Canada's Down Syndrome Magazine

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ISSUE #18

Strength in Numbers:
Exploring Canada's New Down Syndrome Population Study

U-TURN:
Down Syndrome Regression Disorder

The Mindsets Study
Promoting Health and Cognition Through Exercise

Informing is Caring
Information Practices of Canadian Caregivers

Bridging the Knowledge Gap

Plus: **Busting Down Syndrome Stereotypes Community Q&A**

3.21 Canada's Down Syndrome Magazine is a joint publication of

Canadian Down Syndrome Society | Société canadienne de la trisomie 21

Down Syndrome Resource Foundation

In this issue of 3.21 Canada's Down Syndrome Magazine

As researcher Kim Hughes says, "Informing is Caring."

Most families who have a child with Down syndrome begin their journey with little knowledge about Down syndrome. Each step brings them into new terrain, with unfamiliar complexities and systems to navigate on the way to a fulfilling, rewarding life.

We live in a time when more research than ever before is being conducted on Down syndrome and related issues that impact quality of life. However, it can take a long time for the latest information to trickle down to families, where it can make a real difference.

In this edition of 3.21, we aim to bridge this knowledge gap. Within these pages, you'll hear from several professionals who will share their findings on crucial issues including Down syndrome population metrics and its impact on healthcare, Down syndrome regression disorder, and the information practices of Canadian Down syndrome families. In addition, CDSS shares the results of our recent Mindsets study on health and fitness for people with Down syndrome.

Knowledge is power, and we hope this issue will empower you and your loved ones to make your journey the best that it can be.

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Drop us a line and share your article ideas at 321DSMagazine@gmail.com.

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U-TURN:
Down Syndrome Regression Disorder

An Interview with Dr. Jonathan Santoro and Dr. Eileen Quinn

This article is adapted from Season 6, Episode 2 of The LowDOWN: A Down Syndrome Podcast. To listen to the full conversation and access related resources, visit DSRF.org/podcast.

We don't often have breaking news that causes a major stir in the Down syndrome research community, but Dr. Jonathan Santoro and Dr. Eileen Quinn have done just that with their cutting-edge research into Down syndrome regression disorder.

There has long been a recognized phenomenon in which some people with Down syndrome regress in certain areas, seemingly losing skills they had previously mastered. Reported incidences of regressive episodes, which happen at an earlier age than that at which early onset dementia typically becomes an issue, are on the rise, particularly since the COVID-19 pandemic.

As a result, regression in people with Down syndrome is currently receiving a great deal of attention in medical literature, and Drs. Santoro and Quinn are at the forefront of that work. Dr. Santoro is a pediatric neurologist with special training in inflammatory and demyelinating disorders of the brain, spinal cord, and peripheral nervous system. Dr. Quinn, whose younger brother Danny had Down syndrome, is a developmental pediatrician. She is also mom to a 25-year-old woman with Down syndrome.

Hina Mahmood and Marla Folden, hosts of The LowDOWN Podcast, recently sat down with Dr. Santoro and Dr. Quinn to learn more about Down syndrome regression disorder.

Hina: Can you please start by defining regression for us?

Dr. Quinn: Regression is just a loss of previously acquired skills. There are a number of different areas that people can have regression in. It can be in the activities of daily living; people's ability to take care of themselves and wash and dress and that sort of thing. You can also have regression in language and communication, or in motor skills, memory, or behaviour.

Marla: Is regression inevitable in Down syndrome? Does everybody go through regression?

Dr. Santoro: Not necessarily. An important piece when it comes to regression is, when is it happening? In the first ten years of life, regression is often associated with autism spectrum disorder, whereas later on there seems to be this regressive phenomenon in the early teens in females, and right around the onset of puberty in our male patients. The term autistic regression has been used for a long time, but we know that autism doesn't suddenly develop in the teen years. Meanwhile, regressions on the other end of the age spectrum are more related to Alzheimer's disease. So, we are focused on this surprising phenomenon that cannot be attributed to either autism or Alzheimer's.

Marla: When should a parent wonder if regression is happening?

Dr. Quinn: Any child can have good days and bad days. You think they've mastered something, and then suddenly they forget all the words that they used to be able to read. That kind of ebb and flow is pretty normal. I think the time to really be concerned is when there's a substantial change

Kaleigh's Journey

By Cindy Harasen

We are a family of five living in rural Thunder Bay. Kaleigh, our youngest, has Down syndrome. She is now 18. She has always been and still is the joy of our lives. It has been a delight to raise her and watch her grow and thrive. She has always been a sassy dynamo: chatty, energetic, and athletic. She has been incredibly healthy and we have often said that she is the healthiest one in the family. She has accomplished great things as a Special Olympian, cheerleader, model, and actress.

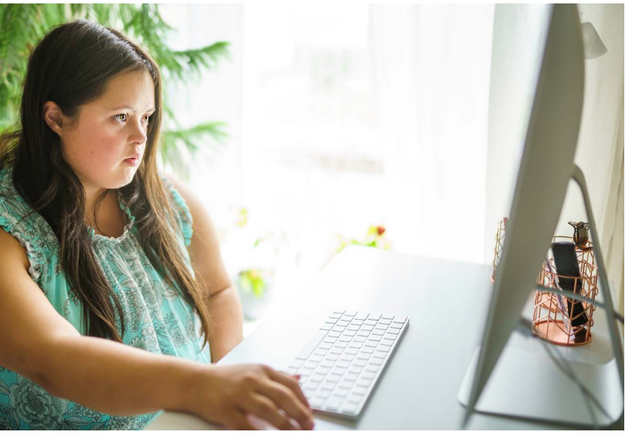
Suddenly, in the spring of 2021, everything changed. Kaleigh's self-talk escalated to the point that it was almost constant, and it began to get harder and harder to connect or get her to engage. She lost focus when doing school work. Her imaginative play escalated and took on an increased intensity. Her love of music and theatre made it seem like a natural progression, but we can look back now and see that there were times when it was often crossing the line into delusions, including obsessive and compulsive writing, and some of her interests were becoming more like obsessions.

Next came the OCD and the inability to touch or turn doorknobs, or open car doors, and eventually the inability to touch anything at all without her hand being wrapped or covered with rubber gloves. She started to have some trouble speaking. Soon after that she began experiencing acute insomnia and her

that doesn't get better in a week or two, especially if they start losing more skills and it really starts to affect their daily life and interfere with their ability to do the things that they used to do.

Dr. Santoro: I tell a lot of families, if your mom and dad radar is going off, that's the time you should be contacting your doctor. There's no set timeframe of ten days, seven days. You know when something's off and those activities of daily living are just evaporating before your eyes.

Marla: We know that autism occurs more frequently in people with Down syndrome, but as you said, the signs of autism typically show up early in childhood (even if the actual diagnosis comes later). We don't typically expect to see autism symptomology appearing for the first time in that 10-20 age range, so if you're seeing a regression or a skill loss in this age group, it typically means something different. Is that what we call Down syndrome regression disorder?



Dr. Quinn: People with Down syndrome can have a milder degree of regression in many areas, and it's important for families to be aware of the different medical conditions that can cause this. If people start to see a change in their child's behaviour or their ability to do things, the first step is to make sure that they are up to date on all the recommended screenings, and consult with their physician about what might be causing the change. We know that things like hypothyroidism, sleep apnea, and other medical conditions that people with Down syndrome are predisposed to can cause changes.

