



*Prader-Willi* SYNDROME ASSOCIATION (USA)

**SAVING AND TRANSFORMING LIVES**

# STRATEGIC PLAN

2019 - 2021



**Saving and Transforming Lives, Together**

# Saving and Transforming Lives



[www.pwsausa.org/2019-2021-strategic-plan/](http://www.pwsausa.org/2019-2021-strategic-plan/)

# Table of Contents

- 2 Letters from Leadership
- 4 Guiding Principles & Historical Timeline
- 6 Life with Prader-Willi Syndrome
- 7 Programs & Services: Five Pillars of Support
- 9 Strategic Goals & Key Actions
- 12 By the Numbers & What We Offer



## Dear Member of the PWS Community

An organization finds its strength in the people who support it, the collective voices of its stakeholders a powerful chorus that can effect change in a way no one individual can. PWSA (USA) was founded on this core belief that together we are stronger; that together we can Save and Transform Lives. For over 40 years, the commitment and support of our diverse community has enabled us to fund life-changing research, deliver life-saving resources and support, and spread awareness and education to make the PWS family stronger than ever.

In the years to come, PWSA (USA) will unveil several new programs and initiatives meant to give the voices in our community even greater opportunity to effect change, and to develop and enhance our **Five Pillars of Support: Awareness; Family Support; Research; Education; and, Advocacy.**

From powerful technology that facilitates meaningful advocacy to a new CommUNITY Alliance task force, these resources will go far to remove barriers, reinvigorate our boards and committees, and improve access to the supports our community needs. We are excited about this renewed focus on outreach and engagement and are confident the strategic plan you are about to read will help us achieve our shared goals.

Four decades have passed since PWSA (USA)'s founding, and it remains unique- in terms of the breadth and depth of all that it offers a rare disorder community – in the world. In that time, we've made great progress in raising awareness of and support for the Prader-Willi syndrome community. But, there is still much to do, and we are counting on you to help us do it.

We are thankful for the support you have given us and look forward to many more years of Saving and Transforming Lives, together.

Sincerely,



**Steve Queior**  
Chief Executive Officer

### Board of Directors

**James Kane, Chair**  
**Tammie Penta, Vice Chair**  
**Julie Doherty, Secretary**  
**Denise Westenfield, Treasurer**  
**Crystal Boser**  
**Mitchell Cohen**  
**Dan Driscoll, M.D., Ph.D.**  
**Joan Gardner**  
**Christine Geraci**  
**Pete Girard**  
**Rob Lutz**  
**Kristi Rickenbach**  
**Paige Rivard**  
**Marguerite Rupnow**  
**Mary K. Ziccardi**



PWSA (USA) NATIONAL OFFICE  
8588 Potter Park Drive, Suite 500,  
Sarasota, FL 34238  
(800) 926-4797  
pwsausa.org

# Prader-Willi

## SYNDROME ASSOCIATION (USA)

**SAVING AND TRANSFORMING LIVES**

Over the past four decades, breakthroughs in medical and scientific research have given us better health and greater hope for the future; social media has forever altered the way we make “friends” and interact with one another; and technology has transformed all aspects of our lives. Though much has changed since PWSA (USA) was founded, one thing remains the same: People are our most valuable resource, and it’s through our combined efforts we can continue to Save and Transform Lives.

PWSA (USA) understands that to continue to meet the needs of our stakeholders, we too must change. We will reach out to our community, make a genuine effort to hear what our members have to say, and listen closely to truly understand how we can best serve them. The Prader-Willi syndrome community is comprised of diverse groups of individuals, each with its own specific needs for support and resources. What’s more, each group serves as a powerful voice that, given the proper platform, can effect positive change. PWSA (USA) is committed to engaging with ALL stakeholders to ensure the PWS community is stronger than ever.

Every day brings new and exciting changes throughout the world and within the PWS community. As we move ever onward into the future, know that PWSA (USA) will work harder than ever to create optimal engagement across all stakeholder groups; strengthen the network of relationships across the PWS community; maximize our stakeholders’ experience; and ensure positive impacts for all.

Thank you for your support, and for sharing your voice.

