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Chloe & Kim

Photo by Hilary Gauld from One for the Wall Photography

# Message from the Chair

## Welcome to Fall everyone.

On Sunday September 24th, WWDSS hosted the **Any Which Way You Can A-Thon** at Waterloo Park. This was the second year at this location and after last years threat of rain, this year, the weather was fabulous. A special thank you to Tara Hart for running this event the past 6 years. This was her last year organizing the event, and we thank her for so many great AWWYCA-thons. I know she will continue to be a very active volunteer in our organization. We are very grateful to all the volunteers, within in our organization and from the community, that helped make this event so successful. Thank you also to so many families that helped fundraise. With the support of our sponsors, families, and friends, **we raised a record breaking \$70,000.**

The "Just ask me" social media campaign and 2024 calendar look amazing. This year's campaign is focused on the challenges that some people with Down syndrome may face with communication. Thank you to all the members that participated. It was great to see so many faces showing up on my social media and to see the photos being shared. Another big thank you to Hilary Gauld at One For The Wall Photography for her beautiful photos and continued support.

On Saturday November 4th, WWDSS held a Mini Conference with a focus on health for those living with Down syndrome. Articles about the different speakers at the conference will be provided in the January newsletter.

WWDSS programs are in full swing for the Fall. **The Speech & Music Social Groups** have been running programs in Waterloo and Guelph, as well as **Teen Hangouts** and **Mom's Night Out**. The **Skills for Independent Living** continued this fall with **On My Own** followed by **SAFE - Safety Awareness for Everyone** which will begin in November. We are also hoping to have a **New Parent's Connection** group running in early winter. Stay tuned for further details.

The Christmas Party will be held at a new location this year. It will be held at Country Hills Community Centre on Sunday December 10. Once again, there will be a pizza dinner, cookie decorating, a visit from Santa, and lots of opportunity to mingle with other families. **Be sure to register for this fun event!** We look forward to seeing everyone there!

As an organization, our thoughts often go to Missing Nathan, a previous resident of the Waterloo Region. He has been missing since May 2023, with not one sighting of him. I do not personally know him but know many of our members do. I think often of Nathan, his family and friends, and hope he is found safe!

Lisa Buurma  
WWDSS Chair

## WWDSS Board of Directors for 2023-2024

<b>Chair</b> Lisa Buurma 519-577-9198	<b>Treasurer</b> Chris Cartile 519-803-5072	<b>Director At Large</b> Janice Duncan 519-578-9361	<b>Director at Large</b> Janine Rorke 519-220-1757
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<b>Secretary</b> Stacey Beattie 519-841-9494	<b>Director At Large</b> Kim Murphy 226-989-2538	<b>Director at Large</b> Arisa Alexanian 519-729-7855	

## WWDSS Committee Leads for 2022-2023

<b>Newsletter</b> Lori Murray	<b>Pizza Pals</b> Susan Powell - Older Group	<b>WWDSS World Down Syndrome Day Celebration</b> Janine Rorke, Jocelyne Bridle, Arisa Alexanian, Matt Williams, Roopa Bose, and Carla Lecourt	<b>WWDSS Christmas Party</b> Mandi Butcher
<b>New Parent Contact – Kitchener-Waterloo &amp; surrounding area</b> Gena Hiller	<b>Pizza Pals</b> Susan Lott - Younger Group	<b>WWDSS Family Picnic</b> Lisa & Ross Buurma	<b>New Parent's Connection</b> Wendy Newbery
<b>New Parent Contact – Cambridge</b> Roopa Bose	<b>WWDSS Calendar</b> Tara Hart Vanessa Richard Katrina Fraser Kate Herron	<b>WWDSS Social Media</b> Vanessa Richard	<b>Moms' Night Out</b> Janice Duncan
<b>New Parent Contact – Guelph/Wellington County</b> Vanessa Richard	<b>Therapy Bursaries</b> Alison Senior	<b>Up Side Down Charity Golf Tournament</b> Steve Nicholson	<b>Teen Hangouts</b> Steve Nicholson and Arisa Alexanian
<b>WWDSS Website</b> Steve Nicholson	<b>Transition Bursary</b> Marianne Domm	<b>Volunteer Coordinator</b> Julie Maxwell	<b>The Office Meetups (18+)</b> Lori Maloney
<b>WWDSS Store</b> Sylvia Cook	<b>Camp Bursary</b> Sylvia Cook	<b>Any Which Way You Can -A-Thon</b> Tara Hart, Sarah Kelly and Janine Rorke	<b>Independent Skills Program</b> Jocelyne Bridle
<b>WWDSS Cooking Classes</b> Vacant	<b>WWDSS Bowling Party</b> Merita Elmazi		<b>Dads' Night Out Guelph/Wellington County</b> Chris Cartile
			<b>Dads' Night Out Waterloo Region</b> Stephen Duncan, Perry Hart

