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

2015 Annual Review
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Message from the Board Chair and Executive Director

Keegan Johnson & Carole J. Barron

Throughout 2015 we continued our focus on our ultimate goal – to eliminate the challenges of PWS.

Researchers have been trying to find out how (or if) different hormones contribute to the challenges of PWS. Two of these hormones are Ghrelin, which is associated with management of hunger, and Melanin Concentrating Hormone, which is associated with the regulation of feeding behavior, mood, sleep-wake cycle and energy balance.

This year FPWR Canada has funded two key projects to further our understanding of these hormones. Specifically, we funded, Dr. Lisa Chopin ($107,967 USD) studying antibodies to ghrelin that contribute to hunger and Dr. Michiru Hirasawa ($85,000 CDN) investigating the role of Melanin Concentrating Hormone. We have also allocated $200,000 to study the effect of dietary interventions in PWS.

In Canada accessing growth hormone remains a significant challenge for families with children diagnosed with PWS. To address this challenge, we have launched a Growth Hormone Access Working Group. The GH working group, is currently obtaining the required clinical and patient evidence to develop a submission to the Government of Ontario in order to have GH as an approved indication for funding. Our plan is to start in Ontario and once we have the data and initial submission, we will work on the additional provinces. While each step requires many smaller steps, the work will bring us closer to ensuring access to growth hormone for every person in Canada who has Prader-Willi Syndrome.

Once again we thank the PWS community for the continued fundraising. Without your support none of this would be possible. Now more than ever before we need your support so that we will see progress in helping our children and young adults overcome the challenges they face.
What has happened in 2015

Overall, FPWR and FPWR Canada have helped fund 19 grants in 2015 for approximately $1.8 million. These funds support projects to define the basic molecular mechanisms underlying PWS, to develop novel drugs for hunger, to test whether existing drugs can be repurposed to treat PWS, and to evaluate both medical and nonmedical interventions to improve the lives of those with PWS in the short term.

Grants Approved for Funding in 2015

1. **EFFECT OF DIETARY INTERVENTIONS IN PRADER-WILLI SYNDROME: FPWR CANADA**
   - FPWR Canada has committed $200,000 CDN to study the effect of dietary interventions in Prader-Willi Syndrome (PWS). PWS is a multi-faceted disorder causing developmental disability, hyperphagia usually with obesity, and behavioral problems including an increased incidence of psychiatric illness. Parents are typically counseled to provide a low-calorie (typically low fat) diet, adjusted for the age and activity level of the child. There is little guidance provided to families or nutrition specialists on the optimal amounts of macronutrients (carbohydrate, fat and protein) in the diets of children with PWS, aside from the importance of meeting minimum requirements for vitamins and minerals and limiting foods with low nutritional value.

2. **ROLE OF MELANIN CONCENTRATING HORMONE IN AN ANIMAL MODEL OF PRADER-WILLI SYNDROME**
   - Dr. Hirasawa’s study will investigate a potential link between Melanin concentrating hormones (MCH), a chemical found only in a certain population of nerve cells within the hypothalamus, and PWS, given the known role of MCH in controlling body weight and reproduction. This will be the first study on MCH in a mouse model of PWS, which may bring promising results for identifying a new therapeutic target.

3. **CHARACTERIZATION OF ANTI-GHRELIN AUTOANTIBODIES IN PRADER-WILL**
   - Dr. Chopin’s studies suggest individuals with PWS may have antibodies to ghrelin that contribute to hunger. She will study those antibodies in depth and determine whether they are contributing to increased appetite. This may lead to new approaches to the prevention of hyperphagia, a major challenge in the management of children with PWS.
Better focus on our newly diagnosed families
This year we completed an outreach to all the children’s hospitals across Canada by sending our “New Parent’s Package” to key contacts within each of these centers. Based on feedback we received, our package was also added to the reference documents database used by Endocrinologists across Canada. Our goal is to provide support and help those families who had a child with a new diagnosis of Prader-Willi Syndrome (PWS).

