ANNUAL REPORT
2015

It Starts with Us!

FOUNDATION FOR
PRADER-WILLI
RESEARCH
Working Toward an Independent Future

THE FOUNDATION FOR PRADER-WILLI RESEARCH
2015: THE YEAR IN NUMBERS

7,300 DONORS

provided financial support for FPWR, in the U.S. alone, helping us to advance Prader-Willi research

FPWR awarded

$2 MILLION

to accelerate high-impact PWS research

FPWR supported scientific collaboration through

3 SCIENTIFIC WORKSHOPS & MEETINGS

attended by top PWS researchers and experts in their fields

Through our world-class grants program,

20 PWS PROJECTS & INITIATIVES

were supported in 6 countries around the world

Findings from FPWR funded studies were published in

22 SCIENTIFIC PUBLICATIONS

OVER 7,000 PEOPLE

across the globe took One SMALL Step to support Prader-Willi research

One SMALL Step
for Prader-Willi Syndrome

FPWR Research Program: It Starts with Us!

As the largest private source of PWS research funding in the world, FPWR continues to energize the field of Prader-Willi research with the support of our dedicated families and donors.

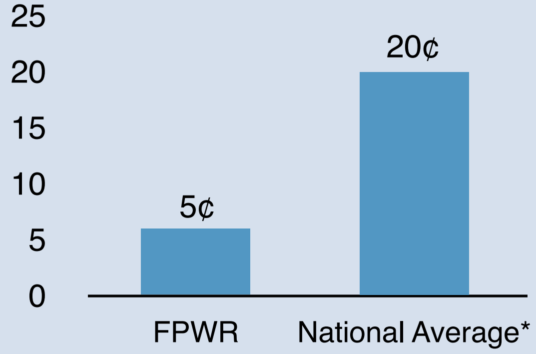
This past year, FPWR was able to support 20 research projects totaling $1,986,000 in financial support, as well as launch the Global PWS Registry, host the first PWS Mental Health Workshop, the first FPWR Scientific Day, and initiate the PWS Clinical Trials Consortium. 2015 also proved to be a year of growth as we expanded our research team to include Nathalie Kayadjanian, our Director of Translational Research, who will develop and drive our translational research program.

FPWR continues to be the driving force in PWS research because of YOU. On behalf of our staff, the board of directors and our children living with PWS, we thank you for your incredible commitment to our programs.

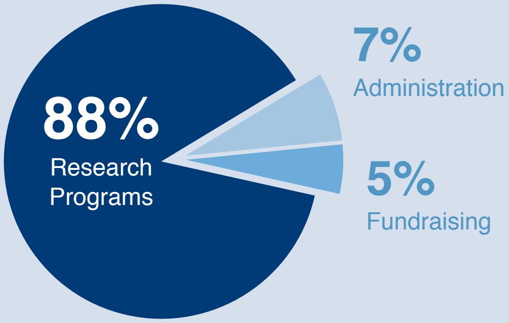
Maximizing Your Investment

FPWR maximizes donor contributions. In 2015, 88% of every donation was used to directly fund research programs. In partnership with the NIH, academic institutions and pharmaceutical companies, FPWR ensures that your dollars are used to effectively accelerate research and advance potential therapies to treat the many challenges of PWS.

How Much Does it Cost To Raise $1.00?



FPWR Functional Expenses



* Association of Fundraising Professionals

The FPWR Translational Research Program: Accelerating Therapeutic Development

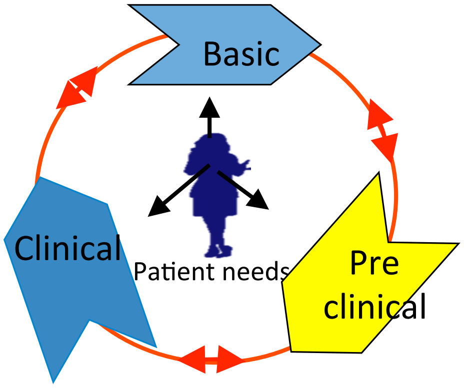
In 2015, we welcomed Nathalie Kayadjanian, Ph.D., to the FPWR Team as the FPWR Director of Translational Research. Dr. Kayadjanian is an expert in translational biomedical research. A neuroscientist by training, she has extensive R&D experience in academia, biotech, and the pharmaceutical industry in Europe and the USA. Nathalie has occupied top management positions in patient-driven non-profit organizations, developing and implementing strategies to accelerate the development of innovative therapies for rare diseases.

