

# Understanding Prader-Willi Syndrome and Autism

OPWSA Virtual Conference

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# What are we going to learn about today?

The core symptoms of Prader-Willi Syndrome (PWS) and Autism Spectrum Disorder (ASD)

How the core symptoms of ASD and PWS overlap and how they differ

What an evaluation for autism should consist of when the patient is diagnosed with PWS

What to do after an ASD diagnosis is made (or is not made)

# Why Talk About Autism at a Prader-Willi Convention?

Research suggests that the rate of autism is higher within PWS population than in general population

PWS and autism share some common behavioral characteristics, but have a few defining features that separate them

Special consideration needs to be taken when evaluating a person who has PWS for autism

# Prader-Willi Syndrome

- Diagnosed through genetic testing of the 15<sup>th</sup> chromosome
- Symptoms occur in phases, starting with failure to thrive as an infant
- Defining symptom is hyperphagia (obesity)
- Common traits:
  - Skin picking
  - Hoarding
  - Tantrums
  - Compulsive behaviors
  - Atypical social skills
  - Insistence on sameness
  - Speech differences
- Only PWS-specific treatment is human growth hormone



# Autism

- Diagnosed through behavioral observations
- Core symptoms relate to social-communication functioning
  - Must be present during early developmental period
  - Cause significant impairment in functioning
  - Cannot be better explained by intellectual disability or global developmental delay

# DSM-5 Diagnostic Criteria for Autism

## **A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:**

- Deficits in social-emotional reciprocity
- Deficits in nonverbal communicative behaviors used for social interaction
- Deficits in developing, maintaining, and understanding relationships
- *Specify* current severity: Severity is based on social communication impairments and restricted repetitive patterns of behavior.

## **B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:**

- Stereotyped or repetitive motor movements, use of objects, or speech
- Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior
- Highly restricted, fixated interests that are abnormal in intensity or focus
- Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment

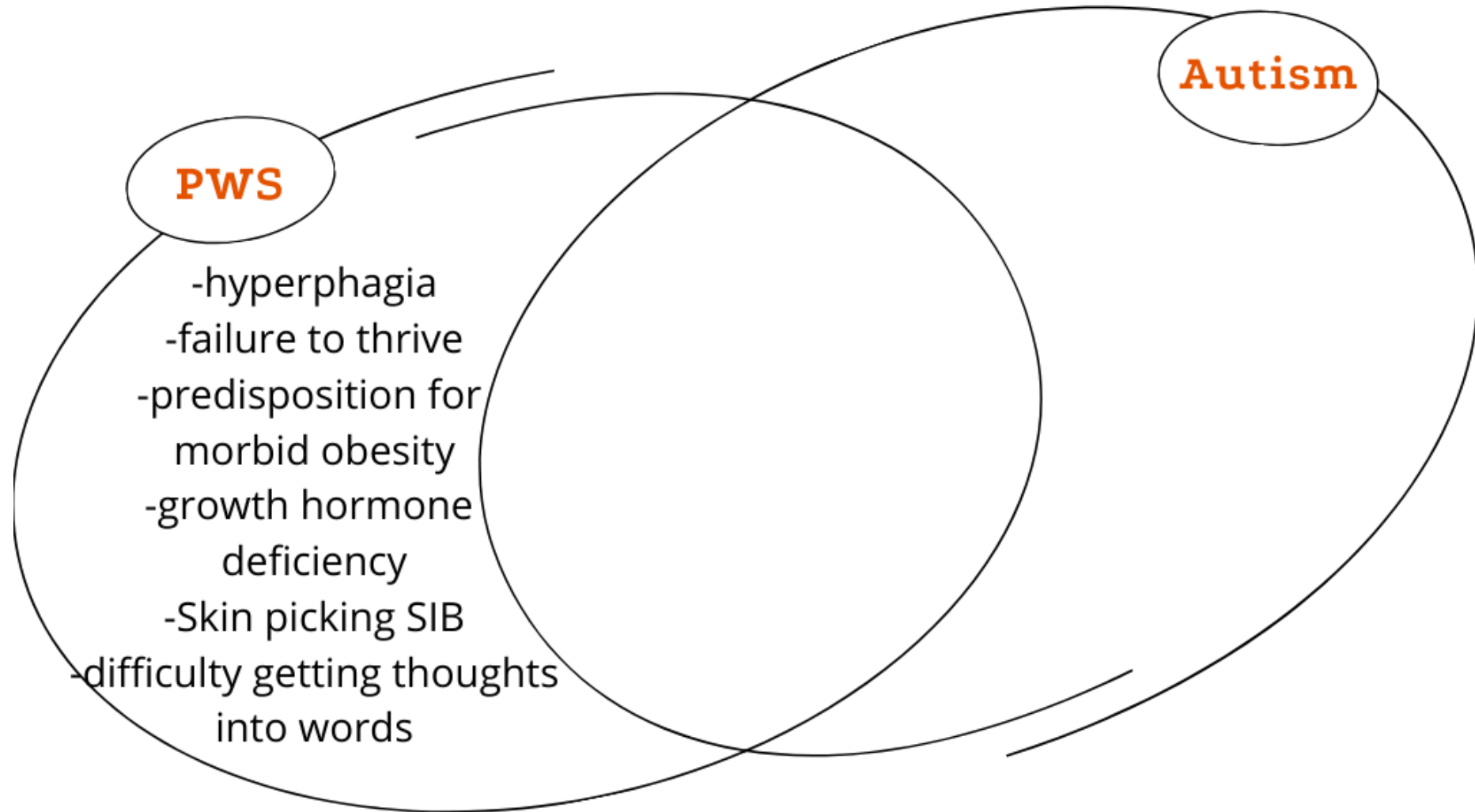
# Joint Attention!

