Prader-Willi SYNDROME ASSOCIATION (USA)

SAVING AND TRANSFORMING LIVES

PEOPLE WITH PASSION AND PURPOSE

2017 Progress Report

www.pwsausa.org

VISION:

Prader-Willi Syndrome Association (USA) is a self-sustaining, internationally recognized leader, empowering those affected with Prader-Willi syndrome to enjoy a productive life in an informed and accepting community.

OUR MISSION:

Prader-Willi Syndrome Association (USA) is an organization of families and professionals working together to raise awareness, offer support, provide education and advocacy, and promote and fund research to enhance the quality of life of those affected by Prader-Willi syndrome.

Contents

Saving and Transforming Lives Together

Dear Prader-Willi Syndrome Association (USA) Supporter:

Identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart, Prader-Willi syndrome is a genetic birth defect that adversely affects appetite, growth, metabolism, cognitive functioning, and behavior. Individuals with PWS face life-long challenges that impact all areas of their lives, including at home and at school. Please see examples of how we worked to help alleviate these challenges on the following pages.

Prader-Willi Syndrome Association (USA) was formed in 1975 to unite parents, professionals, and other interested citizens who share a common purpose: To enhance the quality of life of those affected by Prader-Willi syndrome.

Channeling the strength, commitment, and hope of thousands of dedicated individuals, PWSA (USA) is an organization that empowers the PWS community through shared experiences, research, education, advocacy, and support. With chapters in most states, PWSA (USA) is the only national PWS support organization whose sole purpose is to assist individuals with PWS and their families every step of the way.

Our network of caregivers, medical providers, educational professionals, support staff, and families have worked together for over 40 years to support PWS families by providing information, resources, and support for school, medical, and behavioral management. PWSA (USA) is an important lifeline for individuals and families across the country; without our services, many in the PWS community would have nowhere else to turn. Thank you for your support. **Together we are Saving and Transforming Lives**.

Sincerely,

Michelle Torbert
Chairperson of the Board

> “Individual commitment to a group effort - that is what makes a team work, a company work, a society work, a civilization work.”
>
> **Vince Lombardi**

People with Passion and Purpose

United by passion and purpose, PWSA (USA), fellow Prader-Willi syndrome and rare genetic disease-focused researchers and organizations, volunteers, donors, and families are working together to facilitate research, spread awareness, advocate, and share knowledge for, with, and about the PWS community. It is this transformative power of collaboration that inspires our efforts and motivates us to keep pushing forward as each day brings forth new opportunities to save and transform the lives of those affected by PWS.

Since 1975, PWSA (USA) has created and expanded programs for

Parents of newly-diagnosed children

Deployed life-changing family support programs

Funded cutting-edge research

Provided training and information to school professionals, residential providers, and healthcare providers across the country

With support from the PWS community, our donors, and our volunteers, PWSA (USA) has brought hope, health, and enhanced quality of life to thousands of individuals and families, helping them thrive in the face of a rare genetic condition. **People with passion and purpose working together to Save and Transform Lives…we are PWSA (USA)**.

Sincerely,

Steve Queior
Chief Executive Officer

PWSA (USA):
Founded on the Five Pillars of Support

PWSA (USA) is a collaboration of families, individuals, researchers, healthcare practitioners, and professionals, working together to increase awareness, provide family support, facilitate research, promote education, and advocate for the PWS community.

These five pillars serve as the foundation of who we are, what we do, and what we can accomplish working together to enhance the lives of those affected by Prader-Willi syndrome.

PWSA (USA) FIVE PILLARS OF SUPPORT

Awareness

Awareness is the precursor to action. As such, it is imperative to gain attention for Prader-Willi syndrome and to facilitate conversations about the needs of the PWS community. Educating the public about Prader-Willi syndrome and the unique challenges faced by those affected by it, and spreading the message of what PWSA (USA) does to help individuals and families meet those challenges, are two of our most fundamental tasks.

We elevate awareness and educate through traditional media outlets, social media, group presentations, and personal interactions. Partnering with other organizations to make the most of national and global opportunities to raise awareness, such as "Rare Disease Day" is also paramount to our success.