To provide families with the opportunity to request a “New Parent’s Package” directly from FPWR Canada, we updated our website, www.fpwr.ca. A quick and simple registration now connects families to the “package” and our Community Director.

Our goal is to connect with each and every family who receives the diagnosis of PWS. The role of the Community Director enables her to review the “package” with each family and have one on one conversations to help situate them with their own particular needs.

Board of Directors
Following on the successful transition to the New Not-for-Profit Act in 2014 and the completion of the new By-Law No. 1 in August 2015, FPWR Canada continued to grow its Board of Directors capacity. A number of new Board Members were elected, namely, Jeff Baldwin, Brooke Gibson, Jack Jones, and Holly Sine. All bring special levels of experience and expertise to the Board. At the Executive level changes were completed - Jack Jones, was elected to the position of Vice–President and Jeff Baldwin was elected to the position of Treasurer.

In 2015, Mike Henry who had served as Treasurer since the early beginnings of FPWR Canada, had resigned. Congratulations on your new work responsibilities Mike and thank you for your outstanding contributions to FPWR Canada and the Board!

2015 National Conference
The 5th Annual National Conference, “Sharing Solutions” was held in Calgary, Alberta May 30 & 31, 2015. Brooke Gibson, Conference Chair and her team of volunteers are to be congratulated for their work in organizing the Conference.

We were very proud to have been able to bring together Rachel Wevrick, Ph.D., Dr. Andrea Haqq, Paediatric Endocrinologist, Orthopedic Surgeon, Dr. Harold van Bosse, Dr. Jessica Bohonowych and Marc Landry, Occupational Therapist together with esteemed members of the FPWR community who are working with us to continue our progress and “help our children live life FULL!

A Casino Night was the pre-conference evening event had an excellent outpouring of support from community friends raising over $6,000 for PWS Research!

A special prize for a most unique “wearing blue” was presented to Stephanie Thomas for her “50 Shades of Blue.”
During 2015 the Growth Hormone Access Working Group has been completing work identified through the Board of Directors approved comprehensive plan, namely, to ensure access to growth hormone for every person in Canada who has Prader-Willi Syndrome.

Holly Sine, Working Group Lead and Carole Barron, FPWR Canada Executive Director have held discussions with a number of key informants from the Ontario Ministry of Health and Long Term Care, Exceptional Access Program for drugs to further understand our next steps in requesting GH be included for provincial (Ontario) funding for PWS. The process for submission and the factors required by the Ontario Drug Benefit Management Program enabling the review and consideration of FPWR Canada’s request for GH funding inclusion were identified. These factors include cost effectiveness, clinical evidence, patient impact on improving the quality of life, impact on other health care services, efficacy and safety. Overall impact on economic and budget.

In Canada we do not have a manufacturer with label claim for GH. To that end it was identified FPWR Canada would have to complete a submission to follow the guidelines required by the Ontario Government. The three key points to be submitted included: Clinical Data, Financial Impact, and Patient Impact.

In July 2015, after extensive review of the published list of registered regulatory affairs professionals and conducting interviews, Navneet Sekhon, AxSource Consulting was selected as FPWR Canada’s dedicated specialist who could prepare the submission for all requirements identified by the Government of Ontario. AxSource Consulting Inc. (“AxSource”) specializes in “GXP” (GLP/GMP/GCP) and regulatory affairs (Health Canada, EU & FDA predominantly) & compliance for over 25 years for many start-ups and mature pharmaceutical, biologics, medical device, NHP, cosmetics and related companies.

AxSource has been working closely with FPWR Canada in providing Regulatory Services.

Recently a questionnaire has been prepared and will be circulated to families registered with FPWR Canada. The questionnaire will help us to compile data to support our application to the provincial governments for funding inclusion of GH for PWS diagnosis and NOT just GH deficiency. Without the support of a pharmaceutical company we are moving forward with a physician/clinical application and have held discussions with Endocrinologists who have expressed interest in supporting our application. For this type of application we need to know more details about the community so we can build statistical support.