## WWDSS Representatives

**CDSS Affiliate Representative**  
Arisa Alexanian

**PAAC on SEAC**  
Marianne Domm

**DSAO Representative**  
Mary Casagrande

### Waterloo Region

<b>SEAC – Catholic Primary</b> Kim Murphy	<b>SEAC – Public Primary</b> Roberta Thompson
<b>SEAC – Catholic Alternate</b> Gillian Hadden	<b>SEAC – Public Alternate</b> Jeff Senior

### Guelph/Wellington County

<b>SEAC - Catholic Primary</b> Katrina Fraser	<b>SEAC - Public Primary</b> Amber Barens
<b>SEAC - Catholic Alternate</b> TBC	<b>SEAC - Public Alternate</b> TBC

# Mission Statement

The Waterloo Wellington Down Syndrome Society (formerly the Waterloo Regional Down Syndrome Society) supports and informs individuals, families and the community on issues related to Down syndrome. We advocate for persons with Down syndrome to lead healthy and active lives enabling them to contribute their unique gifts to our community.





# Just Ask Me

by Vanessa Richard

Have you ever started a conversation with someone only for that person to ignore you and talk to the person next to you instead? Have you ever gone to a restaurant and had the waiter ask the person beside you what you want to eat? Has someone ever presumed you can't speak or understand when they speak to you? Has someone ever ignored you simply because the words you're speaking aren't completely clear? These are some of the issues that people with Down syndrome may experience when trying to communicate.

This year for our annual Down syndrome awareness photo series, WWDSS wanted to tackle the challenges some people with Down syndrome may face with communication. We wanted to touch on some of their frustrations and give some tips as to how people can make conversation easier.

This was one of our most challenging concepts to tackle yet as we struggled with communication barriers as well. Many of the quotes from this series came from the caregivers of members rather than the members themselves – for various reasons. Some due to age, some due to limitations of verbal speech, and many other reasons. Some of the quotes that were submitted from the member with Down syndrome had

been elaborated on or grammatically “cleaned up.” While we originally wanted to record most members’ quotes directly to avoid some of these issues, that in and of itself became challenging because many members struggled answering the questions on the spot. So while our goal was open communication, we still struggled in some of the same ways our members struggle with everyday conversation.

Many of our adult members indicated that people often don't speak directly to them, they speak to their friends or family who happen to be with them. Some felt like others talked to them like a baby. Others have said that people do not understand them when they speak. There is sometimes the assumption that the inability to speak or speak clearly means that they also do not have the ability to understand. This couldn't be more untrue.

Communication comes in all forms. Different languages – including American Sign Language, body language & gestures, assistive communication devices with text to speech programming, and more. Some of the amazing advice that our members came up with was to have patience with them. Ask them to repeat themselves if you don't understand them the first time – but make sure you're actively listening

when they do. Give them time. Ensure they are included and respected. They have something to say too!

The average person uses 72.52 microvolts of energy to initiate voice production, but individuals with Down syndrome need to use 131.57 microvolts to produce the same speech.<sup>1</sup> This means that people with Down syndrome use twice as much energy to form speech as a typical person. People with Down syndrome also tend to have large tongues and hypotonia (low muscle tone) – all which play into speech production. People with Down syndrome process visuals faster than they do speech, which means that they may require additional processing time to understand and form a response to a question.

So while communication may be difficult for some people with Down syndrome, the point is that they are worthy of your time and conversation. Take the time and make the effort to get to know someone with Down syndrome. I'm certain you'll find yourself better off for it. JUST ASK THEM!

Sources:

<sup>1</sup>: <https://library.down-syndrome.org/en-us/research-practice/02/3/voice-people-down-syndrome-emg-biofeedback/?fbclid=IwAR2iuvPkbUXBV5yPt4jHbSQa1pabBSVENh26fwT8W14AvEGB9uOyN0isfn0>



Waterloo Wellington  
Down Syndrome Society

# 2024 WWDSS CALENDAR



**\$10 each.**

Order online at  
[wwdss.ca/shop](http://wwdss.ca/shop)





# 2023 ANY WHICH WAY YOU CAN A-THON

by Tara Hart

On Sunday September 24th we gathered together for the second year at Waterloo Park, and this year the weather did not disappoint! The afternoon kicked off with face painting, balloon twisting and some giant outdoor games, all while sipping refreshing Starbucks beverages served by the friendly Starbucks team!

Mark Paine from 96.7 CHYM FM and our member co-host Chloe Murphy welcomed everyone, including a number of dignitaries who came out to join in the celebration. After the Buddy Choir got us warmed up we set off on the 2 km walk route up University Avenue and through the park.