People with Down syndrome, even if they're verbal, may have difficulty expressing what's going on. They might have trouble locating sources of pain or discomfort, and instead of telling you about it, you'll notice a change in their behaviour or skill level. So, you want to screen for thyroid problems. Is he having symptoms of celiac disease? Is he up to date on his vision and hearing tests? You need to rule out these physical issues that can feed into changes in behaviour.

Dr. Santoro: Down syndrome regression disorder (DSRD) is really a diagnosis of exclusion. Our workup is not to diagnose DSRD; our workup is to rule out other explanations for it. What are the common things in persons with Down syndrome, and can we rule them out?

What makes DSRD unique is that symptom onset tends to be pretty quick. We go very quickly from high function to, oh boy, what's going on? Why can't you toilet independently? Why can't you do all these other tasks that you've been able to do in the past? And it happens over the course of a few weeks. In our new consensus criteria that was just released last month, we used a 12-week guideline. It's not the slow decline that we see in Alzheimer's disease or autism spectrum disorder.

THERE ARE EIGHT CORE FEATURES THAT WE LOOK AT:

1. **Altered mental state or behavioural dysregulation:** It can be things like confusion; it could be inappropriate laughter; it can be changes in eating habits: everything from anorexia and not wanting to eat and losing quite a bit of weight, to hyperphasia, just nonstop eating, and mom and dad have to lock the fridge.

2. **Cognitive decline:** This can be things like apathy or an unwillingness to engage with family members and loved ones. A lot of patients will just kind of sit in their room and not do anything in the early stages of the condition. Often there can be either a memory impairment or decreased processing speed, where you'll ask a question and you can tell the gears are turning, but there's not really a response.

3. **Social withdrawal:** This includes the inability to perform the activities of daily living, and increasing rigidity around routine. Having to leave the room may provoke tantrums or aggression. There may be a decrease in eye contact and engagement with others, and it may just seem like they're not enjoying things. We've had many families say that their loved one is just kind of cruising through the motions, which is hard because so many of our young persons with Down syndrome are very animated, life-loving individuals. This is often the most dramatic change that brings people in for care.

4. **Focal neurologic issues:** This could manifest as weakness, sensory changes, or seizures. If you see any of these things, you've got to take the express lane to get evaluated.

5. **Sleep problems:** We see quite a bit of insomnia and circadian rhythm disruption. Insomnia often surfaces very early in the disease process; people will just stop sleeping or drop down to two hours of sleep a night.

6. **Language deficits:** It can start as whispered speech, and then progress to decreased verbal output. In many situations, it will go on to full mutism and not being able to communicate at all, and it crosses domains: not just expressive language but also their ability to point, gesture, or sign.

7. **Psychiatric symptoms:** We'll see anxiety, depression, a lot of OCD. And not the type of OCD where they have to touch the doorknob 50 times before they leave the house, or hyper cleanliness. It's really about rigidity and having thoughts that are just trapped in this circuit. Very often there's a fixation. Sometimes it'll be on a Disney movie or a particular show that they like, but because it's such a repetitive loop, they're almost in that other world, as opposed to the world that they're actively surrounded by.

8. **Movement disorder:** Often this will be catatonia; we see this in about three quarters of our patients. We'll see slowed movement – it almost looks like somebody who has Parkinsons; they'll just kind of shuffle along the hallway floor. We'll see freezing behaviour: we'll ask the person to take a turn, and they kind of clam up and they can't actually initiate that.

behaviour escalated into psychosis (delusions, hallucinations). That summer, she had a complete psychotic break that lasted about 48 hours. It was the first time in my life I had ever called a crisis hot line. We ended up at the emergency department.

Over the ensuing months, many tests led to dead ends. Meanwhile, Kaleigh was catatonic and barely left the house, and was now spending her days in our bed and needed assistance with eating and dressing. The psychosis stopped her from sleeping some days. She wasn't speaking. Some days she whistled. Some days she whispered. Some days her voice only worked in a high pitch whine. There were days and nights when she was in such distress, crying out like an injured animal caught in a trap. Her OCD was intense. We weren't able to touch her, hold her, or hug her. She had packed up all of her belongings and we had to move them out of the house. She was being instructed by voices to move to Brooklyn. They were telling her that we were bad people, instructing her not to take her meds and not to trust us. She refused to use her name and for months went by Vanna; for months she didn't leave the house without a Vanna name tag around her neck.

Losing your child to this diagnosis is devastating and gut wrenching. You are helpless. You lose your child (and for our other kids, their sibling) and are grieving that loss and wondering if she will ever come back, while caring for her and loving her as she is now, and all the while doing as much research as you can to find answers and to feed information to your doctors. And you still have other children and other obligations, and those don't stop. We have screamed, prayed, cried. Crying ourselves to sleep became the norm.

Thanks in large part to Drs. Santoro and Quinn, along with our local team, Kaleigh is now stable. We are incredibly grateful that Kaleigh is doing okay right now, but we can't fall into complacency, and we can't accept 40% from baseline or even 50, 60, or 70%. She deserves to be the best she can be, and we will do whatever it takes.

That's a lot of symptoms, but if you're seeing more than two or three of them, that's an indication that you should get your child in for evaluation.

Marla: That's a hard list for families who are experiencing that. It must be very scary for families who are going through that.

Dr. Quinn: My daughter Sara had a full-blown regression 11 years ago. For us, and in my experience in speaking with other families, I think this is common, the sum total of all those symptoms is that your child is gone. The child that I knew, who was the light of my life and made me laugh out loud every day, was just totally different. I even say it was like Sara died and I didn't have time to mourn her because I had this belligerent stranger in my midst that I had to deal with. It can really be a very catastrophic thing to happen to families. I have families that say their life is divided into pre-regression and post-regression eras.

Hina: A lot of families first started noticing signs of regression during COVID. What are your thoughts on the impact that something like a pandemic can have in triggering regression?

Dr. Quinn: Well, we know people with Down syndrome like their routines. And the majority of them like to be social and they like to be out in the community. The pandemic was very difficult for many people, including those with Down syndrome. That type of stress on them might be the thing that kickstarts regression. As with many conditions, this could be a case where the person has a biological predisposition and then an environmental trigger makes it happen.

Dr. Santoro: To steal from psychiatry literature, the concept is called diathesis stress. You're already predisposed to develop, let's say this autoimmune disease or regression in general. And there's just something that tips you over the edge. If you go into other neuroimmunology literature, this is quite frequently reported. So many patients, for instance, who have multiple sclerosis, their first attack will be preceded by some life stressor. And it's not that the life stressor is causing their multiple sclerosis, it's giving their body that final push off the cliff to actually develop the clinical symptoms.

Hina: How prevalent is Down syndrome regression disorder?

Dr. Santoro: I wish I could tell you. This is still the wild west. Historically, I think a lot of individuals with regression didn't get the name. It was just labeled as early onset Alzheimer's, or it was just seen as part of Down syndrome. Now that we've come up with formal terminology and developed an assessment tool to help physicians identify it, people are coming out of the woodwork saying they've had the symptoms for a long time and they just didn't know what it was. It's similar to what happened with autism in the early 2000's: once we finally had a name for that condition, the rates of autism went up, so to speak. But in reality, we were only now able to actually capture these. I think that it's still rare, but we really don't know how many patients are out there with this.