This is a complex process of government lobbying, government funding and commercial/financial incentives for a small population. The Working Group has a process in place to achieve its goals and believes working with AxSource in preparing our proposal to government the achievement of these goals will be realized.

Website and Facebook
Continuing with our efforts to improve outreach and relationships with our PWS community of families, donors, volunteers and others, in 2015 we renovated our website - www.fpwr.ca - providing enhanced information and opportunity to connect with FPWR Canada Team directly.

As well we initiated an organization specific Facebook page whereby information relating to all aspects of our work is added on a daily basis.
2016 IPWSO Conference
July 20 – 24, 2016

The International Prader-Willi Syndrome Organization and FPWR Canada are proud to announce that the 9th IPWSO Conference will take place in Toronto, Ontario Canada, July 20 – 24, 2016 at Sheraton Centre Toronto located in heart of downtown Toronto.

Tanya Johnson, Conference Chair and Host announced the Conference theme, “Building Global Community” is to eliminate the challenges of Prader-Willi Syndrome. This theme symbolizes the importance of bringing all members of the PWS community together to unite under one global mission.

This conference will provide scientific expertise, valuable resources and will cover topics important to the families and people who have PWS lead productive, independent lives. Parents, caregivers, scientists and professionals will join together to share expertise and collaborate best practices in order to improve the quality of life of all individuals with Prader-Willi Syndrome.

To advance the Conference planning, FPWR Canada secured the Professional Conference Planning Services of Janice Fendley Consulting Inc. Organizers expect more than 600 delegates from around the world and our Canadian culture will embrace all nationalities and provide a rich and inclusive environment. There will be four key Conference streams: Scientific (July 20-22), Professional Caregivers (July 21 & 22), Parents (July 23 & 24) and People Living with PWS (July 23 & 24).

We are indeed appreciative and thankful for the support of the many volunteers and Committees who have come together to move the Conference planning forward namely, the Scientific Conference Co-Chairs, Dr. Theresa Strong, Dr. Rachel Wevrick and Dr. Tony Holland; the Professional Caregiver’s Conference Co-Chairs, Mary K Ziccardi, Norbert Hodebeck-Stuntebeck and Patrice Carroll; the People with PWS Program Co-Chairs, Linda Grande, Belinda Jones and Tammy Gerrish, and Tanya Johnson, Parent’s Conference Chair and her Committee members Amber Roberson, Dana Capobianco and Jackie Waters.

Information and registration (to be launched in January 2016) is available on FPWR Canada website, www.fpwr.ca

Event Sponsors
2015 ONE Small STEP
for Prader-Willi Syndrome

We asked and you delivered in 2015. One SMALL Step Canada was in more cities across the nation than ever before. From coast to coast we had 20 Walks and over 3000 walkers supporting One SMALL Step Campaign.

Thank you to all for recognizing that in order to help people with PWS it starts with us.

Way to go Canada!

A special thank you to all 2015 Hosts. Your efforts are deeply appreciated!
Thank you to all individuals or teams who created a page supporting their walks!

Halifax
Joy-Lynn Suttle, Tasha Tyrell and Belinda Sawler
$7,147.50

Brampton
Jack and Belinda Jones
$45,834.93

Grande Prairie
Tammy Renwick
$22,376.62

Edmonton
Miranda Apesland
$14,270.00

Montreal
Stacey Letovsky
$8,628.00

Happy Valley-Goose Bay
Kristin Simms
$10,137.00

Rivière-des-Prairies
Carole Elkhal and Marco Del Cane
$4,840.00

Fairview
Diana Baird
$19,931.88

Ste-Julie
Patricia Hélie and Stephanie Laberge
$7,972.00

Richmond Hill
Irene McDougall and Nubia Coutinho
$3,728.00

Delta
Suzanne Szabo-McDonald
$21,632.00

Saint John
Jack and Amanda Gardner
$9,638.00

Quebec City
Rhea Utley, Elyse Lavoie and Isabelle Robitaille
$11,787.30

Ottawa
Andrew and Jessica McVey
$23,449.70

Montreal
Adrianna De Luca and Salvatore Giorgio
$9,300.00

Toronto - Trinity Bellwoods Park
Stefania Demaria and Jonathan Santos
$8,567.00

Toronto - Earl Bales Park
Ryan and Olga Cohen
$53,046.00

Virtual Canada
$4,777.00

A special thank you to all 2015 Hosts. Your efforts are deeply appreciated!
Thank you to all individuals or teams who created a page supporting their walks!
2015 One SMALL Step Campaign