Translational Research aims to "translate" findings in fundamental research into meaningful health outcomes, such as medical treatments.

The FPWR Translational Research Program aims to accelerate the development of meaningful therapies for patients with PWS. The number of drug approvals for rare diseases has significantly increased in the last decade. However, the therapeutic development process is long, expensive and inefficient, with a high attrition rate. The primary reason for poor success rates for drugs is the lack of efficacy and safety. We are developing strategies to reduce the drug development time, mitigate the risk of drug development and improve the overall success rate of drugs in clinical trials. By increasing the drug portfolio for PWS and establishing stringent criteria early in the R&D process, we expect to improve the efficiency of drug development for PWS.

> “Reducing failures early in development is far more important than filling a pipeline with poorly chosen late-state products likely to fail, and fail expensively.”
>
> - David Szymkowski, Xencor

Translational Research



Empowering the PWS patient community to drive the R&D agenda, streamline the R&D process and ensure delivery of meaningful therapeutics to the patients

The International Consortium to Advance Clinical Trials for Prader-Willi Syndrome

The PWS Clinical Trials Consortium was created to accelerate clinical trials for PWS by leveraging the expertise and perspective of stakeholders from the pharmaceutical industry, academia, governmental agencies and patient organizations at the national and international level to address unmet scientific, technical, clinical and regulatory needs for clinical trials for PWS.

The Clinical Trials Consortium will:

- Complete a risk-benefit assessment that will help regulators better understand the impact of PWS on patients and caregivers and allow them to better respond to the unmet needs of PWS.
- Establish and validate international guidelines of the nutritional phases of PWS.
- Develop biochemical biomarkers to assess the pre-hyperphagia and hyperphagia stages. These markers will be useful to understand the biological signatures of hyperphagia and develop endpoints so that drug efficacy may be measured.
- Develop and validate new questionnaires and tools to measure and capture the range of behaviors associated with PWS to measure efficacy of treatment against hyperphagia in a clinical trial setting.

The PWS Clinical Trials Consortium has been joined by stakeholders from around the world.

Industry Partners
Alize Pharma
Essentialis
Rhythm Therapeutics
Zafgen

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Encouraging Scientific Collaboration: FPWR Hosts 3 Scientific Meetings in 2015

FPWR supported 3 scientific meetings in 2015 to foster the important interaction of researchers, clinicians and families. We understand the power of bringing together a group of passionate people and the amazing work that comes out of these meetings.

FPWR Scientific Day

In conjunction with our annual research conference, FPWR hosted its first Scientific Day in 2015, bringing together more than 40 scientific experts to share recent advances in PWS research and spark new ideas and collaboration across the research spectrum. Participants included researchers, clinicians, providers, and representatives from pharmaceutical companies.

The day highlighted the broad array of promising studies ongoing in the PWS field, and there was plenty of animated dialogue, sharing of ideas and brainstorming of new ways to understand and treat PWS.

PWS Mental Health Workshop

Mental illness remains a difficult problem for our loved ones. In 2015, FPWR hosted the PWS Mental Health Workshop, bringing together an extraordinary group of mental health experts from around the world with the goal of developing a research strategy to advance the science of mental health in PWS. Workshop participants sought to identify and prioritize key research questions, as well as highlight current opportunities and needs.

The workshop sparked new collaborations, and several outstanding research projects investigating different aspects of mental health in PWS have been funded as a result. Recommendations from the Workshop will guide FPWR in developing future mental health research initiatives and funding priorities.

This workshop was funded by FPWR, FPWR-Canada and PWSA-Colorado.

International Consortium to Advance Clinical Trials for PWS

In 2015, FPWR brought together industry partners and experts in the field of PWS research to form the **International Consortium to Advance Clinical Trials for Prader-Willi Syndrome.**

The Consortium brings together experts from industry, academia, patient organizations and governmental agencies to leverage expertise, capabilities and resources in order to address unmet scientific, technical, clinical and regulatory needs for clinical trials for PWS and ultimately, find a meaningful treatment for PWS.

We Have Take-Off! Announcing the Launch of the Global Prader-Willi Syndrome Registry

2015 saw the launch of the Global PWS Registry. More than 750 PWS participants enrolled in the first 6 months! With a comprehensive series of questions detailing the clinical and social aspects of PWS, the registry will be used to accelerate clinical trials in PWS, initiate new research projects, and allow us to learn more about the challenges our children face.