### **Saving and Transforming Lives,**

**Jim Kane**  
Chair



## PWSA (USA) Advisory Boards & Committees

Scientific Advisory Board  
Clinical Advisory Board  
Adults with PWS Advisory Board  
Professional Providers Advisory Board (PPAB)  
Special Education Advisory Board (SEAB)

Advocacy Committee  
Audit Committee  
Cause of Death Team  
Chapter Relations Committee  
Convention Committee  
Executive Committee  
External Collaboration Team  
Family Support Committee  
Finance Committee  
Fund Development Committee  
Leadership Development Committee  
Publications Committee  
Research Committee  
Residential Task Force  
Strategic Planning Committee

# Guiding Principles

## Our Mission

Prader-Willi Syndrome Association (USA) exists to enhance the quality of life and empower those affected by Prader-Willi Syndrome

## Our Vision

A world where those affected by Prader-Willi Syndrome are empowered and enjoy a productive life in a supportive community

## Our Values

- **Diversity, Equity, and Inclusion:** We treat ourselves and others with respect and compassion. We welcome, foster, and value every person's unique contribution, and promise equitable treatment, access, and opportunity for all.
- **Trust:** We understand the importance of responsibility and accountability in relationships, within the organization, with those we serve, with those with whom we partner, and with the public. We think and act with honesty and integrity.
- **Compassion:** We seek first to understand; we support and show compassion for all people through our words and actions. We create an environment of warmth and inclusion, where everyone is welcome.
- **Optimism:** We look at challenges as opportunities to create change. We collaborate with one another to seek and find solutions, confident in our team's ability to achieve our shared goals.
- **Collaboration:** Building on each other's strengths, we work together to define and achieve shared goals. We support one another understanding that together we accomplish greater results.
- **Productive Efficiency:** We work in an efficient, productive manner to maximize our output and best utilize our resources.



## Strategic Focus Areas



# Historical Timeline

- 1956** Clinical Birth Defect identified and named Prader-Willi Syndrome after Swiss doctors Prader and Willi
- 1971** First PWS Clinic established, located at University of Washington in Seattle
- 1975** PWS Parents & Friends renamed the organization to be Prader-Willi Syndrome Association
- 1976** PWSA grows to 140 members
- 1977** PWSA officially incorporates
- 1978** In addition to the fairly recent newsletter publication, "The Gathered View," "A Handbook for Parents" was published and made available
- 1979** The First Annual National Conference was held, in Minnesota
- 1981** A deletion was identified as the first genetic mechanism, now known to be responsible for the development of PWS, by Dr. David Ledbetter, a former member of the PWSA (USA) Scientific Advisory Board
- 1983** Dr. Merlin Butler, Chair of PWSA (USA)'s Scientific Advisory Board, and colleagues, began unraveling the PWS puzzle when they reported that the chromosome 15 deletion in PWS was contributed by the father
- 1985** PWSA (USA) put on the First Scientific Conference
- 1988** First Official Office opened in Minneapolis, Minnesota
- 1989** Maternal uniparental disomy, or UPD (both members of the 15th chromosome pair came from the mother) was discovered by PWSA (USA) Scientific Advisory Board member Dr. Robert Nicholls; Dr. Morris Angulo, PWSA (USA) Clinical Advisory Board member, presents his work on Growth Hormone Deficiency and children with PWS
- 1991** PWSA (USA) Clinical Advisory Board Chair Dr. Dan Driscoll introduces DNA analysis as means to diagnose PWS
- 1997** National Office moved to Sarasota, Florida
- 2000** Growth hormone was approved by the FDA for PWS
- 2002** PWSA (USA) Crisis (Intervention) Program begins
- 2007** PWS becomes appreciated as an important genetic model to understand obesity and appetite regulation
- The "Gathered View" began to be sent out electronically
- 2009** PWSA (USA) organized the first Hyperphagia Conference
- 2013** First Training Session for the Wyatt Special Education Advocacy Program
- 2015** Average age of diagnosis has decreased from early adulthood to infancy
- 2016** The number of families supported by PWSA (USA) exceeds 6,000
- PWSA (USA) expands Family Support and New Diagnosis staff and services
- 2017** The second of two clinical trials on oxytocin funded by PWSA (USA) is approved
- The 75th educational publication or video published in the last decade, the "New Parent Empowerment e-Booklet" is released
- Moving Forward:** With the support of all the generous and committed members of the PWSA (USA) and the entire PWS community, we will accelerate the delivery of new and enhanced programs to **Save and Transform Lives**, across each and all our 5 priorities: Awareness, Family Support, Research, Education, and Advocacy.