Hina: Moving into treatment options, how can families help their loved ones?

Dr. Santoro: If all other causes are ruled out and the final diagnosis is DSRD, there are a variety of different therapeutics. It's very symptom specific. As more patients have come over to our clinic, we have utilized all sorts of different treatment modalities. It's often a matter of trying different things until we find something that works for the patient. It's common for an individual to be on multiple different therapies at the same time to address various symptoms.

Hina: You've seen some very encouraging results. 50% of the people in your current cohort are regaining some of their lost skills. What are your thoughts on recovery?

Dr. Santoro: It's variable. We've seen efficacy from as low as 10% improvement for some patients all the way to probably 95%. I think families are very hesitant to ever say one hundred percent, but we get many patients close. I would say our median is probably about 60-75% return to baseline. And that's when we add on symptomatic treatments to see if we can push people a little bit closer to their prior functional statuses. The more research we do, the more these outcomes will improve.

Since this interview was conducted, an expert consensus paper on the now named Down Syndrome Regression Disorder has been published, along with another recent paper on the use of immunotherapy as a treatment option and related protocols. A multi-partner double blind study that is furthering the understanding of this disease and providing vital insights into treatments is currently in progress in the US. A closed Facebook group and public Facebook page (started and overseen by Dr. Quinn) provide support and information to families around the globe. If you are concerned that your loved one with Down syndrome is showing signs of regression, please speak with your physician.

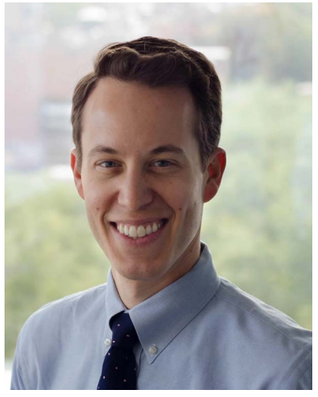
The child that I knew, who was the light of my life and made me laugh out loud every day, was just totally different. I even say it was like Sara died and I didn't have time to mourn her because I had this belligerent stranger in my midst that I had to deal with.

Strength in Numbers:

Exploring Canada's New Down Syndrome Population Study

By Courtney Cassel

CDSS had the chance to speak with leading Down syndrome researcher and Director of the Down Syndrome Program at the Massachusetts General Hospital, Dr. Brian Skotko about Canada being the new country of focus for his ongoing global research into population and birth rate numbers for individuals with Down syndrome.



Courtney Cassel of CDSS: Can you tell us a bit more about your research project into population numbers for individuals with Down syndrome?

Dr. Brian Skotko, M.D., M.P.P: Well, you know, 'if you don't count, you don't matter,' as the phrase goes, and it's been really important to my colleagues and I over the past almost decade now to make sure that we stitch together the most current, accurate numbers that are out there to come up with estimates of people with Down syndrome. People have asked, how many people with Down syndrome exist in this country? Or how many people with Down syndrome are born? Or how many people with Down syndrome are electively terminated? And for us to have accurate conversations, for us to make accurate policy decisions, we need to make sure that those are grounded in - as much as possible - accurate estimates, so that we can all be having a conversation centered on those facts.

So with that, I reached out almost a decade ago to someone who wrote a seminal paper, Gert de Graaf - he's a great guy, and I said, 'I read your research paper and I'm a big fan.' And he wrote back saying, 'Well, I've read some of your research papers, let's talk!' And so Gert and I got together and started talking and then we pulled in our colleague, Frank Buckley, and we have been meeting every month for the past, I don't know how many years, at least close to eight plus. We've had no funding for any of the research that we do, we've done all the work out of passion, and we decided to take on the challenge of collecting data from around the world to be able to come up with these estimates.

I have to make sure I give enormous credit to Gert de Graaf. He is a researcher from the Netherlands and also had a child with Down syndrome, and he's involved in the Dutch Down Syndrome Foundation. Gert has been crunching the numbers and running models and has taken this on as a passion project, and together the three of us, we've brought in additional colleagues based on country specific or paper specific projects. We've been able to proudly publish studies for the United States, Europe, Australia, and New Zealand so far.

Estimates of number of people with Down syndrome in Europe by country, 2015	
Western Europe	**103,220**
Austraia	4,675
Begium	5,645
France	35,064
Germany	40,350
Luxembourg	228
Netherlands	13,353
Switzerland	3,905
Southern Europe	**89,807**
Albania	674
Bosnia and Herzegovina	1,192
Croatia	1,568
Greece	7,283
Italy	36,805
Malta	418
Montenegro	248
Portugal	6,155
Serbia + Kosova	2,756
Slovenia	666
Spain	31,564
TFYR Macedonia	479
Northern Europe	**68,271**
Denmark	2,875
Estonia	493
Finland	4,046
Iceland	205
Ireland	6,442
Latvia	871
Lithuania	1,354
Norway	3,512
Sweden	6,692
United Kingdom	41,781
Eastern Europe	**97,766**
Belarus	3,852
Bulgaria	2,180
Czech Republic	2,285
Hungary	2,610
Poland	17,706
Republic of Moldova	1,583
Romania	4,414
Russian Federation	51,387
Slovakia	1,765
Ukraine	9,983

https://buff.ly/49cvpa2

So now, people with Down syndrome do count, and they do matter in those countries, and we've been able to estimate the population prevalences there from a long time ago, 1950s up until now. And so it was with that, we said, 'Now that we have those countries under our belt, where else can we go exploring?'

And that's when Gert and myself reached out to the Canadian Down Syndrome Society to see if they would partner with us to see if we could apply the model and do something similarly for Canada.

Courtney: I can't imagine how many hours - how many hundreds and hundreds of hours - have gone into the research over the years.

Dr. Skotko: I have to say, of all the research papers that I have written, some of them get a lot of grant funding and make a difference, but this is a project that has had no funding and has had some of the most important contributions. So these papers are among the papers of which I'm most proud.

Courtney: You've named the countries that you've done the study for already, what was the selection process like for that? Was it mainly based on where you were finding collaborators?

Dr. Skotko: So we started with the countries of our interest. I'm here in the United States, Frank is based in the UK, and Gert is based in the Netherlands. So we decided to tackle Europe and all the countries in Europe, which was a major, major endeavor. Then after that, we had a colleague who was in Australia and we had access to some data in Australia and New Zealand. So we went there. Now next on our list is Canada.

In order to be able to do this project, several things need to be in place. One is surveillance data to be accessible and available. So, if a country doesn't collect surveillance data on live births with Down syndrome, then it is hard to get started. So, the country needs to have that data somewhere. Number two, if they have the birth surveillance somewhere, we need to be able to access it. Is it locked behind governmental doors that no one can pry open? Or through appropriate mechanisms, is that data, if not publicly available, able to be gotten? And then number three, it's always helpful to have a local partner within the Down syndrome community who is able to know the country and be able to serve as a liaison, if you will, to make those connections, help us get that data, and then help us make sure that the paper is situated within a cultural context. So all three of those ingredients we believe are in place for Canada, and that's why we're excited to go there next.

Courtney: We fully support the value of finding updated, accurate numbers, especially considering some of the numbers we currently work with we now know to be inaccurate.