THE GLOBAL PRADER-WILLI REGISTRY WILL:

- Generate new insights into PWS
- Drive unmet research and treatments
- Expedite the completion of clinical trials
- Guide standards of care
- Improve the lives of those affected by PWS

3 REASONS YOU SHOULD ENROLL IN THE REGISTRY

1 When you indicate in your contact preferences that you would like to learn more about clinical studies, you will be notified when you meet eligibility criteria for a study!

2 As you complete each survey, you are immediately given access to visualize the survey responses. This allows you to compare your responses with the greater PWS community.

3 Keep all of your medical records in one place. The Registry provides a central repository to store all of your records over time so you know where to find them when you need them!

Do you need help getting started with the PWS Registry?

Watch our getting started video http://bit.do/pwsregistryvideo

Or Email info@pwsregistry.org

Enroll today at www.pwsregistry.org

pwsregistry.org

GLOBAL
PRADER-WILLI SYNDROME
REGISTRY

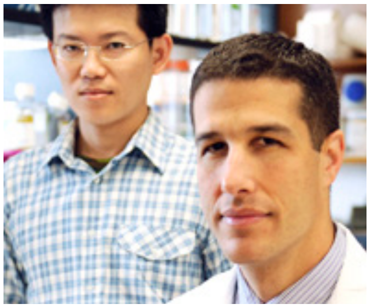
The FPWR Grants Program: Stimulating PWS Research Around the World

The Foundation for Prader-Willi Research is dedicated to fostering and supporting research that will advance the understanding and treatment of PWS. We seek to stimulate research that will improve the lives of individuals with PWS in the near term; we are particularly supportive of research to develop and evaluate new therapeutic approaches for PWS as well as innovative research that will lead to significant advances in the understanding of this disorder.

By funding innovative studies, supporting established and respected PWS researchers, and bringing new and promising researchers into the field, we are working to advance new avenues of research, generate needed research resources, develop novel therapies, and positively impact the lives of all individuals with PWS.

The Foundation for Prader-Willi Research has a professionally managed grant process that selects projects based on the collaborative input of both scientists and parent advocates. FPWR chooses projects that are both scientifically sound and highly relevant for individuals with Prader-Willi syndrome and their families.

Several FPWR-funded scientists, including Drs. Zigman, Jiang, and Chedin, have gone on to receive much larger grants from governmental funding from institutions like the NIH for projects initiated with FPWR funds. The additional funds brought into the field of PWS total well over $6,000,000.



Thank You Advocate Reviewers!

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Ali Shenk
Brandon Shelton
Rhea Utley
Karen and Matt Vogt
Amy Wasser

FPWR FUNDED

20

RESEARCH GRANTS
in 2015

2015 Funded Projects

FPWR proudly funded 20 research projects in 2015, reaching nearly $2,000,000 in funds. These studies covered a broad range of research questions as diverse as the many aspects of PWS, from basic molecular and genetic studies to clinical interventions.

ComuFaces: The perception of communicative faces by infants with PWS. Pascal Barone, PhD., University of Toulouse ($108,000). Infants with PWS seem to pay less attention to external stimulation and have delayed social, emotional and linguistic skills. Dr. Barone's group will explore how infants with PWS perceive communicative faces, a critical component of language, social, and cognitive development. This study will be a building block in the development of new therapeutic approaches for the treatment of socio-cognitive symptoms associated with PWS.

RNA Targets of SNORD116. Tomaz Bratkovic PhD., University of Ljubjana, Slovenia ($41,256). Loss of the SNORD116 genes on chromosome 15 appears to be critical for the development of PWS, and, to date, how these genes normally work is poorly understood. Dr. Bratkovic will apply novel technology to understand the function of this unusual class of genes.

Biological and molecular functions of PWS-encoded small nucleolar RNA genes. Jerome Cavaille, PhD., University of Toulouse ($70,000). This group proposes that SNORD116 snoRNAs may have a role in the production of ribosomes, a key piece of machinery in cells required for protein production. Their study will shed light on why the loss of SNORD116 leads to the symptoms associated with PWS.