Grand Total for Canada

$371,383.93

Over 3,000 people, in 20 locations, walked to support Prader-Willi Research.
The 9th Annual Live Life FULL Gala, in support of Foundation for Prader-Willi Research Canada was a huge success. Thank you to our guests and our sponsors: Scotiabank, Frank H. Hori Foundation and BPA Financial. This year’s Gala raised $56,000, enough to fund one research project. Our annual gala fundraiser was held at Terrace Banquet Centre, over 300 guests enjoyed cocktails, antipasto bar, dinner, dancing, silent and live auction and our grand prize trip for two to Grand Bahia Principe, Jamaica, generously donated by Maritime Travel, Newmarket.

We are grateful to all our loving family and friends who have supported us in our journey over these last nine years.

We are blessed to have the passion of our committee members, the kindness of our donors, and the support of the Prader-Willi community. We thank you for your on-going generosity and support.

Michelle and Manny Cordeiro
Co-Chairs, Live Life FULL Toronto Gala
Montreal

On November 7, 2015 Montreal hosted its 5th annual Live Life FULL Gala at the Le Chateaubriand Hall. Raising $10,000, it was a fabulous event hosting 100 people who enjoyed cocktails, followed by a five-course meal and a night table for dessert! Under the theme of Venetian Casino night, guests were invited to wear a Venetian Mask for the occasion and test their luck at blackjack, poker or roulette for a chance to win a Smart TV.

A photo booth, open bar and dancing the night away with the amazing sounds of DJ Goldstar provided guests with a night of fun and relaxation! Through the generosity of WestJet we had flight tickets for two for any of their destinations!

Thank you to our sponsors Broccolini, Coiffure/Esthétique et Spa De Neuville, WestJet, Autocare, StudioKidz, Loft Déco, Traiteur Café Milano and Livingston International.

We are thankful for the support of all the Quebec families who come to celebrate with us, all the wonderful volunteers who dedicated their time to selling tickets and helping the event to be a great success.

Carole Elkhal and Marco Del Cane
Co-Chairs, Live Life FULL Montreal Gala

Guelph

We are so pleased that our 6th Annual Guelph Gala was another success. Our event was well attended with just over 240 people. We raised close to $30,000!

In keeping with our theme from past Galas, we focussed our message on building awareness, raising funds for research and having fun. It was encouraging to see many new faces and we were also happy to have Carole Barron, Executive Director, FPWR Canada speak on behalf of the Foundation. Through Carole’s address she educated the community of Guelph on the Special Research Projects FWPR Canada has been able to fund through fundraising efforts such as our Gala. In addition, she gave a snapshot of some promising research and spoke about the 2016 IPWSO Conference in Toronto.

We are happy to say we are booked for our 7th Annual Guelph Gala which will be held June 3rd, 2016. Thank again to everyone for your continued support.

Sarah and Ryan Kelly
Co-Chairs, Live Life FULL Guelph Gala
Congratulations to Association Prader-Willi Quebec for their Annual Golf Tournament

On June 14, 2015, Association Prader-Willi Quebec held their annual golf tournament raising over $28,850 for Prader-Willi Research. Special thanks to Anne-Marie Blais, Maxime Beaupré, Geneviève Charbonneau and Jean-Sebastien Lefebvre for their great efforts.

Thank you to the families and volunteers who helped make this event another amazing success!

Congratulations to Tad Gacich, Board Member and Golf Tournament Host.