Dr. Skotko: I think that our predecessors did their best in making an educated guess, but thanks to Gert's scientific and mathematically sophisticated modeling, we can do better, and we can be more precise, but the data that the model produces is only as good as the data that we have access to. And so that's why we're very grateful for being able to find the data that countries have been collecting, identify the data specific to Down syndrome, and then really make good estimates.

Courtney: Beyond population numbers, what other data is being collected?

Dr. Skotko: I wanted to mention that one of the other big ticket items that we have been able to bring some mathematical clarity to is the number of babies with Down syndrome that are being born over time, and consequently the estimated number of selective terminations or abortions related to Down syndrome, and ultimately the changes - if any - to the overall population of people with Down syndrome. So to break that down, every year we have babies that are born, babies that are naturally miscarried, and then we have fetuses and pregnancies that are selectively terminated after a pregnant person gets a prenatal test and decides not to continue the pregnancy based on the diagnosis of Down syndrome. Now, through our modeling, we've been able to estimate each one of those numbers and we can ultimately come up with a statistic known as the selective reduction rate. So, for example, in the United States, if I were to say we have a 33% reduction rate, it means based on our recent numbers, there were 33% fewer babies born with Down syndrome than could have been born as a consequence of selective termination.

We've been able to calculate that for every country that we've studied, including all the countries in Europe and in Australia and New Zealand and in the United States. And so this also has been important for people within the Down syndrome community. In order to have an honest discussion, we need to start with honest data and the most accurate data.

IN ORDER TO HAVE AN HONEST DISCUSSION, WE NEED TO START WITH HONEST DATA AND THE MOST ACCURATE DATA.

Courtney: That's interesting that you mention it, because we were recently having a conversation with the Down Syndrome Association of Iceland who are faced with questions surrounding selective terminations and advocating for a dwindling population of individuals with Down syndrome. This information would certainly help guide those conversations.

Dr. Skotko: If you take a look at our fact sheets, specifically our Europe fact sheet which includes Iceland, what we do is we break down what the numbers mean in a way that should be understandable, ready to use, family friendly, and patient friendly. We have fact sheets publicly available for Europe, U.S., and Australia on my website at brianskotko.com. From these fact sheets, you could see some countries like Ireland have more babies born with Down syndrome in 2011 - 15 than in the early 1980s - 43% more. But we also look at the reduction rate, and while Iceland in the period 2011 - 15 has a 69% reduction rate, it is not the largest reduction rate of all the countries we've seen. For example, Spain has a higher reduction rate of 85% in 2011 - 15 than Iceland.

Courtney: That's interesting that Iceland has become the poster child for that conversation because of their small population, but not necessarily because they have the highest reduction rate.

Dr. Skotko: Well, I think it shows the power of media. There was a prominent media piece written about Iceland and it was able to capture the emotions of it. That was before our paper came out. Then our paper came out and showed that Iceland certainly is there, but they're followed by lots of other countries who have even bigger or smaller reduction percentages. So now we actually have the data to provide that context. But it also shows how much media can draw attention to our particular topic, which I think it did a really nice job of exploring the nuances and also explaining the situations in terms of the actual numbers.

My colleagues and I are also dedicated to making sure these numbers are not static. You can see we've looked at years all the way back from 1950 to now. As we have the ability, as we have the bandwidth, and as new data comes out, we would like to continue to update those because those could be important barometers for how policy changes might change the numbers.

So as new prenatal testing is accepted in a country or reimbursed by a country, do we start to see more selective terminations and fewer babies with Down syndrome being born? That would be one hypothesis, and that would be something we would be able to measure as we continue to add to those graphs as new data becomes available.

Courtney: You said this has been a passion project and focus for you for the last decade, are there other studies that you would like to undertake or other areas of research that you see as incredibly urgent?

Dr. Skotko: Getting healthcare into the hands of everyone who has Down syndrome and their family members. So how do we democratize healthcare? Why do some people have access to the best specialty doctors and some do not? I'm fortunate enough to be the director of a Down syndrome program at Massachusetts General Hospital affiliated with Harvard Medical School, but it's not lost on me that most people, including my own sister with Down syndrome who lives in a different state, don't have access to that type of care. So we were able to research and build Down Syndrome Clinic to You (DSC2U), an online platform where families can purchase a report with up-to-date information about their loved ones, putting healthcare into the hands of all families. The next thing I'm interested in is, how do we get families to tap into that? And how can we get them to use that platform to bring their loved ones with Down syndrome up-to-date to be as healthy as they can be right now? Families are not using it. So we need to better understand what the barriers are for them and how we can help make them aware of the platform. Because without health, we can't really maximize our enjoyment of life. The goal is to make sure we play offense rather than defense, so that people with Down syndrome really do maximize their full potential.

Courtney: The disparity in healthcare available, especially in rural and remote communities, is something people experience here in Canada as well. Often we hear caregivers and other community members ask, how do we bring healthcare professionals up-to-date on the information available? How do we get them to provide an accurate depiction of life with Down syndrome?

Dr. Skotko: The power of DSC2U is it puts the information and the details in the hands of caregivers so they can advocate on behalf of their loved one with Down syndrome, go to the next doctor's appointment informed, and be able to empower their local physician to make those changes. So no longer do caregivers need to be in the dark.

Courtney: Are there any other comments or advice that you would like to give to our readers before we end our conversation today?

Dr. Skotko: I would say, stay restless. And by that, I mean don't settle for second best or third best. If things seem to be just okay, that's not good enough for our loved ones with Down syndrome. Complacency will slow advances that still need to be made. We need to tap into that restless energy that we all experience and collectivize to continue to lock in the changes that are still needed for our community because the biggest thing that could get in the way is if a lot of individual families become complacent and settle, and the torch of advocacy starts to dim. So stay restless.

Courtney: Thank you so much for your time today, Dr. Skotko. If anyone would like to learn more about DSC2U and how to register for the platform, please visit dsc2u.org.

The Mindsets Study

Promoting Health and Cognition Through Exercise

By Sarah Caraher

The recently released global Mindsets study by Dr. Dan Gordon of Anglia Ruskin University developed in partnership with the Canadian Down Syndrome Society (CDSS) explored a question that has never been asked before: 'Can physical activity benefit cognitive processing for individuals with Down syndrome?' The answer has important implications for the health of individuals with Down syndrome and the advice healthcare professionals give concerning fitness and exercise.

Spanning hundreds of hours and involving 80 participants from 10 countries, the Mindsets Study began in 2020. After two years of collecting data, researchers found that walking for 30 minutes three times a week can lead to improved information processing and attention in individuals with Down syndrome **after just eight weeks**.

Participants were assigned to one of four groups for the duration of the study. Individuals in an exercise-only group completed cardiorespiratory exercise, while a second group took part in a series of cognitive and executive function exercises provided by BrainHQ. A combined group completed both physical and cognitive exercises, while the fourth group, the control group, completed neither.

Participants were provided with a Fitbit to record steps completed, distances covered, speeds, and heart rate. Participants also logged their activity and communicated with the research team through a bespoke Mindsets app. At the start and end of the eight-week period, all participants took physical and cognitive assessments.

Researchers noted a significant improvement in speed and accuracy of decision making for the exercise-only group, the cognitive training group, and the combined group. They also noted a significant reduction in errors and an increase

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in correct responses in a series of cognitive and executive function exercises in those who exercised. The results of the study suggest that exercise should not be avoided by people with Down syndrome, but integrated into a daily routine in order to promote physical and cognitive well-being.

