



Ontario Prader-Willi Syndrome Association

Fall Family and Caregiver Conference

DRAFT AGENDA

Saturday, November 2nd, 2024

9:00am Registration

9:30am Welcome Remarks

Jennifer Coens

OPWSA Executive Director

Rob Pividor

OPWSA Co-Chair

9:45am FPWR Canada Update

Mark Joseph

FPWR Canada President

9:55am **Supporting Mental Health in PWS: Insights from the DAGSY Clinic at SickKids**

In this presentation, Dr. Louise Gallagher will describe what to expect from the DAGSY Clinic, and how the clinic is helping children and families with PWS.

Dr. Louise Gallagher

Consultant Psychiatrist and Chief of the Child and Youth Mental Health Collaborative, SickKids and CAMH

10:30am **PWS Research at SickKids**

This presentation will highlight current PWS research and trials that are currently ongoing, and will also showcase how the research studies at SickKids aim to better understand hyperphagia and social cognition in PWS.

Dr. Sarah-Marie Feighan

Research Fellow at the Centre for Brain and Mental Health, SickKids Research Institute

11:30am **The Ultimate Conundrum in PWS: Meeting Nutritional Needs When Low Calorie Goals are in Place**

In this presentation, Melinda Lamarche RD, will go over how to ensure people living with Prader Willi Syndrome and those who care for them can ensure they are getting all the nutrients they need. Especially those nutrients that are crucial for those with PWS, while trying to follow a lower calorie diet. In addition, Melinda will share some recipe and meal plan ideas that follow the RED-YELLOW-GREEN dietary pattern that many patients and caregivers are familiar with.

Melinda Lamarche

Registered Dietitian, Kindercare Pediatrics

12:00pm **OPWSA AGM – 2024 Program Recap**

Jennifer Coens

OPWSA Executive Director

12:15pm Lunch

1:00pm **Supports for Success**

This presentation will provide an overview of behavioural presentations associated with PWS, and will feature the principle of "No Hope, No Chance, No Disappointment", as well as provide some tips for learning supports, environmental safeguards and management strategies.

Radana Ulrych, B.A.,

Clinical Supervisor, Community Living Dufferin

2:00pm	<p>Parent Panel – The PWS Journey In this moderated, interactive session, a panel of parents will share their experiences and insights at various ages and stages. Hear how others have navigated challenges like family dynamics, dealing with doctors, life at school and beyond ... come prepared to ask questions and learn from one another!</p>	<p>Cathy Mallove (Moderator) Chair, OPWSA Residential Options Family Support Network & PWS Parent</p> <p>Lindsay Bouwkamp PWS Parent</p> <p>Jack Jones PWS Parent</p> <p>Mark Joseph FPWR Canada President & PWS Parent</p> <p>Natalie Wilby PWS Parent</p>
2:45pm	<p>Break</p>	
3:00pm	<p>OPWSA AGM – 2024 Fundraising Initiatives and Plans for 2025</p>	<p>Jennifer Coens OPWSA Executive Director</p> <p>Rob Pividor OPWSA Co-Chair</p>
3:20pm	<p>Family Gatherings</p>	<p>Breakout Discussions with Parents and Caregivers</p>
4:50pm	<p>Wrap-Up</p>	

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