Characterization of Anti-Ghrelin Autoantibodies in Prader-Willi Syndrome. Lisa Chopin, PhD., Queensland University of Technology, Australia ($107,957). Dr. Chopin's studies suggest that individuals with PWS may have antibodies to ghrelin that contribute to hunger. Here, she will study those antibodies in depth and determine whether they are contributing to increased appetite. (*Funded by FPWR Canada*)

Evaluating the Parent-focused Remote Education To Enhance Development (PRETEND) Program in PWS. Anastasia Dimitropolis, PhD., Case Western Reserve University ($75,586). This project will focus on understanding the social-cognitive characteristics of PWS and will evaluate an educational program to optimize learning, play, and joint engagement between young children with PWS and their parents.

Therapies on the Horizon

Oxytocin was one of many potential therapeutics to make the headlines in the PWS community in 2015. FPWR was pleased to see Dr. Hollander's Phase 2 study of oxytocin get under way. The results will help us understand the potential of oxytocin in PWS. A new collaborative team project led by Dr. Einfeld will advance our understanding of oxytocin and the autonomic nervous system in PWS, laying the groundwork for additional human studies. Dr. Muscatelli's funded project will examine the optimal timing of oxytocin administration in animal models of PWS, while additional funds were set aside to support the upcoming Phase 2 study to optimize oxytocin dosing in individuals with PWS.

Because we believe that advancing multiple potential therapies in parallel is critical to addressing all the needs of our population, we funded additional studies investigating cutting-edge genetic therapy strategies, examining how 'repurposed' drugs from other indications can be used in PWS, and evaluating medical devices. These approaches may alleviate hyperphagia, restore normal circadian rhythms, and improve behavior in PWS.

2015 Funded Projects

Oxytocin and the Autonomic Nervous System in Prader-Willi Syndrome. Stewart Einfeld, PhD., University of Sydney ($195,050). Dr. Einfeld will work with a team with experts on oxytocin (Dr. Sue Carter), the autonomic nervous system (Dr. Steve Porges) and PWS (Dr. Leopold Curfs) to investigate disruptions of these systems in PWS and lay the groundwork for informative clinical trials. (*Partially funded by FPWR-UK*)

Methylation Test Validation for Combined Prader-Willi and Fragile X Syndrome Newborn Screening. David Godler, PhD., Royal Children's Hospital, Australia ($100,950). Dr. Godler is developing a cost-effective test to be incorporated into newborn screening, which may allow accurate and early diagnosis of all babies with PWS.

Proof of Concept Study of Vagus Nerve Stimulation From an External Device in Prader-Willi Syndrome. Tony Holland, MD., University of Cambridge ($104,492). Dr. Holland did a small pilot study on the use of VNS in PWS and found an unexpected beneficial effect on behavior. Here, he will do an expanded clinical trial, using a new, noninvasive device, and measure effects on behavior.

Development and Validation of Ghrelin *O*-Acyltransferase Inhibitors for Treating Hyperphagia in PWS (Year 2). Jim Hougland, PhD., Syracuse University ($75,600) Dr. Hougland is continuing studies to develop a novel class of drugs that disrupts ghrelin in PWS. In the second year, he will optimize the inhibitors and test them in cells.

Reactivation of the PWS Locus via Disruption of the ZNF274 Silencing Complex. Marc Lalande, PhD., University of Connecticut ($108,000). This group is working to reactivate the PWS region on the maternal chromosome by identifying and disrupting the "OFF" switch. They have identified a component of the switch-off mechanism, which they will try to disrupt in PWS stem cell lines. If successful, the approach will advance the understanding of how imprinting occurs, and may represent an important step towards potential genetic therapy of PWS.

Rapamycin Treatment to Correct the Circadian Motor Imbalance in the SNORD116 Deletion Mouse Model of PWS. Janine LaSalle, PhD., University of California, Davis ($72,989). Dr. LaSalle has identified a defect in circadian rhythm genes in PWS. Here, she will see if a common drug, rapamycin, can correct that defect in a mouse model of PWS.

The Role of SNORD116 in the Neuroendocrine Phenotypes of Prader-Willi Syndrome. Rudy Leibel, MD, Columbia University ($86,400). Dr. Leibel's group has been using PWS induced pluripotent stem (iPS) cells to investigate how loss of the critical SNORD116 genes in the PWS regions leads to the characteristics of PWS. Their work suggests a common underlying mechanism responsible for many of the neuroendocrine disruptions. Here, they will further elucidate the cellular changes in PWS and use advanced genetic manipulation of iPS cells to understand PWS at the cellular level.

