



Ontario Prader-Willi Syndrome Association

OPWSA AGM



WELCOME REMARKS



Ontario Prader-Willi Syndrome Association



Jennifer Coens

OPWSA Executive Director

OPWSA AGM



Ontario Prader-Willi Syndrome Association



Rob Pividor
OPWSA Co-Chair



Holly Sine
OPWSA Co-Chair

2020-2021 OPWSA BOARD OF DIRECTORS



Rob Pividor
Co-Chair



Holly Sine
Co-Chair



Colin Dickie
Treasurer

2020-2021 OPWSA BOARD OF DIRECTORS



Cathy Mallove



Cathy Shiner



Kristina MacDonald

2020-2021 OPWSA BOARD OF DIRECTORS



Lee Wigmore



Maria Fernandes



Marla Fine

2020-2021 OPWSA BOARD OF DIRECTORS



Dr. Reena Kilian

Medical Advisor



Dr. Sanjukta Basak

Medical Advisor

2021 OPWSA PROGRAMS

- 1K A Day Challenge for PWS Champions
- PWS Awareness Month
- Adventure Project for Individuals with PWS
- Back to School Campaign
- PWS Week at Shadow Lake
- Virtual Conference
- Animal Care Program
- Website Redesign & Revamp
- Fundraising Events/Initiatives
 - Toques for PWS
 - Wines Among the Vines
 - Cheers to Charity
 - CEWS Funding

1K A DAY CHALLENGE

- Ran throughout February and August 2021.
- Challenge individuals with PWS and their supporters to walk/run at least 1K A Day, or participate in 30 minutes of physical activity throughout the month.
- Those that completed the challenge received a certificate and a prize.
- Adult individuals with PWS expressed that the challenge helped keep them motivated to be physically active every day.



PWS AWARENESS MONTH

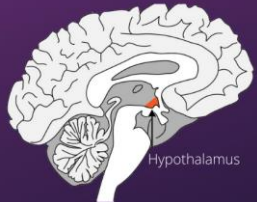
- Runs throughout May, PWS Awareness Month
- Daily “Did You Know” posts that share facts about PWS on Facebook and Instagram
- Daily PWS Everyday Challenge posts to engage individuals with PWS to participate in an activity (exercise, crafts, etc.) on Facebook and Instagram
- Shared four stories from families in our community throughout the month. The last post reached 5474 people and had 994 engagements
- Hosted Dance Party for individuals with PWS on PWS Awareness Day, Friday, May 28th

PWS AWARENESS MONTH 2021

DID YOU KNOW?

Individuals with PWS have a dysfunction in the portion of the brain called the hypothalamus, which plays a crucial role in many bodily functions, including regulating:


- ▷ Hunger
- ▷ Body Temperature
- ▷ Pain
- ▷ Emotions
- ▷ Puberty
- ▷ Fertility
- ▷ Sleep
- ▷ Fluid Balance



Hypothalamus

This Photo by Unknown Author is licensed under CC BY-NC-ND

SOURCES
<https://www.pwsausa.org/what-is-prader-willii-syndrome/>



PWS AWARENESS MONTH 2021


PWS EVERYDAY CHALLENGE

DAY 1

Day 1: Post about PWS + Walk

It's that time of year! Help spread PWS Awareness to others in your community by posting a messaging, or sharing a post from OPWSA, or by encouraging others to get involved in the PWS Everyday Challenge.

WHAT WILL YOU DO TO KICK OFF THIS MONTH?



PWS AWARENESS MONTH FEEDBACK

- Commented on various Did You Know posts shared by one of our members:
 - “I wasn’t aware the effects were as varied and far reaching. Thanks for sharing.”
 - “I’ve never heard of this before, thanks for sharing all this information.”
 - “Thank you for sharing. Before you started sharing _____’s journey, I had never heard of PWS. I always read your posts and appreciate all the information.”
 - “I think it’s great that you are sharing your journey.”
 - “Thank you for teaching all of us about your super child and her condition.”
 - “Learning so much, thanks for sharing.”
- Commented on a Did You Know post shared by PWSA NZ:
 - “Really good to get information like this which helps understanding of PWS.”
 - “Yes thank you and put very simply so people can understand.”

