

**FPWR Canada National Family Conference
Make it Happen!**

**Agenda: Saturday, May 4, 2019.
(Location: Novotel, Mississauga at Sussex Centre)**

9:30– 10:00a.m.	Conference Registration
10:00 – 10:10 a.m.	<p>Opening Remarks from Tanya Johnson Conference Chair, VP and Co-founder of FPWR Canada</p> <p>Chair, 2019 FPWR Canada National Medical Conference Location: Grand Ballroom</p>
10:10 – 11:20 a.m.	<p>Sleep Panel: Dr. Colin Shapiro (PhD, FRCPC), Dr. Phyllis Zee, Chief of Sleep Medicine in the Department of Neurology at Northwestern, Dr. Lara Pullen (PhD, President and Founder of Chion Foundation)</p> <p>Learn about sleep Issues in PWS and possible treatments/supplements that are available. Provigil, Pitolisant, Tryptophan, C-PAP machine have all been tried in our PWS Community. Do they work? Are they available in Canada? Do they improve sleep issues, why or why not? Are they safe?</p>
11:20 – 12:30 p.m.	<p>Dr. Jill Hamilton Head of Endocrinology at SickKids Hospital, Toronto</p> <p>Growth hormone is a known and effective treatment for PWS for many years. Dr. Hamilton will review its benefits, risks, proper dosage and the various ways to access it in Canada. She will also review Puberty in PWS (what that looks like and ways to address it). Dr. Hamilton is working with Levo Therapeutics to run our first clinical trial at SickKids Hospital. She will give a brief overview of the logistics but details of the trial will be explained by Levo at 4pm today.</p> <p>Celine Lepage GH submission update / Drug access in Canada Celine LePage (Parent who leads FPWR’s Drug Access committee) will give a brief update on her progress and share information she has gathered over the past 6 months and what we can do as a community to gain drug access in Canada more efficiently.</p>
12:30 – 1:40 p.m.	<p>Lunch Sponsored by Levo Therapeutics Let’s Talk Nutrition with Dr. Kaleigh Zinger ND</p> <p>Kaleigh will show us how diet can impact mood and behaviour? She will also introduce the MODIFIED Ketogenic Diet and show us how it can help everyone.</p>

1:40 – 2:30 p.m.	<p>Elizabeth Roof Psychologist and Senior research specialist at Vanderbilt University Tennessee</p> <p>Elizabeth will share her expertise on behavioural strategies and possible therapies/treatments for all people with PWS. She will also show us how to improve social functioning and how research has led to developing effective strategies for addressing the social challenges people with PWS experience.</p>
2:30 – 3:30 p.m.	<p>Breakout Sessions</p> <p>0-4 – New Parent Sharing Parents will share tips and stories of hope to help you get started in this journey. Location: Mississauga Room West</p> <p>4-17 – Special Education Advocacy (Tanya Johnson – Special Education Teacher) Learn how to advocate for your child in the school setting, most important parts of the IEP and how to work with school team to help your child reach their maximum learning potential. Location: Grand Ballroom</p> <p>17+ - Adults with PWS More time with Elizabeth Roof and Patrice Carroll (Latham Centre) to discuss strategies and treatments related to mental health/behaviour and life beyond high school. Location: Mississauga Room Centre</p>
3:30 – 4:00p.m.	<p>Break/Visit Booths</p> <p>Welcome Levo Therapeutics, Path for PWS, OPWSA, Community Living</p>
4:00 – 5:00 p.m.	<p>Dr. Theresa Strong, PhD, Director of Research Programs, FPWR</p> <p>Updates in research and clinical trials available to Canadians. What has FPWR Canada funded and what have we learned? Where are we now and where are we going? Why is it important to participate in the Global PWS registry?</p> <p>Levo Therapeutics Find out about a promising treatment to reduce anxiety and hyperphagia (Carbetocin) and how you can enrol in the study right here at SickKids Hospital.</p>
5:00 – 5:45p.m.	<p>Keegan Johnson (Co-Founder of FPWR Canada) A Father’s Perspective</p> <p>Keegan will share personal stories of how we got our son, Dante (14 years old) exercising daily and how we make it work. Keegan’s parenting style is unique and his positive but firm approach has led to many successes. He will share his journey with PWS and share the importance of why we need to come together as one community to “Make it Happen”.</p>