“two people paying **attention** to the same thing, intentionally and for social reasons”

<https://www.med.unc.edu/ahs/asap/resources/about-joint-attention/#:~:text=What%20is%20Joint%20Attention%3F,intentionally%20and%20for%20social%20reasons>

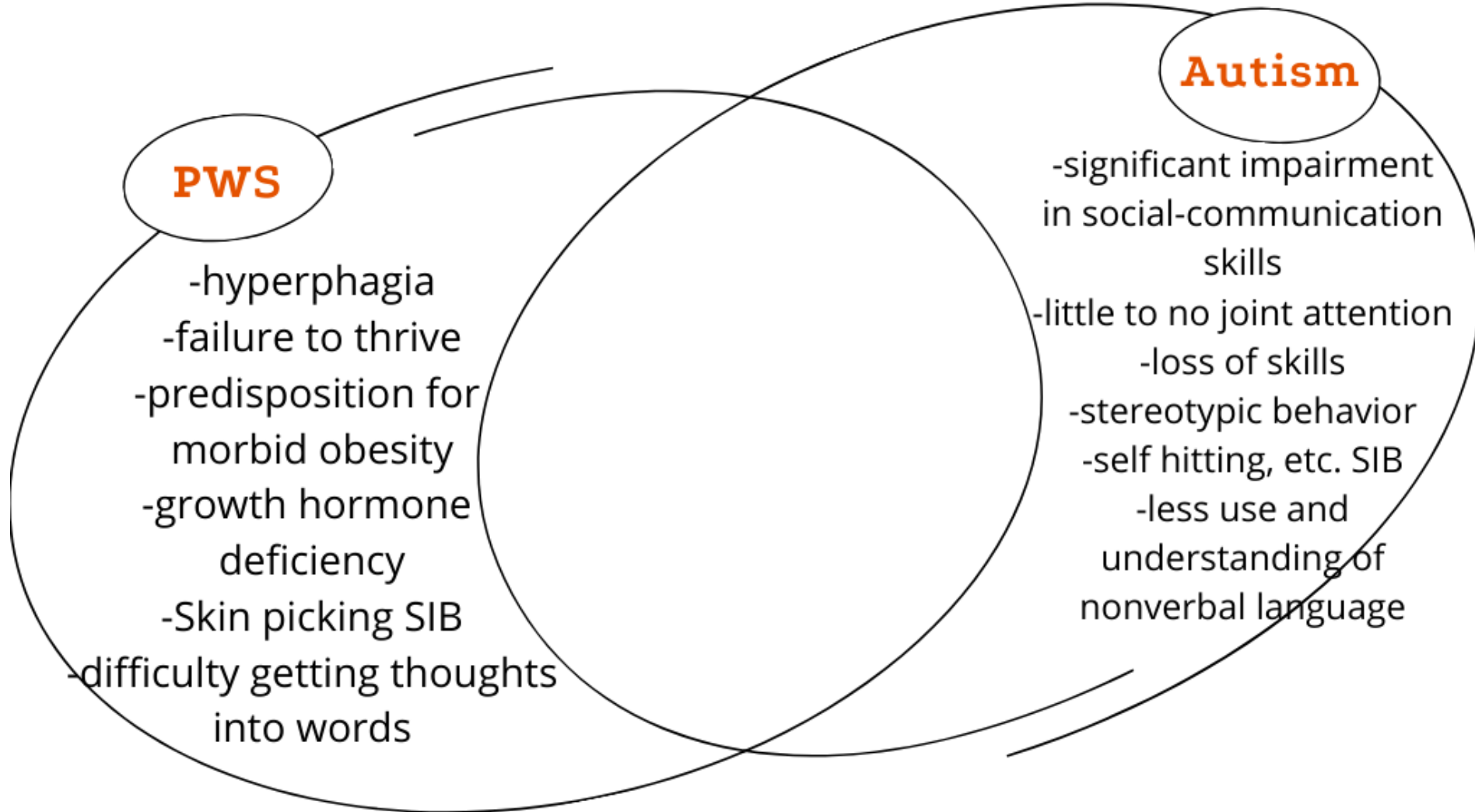


# Symptoms of PWS and Autism

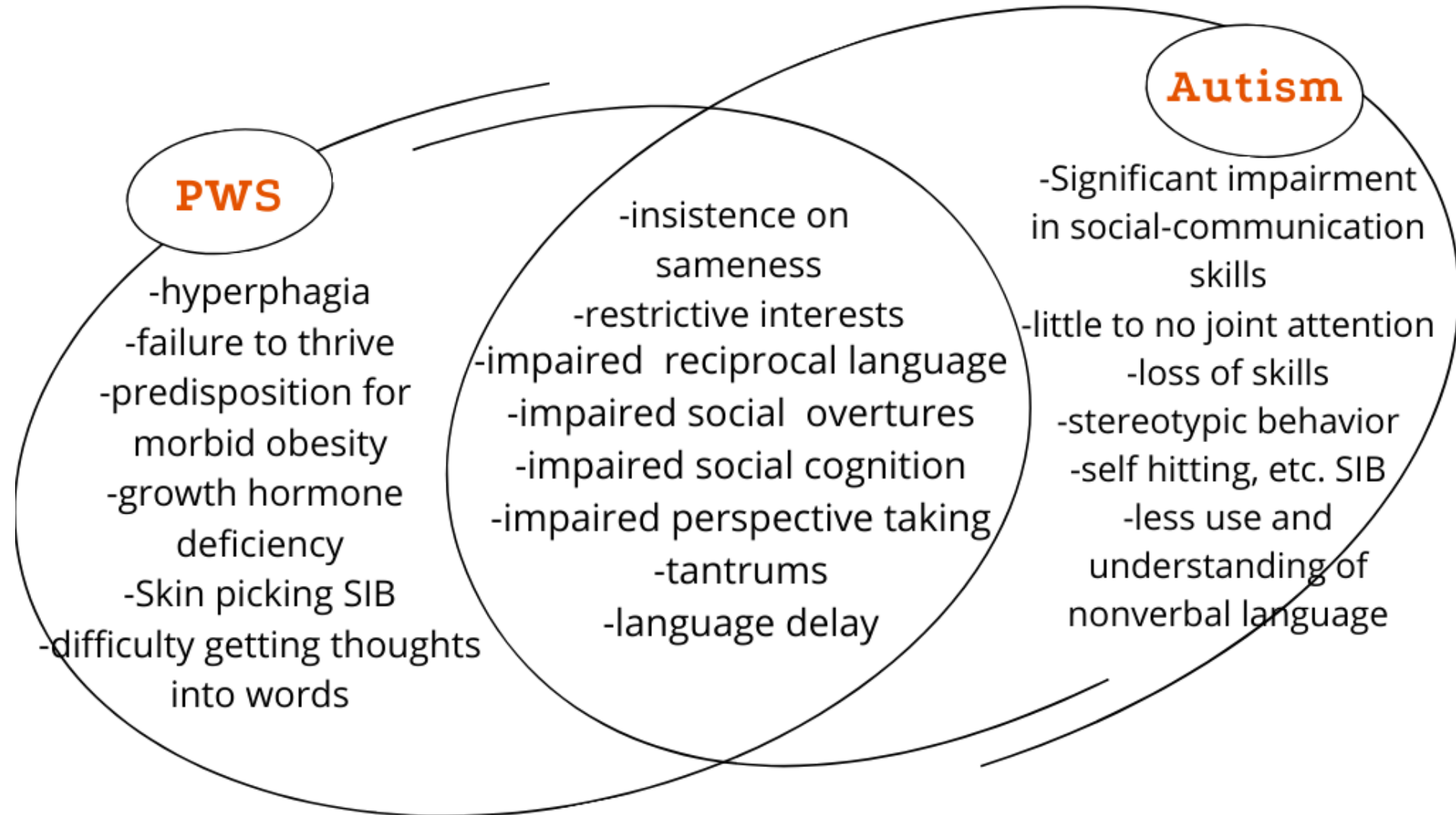




# Symptoms of PWS and Autism



# Symptoms of PWS and Autism






Given the subtle differences in the behavioral symptoms of PWS and autism, it is recommended that a comprehensive autism evaluation be completed.



*Who can diagnose  
autism?*

- Recommended that evaluation be done by a multidisciplinary team
  - A team member should be qualified to administer ADOS-2
  - A team member should be qualified to evaluate possible motor-speech disorder
- 

# What do I do if an autism diagnosis is not made?

## Review

- Review report and ask team any questions

## 2<sup>nd</sup> opinion

- Get a 2<sup>nd</sup> opinion if you feel that evaluation was not comprehensive enough

## Continue services

- Continue pursuing services you feel are necessary

## Keep eye

- Keep an eye on concerning symptoms

## Reeval later

- Consider another evaluation later in time
- research supports that autism symptoms become more obvious as individuals with PWS age