Role of Melanin Concentrating Hormone in an Animal Model of Prader-Willi Syndrome. Michiru Hirasawa, PhD., University of Newfoundland. ($84,000 CAD) Melanin concentrating hormone (MCH) is an important regulator of appetite in the brain, but it has not been studied in PWS. This study will examine whether this brain chemical is disrupted in a mouse model of PWS. (*Funded by FPWR-Canada*)

Investigating Neural Development in an Induced Pluripotent Stem Cell Model of Prader-Willi Syndrome. Guo-Li Ming, PhD., Johns Hopkins Univeristy ($108,000). The Ming laboratory studies the characteristics of neurons derived from individuals with mental illness, examining changes at the cellular level. They will derive neurons from the skin cells of individuals with PWS and elucidate cellular changes. This represents the first step in screening molecules that may restore normal cell function.

2015 Funded Projects

Activation of Silenced Genes in Prader-Willi Syndrome. Rob Nicholls, PhD., University of Pittsburgh ($108,000). This project will use cutting-edge CRISPR technology to evaluate the feasibility of activating the silenced genes in the PWS region. Successful completion of the goals will be a first step to genetic therapy.

Linking the Cellular Function of MAGEL2 to Its Role in PWS. Ryan Potts, PhD., St. Jude, TN ($108,000). In order to function properly, proteins not only have to be expressed at the correct levels, they have to be in the right place in the cell to do their job. This group will explore the role that the PWS gene MAGEL2 has on protein trafficking in neurons. The results from this project could provide valuable information on how the loss of MAGEL2 in PWS leads to impaired function in the hypothalamus region of the brain.

Gene Expression Analysis in PWS Subject-Derived Dental Pulp Stem Cell Neurons. Lawrence Reiter, Ph.D., University of Tennessee Health Sciences ($108,000). Dr. Reiter has expertise in disorders of chromosome 15, including chromosome 15 duplication syndrome. He will study neurons derived from ‘baby teeth’ from PWS and other 15q disorders to identify genetic changes that might be contributing to features of autism in PWS.

Mechanisms of Sleepiness and Other Sleep Disorders in a Mouse Model of PWS. Thomas Scammell, MD, Harvard Medical School ($108,000). This group will explore the mechanism of daytime sleepiness and cataplexy in PWS. They hypothesize that lower levels of oxytocin neurons and orexin signaling contribute to these issues. These experiments will provide insights into how changes in the hypothalamus region of the brain cause sleep/wake symptoms of PWS. Armed with a better understanding of these brain circuits, researchers will be better able to develop new and more effective therapies for PWS.

Regulation of Ghrelin and Serotonin Receptors by SNORD115. Stefan Stamm, PhD., University of Kentucky ($108,000). The biological mechanism for low levels of growth hormone in PWS remains unknown. This group hypothesizes that the underlying cause is a cascade effect from the PWS gene SNORD115 → the serotonin receptor → growth hormone release. The results from this project could offer a new avenue for treating hormone deficiencies in PWS. It also opens the door for future research questions about whether the serotonin receptor interacts with other receptors and is a potential “master regulator” of endocrine issues in PWS.

Project Funding 2004 - 2015

Year	Projects	Financial Support
2015	20	$1,986,280
2014	17	$1,228,767
2013	17	$1,088,317
2012	8	$412,780
2011	11	$477,388
2010	7	$317,580
2009	5	$209,994
2008	8	$377,063
2007	7	$305,000
2006	5	$200,000
2005	4	$100,000
2004	4	$160,000
TOTAL	**113**	**$6,863,169**

Ghrelin: Is it Detrimental, Beneficial, or Inconsequential in Prader-Willi Syndrome? Jeffrey Zigman, MD, PhD., University of Texas Southwestern Medical Center ($108,000). Ghrelin levels are elevated in PWS, but why, how, and whether it plays a role in hyperphagia or other aspects of PWS are all still unanswered questions. This project will explore if ghrelin plays a protective role in PWS with regard to growth hormone deficiency, hypoglycemia and mental health issues, but a detrimental role with regards to extreme food-seeking behaviors and obesity. Clarifying the role of ghrelin is a critical step for future therapies designed to target the ghrelin system in PWS.

2015 Event Hosts

FPWR funding for PWS research is only possible by the collective fundraising efforts of dedicated parents and volunteers from around the country! We extend our sincerest gratitude to our dedicated hosts!