Over 60 golfers joined Tad at St. Andrews Valley Golf Club for the 7th Annual FPWR Canada Golf Tournament raising over $10,000 for PWS Research. Thank you to Tad and his committee for their on-going fundraising and support.

A very special thank you to the sponsors, families and golfers.
Special Events

Cuddle up and Read

In May, St Ignatius of Loyola Catholic School in Guelph ON partnered up with FPWR Canada to launch a read-a-thon called “Cuddle Up and Read for Prader-Willi Syndrome Research.” The Read-a-thon ran from May 5th to May 26th and raised approximately $3,000 for FPWR Canada. Most importantly it raised a tremendous amount of awareness throughout the school and community. As part of the fundraiser, Lunch Box Orders hosted a fundraising lunch from May 14-June 25 featuring The Shed Market in Guelph. With every meal purchased a donation was made to FPWR Canada. The key to the success of this event was the initial launch day on May 5th. Sarah Kelly put together 3 different presentations each tailored to Primary, Junior and Intermediate grade levels. The presentation focussed on some of the challenges children with PWS face each day. This provided the ground work so students could seek pledges and speak confidently about PWS. The students and faculty were grateful to learn about this complex genetic disorder. In addition, they were able to learn more about one of their fellow classmates and students, Clare Kelly.

Steak Fry

Jana Floer and Kathie Bloor and their team of volunteers worked hard to put together their first fundraiser, a Steak Fry Dinner that took place in Gladmar Park, Saskatchewan.

Oliver’s Labels

Oliver’s Labels is the very best kids’ labels around! They are cute, colourful and ultra-durable personalized labels and tags for kids. In September 2015, FPWR Canada invited friends and family to order from Oliver’s Labels, where 20% of proceeds from the sale would be donated to PWS research. Thank you for your on-going support, we raised $90.00 in just four months. We will continue to fundraise through Oliver’s Labels in 2016.

Mechanical Contractors Association of BC (MCABC)

Special thanks to the Mechanical Contractors Association of BC (MCABC) who are beaming with joy after donating the funds raised during their annual Holiday Fundraiser held on December 3rd, 2015 to FPWR Canada. Thanks to the combined generosity of silent auction donors and participants, together, they raised over $4500.00 supporting Prader-Willi Research.

Thank you for joining the fight to ensure that our loved ones have a healthy, happy life and an independent future!
Special Donors

Scotiabank

FPWR Canada extends its deepest thanks to Scotiabank who for the past four years has been our title sponsor for One SMALL Step in Canada. Contributing $50,000 annually in support of Prader-Willi Research, through their financial support we have been able to not only exceed our OSS campaign goals but, at the community level, inspire more families and volunteers to get started and host their own walks.

In 2015 we were advised this was their final sponsorship year. On behalf of FPWR Canada we say “Thank you Scotiabank for your support throughout the years.”

Frank H Hori Charitable Foundation

On May 22, 2015, FPWR Canada was the grateful recipient of a cheque in the amount of $15,000 from The Frank H. Hori Charitable Foundation. This donation, made in support of their grandniece, Miss Georgia King, is designated for academic development in children who have Prader-Willi Syndrome. Georgia has Prader-Willi Syndrome.

Frank H. Hori was a very successful and caring businessman and community member who understood the importance of social and academic development needs to the quality of life of children who have Prader-Willi Syndrome.

FPWR Canada is very grateful to the caring and generous donation from The Frank H. Hori Charitable Foundation supporting PWS research. This generous donation means we are able to continue in our efforts to fulfill our Mission “to eliminate the challenges of PWS through the advancement of research.”

Through this donation, The Frank H. Hori Charitable Foundation is helping make it possible for FPWR Canada to continue to search out new academic learning research opportunities. Without donors such as The Frank H. Hori Charitable Foundation, we could not realize our research goals and for this FPWR Canada is truly grateful.

Recognizing special community donors!

BPA (Benefit Plan Administrators Limited)

BPA has served members and beneficiaries in their local communities since 1958. BPA is dedicated to providing a superior benefits experience to their members, businesses, and trusts in the local communities in which they live and operate.