Raising Awareness: Outreach Through Events

PWSA (USA) hosts or co-hosts several annual and biennial events to raise funds and awareness for the Prader-Willi syndrome community. Coordinated by individuals and PWSA's state chapters, events such as On the Move walks and runs provide fun and engaging opportunities to introduce others to the needs of the PWS community. The biennial PWSA (USA) National Convention is another popular event that brings medical and residential professionals, researchers and scientists, families, and individuals together to share information and support. National and local awareness and fundraising events include:

- Create Your Own FUNraisers
- On the Move run/walks
- Major fundraising events, such as the annual Clint Hurdle "Hot Stove Dinner"
- Biennial PWSA (USA) National Convention

Raising Awareness: Outreach Through Publications

Communication of professional advice, industry best practices, and more is available through PWSA (USA)'s robust catalog of publications.

Accessible online and in print, PWSA (USA) produces dozens of brochures, white papers, articles, and a bi-monthly information-packed newsletter to keep families, caregivers, and school, medical, and residential professionals up-to-date on the latest PWS information.

PWSA (USA)'s website and mobile app are other "go to" sources of PWS information available for families and professionals. In addition to blogs and articles, visitors to the site or app can find resources such as the Wyatt Special Education Advocacy Training modules and PWSA state chapter contact information.

Raising Awareness: Outreach Through Local Relationships

With 33 state chapters throughout the country, individuals and families seeking local help and support can connect with a caring group of individuals who understand the complex needs of those affected by PWS. Whether they need assistance with new diagnosis, a school crisis, or a medical referral, help is never more than a phone call away.

Family Support

The PWSA (USA) Family Support & Crisis Intervention Team includes family support counselors, a medical coordinator, new parent support coordinators, and a special education specialist. These dedicated professionals coordinate programs to help families with behavior modification, nutrition education, crisis intervention, education, advocacy, guardianship, and medical intervention. In 2017 alone, the PWSA (USA) Family Support team handled over 2,370 family crisis and medical consultations and provided staff and material support to the families of 218 newly-diagnosed children.

Family Support: Special Education Advocacy

PWSA (USA) is committed to helping individuals with PWS have a positive and successful school experience. Skilled Family Support team members are available to attend education planning meetings (either in person or by phone) and to provide information and training to school professionals working with children with PWS. PWSA (USA) also makes available the Wyatt Special Education Advocacy Training (WSEAT), a web-based course designed to equip parents and guardians with the information, skills and tools they need to be more effective special education advocates for their children. Finally, the Family Support Team produces *School Times*, an electronic newsletter that focuses on timely and helpful school-related topics available to families and school professionals.

Family Support: Managing the Day-to-Day

Families affected by Prader-Willi syndrome face many unique challenges, and without adequate support can quickly find themselves in crisis. Family Support team members help parents and guardians answer questions like:

- How can appropriate behavior and weight management be encouraged and supported?
- How can siblings be helped to understand and support their brother or sister with PWS?
- How can a couple cope with the stress of raising a child who has special needs?
- How do caregivers take care of themselves while caring for a child with PWS?

In addition to the many online resources available on the PWSA (USA) website, help can be found over the phone, via email, through Facebook support groups, or in-person.

Family Support: Adults with PWS

Adults with PWS require specialized care that many residential providers are not equipped to provide. Family Support team members offer professional provider training and education to ensure individuals with PWS receive the services and attention they need. In addition to spreading awareness and education through training, the Family Support team also produces *Residential Times*, an electronic newsletter focused on adults living with PWS, their families, and the professional caregivers who support them. Topics covered in the newsletter include:

- Do's and don'ts for improving the parent-provider relationship
- Information on the Achieving a Better Life Experience Act (ABLE)
- Advocacy network updates

Family Support: Funds Invested in Services

Average Invested by PWSA (USA) in Family Support Case
$373 per PWS Family

Average Invested by PWSA (USA) in New Diagnosis Case
$665 per PWS Family

- Amount of budget allocated to Family Support services — $948,400
  Components including Crisis & Family Support, Medical Intervention & Support, New Diagnosis Support, Education, Family Advocacy, and more.

