

Canada's  
Down Syndrome  
Magazine

# 3.21



Spring 2022  
ISSUE #10

**HEALTHY  
START:**  
*Preventative  
Health Care for  
Children with  
Down Syndrome*

**THE JOURNEY:**  
*Health Stories  
from the  
Community*

**Down  
Syndrome  
and Medical  
Complexity**

*The*  
**Medical**  
*Issue*

**Plus: MEDICAL ADVOCACY & COVID-19 IN CANADA**  
*An Interview with Yona Lunsky and Robert Balogh*



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Canada's  
Down Syndrome  
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is a joint publication of



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As this issue lands, the world is marking two years of the Covid-19 pandemic. That's two years of having physical health and medical issues at the forefront of our minds on a daily basis.

Research throughout the pandemic has revealed that individuals with Down syndrome carry an increased risk of severe cases of Covid-19, as measured in hospitalization and mortality rates. The reasons for this are many, but a big one is that many individuals with Down syndrome have one or more additional health concerns that don't mix well with the coronavirus.

That's not a reason to fear, but it is a reason to ensure that every person with Down syndrome is receiving the best possible medical care and living in such a way as to maximize their health. In this issue of 3.21: Canada's Down Syndrome Magazine, we bring you insights from some of Canada's top doctors and researchers specializing in Down syndrome, along with stories from self-advocates and caregivers who generously share their medical experiences. We hope this equips you and your loved ones to live your best, healthiest life.

Our editors would love to hear from you! Drop us a line at [321DSMagazine@gmail.com](mailto:321DSMagazine@gmail.com) with your thoughts, story ideas, and opinions.

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# HEALTHY START:

## Preventive Health Care for Children with Down Syndrome

*By Dr. Aven Poynter, with Glen Hoos*

**T**hanks to medical research, a better understanding of Down syndrome, and shifting societal norms, people with Down syndrome can expect to live longer, healthier, and happier lives than ever before. However, when a child with Down syndrome is born, his or her family is quickly introduced to a world of medical specialists, tests, and appointments that they may have never previously encountered. Those early days can be undeniably overwhelming.

Cardiology, neurology, oncology, otolaryngology, gastroenterology, psychiatry, urology, ophthalmology, audiology... It's a whole lot of 'ologies,' and a whole lot to keep track of. Here, we'll cut through the confusion and explain the most important steps to ensuring a healthy start for a child with Down syndrome.

### BIRTH

As it does for all of us, the medical journey of a person with Down syndrome begins at birth, with a physical exam. If Down syndrome was not diagnosed during pregnancy, it is usually identified at the time of the newborn physical exam. As a

pediatrician, I was often called in to see a baby shortly after birth because the family doctor and nurses noticed some of the common physical characteristics of Down syndrome.

In many cases, I would be the first professional to tell the parents that their baby may have Down syndrome. At these times, I always wanted to convey that we (the medical team) were here to support them, and we expect that their child is going to grow up to be healthy and happy and achieve his or her potential. It is a big piece of news for the family – not necessarily a terrible piece of news, but not what people are expecting to hear. Everyone reacts differently. Some have a lot of questions right out of the gate, but in many cases parents would just be trying to take it in, and the questions wouldn't come till later.

Another thing we're looking at in the initial physical exam is the heart. Many babies with Down syndrome are born with a cardiac defect, which may be apparent when we hear a heart murmur. All babies with Down syndrome should be seen by a cardiologist. Depending on what kind of murmur we might hear and what the infant's oxygen levels are, it may be a really, really urgent referral – like, today – or it may be a referral that

can wait a few days. If the baby is very stable from a cardiac point of view, and we don't hear a murmur, then we can probably wait a few days or even a couple of weeks.

We also need to ensure that the gastrointestinal system is working properly, in terms of feeding, possible vomiting, possible constipation. We observe for signs of bowel obstruction, which is not common, but a little bit more common than in typical kids.

We monitor all babies for jaundice, which is more common in babies with Down syndrome, but not a big problem. If they're too jaundiced, we treat it the same as we would with any other baby.

As with all newborns, we do a heel prick for metabolic screening, which includes screening for hypothyroidism – a condition which is much more common in people with Down syndrome. It's usually acquired a bit later in life, but there is a slight increase in congenital hypothyroidism.