# Life with Prader-Willi Syndrome

## Prader-Willi Syndrome: A Rare Genetic Disorder

Prader-Willi Syndrome (PWS) is a complex, non-hereditary genetic disorder characterized by low muscle tone, short stature, incomplete sexual development, cognitive challenges, 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, and is the most commonly identified genetic cause of obesity.



## Every Stage of Life

The impact of PWS on those affected is comprehensive and life-long. Beginning in infancy, individuals with PWS face many complex medical, behavior, and social challenges that will affect their health and well-being. Lack of awareness and understanding can aggravate difficult situations. But, with the proper support, tools, and resources, PWS is manageable, and individuals with PWS can lead full and active lives.

## A Lifetime of Support

From the moment of diagnosis, PWSA (USA)'s Family Support team offers hope and guidance to families as they transition through each stage of their loved one's life. Whether it's reassurance during a medical emergency, advocacy during the school years, or help securing safe and supportive residential care for an adult, the PWS community turns to PWSA (USA) in their times of greatest need.



# Our Five Pillars of Support Programs & Services

PWSA (USA) is a collaboration of families, individuals, researchers, healthcare practitioners, and professionals, working together to strengthen efforts in areas of Awareness, Family Support, Research, Education, and Advocacy. These five pillars serve as the foundation of who we are, what we do, and WHAT we can yet accomplish as we work together to improve the lives of those affected by Prader-Willi syndrome



## PWSA (USA) FIVE PILLARS OF SUPPORT



**AWARENESS**



**FAMILY SUPPORT**



**RESEARCH**



**EDUCATION**



**ADVOCACY**

### Awareness

Awareness is the precursor to action. As such, it is imperative to gain attention for PWS and PWSA (USA) in order to facilitate conversation about our community and our needs. Spreading the message of who we are and what we do is one of our most fundamental tasks.

### Family Support

PWSA (USA)'s targeted programs dealing with behavior modification, nutrition education, crisis intervention, education advocacy, guardianship, and medical intervention are an important lifeline to our families. In 2016, our staff team handled over 2,370 family crisis and medical activities and provided support to the families of 218 newly diagnosed children.

### Research

PWSA (USA) has been supporting research since 1983. Many of the world's most renowned PWS researchers and clinicians are on our scientific and clinical advisory boards; together they dedicate thousands of hours yearly to enhance research, write educational materials, and provide consultation. Nearly all of the major breakthroughs in understanding and treating PWS have come from these pioneers and heroes. PWSA (USA) has funded over \$2,000,000 in research projects and is committed to facilitating further breakthroughs through ongoing research grant opportunities.

### Education

Education is one of PWSA (USA)'s most comprehensive initiatives. "Education" encompasses informing the public; familiarizing medical providers and school professionals with the needs of the PWS community; providing parents and caregivers with information to enable them to meet the needs of their loved one with PWS. Information and resources distributed by PWSA (USA) have been, and continue to be, fundamental to our ability to save and transform lives.

### Advocacy

In order to fulfill our mission, the organization must inform the world of critical public policy issues and leverage the ability of grassroots supporters and state chapters to effect positive change. Because many do not know about PWS and its impacts, extra strategic effort is needed to pass legislation, budgets, and regulations that help our cause, and to – of course – defeat proposed laws, budgets, and rules detrimental to our community.

## 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. With the help of its stakeholders, PWSA (USA) has brought hope, health, and enhanced quality of life to thousands of individuals and families. PWSA (USA) channels its supporters' passion and dedication into substantive, meaningful measures that really do *Save and Transform Lives*.