Many people in the Down syndrome community have witnessed the benefits of exercise first-hand and suspected that there may be a link between physical activity and cognition, but Mindsets is the first study to attempt to quantify this correlation. Although the question posed in the Mindsets study is seemingly simple, it is critical that gaps in health and wellness research like this are closed because it will enable individuals with Down syndrome and caregivers to make informed decisions based on accurate, updated data.

We need to continue to invest in dedicated health and wellness research for people with Down syndrome, especially as they are often omitted from relevant health studies. A critical example of this lack of inclusion can be seen in the drug trials and treatments for Alzheimer's disease. Despite the fact that Alzheimer's is the leading cause of death in people with Down syndrome over the age of 35, there are very few safety studies for Alzheimer's treatments in people with Down syndrome. This absence of information could have ramifications on the ability to treat the disease, as regulating bodies must wait for more research before approving certain Alzheimer's treatments.

Studies like Mindsets not only address an existing knowledge gap, they also help to break down stereotypes about people with Down syndrome. There is a common misconception that people with Down syndrome can't or shouldn't exercise. Some parents are even warned by healthcare providers against their child over-exerting themselves, or are told that there are physical actions their child will never be able to perform. While there are exceptions to every rule (an individual with Down syndrome could have a medical diagnosis that prevents them from exercising too vigorously) the Mindsets data shows that for most people with Down syndrome, regular exercise is beneficial.

Alongside the research, individuals with Down syndrome are doing their part to demonstrate that fitness can and should be embraced - individuals like marathon runner Kayleigh Williamson, two-time World Champion gymnast Chelsea Werner, and Kyle Landi, the first competitive bodybuilder with Down syndrome in Canada. These athletes already know that having Down syndrome has not limited them from achieving success.

> "I was so proud of myself. Eating healthy and running has helped me get healthy. I can now run in memory of my grandma."
>
> *- Kayleigh Williamson on her recent achievement of becoming one of the first women with Down syndrome to complete the NYC Marathon.*

In addition to the cognitive improvements indicated by the Mindsets Study, individuals who exercise regularly enjoy a multitude of health benefits that people with Down syndrome should not be denied based on false or inaccurate assumptions. Physical activity can improve heart function and promote good mental health, which is of particular importance as mood disorders like anxiety and depression have been found to be more prevalent in people with Down syndrome than the general population according to a U.S. study in 2022. On the other hand, a lack of exercise poses potential health risks. People with intellectual disabilities spend an average of 60% of their day in sedentary behaviour, which has been linked to increased cardio-metabolic risks, obesity, and cancer risks.

Reducing health risks and maintaining an active lifestyle through exercise are particularly important as people with Down syndrome age. Advances in medical diagnostics and treatment have more than doubled the life expectancy of Canadians with Down syndrome in the last 40 years, and while this is a statistic worth celebrating, it also means that continued research into health and wellness is more vital than ever. Data specific to individuals with Down syndrome provides greater insight into healthcare needs, allowing caregivers and self-advocates to establish healthy routines earlier.

"Improved cognitive function can lead to increased quality of life, which is important given this is the first generation of people with Down syndrome who will generally outlive their parents." - Dr. Dan Gordon, Associate Professor in Cardiorespiratory Exercise Physiology at Anglia Ruskin University and Senior Author of The Mindsets Study.

Despite all of the potential physical and cognitive health benefits, individuals with Down syndrome tend to exercise less than their neurotypical peers. Only 13.5% of adults with intellectual disabilities meet recommended physical activity guidelines, compared to 30.8% of the general population. This is often because of environmental and social barriers that people with intellectual disabilities have to navigate in order to be physically active. In addition to limiting stereotypes associated with exercise, common obstacles include lack of money, challenges with transportation, and an absence of support from caregivers.

Understanding the importance of physical fitness for people with Down syndrome is the first step towards ensuring there are more accessible opportunities for exercise. Data collected from the Mindsets Study is currently being used by CDSS to create a new health and wellness program for adults with Down syndrome, which will be available in March 2024. Participants will have free access to daily exercises, mental health tips, videos from fitness mentors, and nutrition advice to help form healthy lifestyle habits. Participants will be able to track their progress, checking in with their mental and physical wellness as they move through the program and witness the benefits of exercise first-hand.

What began as a simple question about exercise and cognition will ultimately have a profound impact on the health of Canadians with Down syndrome and their ability to fully participate in daily life. If you or someone you know is interested in joining the Mindsets Wellness Program, please pre-register with your name and email at cdss.ca/Mindsets.

Informing is Caring

Examining the Information Practices of Canadian Family Caregivers of People with Down Syndrome

by Kim Humes with an introduction by CDSS

There is a growing dependence on the Canadian healthcare system; 75% of caregiving in Canada is currently done by unpaid caregivers (Rexall Care Network). This can take a great toll on a person's health, well-being, and finances. CDSS has made advocacy for aging Canadians and their caregivers a strategic priority, working with the Canadian government and other federal organizations to enhance a system of support and recognition to meet the needs of current and future caregivers.

In 2023, the Here I Am photo essay reached millions of people, bringing international awareness to Canada's rising population of aging individuals with Down syndrome. We also brought attention to the continued dedication and contributions of family and other caregivers who provide excellent care and supported living options for their loved ones as they age. In 2024, CDSS is presenting a learning series that focuses on aging and Down syndrome, as well as a curated library of resources for people who care for adults with Down syndrome. A national caregiver network will also be launched, providing a place for caregivers in our community to connect. Further research will help to identify and address family-perceived gaps in services. If you are interested in participating in CDSS's caregiver research or have questions about the upcoming caregiver programs, please reach out to info@cdss.ca.

We appreciate the passion and dedication of students who help to conduct much-needed research into the caregiving landscape in the Down syndrome community. We would like to share with you this study by Kim Humes, a recent Master's graduate of Dalhousie University and sibling caregiver, who has explored the current information practices of Canadian family caregivers of individuals with Down syndrome.

As part of the requirements for my Master of Information Management (MIM) program at Dalhousie University, I had to complete a research project. We were able to choose any topic we wanted related to information management. I immediately knew I wanted to explore the information practices of caregivers of people with Down syndrome. Why? My older sister has Down syndrome, so I have been a secondary caregiver all my life (I will eventually become a primary caregiver). I am a keen storyteller, so I knew I wanted to collect stories from other family caregivers of people with Down syndrome. As an information manager in training, I am fascinated by information behaviours. I was lucky enough to combine these passions into one topic: "Informing is Caring: The Information Practices of Canadian Family Caregivers of People with Down Syndrome." The following is a summary of my study and results.

The Caregiving Landscape: What do we know?

A caregiver is "a person who gives unpaid care to someone who has a physical or mental health condition, or who is chronically ill or frail" (Caregivers Nova Scotia). Caregivers are vital to society and family members are increasingly assuming the role of caring for ill or aging loved ones. One in four Canadians aged 15 and older (7.8 million people) provide care for family members or friends with a long-term condition (Statistics Canada, 2022).