- Number of Family Support activities in 12 month period — 2,371

  1. New Diagnosis Support Component — 210 Service Activities

     New Diagnosis Funding — $139,650

     Average Invested in New Diagnosis Case — $665

  2. All Other Family Services — 2,161 Service Activities

     All Other Family Support Funding — $808,750
     Average Invested in Family Support Case — $373

     NOTE: Overall average cost of family support activity is $400.

- Translating Donation Amounts into the Good Work They Can Fund:
  - A $10,000 donation can put 15 families with a newly-diagnosed child on to a path Saving and Transforming Lives of the children and their entire families.
  - Monthly giving of $100 will fund the annual Family Support services for 3 families.
  - $40,000 raised in the Family Support Campaign can make all the difference in the health, safety, and quality of life for 100 families this year and beyond.

- Additional PWSA (USA) Funds Invested in Research:
  NOTE: The average amount invested in research in 2016 and 2017 was over $454,000 annually.

  This amount is separate from, and additional to, the $948,400 above.

Research

Since 1983, PWSA (USA) has been at the forefront of Prader-Willi syndrome scientific study. Many of the world's most renowned PWS researchers and clinicians are on PWSA (USA)'s Scientific and Clinical Advisory boards, and the organization has invested more than $2 million to facilitate life-changing research over the past ten years. The synergy between PWSA (USA)'s advisory boards and research committee is magnified by ongoing collaboration with other PWS and rare disease researchers and organizations, and daily interaction with parents, caregivers, and individuals with PWS. Through PWSA (USA), the powerful combination of experience and information come together to inspire change and enhance the quality of life of individuals with PWS and their families.

Research: Uniting Science and Experience

The 2017 PWSA (USA) National Convention featured a special session for individuals interested in learning more about the organization's research program. A special focus was made on familiarizing parents with PWS research with presenters sharing basic information about PWS research and encouraging questions from the audience.

Research: 2017 and Beyond

While all Prader-Willi syndrome research is important, PWSA (USA) is particularly interested in facilitating research that can more immediately enhance quality of life of individuals affected by PWS. The desire to find more and better treatment options to manage and diminish challenges inherent to Prader-Willi syndrome will guide PWSA (USA)'s research initiatives now and into the future. PWSA (USA)'s research committee and advisory boards aim to:

- Devote more resources to support development of new therapeutic interventions
- Increase efforts to collaborate with external research partners, such as pharmaceutical companies and the Foundation for Prader-Willi Research
- Evaluate the current grant-making process to ensure a treatment-based research focus
- Encourage innovative research models
- Create new opportunities for researchers and scientists to promote collaboration and information sharing

Research: Recent PWSA (USA) Investment in Innovation

RDCRN	**$25,000**
PWS Consortium – 4 Separate Institutes	**85,000**
University of Florida	
University of Southern Florida	
KUMC – Butler	
Regents of California	
"Oxytocin Study" DMCC	
Oxytocin Stage Two	**324,178**
Miller, Dr. Jennifer, M.D.	
University of Florida	
Hormone Secretion Deficits in PWS	**240,000**
Nicholls, Dr. Robert, Ph.D.	
Children's Hospital of Pittsburgh Foundation	
The Effect of Growth Hormone Substitution on Sleep Disordered	**78,034**
Breathing in Young Children with PWS	
Choong, Dr. Catherine, M.D.	
University of Western Australia	
Profiling of the Gut Microbiomes in Children with PWS	**32,190**
Haqq, Dr. Andrea, M.D.	
University of Alberta	
Male Caregiver Study	**5,000**
Caldwell, Leon, Ph.D.	
Stipend/Support Research Students Interested in PWS	**6,000**
Kimball, Ted (Under Direction of Dr. Merlin G. Butler, M.D., Ph.D.)	
Prevalence of Dysphagia/Reflux Contributing Factor	**33,955**
Yeung, Dr. Karla Au, M.D.	
Johns Hopkins to Valley Children's, Fresno, CA NOW	
Telehealth Intervention of Early Social Cognitive Process	**59,931**
Dimitropoulos, Anastasia, Ph.D.	
Case Western Reserve University	
International Clinical Trials Consortium	**20,000**
TOTAL 2016-2017 GRANT ACTIVITY	**$909,288**

Education

Education is one of PWSA (USA)'s most comprehensive initiatives and includes informing the public as to what Prader-Willi syndrome is and the effect it has in people's lives; familiarizing medical providers and school professionals with the needs of the PWS community; providing parents and caregivers with information to help them care for their child with PWS; and alerting legislators to the challenges faced by those affected by PWS. The white papers, brochures, presentations, videos, webinars, and online resources distributed by PWSA (USA) are life-changing, and often life-saving, sources of information for individuals and families affected by Prader-Willi syndrome.