# Strategic Goals & Key Actions

## Relevant & Impactful Programs and Services

Helping individuals, families, and the entire Prader-Willi syndrome community is absolutely the paramount objective for Prader-Willi Syndrome Association (USA). Our organization exists to empower those affected by PWS and improve their quality of life.



### **Goal 1** Develop, deliver, and evolve excellent programs and services to be responsive to stakeholder needs

#### **Key Organizational Actions:**

|     |  |
|-----|--|
| 1.1 | Deliver excellence across all “Five Pillar of Support” programs and services: Awareness, Family Support, Research, Education, Advocacy                         |
| 1.2 | Identify and implement the most efficient and effective program and service delivery models for key PWSA (USA) activities                                      |
| 1.3 | Strengthen engagement and communication with PWS community stakeholders to assess program impact and identify the relevancy of available programs and services |
| 1.4 | Assess the continued relevancy of each program by measuring and evaluating its impact as appropriate (e.g. annually or biennially)                             |



To continue to deliver a lifetime of quality support to members of the PWS community, we must offer services to individuals of all ages. Expanding knowledge about PWS with the public and with professional providers helps us increase our positive momentum. And strengthening the voice of our community is also a necessary step to fulfilling our mission.

### **Goal 2** Effectively support those affected by PWS and those who serve those affected by PWS

#### **Key Organizational Actions:**

|     |  |
|-----|--|
| 2.1 | Review and adjust/enhance Family Support services across the age spectrum – from programs for those with newly diagnosed children to families and caregivers of older adults             |
| 2.2 | Using feedback from PWS community stakeholders, create/refine the resources, tools, and capacity to meet Family Support and Advocacy needs in the PWS community                          |
| 2.3 | Establish an organization-wide capacity to create positive impacts through advocacy by effectively implementing a coordinated set of legislative and regulatory public policy strategies |
| 2.4 | Build public awareness of and support for the PWS community and for the programs and services of PWSA (USA)  |

## Effective Engagement, Management & Leadership

It all starts and ends with committed people doing great work. Engagement that is meaningful and that creates positive impacts is central to the vision of PWSA (USA) – be that involvement of family members, volunteers, staff, and/or partners and allies working on our team Saving and Transforming Lives.



### **Goal 3** Deliver the PWSA (USA) mission through exceptional governance and organizational excellence

#### **Key Organizational Actions:**

|     |  |
|-----|--|
| 3.1 | Deliver outstanding service and results by attracting, retaining, and optimizing an engaged and diverse group of employees and volunteers  |
| 3.2 | Adopt intentional and promising practices and structure that guide the development of an exceptional team while ensuring accountability to the PWS community and supporters  |
| 3.3 | Translate strategic priorities into bold action plans that identify specific ways the board, chapters, advisory boards or councils, committees, staff, members and partners can contribute to the organization's success |
| 3.4 | Develop and implement accountability standards and corrective measures to ensure program alignment with PWSA (USA)'s mission.  |



# Sustained Financial Stability

A plan without funding is just a dream. To deliver the Five Pillars of Support and attain the mission to enhance the quality of life of those affected by PWS, supporters need to be engaged in our work and see our impact. Stewardship of all resources entrusted to the cause is critical.



## Goal 4 Implement sustainable financial practices that ensure PWSA (USA) can meet the needs of the PWS community

### Key Organizational Actions:

|     |  |
|-----|--|
| 4.1 | Refine the business model to invest in effective strategic initiatives and impactful programs that ensure sustained financial stability                      |
| 4.2 | Develop an integrated fund development plan that establishes financial goals for each income stream and the corresponding strategies to accomplish the goals |
| 4.3 | Develop the internal capacity to achieve the goals set forth in the fund development plan  |
| 4.4 | Create a culture of philanthropy and engagement throughout PWSA (USA) and the PWS community  |