2015 Event Hosts

Vicki Almond
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Lori Avery
Diana Baird
Veronica Baker
Carson Blackwelder
Craig and Becky Borgen
Jeeni Breen
Ashley Brown
Dianne Bryden
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Susan Hedstrom
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Melissa Howard
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Elaine Johnson
Belinda and Jack Jones
Jeannine Kowal
Katie and Adam Larson
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Glen Loauson
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Irene McDougall
Andrew McVey
Laura Miesle
Lisa Millard
Crystal Miller
Heather and Steve Osterman
Karine Pagnon
Stacy Painter
Amy Porter
Tammy Renwick
Maegan Richard
Caroline Richard
Paige Rivard
Johanna Rocha
Jonathon Santos
Catherine Shaw
Jennifer Sharman-Koh
Kristin Simms
Renee and Brent Snyder
Gwyn Spearman
Joy Suttle
Anne Taylor
Stephanie Thomas
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Brittany Wissing

2015 Leadership Circle

Thanks to over 7,300 individuals and corporate donors, the Foundation for Prader-Willi Research funded nearly $2 million in research in 2015. The top donors and fundraisers, contributing $5,000 or more in 2015, are listed here. We thank you for your passionate support of our mission and families!

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Samuel and Beatriz Viroslav
Alice and Sergio Viroslav
Visa
Teresa and Joseph Walker
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2015 Financial Highlights

The Foundation for Prader-Willi Research is extremely conscientious with the donations entrusted to our care. In 2015, 88% of every dollar spent went directly to research programs. As our most dedicated friends and supporters, you make our work possible. Thank you for all that you do!

As of December 31	2015 (unaudited)	2014	2013	2012
Assets				
Cash	$4,925,629	$3,669,858	$2,223,507	$1,838,387
Receivables	$0	$363,108	$50,000	$5,000
Other Assets	$2,800	$34,756	$3,102	$1,204
Total Current Assets	**$4,928,430**	**$4,067,722**	**$2,276,609**	**$1,844,592**
Liabilities				
Grants Payable	$1,875,348	$751,108	$643,625	$189,332
Accounts Payable	$54,475	$42,798	$2,088	$3,901
Accrued Liabilities	$20,958	$24,397	$4,268	$1,663
Total Liabilities	**$1,950,782**	**$818,303**	**$648,998**	**$194,896**
Total Net Assets	**$2,977,648**	**$3,249,419**	**$1,627,611**	**$1,699,396**
Total Liabilities and Net Assets	**$4,928,430**	**$4,067,722**	**$2,276,609**	**$1,894,292**
Revenue	**$3,026,786**	**$3,249,443**	**$1,499,989**	**$1,311,850**
Total Expenses	**$2,991,161**	**$1,686,403**	**$1,294,949**	**$693,575**
Programatic Expenses	**$2,623,246**	**$1,465,038**	**$1,062,386**	**$538,355**
Programatic Expense Percentage	**88%**	**87%**	**82%**	**78%**
Increase in Net Assets	**$35,625**	**$1,563,040**	**$205,040**	**$618,275.16**
Total Projects Funded	**$1,986,280**	**$1,177,360**	**$1,041,718**	**$457,264.00**
Number of Projects Funded	**20**	**20**	**18**	**7**

FOUNDATION FOR
PRADER-WILLI
RESEARCH
Working Toward an Independent Future

It Starts with Us!

Our mission is to eliminate the challenges of Prader-Willi syndrome through the advancement of research.

FPWR HAS FUNDED

113

RESEARCH GRANTS
SINCE 2003

FPWR is dedicated to fostering and supporting research that will advance the understanding and treatment of PWS. To date, FPWR has invested $6,863,169 in funding to leading scientists and research laboratories around the world.

113 research projects have been funded since 2003, covering:

- genetics and pathophysiology of PWS
- development of mouse models of PWS
- hunger, obesity, and reward circuits of the brain
- development of new therapies for PWS
- understanding sleep disturbances in PWS
- improving academic and learning skills for children with PWS

For a complete listing of FPWR projects and details on the research, please visit http://fpwr.org/funded-projects

FPWR STAFF

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Executive Director

Nathalie Kayadjanian, PhD
Director of Translational Research

Jessica Bohonowych, PhD
Associate Director of Research

Hannah Berger
Director of Development

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