Education: Ensuring Equal Access to All

Launched in February 2017, the online version of the Wyatt Special Education Advocacy Training series (WSEAT) is a free resource for parents and school professionals. Named in memory of David Wyatt, PWSA (USA)'s first Crisis Intervention and Family Support Counselor, the WSEAT:

- Includes 7 modules covering a range of special advocacy topics, including how to address PWS specific school challenges
- Allows viewers to watch one or all modules, focusing on the information most pertinent to them
- Includes downloadable resources for each module
- Includes free copies of From Emotions to Advocacy: The Special Education Survival Guide
- Provides recommended resources for additional learning

Education: Information on the Go

Smart phone users can now carry important information and resources with them wherever they go by downloading the free PWSA (USA) app to their smart phone. Through the app, users can:

- Share important medical information with medical professionals
- Watch school videos with a child's IEP Team
- Stay up-to-date on the latest PWS research news
- Provide ER staff with key medical alerts during emergencies
- Conveniently explore family support and other available resources

Education: National Convention with Multiple Conferences

The biennial PWSA (USA) National Convention is where researchers, medical professionals, educators, professional providers, and families come together with the common goal of improving the lives of individuals diagnosed with Prader-Willi syndrome. Programs are tailored to the needs and interests of professionals, families, and individuals with PWS, and planned social activities allow for networking and relationship building. Convention offerings include:

- General Conference
- Medical & Scientific Conference
- Professional Providers Conference
- Young Infant Program (YIP):
  0 – 1 years old and 2 – 6 years old
- Youth & Adult Program (YAP):
  7 years and up
- Sibling Program
- New Parent Mentors
- Chapter Leaders

Advocacy

Effective advocacy is essential to ensuring health, safety, and enhanced quality of life for those affected by Prader-Willi syndrome. As such, PWSA (USA) is committed to informing the PWS community of critical public policy issues and leveraging the power of grassroots supporters to effect change. Because Prader-Willi syndrome is considered a "rare disease," extra effort is needed to raise awareness amongst the public and elected officials to guarantee the passage of legislation and regulations that help our community, and to defeat those that do not. PWSA (USA) also promotes individual-focused advocacy, providing training and assistance to parents and caregivers that empower them to advocate for their child or loved one with PWS.

Why It Matters

While the PWS community might not have the resources of groups with greater numbers, change is still possible. More and better education, effective communication, and strategic alliances with partners in the PWS and rare disease communities can help ensure:

- The "pre-existing condition" insurance status is maintained, and that health care remains affordable
- Individuals with PWS have access to appropriate residential and day programs to learn job skills
- Education and training is available for those affected by PWS
- Communities and schools are aware of and are equipped to work with individuals with PWS and their families
- New medicines and treatments are readily available

Financials

PRADER-WILLI SYNDROME ASSOCIATION (USA)
STATEMENT OF ACTIVITIES
For The Year Ended December 31, 2016