We returned to the smell of the sausages being grilled by Abdi and his team, which were enjoyed with a variety of other delicious treats generously donated by

our food and beverage sponsors. After announcements we sang and danced to our favourite entertainer, Erick Traplin! It was an awesome end to an awesome event—we're so glad that so many people came out to enjoy it!

Thank you to the many amazing volunteers who worked so hard to make the Any Which Way You Can A-thon a huge success, to our generous sponsors and all of the businesses who donated prizes. Because of the efforts of all the volunteers, sponsors, member families and friends, we were able to raise an astounding \$70,000 to support people living with Down syndrome and their families! Thank you to everyone who registered to raise funds, everyone who donated, and everyone who came out to join us in celebration on September 24th. We appreciate every single one of you!

## A BIG congratulations to our top 10 fundraising teams this year:

- |                        |        |
|------------------------|--------|
| 10. Callie Delafranier | \$1960 |
| 9. Victoria Foster     | \$2305 |
| 8. Emmie Warren        | \$2595 |
| 7. Noelle Hart         | \$2905 |
| 6. Everett Kocher      | \$3840 |
| 5. Kate Buurma         | \$4050 |
| 4. Dadyar Yasin        | \$5000 |
| 3. Faye Kraemer        | \$6350 |
| 2. Kailyn Murray       | \$6920 |
| 1. Michael Nicholson   | \$7445 |

I am so thankful to have had the opportunity to plan this wonderful event for the past six years, and I am thankful for those who went before me and to those who will be taking it over. It's truly incredible to see what we can do when we all work together.





Any which way  
**you can A-thon**  
 Waterloo Wellington Down Syndrome Society

## Thank you to our Event Sponsors!

### Platinum

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 Collaborate. Empower. Succeed.

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 Andrea  
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 ZEHRS (CONESTOGA BLVD CAMBRIDGE)  
 ZEHRS (FRANKLIN BLVD CAMBRIDGE)  
 ZEHRS (HOLIDAY INN DR CAMBRIDGE)







# Teen Hangout

by Arisa Alexanian

In September, our teens got together to reconnect after the summer. We shared some yummy pizza from Pepi's Pizza and lots of laughs.

We then spent the evening picking our favourite songs to sing karaoke style and could be heard belting out the tunes with some pretty fancy dance moves for the next few hours.

Taylor Swift would be proud of the moves our teens were showing off to "Shake it"!

Stay tuned to your email for info on our next get together in November.

## WWDSS Teen Hang Out Event

Join us for a fun gathering of virtual reality, pizza, drinks and tons of fun!

**DATE** Saturday November 11  
**TIME** 4:50 - 6:30 pm  
**WHERE** CTRL-V Virtual Reality  
**COST** \$10 per person  
 (subsidized by WWDSS)

Pre-register by November 5 to secure your spot.

Support workers will be present and parents are not expected to stay.

REGISTER AT: [www.wwdss.ca/event](http://www.wwdss.ca/event)

# BUDDY CHOIR is back in person!

Buddy Choir was happy to perform at The Any Which Way You Can A-thon! We continue to meet every Monday from 6:30 pm until 8:00 pm at Forest Hill United Church 121 Westmount Rd East Kitchener.

*In January we will be moving locations for our rehearsals to 109 Studio B Ottawa St. S Kitchener!*

Buddy Choir is for anybody who loves to perform and share a vision of inclusion.

**Please join us!!**





# Our Studio

by Ren Franklin, Madeline Young, Twyla Fliestra,  
Alison Ashford, Ryan Steel and Andy Skopec

Our Studio Tuesday Entrepreneur group would like to thank WWDSS for giving us the opportunity to sell our butter tarts at the Any Which Way You Can A-thon!

We sold almost \$700 worth of tarts! After figuring out our expenses we shared our profits and were happy to donate \$120 to WWDSS to help towards your fundraising efforts.



The Office continues to meet biweekly on Zoom. We have decided to change our meetings up and meet in person more regularly. Here is our schedule until Christmas.

Date	Activity	Location/Leader	RSVP By
October 24	Karaoke Party	205 Victoria St S, Kitchener, ON N2G 4Z7	
November 7	ZOOM Meeting	Telisa Schmidt Leader	
November 21	Movie Night	Galaxy Cinemas Waterloo	Nov. 14
December 5	ZOOM Meeting	Kristin Nielson Leader	
December 19	Dinner Out	Crabby Joes in Waterloo for The Office and family members	Nov. 1

# New Upper Grand District School Board representation

by Amber Barens

My name is Amber Barens and I'm the Special Education Advisory Committee (SEAC) representative for Upper Grand District School Board: Primary. I have a seven year old daughter named Kimberly with Down syndrome who is in grade 2 and a four year old son named Aiden who just started JK. I am very new to the SEAC role and have no previous experience or knowledge but intend to learn as much as I can. I wanted to become a SEAC member because I felt like it was one of the best ways I could advocate for our kids and make a positive difference in their lives. I am very excited to work with the school board and families, to help them find the next step or answers that they need and also to share what we do in this wonderful organization.