Canadian family caregivers contribute a staggering amount of unpaid labour to society, about 5.7 billion hours of care each year (Bielski, 2023). The estimated imputed economic cost to replace family caregivers with the paid workforce is $25 billion (Canadian Caregiver Coalition, 2013). 95% of Canadian carers believe their important role is not widely recognized by society (Embracing Carers, 2020) and more than one third of caregivers are distressed (Canadian Institute for Health Information, 2020). Research shows that caregiving is stressful, mostly done by women, and requires robust networks. Family caregiving not only props up our strained medical system, but allows seniors to age in place and people with disabilities to integrate into their community.

Care Work and Down Syndrome: Why is this topic important?

There are tens of thousands of Canadians with Down syndrome, and although their needs vary, most people with Down syndrome have reduced independence in performing daily activities and require help from a caregiver - and their need is growing as they age. In just three decades, the average life expectancy for a person with Down syndrome has increased from 25 to 60, but advancements in age also come with additional health concerns. The risk of developing Alzheimer's disease increases with each decade of life after age 40, and the overall lifetime risk of developing Alzheimer's disease is more than 90% (Fortea et al., 2021).

Due to its importance in society and the immense effort involved, many scholars are attempting to reframe unpaid caregiving as an invisible form of work (care work). Information practices are also a form of work (information work). In this information-rich age, finding and using information can be very time-consuming and frustrating. For caregivers, care work and information work are intertwined and interdependent. As Dr. Nicole Dalmer writes: "information work (the seeking, use, evaluating, or sharing of information) is crucial to the work of caring for oneself and for others... information is fundamental to good care, enabling, and empowering carers to make better choices and take control." (2018). The Canadian Caregiving Coalition found that a crucial outcome impacting family caregivers is appropriate information and support systems "to help them fulfill their caregiving role in a sustainable and safe manner" (2013). Caregiver information needs

are complex, ever-changing, and wide-ranging. Factual, accessible, and understandable information is essential for family caregivers because it enables and empowers them to provide the best care possible.

Study Design and Results: What did I learn?

The research questions guiding this study were:

- Where do caregivers of people with Down syndrome find, use, share, and manage information?
- What tools do they use to find, use, share, manage, and understand information?
- What factors (within and beyond their control) influence how they engage with supportive information?
- What barriers do caregivers of people with Down syndrome encounter within their information practices and what strategies do they use to overcome those barriers?
- Do the information resources meet the needs of the caregivers and if not, how could those gaps be filled?

I collected my data through virtual, semi-structured interviews with six adult caregivers of people with Down syndrome across Canada. Here is what they told me:

1. They need clear, personalized, centralized, and consistent information.
2. They need to know where to find this information.
3. They need opportunities to exchange information with other Down syndrome families.
4. They need more sensitive and empathetic service from medical and government professionals.

Study recommendations: What should we do?

Given the key findings above and the caregiving consultants' call for "more peer support groups, forums, and

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informational hubs for caregivers to connect and learn from one another" (Bielski, 2023), my main recommendation is to develop a national database for family caregivers of individuals with Down syndrome in Canada.

I would envision this being a public, easily searchable, continuously updated online portal where caregivers and care recipients can find answers. The records would include entries for government and community resources available across the country for people with Down syndrome and their carers (respite, funding, health services, community services, social supports, recreational opportunities, parent advocacy groups, research organizations, etc). Entries would have contact information and a web address for each resource to enable caregivers to easily make a direct connection. This database should be hosted and managed by the Canadian government, in partnership with provincial agencies, in consultation with Down syndrome and caregiving advocacy organizations. This is the best partnership because governments have resources and reach, while community organizations have specialized knowledge and relationships with users.

This national database would achieve the following outcomes:

1. Provide a central information source for caregivers of people with Down syndrome.
2. Ensure that the information caregivers of people with Down syndrome are accessing is timely and trustworthy.
3. Empower caregivers of people with Down syndrome to take the information that applies to them and ignore the rest.
4. Educate medical and government professionals about caregiver needs, the needs of Canadians with Down syndrome, caregiving services, and general services for individuals with Down syndrome, allowing them to make informed, evidence-based recommendations.
5. Highlight redundancies and inefficiencies in caregiving, services, and information for individuals with Down syndrome and their caregivers.

Caregivers who are not tech-savvy could access the portal through a trusted member of their healthcare team (e.g. doctor, social worker), a community service member (e.g. librarian), or other family members or friends. A support hotline would be useful with trained service agents to provide users with guidance and problem-solving.

A national database like this is an ambitious project. It would take a lot of resources to set up and maintain, and a lot of cooperation. It is daunting, no question. However, there is clearly a demand for this type of service, and the benefits could be enormous. It would save many people time and energy and ease the burden on many social services. If professionals can address needs more quickly and comprehensively, this means quicker appointments and consults. If caregivers can find quick answers to their own questions, it may reduce the need for them to consult professionals in the first place. A model like this, if successful, could be tailored to other types of caregivers and recipients, potentially benefiting even more citizens. Good planning and consultation is crucial. The first step would be organizing consultations between the government, community organizations, caregivers of individuals with Down syndrome, and Canadians with Down syndrome using proven project management and program evaluation techniques. A true user-centric approach is needed with Canadians with Down syndrome and their caregivers involved in the decision-making at all levels of the project.

Conclusion

I embarked on this study hoping to gain insight into the state of the information landscape for caregivers of people with Down syndrome in Canada. What did I find out? The systems are fragile, decentralized, unreliable, and driven mostly by caregivers themselves. A lot of information exists, but it is often outdated, biased, and hard to find. Teaching information literacy is certainly important, but our information systems need to be better.

In summary, we need more research into caregiving for individuals with Down syndrome and caregiver information practices. We need better informed and compassionate healthcare and community professionals. We need better organized, accessible, and trustworthy information readily available to vulnerable populations. The 2020 Canada Carer Well-Being Index posed some tough but important questions to consider: "Who is caring for the carer? Carers… often sacrifice their own health and well-being for the sake of people they love… they are undercounted, unheard, and struggling. The question ahead is, what are we going to do about it? Now more than ever…governments, public entities, the private sector, and all citizens of the globe have a role to play in addressing that problem. In moving forward, carers should not have to face these hardships and inequities alone. As a society, we can help them, together."

The full report for this study is available upon request. Please send all requests and study inquiries to khumes@dal.ca.

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Q&A

Busting Down Syndrome Stereotypes

1. What is a common idea about Down syndrome that you have found to be untrue?

Cynthia Hanratty (mom of Quinn, Invermere, BC)

I could write a whole essay answering this question! The stereotypes regarding individuals with Down syndrome are plenty and, as a parent, you hear them from everyone - medical staff, school staff, family, and friends. I think the key thing to remember is to take it all in stride and use these conversations as an opportunity to inform and educate those around us.

If I have to pick just one common idea about Down syndrome that is untrue, it would have to be about Quinn's overall abilities. When we were first given Quinn's diagnosis of Down syndrome it came alongside a long list of things to "watch out for," "that she wouldn't do," or that she'd "be very delayed in." Sure, she's behind her peers developmentally in some aspects of her life… but has she been able to accomplish all the same developmental milestones as her peers?

She sure has! Does she read like a rock star? You bet! Is she striving everyday to be independent, connect with peers, and be a great big sister? Absolutely! Does she know she has Down syndrome? Not only does she know… she is PROUD of it!

So… to sum it up - our family has had the privilege of learning that the idea that individuals with Down syndrome lack the ability to understand and achieve goals on the same level as their peers is… FALSE.