# What to know about an autism diagnosis

- A medical diagnosis is NOT the same thing as an educational classification
- You choose who you want to share the information with
- May open the doors for more services

# Sources

- Bennett JA, Germani T, Haqq AM, Zwaigenbaum L. 2015. Autism spectrum disorder in Prader–Willi syndrome: A systematic review. *Am J Med Genet Part A* 167A:2936–2944
- Dykens EM, Lee E, Roof E. Prader-Willi syndrome and autism spectrum disorders: an evolving story. *J Neurodev Disord*. 2011;3(3):225-237. doi:10.1007/s11689-011-9092-5
- Dykens, E.M., Roof, E., Hunt-Hawkins, H. *et al.* Diagnoses and characteristics of autism spectrum disorders in children with Prader-Willi syndrome. *J Neurodevelop Disord* **9**, 18 (2017).  
<https://doi.org/10.1186/s11689-017-9200-2>
- <https://www.pwsausa.org/what-is-prader-willi-syndrome/>
- <https://www.autismspeaks.org>

Thank you Elizabeth Roof for your  
guidance!



Thank you for  
your  
attention!

Questions or  
comments?



# Ontario Autism Program

The Ontario Autism Program (OAP) offers support to all eligible families of children and youth on the autism spectrum. Children and youth who have been diagnosed with autism spectrum disorder (ASD) by a qualified professional are eligible for the program. Children receive services and supports until the age of 18.