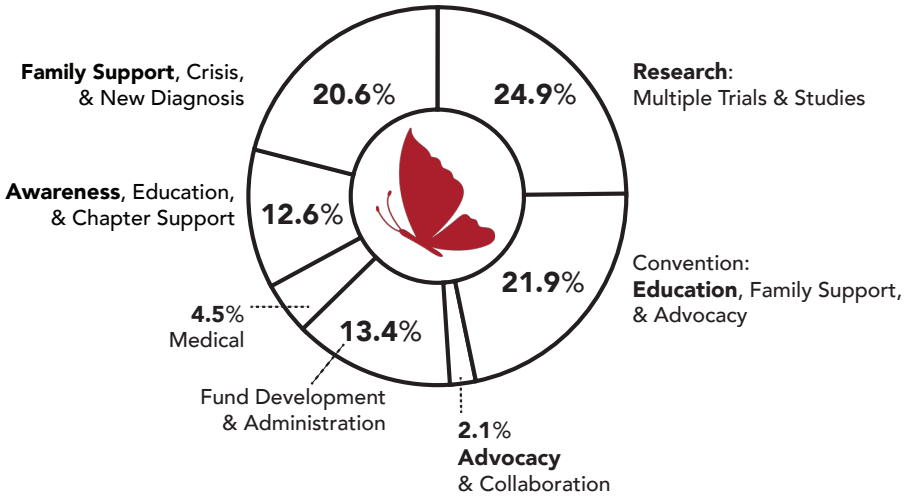
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
SUPPORT AND REVENUES				
Support				
Contributions	$ 945,065	$ 594,069	$ 26,050	$ 1,565,184
Fundraising contributions	386,356	--	--	386,356
Conference income	1,692	30,000		31,692
Donated services	710,406	--	--	710,406
Revenues				
Educational material sales	18,496	--	--	18,496
Membership dues	55,875	--	--	55,875
Investment income/(loss)	77,795	--	--	77,795
Net assets released from restrictions				
Satisfaction of program restrictions	356,071	(356,071)	--	--
TOTAL SUPPORT AND REVENUES	2,551,756	267,998	26,050	2,845,804
EXPENSES				
Program Services				
Crisis intervention and support	355,715	--	--	355,715
Education	36,139	--	--	36,139
Medical intervention and support	385,958	--	--	385,958
New diagnosis support	79,206	--	--	79,206
Chapter, affiliated and local support	52,265	--	--	52,265
National conference	106,211	--	--	106,211
Advocacy, awareness, external collaborative relationships	188,720	--	--	188,720
Research	577,129	--	--	577,129
Total program services	1,761,343	--	--	1,761,343
Supporting services				
Administration	332,035	--	--	332,035
Fund development	128,821	--	--	128,821
Total supporting services	460,856	--	--	460,856
TOTAL EXPENSES	2,222,199	--	--	2,222,199
CHANGE IN NET ASSETS	329,557	267,998	26,050	623,605
NET ASSETS AT BEGINNING OF YEAR	535,395	1,070,297	133,884	1,739,576
NET ASSETS AT END OF YEAR	$ 864,952	$ 1,338,295	$ 159,934	$ 2,363,181

Audit performed by Lawrence A. Kraujalis, CPA, P.A.

SAVING AND TRANSFORMING LIVES

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

2017 PWSA (USA) FUNDS



The total of the investments represented on the chart 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 your organization's resource are used to help individuals, families, and our cause.

Who We Are:
People with Passion and Purpose

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Devon Young, Development & Communications Specialist
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Who We Are:
People with Passion and Purpose Continued...

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Merlin Butler, M.D., Ph.D., *Kansas University Medical Center, Kansas City, KS*
Kathy Clark, R.N, M.S.N., CS-BC, *Coordinator of Medical Affairs, PWSA (USA)*
Janalee Heinemann, M.S.W.

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EXTERNAL COLLABORATION TEAM:

Rob Lutz (Team Leader), Leon Caldwell, Rob Seely, Joan Gardner

Special Thank You to PWSA (USA) Leader, Janalee Heinemann

Janalee Heinemann is a name that has been synonymous with Prader-Willi Syndrome Association (USA) for almost four remarkable decades. From her start founding the Missouri Chapter in 1980 to her 10-year stint as Executive Director, she has grown this organization from a 2-person office, to an established national organization providing multiple types of support for those affected by PWS. We would like to take this opportunity to extend our sincere gratitude to Janalee for her 37-years of unparalleled leadership, dedication, service, and commitment.

Our CommUNITY Needs YOU

PWSA (USA) is serving more individuals and families than ever before. Because we do not charge for the services we provide, nor do we receive any government funding, we're counting on you to help us Save and Transform Lives.

Regardless of size, your gift is important and will make a real and meaningful difference in the lives of those affected by Prader-Willi syndrome.

Text PWSAUSA to 444-999 to donate, donate online at www.PWSAUSA.org, or mail your donation to the address below.

Thank you for your support!

Prader-Willi Syndrome Association (USA)
8588 Potter Park Drive, Suite 500
Sarasota, FL 34238

PROGRESS REPORT 2017

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