Sheryl Gray (mom of Nick, Delta, BC)

Prior to living life with Nick, I assumed people with Down syndrome were content in their lives, as managed for them. I was wrong! Nick has plans for himself that I'm not always aware of, and he makes his needs known to people in his circle. He wants more than the familiar lull of day-to-day life, whether it's learning a musical instrument, dancing on stage, playing a new sport, spending time with friends - he is looking for ways to live his best life, his way, on his terms. He takes huge pride in a new task accomplished, a victory, a fear overcome, and enjoys recognition!

Matthew Tolmie (self-advocate from Windsor, Ontario)

We are not fast enough to get things done that people want us to do (like getting tasks done at work). That I'm not able to live on my own and do daily essentials. That I am not able to make and follow a daily routine to get my day going, like making my own coffee/breakfast, doing my own hygiene, and going for my daily walk.

Hillary and John Myhal (parents of Charlotte, Ajax, ON)

When we first received Charlotte's diagnosis, it felt like there was such a big focus on all the things she wouldn't be able to do. It was really hard at the start to picture what her future could look like.

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That didn't last long as we quickly learned that Charlotte can do everything! She can fall in love, she can go to college, she can have a career. Some things might take her a little longer to learn, and that's okay! She shows us every day just how capable she is. She is determined and self-driven and we are so proud to be her parents.

Down syndrome doesn't mean Charlotte can't dream as big as the rest of us. Her future is bright and we are eager to see the beautiful life that Charlotte will choose to lead.

Holly (Mom of Jax and Niko, Medicine Hat, Alberta)

So many common ideas about Down syndrome are absolutely untrue. I can't pinpoint just one. The one that always gets me is "people with Down syndrome are always happy." That's very untrue! My boys have all the emotions and go through them many times throughout the day. Sad, angry, frustrated, happy, excited… they are definitely not always happy! I wish they were. Other common ideas are that they won't have friends, won't be included, they will struggle in school, they won't thrive, etc. My boys are thriving! They are treated like all the other kids. They have the best of friends and are fully included in their school environment and with their friends at home. They are loved by their peers and treated as an equal.

2. What is one thing you wish people knew about life with Down syndrome?

Cynthia Hanratty

It's not scary and it's not something we would change if given the opportunity. As parents, we feel honoured to be given the chance to connect with this beautiful community – a community and friends we would have never met if Quinn didn't have that extra chromosome. So please, don't EVER feel sorry for an individual or family because they have a disability – because it truly is an enriching experience.

Sheryl Gray

As a family, life with Down syndrome has pushed us all to be better versions of ourselves. Whether that's learning how to speak up and advocate, or being the one in a group to call out inequities, or just being more inclusive with all people - our family journey has been incredibly positive. Nick is the glue that binds our family and we're grateful to him for the lessons he teaches in love, acceptance, kindness, and determination.

Matthew Tolmie

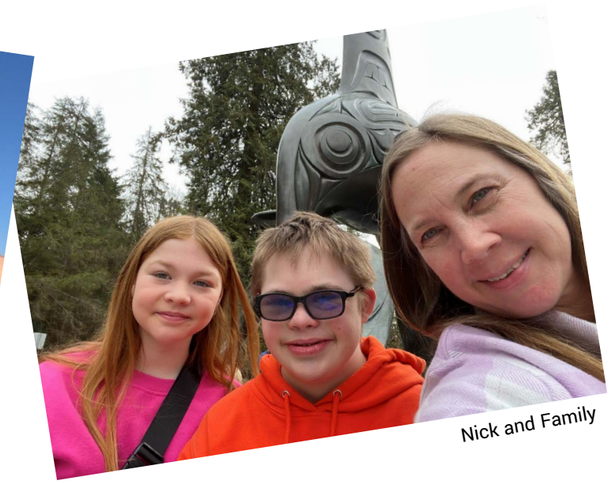
When you give a person who has Down syndrome a chance to work it helps us have a more balanced life.

John and Hillary Myhal

There's a great stat out there that states that "99% of families believe that they are happier thanks to having a family member who has Down syndrome." This totally resonates with us, and we couldn't imagine life any other way.

Sometimes when we tell people that our daughter has Down syndrome, we're met with a well-meaning sympathetic comment, or some type of comment on how hard it must be. We're quick to let them know that life is so fulfilling and fun with her, and that she truly brightens up the lives of everyone she meets. We dream of the day where they're just as excited for us as other members of the Down syndrome community.

Quinn and Family


Nick and Family

Charlotte and Family

Jax, Niko, and Family

Holly

Life with Down syndrome is AMAZING! Of course it has its challenges but that's true with all kids. My absolute favourite thing about our life with Down syndrome is that it has forced us to slow down and enjoy the little things in life.

3. What resources have helped you learn about Down syndrome?

Cynthia Hanratty

How about I start with what didn't help? My advice to all new parents: don't google Down syndrome! It will suck you into a world of medical jargon and ignorance.

What did help? Connecting to other families and parents who also have a child (or in some cases children) with Down syndrome. Meeting others who "get it," who you don't feel you need to explain everything to, and who have walked in your shoes before, was by far the best resource for our family.

Connecting to the local Down syndrome societies and support agencies (like DSRF!) and taking advantage of the knowledge, experience, and understanding they provide is something we're grateful for.

Sheryl Gray

My "DS moms" are my go-to when I have a concern, question, frustration... I connected with a few parents at an infant sign language course held at DSRF in 2011, and quickly realized these were my people! Facebook chats keep us connected even when we're busy and live across multiple cities, and are a steadfast source of resources, validation, shared pride, and many times, some laughs.

Matthew Tolmie

The people who love me guide me to be independent. I teach people what I need and they support/guide me with things like paying bills, shopping, how to decorate my own place with furniture, paint, etc. Schools use co-op programs to help me find jobs. Hanging out with my family, friends, and coworkers improves my social skills, communication, and how to use my community safely on my own. People teach me things about life and how to look things up on the Internet.

John and Hillary Myhal

Instagram was a huge help! We received a prenatal diagnosis in April of 2020. Because of the COVID closures, we weren't able to see anyone in person and medical professionals were quick to list all the things she wouldn't be able to and all the medical complications she could face. We were so excited to be having our first child and then after one phone call, it felt like we couldn't picture Charlotte's future anymore. We had so many questions about what life would be like for her. We started following other Down syndrome families on Instagram and I felt like we had our hope back. We saw how amazing the children and adults with Down syndrome were doing, how happy their families were, and how great life was with an extra chromosome! It felt like we could celebrate the pregnancy again instead of fearing it.

Holly

The resource I have found the most invaluable is connecting with other moms who have children with Down syndrome. Connecting with an online community on social media has been everything. Having a community who gets it, who you can turn to for advice and support, is huge. To feel seen, heard, and understood. To have a place you can go and vent, complain, not feel judged, and people who completely get it has absolutely been my go-to resource.

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Down Syndrome Film Festival Sequel Set for April

Following a highly successful premiere last year, DSRF's Down Syndrome Film Festival returns on April 20, 2024 at Burnaby's James Cowan Theatre.

This year's feature presentation will be the 2022 film *Color My World with Love*, which originally premiered on Hallmark Movies & Mysteries. When Emma's daughter Kendall becomes engaged, Emma is concerned. Kendall and her fiance have Down syndrome, and Emma worries she's not ready to take this step. Lily D. Moore and David DeSanctis play the happy couple, while DSRF's own Tiana Kirkegaard appears in a supporting role.