ADVENTURE PROJECT

- Received funding from the Government of Canada's Emergency Community Support Fund and the Toronto Foundation.
- 40 individuals were able to receive funding as a result of participating in the program.
- Many families utilized the funding to hire their own support staff to take their child out for activities or to spend time with the child so that the parents would be able to enjoy a break. While other families used the funding to purchase supplies that would assist in providing comfort for the individual with PWS while at home. Some examples included arts and crafts materials, home-based equipment like balance boards, puzzles, and weighted blankets.

ADVENTURE PROJECT FEEDBACK

- “Quite honestly this support has preserved my sanity. It's very nerve racking spending so much time in lock down. Trying to balance work and _____ - some days my patience wears thin. Without distractions _____ becomes more focused on finding food and her questions about food are relentless. On days when I'm busy at work it's almost impossible to get work done...Dropping her off at _____'s for an hour or two is a welcome break.”
- “At this very challenging time, when all _____'s programs were suspended in person or offered virtually on a limited basis, this has enabled _____ to have regular, consistent and timely engagement with his support worker. This engagement provided very important respite, as a widow and single mom, I'm working at home and unable to give _____ the attention he needs.”
- “This funding has had a huge impact on both _____ and our family...._____ always thrives on spending time with other adults. He loves to be creative and both _____ and _____ taught him some great hands on skills. He continues to knit away at his placemats and is very proud of the ornaments that he was able to make. My husband and I enjoyed having time on our own, knowing that _____ was safe and that he was being encouraged to develop new skills.”

BACK TO SCHOOL CAMPAIGN

- Ran throughout the month of September.
- Each week approximately 3-5 posts were shared on both Facebook and Instagram about tips, resources, and information about returning to school.

OPWSA Back to School Campaign 2021

Re-establishing A Morning Routine

It can be tough getting back into the swing of things, and if the morning routine for getting up and ready for school has been a challenge, it could be time to re-establish or tweak the routine.

- Start by creating a list of tasks that need to be completed before school, for example: brushing teeth, eating breakfast, etc.
- Once you have your list, you can decide on a wake-up time that will give your child ample time to complete all the tasks on their list. You may not get it right the first time, and that's okay!
- Create a visual schedule, and write down in chronological order, the morning routine tasks. There are lots of examples online!
- Make sure to incorporate positive reinforcement, such as praise, earning screen time, or some other type of reward system that works for your child.

morning routine	
<input type="checkbox"/>	get dressed
<input type="checkbox"/>	eat breakfast
<input type="checkbox"/>	brush teeth
<input type="checkbox"/>	go potty
<input type="checkbox"/>	backpack/pocket
<input type="checkbox"/>	go to school

www.laurascraftylife.com

OPWSA Back to School Campaign 2021

Individual Education Plan (IEP)

An Individual Education Plan (IEP) is a written plan describing the special education program and/or services required by a particular student, based on a thorough assessment of the student's strengths and needs. The IEP sets out the learning expectations of the student and any accommodations and services the student needs in order to meet those expectations. IEPs are curriculum based and should focus on modifications and accommodations in order to assist the student with progressing through the Ontario Curriculum. Parents/guardians must be consulted during the development of the IEP.

IEPs must be completed within 30 days of a student beginning a special education program. If your child is continuing to receive special education programming or support this year, this means 30 school days from the first day of school. The 30 school day deadline will vary, depending on the date that your child started school.

OPWSA Back to School Campaign 2021

Know Your Rights with IPRCs

- Parents are allowed to be present and share information about their child at IPRC meetings where decisions are made.
- Parents are allowed to request other people to attend the IPRC meeting with you, for example, OPWSA.
- Review meetings can be held yearly.
- Parents can give or refuse assessments that are requested by the school.
- Parents review the IPRC decision and, if they agree with it, sign it. If applicable, a specific placement offer is then mailed to the principal who will share it with the parents. The parents are then invited to visit the program before deciding to accept it.
- Parents are able to appeal a decision that was made by the IPRC.
- IEPs are mandatory if an IPRC has been done and must be in place within 30 days of the IPRC decision. However, an IPRC is NOT required in order for a student to have an IEP.

Most School Boards have a Parents Guide about IPRCs which can provide further information on the process and expectations.