The confirmation of the diagnosis of Down syndrome, and the type of Down syndrome, is made by chromosomal analysis, which is done by a blood test. We also do a complete blood count (CBC) because there may be problems with the red blood cell count (polycythemia) or with the white blood cell count. Transient myeloproliferative disorder, a condition in which the bone marrow is making a lot of white blood cells, is something that occurs in some newborns and very young infants who have Down syndrome. There's no treatment needed, just monitoring; generally we would refer these babies to a hematologist to help us monitor them until it resolves, which might be within a few weeks or a few months. Myeloproliferative disorder itself is not a major concern; however, babies with Down syndrome who have had it are at increased risk of leukemia later on in childhood or adolescence, so we keep a closer eye on that going forward.

All of this testing feels like a lot for families who are already dealing with an unexpected Down syndrome diagnosis, but actually, much of it is standard testing that all babies go through. There's definitely extra, though, when you've got a little one with Down syndrome.

INFANCY

Just like at birth, many of the medical routines for an infant with Down syndrome are the same as for any baby, including routine well baby care; routine immunizations at two, four, six, and twelve months; monitoring their weight and growth, which will be plotted on a growth chart for Down syndrome. They should also have influenza immunization, because they are at increased risk of respiratory infections and bronchitis.

If the baby has a cardiac defect, they may also be eligible for RSV prophylaxis, depending on their cardiac status and their lung status. Blood tests need to be done every six months during infancy to check thyroid and blood count.

Even if the newborn hearing screen was normal, hearing tests should be done every six months starting in infancy. Most babies and young children with Down syndrome end up needing to see an ear, nose, and throat surgeon; many need tubes in their ears because they have chronic middle ear effusions. Some will have neurosensory hearing loss. So, we generally want pediatric ENT referral fairly early in life with regular follow up.

Similarly, all babies with Down syndrome should see an ophthalmologist (an eye doctor, preferably a pediatric one) – not just an optometrist. An optometrist assesses vision, but most young children with Down syndrome aren't going to be able to tell you which way the E is pointing on the vision chart. An ophthalmologist, on the other hand, uses special lenses to look at the retina, look for cataracts, etc.



All infants should see a dentist for their first dental checkup before their first birthday. The first appointment is usually a get-to-know-you session, with toothbrushing instructions for parents.

Your child's pediatrician or family doctor will coordinate the care, and make referrals to specialists as needed. Aside from medical concerns, the other thing that should be done shortly after birth is referral to the local infant development program (IDP). The IDP will provide developmental support such as speech therapy, occupational therapy, and physiotherapy. You will also want to connect with Down syndrome organizations in your area, some of whom may provide support services tailored specifically to children with Down syndrome.

EARLY AND MIDDLE CHILDHOOD

Most of the routines established during infancy will continue through early childhood and beyond. This includes monitoring eating and growth; routine immunizations including influenza; regular blood tests and screening for hypothyroidism, iron deficiency and celiac disease; regular hearing tests, follow-up with your ear, nose, and throat specialist, and treatment of respiratory infections; annual appointments with the ophthalmologist; regular dental visits; and ongoing work with speech therapists, occupational therapists, and physiotherapists.

Before participating in some sports, children with Down syndrome may be required to have neck x-rays to check for atlanto-axial instability, which can impact their ability to safely participate. You should also watch for symptoms such as changes in the way the child walks; getting easily tired when walking; pain, numbness, or tingling in the neck, shoulder, arms, or legs; head tilting to one side; trouble moving the neck or holding it up; loss of bladder or bowel function; or weakness in the arms or legs.

At this age, you will also want to begin to keep a close eye on your child's sleep habits. Obstructive sleep apnea is very common in people with Down syndrome. Sleep apnea can have cascading impacts, contributing to behavioural problems, mental health issues, and physical health concerns.

If the child is thriving and isn't displaying behavioural, mental, or physical manifestations of sleep deprivation, and they aren't snoring, a sleep study is not necessary. However, if you notice changes in any of these areas, it could be an indication of a sleep disorder, which a sleep study can help diagnose. Unfortunately, sleep studies can sometimes be easier said than done. For one thing, getting access to polysomnography can be really difficult. And if you do, many children and teenagers with Down syndrome resist the testing, which involves having



SUGGESTED RESOURCES

- ✓ American Academy of Pediatrics guidelines for the medical care of infants, children and adolescents with Down syndrome
- ✓ American Academy of Pediatrics Family Guide
- ✓ Canadian Health Watch Table
- ✓ Down Syndrome Growth Charts
- ✓ DSRF Physicians Letter
- ✓ CDSS Hub - New Parents & Early Years



a lot of equipment attached to them and then being told to sleep. Then, if they are diagnosed with obstructive sleep apnea the treatment is CPAP (continuous positive airway pressure), which entails sleeping with a mask that is connected to a compressor by a flexible tubing. This, again, can be met with a lot of resistance.