FPWR Canada has been the grateful recipient of over $10,000 annually supporting the One Small Step event in Brampton, Ontario and the Toronto Live Life FULL Gala.

Very special thanks to Jeff Baldwin, President & CFO and his team at BPA for their support!

ARC

ARC encourages their employees to be personally involved with charitable organizations in their community.

FPWR Canada has been the grateful recipient of $7,500 in 2015 supporting the One Small Step walk in Calgary, AB. For over five years ARC has demonstrated its commitment and support of FPWR Canada fundraising initiatives.

Thank you ARC for your annual sponsorship of OSS Calgary AB!
Special Donors continued

Mentor College
Mentor College held its 2015 Fashion Show on April 18. This event recognized and showcased one of the biggest influences on and contributors to our culture, religion, and everyday life: art. From the aria from the Italian opera, Tosca, by Guacomo Puccini, Vissi D’arte itself translates to, “I lived for my art.” Funds raised from the Fashion Show were donated to SickKids Foundation and FPWR Canada. Michelle Cordeiro, Operations Director, FPWR Canada was presented with a cheque for $20,000 by members of the 2015 Fashion Show Committee.

Again on November 18, 300 Mentor College students gathered for the 6th Annual Mentor College Business Conference. Mentor College was proud to host several excellent speakers who came to discuss this year’s theme: how to “Gain the Edge” in the business world. Jack Jones, Vice-President, FPWR Canada was invited to speak about our organization and his personal experience with PWS. While in attendance he was presented with a cheque for our organization $5,000 from the Mentor College Business Committee.

Thank you to Linda Starcevic for connecting Mentor College and FPWR Canada!

Special Thanks to Provincial PWS Associations

**British Columbia Prader-Willi Syndrome Association**
Heather Beach

**Ontario Prader-Willi Syndrome Association**
Holly Sine (Co-Chair) and Rob Pividor (Co-Chair)

**Association Prader-Willi Syndrome Quebec**
Anne-Marie Blais

**Alberta Prader-Willi Syndrome Association**
Brooke Gibson and Miranda Apesland
Thanks for Stepping up to the challenge in 2015 Canada. I hope by having the opportunity to talk more closely with you and listen to your needs has in some way inspired you to do more. As we move forward we need to understand that if we want things to evolve and continue to grow, we need to do it all together.

So by hosting a walk, helping another family, becoming a volunteer, sharing your story, sharing your abilities and knowledge or taking action of any kind, you are helping your community and yourself in the end.

We ALWAYS need your help to be able to help our loved ones. It takes an entire community to move things forward. **LET’S DO IT, LET’S STEP UP CANADA!**

Carole Elkhal  
FPWR Canada Community Director

It has been a pleasure to work with such an amazing dynamic group – the Prader-Willi Syndrome community. As we are all working toward an independent future – Thank You to all your efforts and generosity this past year we are one step closer to reaching this reality.

My daughter Julia has enriched my life and continually provides me with the encouragement to persevere in our mission. I’m inspired everyday by her and the efforts put forth by parents, caregivers, supporters, and volunteers – together we are making a difference.

We have proven that there really is power in numbers and because of this inner strength and determination we are one step further in our mission to eliminate the challenges of PWS through the advancement of research. I look forward to another successful year as FPWR Canada reaches new heights in 2016.

Michelle Cordeiro  
FPWR Canada Operations Director

For the dedication, insight and response to changes and challenges implemented throughout the past year – thank you!

Members of the Board

Keegan Johnson  
Chairman  
Jack Jones  
Vice-Chair  
Jeff Baldwin  
Treasurer  
Mark Bagatto  
Director  
Peter Evans  
Director  
Brooke Gibson  
Director  
Tad Gacich  
Director  
Mark Giroux  
Director  
Holly Sine  
Director  
Rachel Wevrick, Ph.D.  
Scientific Advisor  
Mike Henry  
(Resigned June 2015)
Thank you to all donors from the past year, without you our achievements would not be possible.