PWS WEEK AT SHADOW LAKE

- Took place from Sunday, September 12th to Saturday, September 18th
- Limited numbers were allowed due to COVID-19 protocols and Shadow Lake staffing, so we had 18 campers attend
- We had amazing weather and it was so great to see folks face-to-face again!



PWS WEEK AT SHADOW LAKE FEEDBACK

- “Just wanted to give you a big thank you for all you did this week at "the best ever P-W camp"! _____ always telling me Jenn did this, Jenn did that(waited for her to catch up walking up the hill for Mayday. She told us about all the great food, which sounded way better than regular week! She was also very happy with the games, all activities you planned and the gifts she came home with(guitar and torch, etc)...”
- “I just wanted to thank you for EVERYTHING that you do to make Shadow Lake happen. _____ had a really good time and hasn't stopped talking about it since he got home yesterday. The fact that he stays the entire week without once saying he wants to come home is all the proof you need! We are already looking forward to next year ... fingers crossed!”



ANIMAL CARE PROGRAM

- OPWSA is currently exploring a pilot project around individuals with PWS volunteering at animal shelters or clinics.
- If your loved one is currently already doing this, we would LOVE to talk to you to find out more.
- If your loved one isn't already volunteering at an animal shelter or clinic, but would be interested in doing so, we'd be interested in hearing from you too.
- Roll-out of the pilot project should begin in the Spring of 2022.

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.

WINES AMONG THE VINES

- Took place on Saturday, May 22nd via Zoom
- 66 people purchase tickets
- Combination of a wine tasting, cooking demonstration and a drag show
- Raised \$2000 for OPWSA
- Feedback from the night:
 - Thank you for putting this together. We had such a great time!!!!
 - Thanks to everyone – super fun night!
 - What a wonderful event!! Sign me up for the next ones!!!! And that wine...honestly....DELICIOUS
 - Thank you for a lovely evening everyone

CREEKSIDE WINERY



Creekside Estate Winery continues to provide an exclusive wine offer in support of OPWSA

www.creeksidewine.com



- Throughout 2021, when you place an order for **ANY** bottle of Creekside wine from their website using our special code, **OPWSA2020** (all caps), **10% of your purchase will be donated to OPWSA**
- With the purchase of 6 or more bottles (mixing and matching is allowed) your wine will be delivered with free shipping in Ontario

NEW WEBSITE



Donate

About us

Resources

How we can help

Connect

Events

Blog

Contact us

The Ontario Prader-Willi Syndrome Association welcomes you!

Welcome, and thank you for taking the time to visit the Ontario Prader-Willi Syndrome Association (OPWSA) website! We're a strong community of caregivers, families, doctors, and individuals with Prader-Willi Syndrome (PWS) whose main objective is to support individuals with PWS and their caregivers through resources and education. We strive to ensure that individuals with PWS and their families live happy and meaningful lives with the support of a community behind them.



Become a member



What is PWS?



New Diagnosis



Resources



Get Involved

PLANS FOR 2022

- Instituting Executive Team to oversee the organization
- Roll-out of the OPWSA Donor Program
- Animal Care Program Pilot Project launch
- Launch of redesigned and revamped OPWSA website
- Nutrition resource development
- Continuation of existing programs
 - Family Gatherings (either online or in-person)
 - 1K A Day Challenges
 - PWS Awareness Month
 - Wines Among the Vines
 - PWS Week at Shadow Lake
 - Back to School Campaign
 - Fall Conference (in-person...we hope!)
 - Cheers to Charity

2022-2023 OPWSA BOARD OF DIRECTORS

- OPWSA is currently seeking nominations for our 2022-2023 Board of Directors.
- We are looking for people to join our Board who are passionate about their work and willing to actively participate as part of a team, impart expertise, share knowledge, and volunteer their personal time to support OPWSA programs and initiatives.
- We are accepting nominations for all Board positions and from any region in Ontario.
- In order to be considered by the Nomination and Election Committee, nominees must submit a letter of reference, and their resume along with a cover letter which indicating the Board Position they are applying for, as well as their level of interest and what they plan on contributing during their two-year term as part of the OPWSA Board of Directors.

<https://www.opwsa.com/call-for-board-members>

Virtual Dance Party

- Date: Friday, November 12th
- 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!

