expert physician authored, with a free smartphone version

Publications and Website

- Bi-monthly educational newsletter for all members, including the latest in medical information, research and treatment
- Educational, supportive, and medical publications including DVDs available

Awareness/PR/Development

- Booths/Presentations at medical conferences nationally and internationally
- Biennial national PWSA (USA) Convention for families and professionals
- Annual national PWS Awareness Month

CORPORATE PARTNERS

Prader-Willi
SYNDROME ASSOCIATION (USA)
SAVING AND TRANSFORMING LIVES

PWSA (USA) works with Corporate Partners to coordinate the efforts of PWSA (USA) and corporate leaders, in a collaborative environment, to advance the field of Prader-Willi Syndrome research, patient care, and family support. Positive recognition and other benefits are provided at each of three levels of partnership. Both PWSA (USA) and Corporate Partners benefit from the relationship, as each assists the other in achieving its mission.

Custom packages to maximize your benefits - Gold (below), Diamond, and Platinum (shown on next page)

GOLD LEVEL BENEFITS *$10,000 Investment*

Positive Recognition

- Exposure to PWSA (USA) families via a listing on PWSA (USA) website which has 160,000 visitors and over 500,000 page views annually, with a link to your corporate website
- Listing in the "Gathered View" bimonthly newsletter which is circulated to 4,000 readers, providers, and researchers

Valuable Connections

- Coordinate with PWSA (USA)...if appropriate, we can communicate your needs to our database of 8,000 patients and 12,000 parents and caregivers. PWSA (USA) is by far the largest and oldest PWS advocacy group in the world
- Annual in-person meeting with PWSA (USA) leaders
- Potential interaction with parents and caregivers (including for market research and advisory boards)

Strategic Assistance

- Clinical trial recruitment assistance, if needed and appropriate
- Support with FDA dialogues to provide context for the FDA on unmet needs, natural history of PWS, and clinical manifestation for PWS
- Potential introduction to world-class experts and key opinion leaders in PWS who frequently collaborate with PWSA (USA)

PWSAUSA.ORG Questions? contact Steve Queior **squeior@pwsausa.org | 941-487-6730**

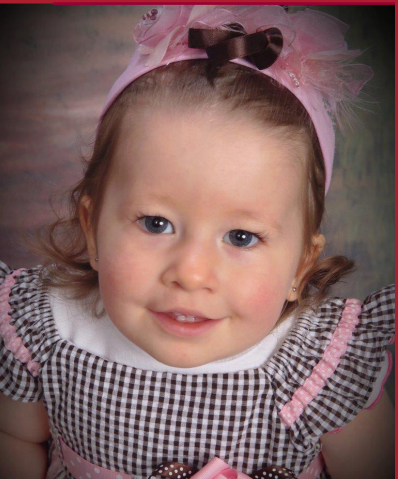
CORPORATE PARTNERSHIP

Prader-Willi
SYNDROME ASSOCIATION (USA)
SAVING AND TRANSFORMING LIVES

The elite **Diamond** ($15,000 investment) and **Platinum** ($20,000 investment) levels include all the Gold level benefits, and more.

ADDED BENEFITS	DIAMOND	PLATINUM
Company name/logo on PWSA (USA) website homepage	●	●
Featured link to company's website from PWSA (USA) website	●	●
Exhibit booth with primary location	●	●
Ad space in our newsletter, the "Gathered View" one calendar year	●	●
Opportunity to interact with key staff and thought leaders (including PWSA (USA) Scientific Advisory Board and Clinical Advisory Board)		●
First right of refusal for biennial convention preferred sponsorship opportunity		●
Top level recognition in PWSA (USA) Annual Report		●
Logo featured in all digital communications for one calendar year		●
$1,000 towards a 2019 PWSA (USA) National Convention sponsorship		●

LEVEL SELECTION & COMMITMENT



Partnership Level

Please select :

☐ **GOLD** ☐ **DIAMOND** ☐ **PLATINUM**

Corporation

Your Name *Title*

Email *Phone*

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