This is not meant to discourage testing, as sleep apnea is a significant concern that needs to be addressed. Just realize that, for most children, it will likely be a lengthy process rather than an overnight solution. The likelihood of sleep apnea increases with age; for many individuals, the willingness to cooperate with the testing and treatment may also improve over time.

Early childhood is also when some neurodevelopmental, neuropsychiatric, or psychiatric problems are more likely to show up, particularly after a child begins school. Two of the big ones are autism and ADHD.

Ideally, autism would be diagnosed when a child is two or three years old, so early intervention can start. This is more often the case for children who do not have Down syndrome, but unfortunately an autism diagnosis often comes later for kids with Down syndrome, due to the overlap in symptoms between the two conditions. Nevertheless, children with Down syndrome have higher rates of autism than the general population, and it's important to identify it as early as possible.

Likewise, ADHD, anxiety disorders, and obsessive compulsive disorder are more common in children with Down syndrome,

although they may be more difficult to diagnose. Often these issues begin to emerge in the elementary school years. We have to be careful to avoid diagnostic overshadowing, where we attribute every problem to Down syndrome, when there may be other issues contributing that can be addressed through therapy or medications.

LATE CHILDHOOD AND BEYOND

Most of what we've covered above will continue as the child grows older. In addition, the typical issues of adolescence will become relevant, including puberty, sexuality, and skin issues. These tend to occur around the same age as in the general population, and individuals with Down syndrome will need additional guidance in navigating these issues and understanding the changes happening in their body. We invite you to refer to the Summer 2021 issue of 3.21 Magazine (The Teen Issue) for more information on this vital topic. During the mid-teens, your doctor will assist you in beginning the transition to adult medical services.

Every person with Down syndrome is unique. No one child is likely to exhibit concerns in all the areas covered here. The medical life of an individual with Down syndrome can be complex, but we have come so far from the days when these health factors significantly limited lifespans and expectations. Your personal team of medical professionals is here to support you in building a long, healthy, and happy life. ●



*Dr. Aven Poynter is a recently retired Pediatrician, and the past president of the BC Pediatric Society. She is the recipient of the Canadian Paediatric Society Distinguished Community Paediatrician Award and is a clinical assistant professor at UBC. She has also contributed to legislative documents advocating for increased support for neuro-diverse children.*

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Adrianna Cañete Costache is a cheerful, bright-eyed, five-year-old little girl with an infectious smile and a love and appreciation for music. She has Down syndrome, partial deafblindness, and communicates expressively with the use of her body language. She underwent heart surgery at four months old.

Her mom, Catherine Cañete, knows what Adrianna is saying; the two are never apart and deeply connected. Catherine can tell how Adrianna's feeling, for example, by how active and playful her daughter is being. "She understands a lot of things. She may not be able to say it, but she understands." Adrianna touched her thumb to her pointer finger, forming an 'okay' gesture with her hand in response to her mom's words, showing she clearly agreed with her.

A typical day for Adrianna involves being fed through her gastrostomy tube (G-tube), taking her medication, virtual meetings with her doctors and therapists, and virtual school at ten o'clock. If it's a difficult day, or if Adrianna is in critical condition in the hospital, they will skip school and do activities on their own time and pace. "We read books. I also try to do therapy, make her do some exercises," such as weight bearing on her feet and trying to get her to stand.

Catherine doesn't want her daughter to miss out on typical activities kids her daughter's age are enjoying, though it's been difficult on their family as Adrianna has various medical complexities and has spent most of her life in the hospital. Marcel Costache, Adrianna's dad, is handy and recently hung a swing inside their home for Adrianna to get a park-like experience. "We normally don't go out, even before the pandemic occurred; it has always been like this because of her being so fragile, so we have to be creative for her."

At the beginning of our Zoom conversation, Catherine took a few minutes to rinse the feeding bag and tubing for Adrianna's next scheduled feed and then settled in on a couch of cozy cushions and blankets beside her daughter. "She loves to snuggle with me," Catherine explained, but she also stays close to her daughter for good reason. Constant care and management of medical equipment and medications are a reality of their family's life. "When doctors knew about her heart condition and having Down syndrome at 38 weeks, they offered me termination of pregnancy, but hearing that was an insult to my grieving heart as I was about to give birth to my most awaited first-born. At that time, I didn't know the extent of the complexity of the medical issues; nevertheless, I am so happy of my decision of keeping my precious Adrianna and I am blessed to be her mother."