The DSFF will also include the Burnaby premiere of *Chicken*. *Chicken* tells the story of a down-on-her-luck, recently-single sister. She is forced to move back into her childhood home. She reconnects with her brother, who has Down syndrome. *Chicken* stars Leo Award-winning DSRF student Aaron Waddingham alongside Lucy McNulty.

DSRF's latest short film *CrossRoad: Where Down Syndrome Meets Autism* will also screen. Three families whose child has both Down syndrome and autism open their lives to let us see both the joys and the challenges they experience as they navigate multiple disabilities. DSRF speech therapist Liv Meriano explains the similarities and differences between the two conditions, why it can be difficult to identify autism in a child who has Down syndrome, what to do if you suspect your child might have autism, and how to support a child with Down syndrome and autism.

Following the films, the stars and creators of all three will participate in an audience Q&A. Tickets are going very quickly; visit DSRF.org/FilmFest to reserve your seat.

Smashing Stereotypes on World Down Syndrome Day

There are all kinds of misconceptions about people with Down syndrome, and it's time to set the record straight.

This year's World Down Syndrome Day theme is "end the stereotypes." DSRF's Speaking Out students are doing their part by producing a video project that will expose the fallacies and show that people with Down syndrome can't be put in a box.

The video will debut on World Down Syndrome Day on all DSRF's social media channels – and that's just the beginning of our WDSD celebrations.

As always, we'll be rocking our socks, and we've got the official socks of World Down Syndrome Day – plus shirts and other goodies – on sale now. We'll also be hosting a live recording of the LowDOWN Podcast in which adults with Down syndrome will share their thoughts on Down syndrome stereotypes, lighting up the city of Vancouver in yellow and blue, and giving you the opportunity to directly support students with Down syndrome through our annual 3-2-1 one-day campaign.

World Down Syndrome Day

Get all the details on World Down Syndrome Day at DSRF.org/WDSD.

$72,000 Raised to Help Children with Down Syndrome Flourish for Life

The Down Syndrome Resource Foundation has the most generous supporters, and you proved it again by collectively contributing $72,000 to DSRF's 2023 Flourish for Life campaign – making it the most successful year-end giving campaign in the organization's history.

Donations to Flourish for Life directly support DSRF's vital preschool programs, equipping children with Down syndrome for school success and giving parents confidence as they approach this new stage of life. Those first few years of education lay an indispensable foundation, so it is imperative that students be given every opportunity to succeed.

In one grateful parent's words: "Everyone who meets our daughter is floored by what she can do. That credit is shared between her and DSRF."

And, we would add, that credit is also shared with all our wonderful supporters, without whom it would not be possible for us to do this essential work. Thank you for being a part of our mission to help people with Down syndrome Flourish for Life!

Down Syndrome Resource Foundation

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Thank you to the 145+ donors who gave generously to the 2023 Flourish for Life campaign – our most successful year-end campaign to date!

More than 300 students, families, and supporters celebrated the magic of the holiday season together at DSRF's Magical Morning holiday breakfast in December. Thank you to event sponsors BC Maritime Employers Association, BLG, CIBC Asset Management, CTV, Gardenworks, LiUNA Local 1611, Phillips, Hager & North Investment Management, and Woodhouse & Associates, as well as emcees Mona Mahmoud and Chris Sayer, Rick Scott, Santa, and all our wreath decorators and entrepreneurs with Down syndrome for making it a wonderful event.

The Amur Financial Group made an extremely generous donation of $30,000 for DSRF's programs and services for people with Down syndrome of all ages. We are deeply thankful for their support.

The City of Burnaby has provided a $14,000 grant in support of DSRF's one to one programs for children with Down syndrome. We are grateful to live in our wonderful city!

Social Venture Partners gave $5,000 towards our ongoing work in the areas of equity, diversity, and inclusion. This is a major internal priority for our organization and we thank SVP for helping us advance this important work.

Thank you to the Lohn Foundation, which has provided a $3,500 grant for DSRF's educational programs.

Thank you to the Hamber Foundation, which has provided a $2,000 for DSRF's educational programs.

UPCOMING AT DSRF

World Down Syndrome Day: ***March 21, 2024***

Down Syndrome Film Festival: ***April 20, 2024***

Run Up for Down Syndrome: ***June 2, 2024***

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CDSS SPOTLIGHT

End The Stereotypes World Down Syndrome Day 2024

This World Down Syndrome Day, come together to End The Stereotypes and celebrate the abilities of individuals with Down syndrome around the world. Be a part of sharing an important global message - watch our social media channels on March 21st to see what we mean! You can also find resources like presentations, social media posts, posters, and lesson plans to help you raise awareness at cdss.ca/world-down-syndrome-day

Join the Down Syndrome Walk June 15th!

Step Beyond Stereotypes this Saturday, June 15th for our annual Down Syndrome Walk! Our Down Syndrome Walk Ambassadors will be hosting local events across the country to raise funds for critical programs and resources for Canadians with Down syndrome. Help us make an impact in someone's life by joining this national event! You can host your own event, find an Ambassador event in your area, or make a donation to help a Down Syndrome Walk Team meet their fundraising goal. Register for the walk, find a local Ambassador event, or make a donation today at DownSyndromeWalk.ca.

Coming March 5th
Your Health Journey Starts Here

Introducing Mindsets, a free wellness program for adults with Down syndrome! Build a daily exercise routine, get motivated with Mindsets Mentors, discover new sports and activities, learn about mental health and nutrition, and track your progress with the Mindsets app. Pre-registration begins March 5th, 2024 at cdss.ca/mindsets

Upcoming Events

Thursday, March 7th, 2024
Join CDSS for the grand opening of ODEN's David Onley photo exhibit at Withrow Common Art Gallery in Toronto. The exhibit includes a presentation about the life of David Onley and his disability employment work. It also features a CDSS display of Down syndrome employment facts, stories, and photos by Hilary Gauld, capturing the working life of individuals with Down syndrome.

Thursday, March 21st, 2024
CDSS is proud to be accepting an award from Down Syndrome International for our work with Inployable at the WDSD UN Conference in New York City this year! If you will be attending the conference, please reach out to connect with our team at the event: cdss.ca/contact

Canadian Down Syndrome Society | Société canadienne de la trisomie 21

ARE YOU A SIBLING CAREGIVER LOOKING FOR SUPPORT?

The CDSS Sibling Caregiver Network can connect you to educational resources, training webinars, financial aid information in your province or territory, and most importantly, other sibling caregivers across Canada who have experience and advice to share with you.

If you are interested in receiving information about this new national network for connecting and supporting sibling caregivers coming later this year, please leave your information at cdss.ca/sibling-caregiver-network

JOIN OUR COMMUNITY

FIND US / TAG US

@CdnDownSyndrome on all our platforms

CDSS.ca

Down Syndrome WALK

Step Beyond Stereotypes

Saturday, June 15th

Join us in this unique event that mobilizes the power of our community! Ambassadors across Canada are hosting local events to unite and Step Beyond Stereotypes. Get involved by hosting your own event, attending an Ambassador event, or making a donation. Learn more at:

DownSyndromeWalk.ca

Canadian Down Syndrome Society