# Waterloo Catholic SEAC Report

by Kim Murphy

At our Sep 6/23 meeting we received a presentation from the Senior Manager of Equity Services, Lynn Garrioch. We reviewed the WCDSB equity website at <https://www.wcdsb.ca/equity-diversity-and-inclusion-webpage/> and also learned about the resources available to staff at the board staff. We also discussed revisions to the WCDSB SEAC Brochure.

At our Oct 4/23 meeting Erin Lemak, Principal of Student Services & Education and Community Partnership Programs reviewed the Special Education Plan and the Special Education PS Plan for the year.

### WWDSS WCDSB SEAC Representatives:

**Primary:** Kim Murphy

**Alternate:** Gillian Hadden

As your SEACs Representatives, we are available as a resource for parents and as a voice for concerns related to our children.





Waterloo Wellington  
Down Syndrome Society



# CHRISTMAS



**Come and enjoy Socializing,  
Santa, Pizza and Snacks.**

Anyone who wishes to attend must sign up on the events registration page of the WWDSS website (this will be available in early November).

Registration is mandatory so that organizers can account for food and any dietary needs.

**Keep an eye on your email for more info.**

**Calendars, merchandise  
and door prize tickets will be  
available for purchase.**

**Date** Sunday Dec. 10, 2023  
**Time** 2:00 pm to 5:00 pm  
**Location** Country Hills  
Community Centre  
(100 Rittenhouse Rd.,  
Kitchener)



# Mother's Night Out

By Janice Duncan

On Friday October 13, 2023 the Mother's Night Out Group met at Market Sports (800 King St. N Waterloo). We braved the cool night with some light conversation & laughter (trying to get the golf ball into the hole). At some of the holes we felt like we were putting in the dark. The 18 holes that we played included lots of obstacles and elevation challenges. Perfect for arranging another day & time for mini golfing but I will arrange when the weather is much nicer.



## Save the date

### Skills for Independent Living Program

November 9 - December 14

S.A.F.E. Safety Awareness for Everyone

### Moms' Night Out

November 16: Zoom conversation

November 30 or December 8:

Dinner at Del's Italian Kitchen

### Mother's Connection - TBA

### Teen Hangout - November 11

### Christmas Party - December 10

### The Office - November 7, 21 - December 5, 19

### Speech & Music Social Group (Guelph) -

January 13, 27, February 17, March 2, 16, 30

### Speech & Music Social Group (KW)

See insert for dates.

# Meet our new WRDSB SEAC Trustee: Carla Johnson

by Roberta Thompson

I have had the pleasure to meet and sit at the Waterloo Region District School Board (WRDSB) Special Education Advisory Committee (SEAC) table with Trustee Carla Johnson. Carla is a passionate advocate for students with diverse needs. She adds a unique perspective to the Trustee Board, she is neuro divergent and has close family members that have learning disabilities. She understands the challenges that we face and welcomes conversation. Our monthly meetings cover topics from ableism, school funding, student support, to name a few, and through these discussions Carla has offered knowledge based perspective and real life - lived examples. We are very fortunate to have this strong and knowledgeable voice to represent SEAC on the Board of Trustees.

### Carla Johnson

Municipality: Cambridge / North Dumfries

Phone: 226-753-7292

Email: carla\_johnson@wrdsb.ca

**A note from Carla:** It is truly an honour to serve Cambridge & North Dumfries as a Trustee. The WRDSB was my employer for my career as a middle school teacher. I have seen firsthand how vital our public education system is to our whole community. I look forward to championing all the creative and genius things happening in our schools. In spite of the many challenges these last few years, teachers and education workers continue to bring compassion and creativity to their classrooms every day. Our schools embrace every student that walks through our doors and nurtures the intelligence and growth of each individual. I will listen closely to our community and advocate for the needs and concerns. Together, we have the crucial job of preparing our students to be astute leaders for the future and I am very proud to be a partner in this great work.

**Please remember to reach out to your SEAC representative so that we can advocate for our families. Your identity would not be shared, we present general challenges and questions from families that one or more family may be facing. Also, if you are having difficulty, or would like to talk something over please reach out. You can make initial contact via the [info@wwdss.ca](mailto:info@wwdss.ca) webmail, and we will get back to you.**



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