# By the Numbers

 **5,625**  
Generous  
Donations

 **2,370**  
Families Helped



 **815**  
Attended  
National  
Convention

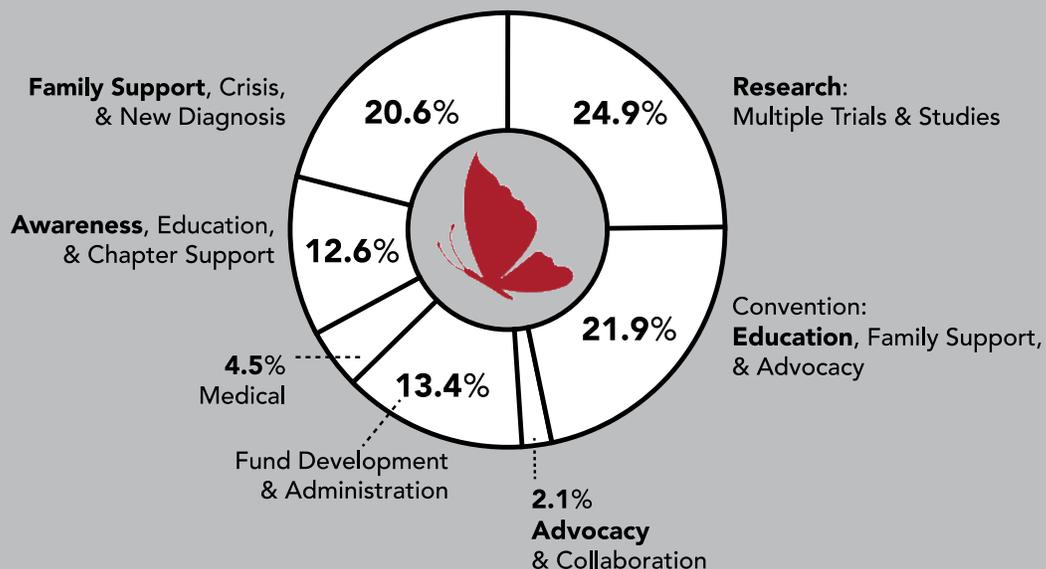
 **218** Newly  
Diagnosed Families  
Supported

 **9,260**  
Free Materials  
Provided to Families

The total of the investments represented on the chart below is \$2,251,076, and the percentage allocations are based on the annual Prader-Willi Syndrome Association (USA) audit done by an outside CPA firm. PWSA (USA) board members and staff work very hard to make sure that the great majority of the organization's resources are used to help individuals, families, and the cause.

## More than 6 of Every 7 Dollars Go to Programs & Services

### PWSA (USA) FUNDS



# What PWSA (USA) Offers

## A Sampling...



## Family Support

### 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

- Counseling with trained staff with advanced degrees
- Support for medical, behavioral, legal, school and placement crises
- Information and referral services

### Advocacy

- Special education advocacy on behalf of students with PWS including information about IEPs, PWS-specific school strategies, and a resource flash drive for educators.
- Advocacy to help people and families living with PWS get needed benefits and services including SSI and essential therapies.
- Support through the 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](http://www.pwsausa.org/links/chapter.htm)
- A State Leader's Team coordinates with the national office to deliver support services.

## Medical and Research

- 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 the biennial national PWSA (USA) convention
- Publishing of Medical Alert booklets and medical handouts that are PWS-expert physician authored, with a free smartphone version
- Research grants awarded annually

## Publications and Website

- Extensive website information with downloadable publications and targeted webinars
- Bi-monthly educational newsletter for all members, including the latest in medical information, research and treatment
- Educational, supportive, and medical publications including DVDs available
- Moderated PWSA (USA) e-mail support groups

## Awareness/PR/Development

- Booths/Presentations at medical conferences nationally and internationally
- Biennial national PWSA (USA) Convention for families and professionals
- Support for fundraising and chapter efforts
- Annual national PWS Awareness Month
- Support individual awareness efforts
- Awareness merchandise



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

Save the Date



Unmask the  
Possibilities

PWSA (USA) 2019  
NATIONAL CONVENTION  
AWARENESS FAMILY SUPPORT RESEARCH EDUCATION ADVOCACY

October 23-26 | Orlando, FL

PWSA (USA) NATIONAL OFFICE  
8588 Potter Park Drive, Suite 500, Sarasota, FL 34238

 (800) 926-4797  [pwsausa.org](http://pwsausa.org)