<https://www.ontario.ca/page/ontario-autism-program>

## Eligibility

To register for the Ontario Autism Program, your child must:

- be under age 18
- currently live in Ontario
- have a written diagnosis of autism from a qualified professional

Your child's written diagnosis must include:

- your child's full name and date of birth
- the date of your child's assessment
- a statement indicating that the child meets the diagnostic criteria for autism spectrum disorder
- the qualified professional's name and credentials

# Cheers to Charity



- \$10/Ticket
- 1500 Tickets Printed
- Prizes:
  - \$1000 worth of gift cards
  - \$500 worth of gift cards
  - 2 x \$250 worth of gift cards
  - 5 x \$100 worth of gift cards
  - 10 x \$50 worth of gift cards

**Raffle proceeds go towards supporting OPWSA's key programs:**

PWS Week at Shadow Lake Camp, First Trike Program, Family Fun Day, Fall Conference, free fridge locks to Ontario members, and family gatherings.

# Virtual Dance Party

- Date: Friday, November 12<sup>th</sup>
- Time: 4:30pm – 5:00pm EST
- Description:  
Michelle Hillier from Experience Groove will be hosting a 30 minute Virtual Dance Party/Wellness-Focused Movement Experience for individuals with PWS of all ages. No dance experience required! Just come and have fun!





Ontario Prader-Willi Syndrome Association

Thank You!