

**8th Annual FPWR Canada National Conference**  
**It's BUZZ Worthy...**

**Agenda: Saturday, May 13, 2017**

**(Location: Sheraton Gateway Hotel – Toronto International Airport)**

**Morning Sessions:**

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| 8:15 - 9:00 a.m.   | <b>2017 Conference Registration</b><br>Location: Alpine Room (Lower Level)   |
| 9:00 – 9:15 a.m.   | <b>Opening Remarks from Belinda Jones and Michelle Cordeiro</b><br>Co-Hosts, 2017 FPWR Canada National Medical Conference  |
| 9:15 – 10:30 a.m.  | <b>Dr. Theresa Strong</b><br>Ph.D., Professor of Medicine, University of Alabama at Birmingham; and Chair, Scientific Advisory Board, FPWR<br><br><b>Clinical Trials and 5 Year Research Plan &amp; Global Registry</b><br>Theresa will provide a review of the initiatives funded by FPWR. This will include an overview of newly funded studies, outcomes from previously funded projects as well as new opportunities and advances in PWS research. She will share exciting news about PWS clinical trials and the 5 Year Research Plan and what we need to do to <b>move research forward!</b> |
| 10:30 – 11:15 a.m. | <b>Karen Balko, RD BaSc and Dr. Sanjukta (San) Basak MSc, MDCM, FRCPC</b><br><b>Approach to Healthy Nutrition in PWS</b><br><br>Karen Balko, RD and Dr. Sanjukta Basak will provide an evidence based review of the nutrition approaches for management of PWS. The talk will focus on best nutrition practice as well provide a review detailing the current literature and use of nutritional supplements in PWS.  |
| 11:15 – 11:30 a.m. | <b>Break</b>   |
| 11:30 – 11:45 a.m. | <b>Dr. Jill Hamilton, MD</b><br><br><b>Growth Hormone Submission to ODP (Part 1)</b>   |
| 11:45 – 12:00 p.m. | <b>Holly Sine</b><br><br><b>Volunteer GH Working Group Growth Hormone Submission to ODP (Part 2)</b>   |
| 12:00 – 12:15 p.m. | <b>Cathy Mallove</b><br>Chair, Ontario Prader-Willi Syndrome Association Working Group<br><br><b>OPWSA Residential Options Working Group</b>   |
| 12:15 – 12:30 p.m. | <b>Holly Sine, Co-Chair OPWSA &amp; Jennifer Coens, Executive Director</b><br><br><b>Update from Ontario Prader-Willi Syndrome Association</b>   |
| 12:30 – 1:15 p.m.  | <b>Lunch</b>   |

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**Afternoon Sessions:**

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| 1:15 – 1:45 p.m. | <p><b>Carole Elkhil – Community Director</b></p> <p><b>One Small Step Presentation</b></p>   |
| 1:45 – 2:15 p.m. | <p><b>Ron Malis, B.A, B.Ed, M.B.A. Financial Advisor</b></p> <p><b>Planning for the Future, Financial Solutions for People with Disabilities and their Families – Wills, RDSP, Estate Planning</b></p>   |
| 2:15 – 3:15 p.m. | <p><b>Patrice Carroll, Manager of PWS Services, Latham Center</b><br/> <b>Lee Chamberlain, Vice President for Operations, Latham Center</b></p> <p><b>Executive Dysfunction/Oppositional Defiant Disorders/Positive Behaviour Support</b></p> <p>Patrice Carroll has been working with people with Prader-Willi Syndrome since 2000. Patrice is on the PWSAUSA Professional Providers Advisory Board and consults to providers and families nation-wide on working with people with PWS. We see common traits and behaviors in many of our kids with PWS and many of these are caused by an Executive Dysfunction Disorder. Executive processes allow us to create and carry through with goals, to self-monitor and regulate our emotions, to plan, and to inhibit our responses (think before acting). People with PWS have a deficiency in these areas.</p> |
| 3:15 – 4:00 p.m. | <p><b>Break and Networking</b></p> <p>Break off into groups, selected topics will in Recreational Respite (Petrina from Recreational Respite), One Small Step (Carole E.) and Behaviour Support (Patrice and Lee)</p>  |
| 4:00 – 4:30 p.m. | <p><b>James Noronha, Manager, Program Services, Special Olympics</b></p> <p>An introduction to the Special Olympics movement its mission and program and how it can benefit families, support friendship and allow our athletes to experience the joy of sport. The presentation will cover the history of the movement, research, the integration of health and wellness and future development and opportunities. There will be an opportunity to answer questions you may have about this important resource.</p>   |
| 4:30 – 5:00 p.m. | <p><b>Jack Jones, FPWR Canada Vice-President</b></p> <p><b>Create YOUR Buzz!</b></p> <p>Get involved! A talk about how you can create a buzz and spread the word to further research.</p>  |
| 5:00 – 5:30 p.m. | <p><b>Wrap-Up – Belinda Jones and Michelle Cordeiro</b></p>  |