# Hospitalized:

## Down Syndrome and Medical Complexity

By Adelle Purdham



The rate of medical complexity for children and youth in Canada is 948 per 100,000 children and youth — about 1% of the population.\*

\* Data collected in 2015-2016



In Adrianna's first month of life, she suffered a stroke that rendered the left side of her body semi-paralyzed. The stroke led to a series of ongoing seizures that evolved from one type of seizure to another. Both of her lungs collapsed from Respiratory Syncytial Virus (RSV), which almost took her life. Adrianna has faced pneumonia, in addition to recurring reflux that caused an abdominal hernia that needed surgical repair. For a time, she was lethargic and stopped waking up. Her neurosurgeon suggested a hemispherectomy, which is a surgical procedure that would disconnect the right side of her brain from the left. There were complications from the surgery, fluid accumulated in her brain, and she was diagnosed with hydrocephalus, which needed to be treated with a VP shunt to drain the fluids. Unfortunately, the shunt malfunctioned, and this marked the start of thirty brain surgeries.

"She went into a coma so many times," Catherine said. "You start to appreciate everything, what you have, and what you had in the past. And now you understand things can be different in a snap. Every single moment of your life

means a lot. And not only that, but to be able to share that (knowledge) with others. This life that we have is meant to be shared. This is not for our own, to be kept. This is for people to understand and learn from."

Catherine and her family would like to thank the incredible Neurosurgeon team at SickKids, "Adrianna's heroes," led by Dr. George Ibrahim and Sara Breitbart, Nurse Practitioner, and everyone in Adrianna's medical team: SickKids Pediatric Team 7B, 7D, 7C, Cardiology Team 4D, and Holland-Bloorview Brain Injury Rehabilitation Team (BIRT), who she says have gone above and beyond to help Adrianna survive the long and hard ordeal of her 5-year-old life.

.....

About forty minutes into my interview with Catherine, Adrianna became ill. Catherine effortlessly wiped her daughter's face with a cloth, then used a suction machine, which prevents her daughter from aspirating. "She's just had surgery for reflux; I can't leave her."



Children with medical complexity encompass a diverse group of individuals with a range of conditions, needs, limitations and medical fragility, but most share these characteristics: complex chronic conditions, functional limitations, high health care use and a high need for caregiving.



As we commenced the second hour of our Zoom call, Adrianna began experiencing small seizures, which she can have up to 30-50 times a day. I thought she was babbling happily, but her mom knew better. "Right now, she's having seizures," she said. "Her eyes are deviating to the left. A focal seizure." Shortly after, Catherine expertly doled out medicine through a syringe.

The reality of their situation, and for the 97,600 children and youth in Canada who have medical complexities, is the need for around-the-clock caregiving. "I have no support; she's a 24-hour watch in the middle of the night. She still wakes up and sometimes coughs and needs suctioning. It's constant suctioning because of her reflux."

Seeing for myself the all-consuming nature of Adrianna's care, I asked Catherine how she has time to cook. "I'm glad you asked," she said with a smile. "I have to get creative." She keeps a garden filled with herbs and vegetables on her balcony in the summertime. Occasionally, pre-Covid, Catherine and her family were able to get some reprieve from a support worker. During that time, she would get enough groceries for one or two months. In the middle of the night, when Adrianna slept, Catherine prepared days and weeks' worth of freezer meals for her family. "You have to be organized."

What Catherine does not get a lot of, is sleep. While Adrianna is in hospital, she stays by her side and sleeps on a bench. Once, for months, they were in a larger common room shared with other families and all she had for a bed was a chair.

Marcel, Adrianna's father, is a building superintendent. Catherine is a qualified nurse, who also specializes in cardiac care, in the Philippines and U.S. She recently completed her RPN requirements and is currently working on becoming a registered nurse in Ontario so she will be able to use her talents of caring for others and bring her family some financial relief. The difficulty is in finding a job that will work with their family's situation without compromising care for Adrianna's complex needs.

Adrianna isn't ambulatory or mobile, and as she continues to grow, Catherine has been exploring purchasing an accessible van, as well as a ceiling lift option, but the price tag for the lift alone is steep—\$11,000. The couple have no family in Canada and a small support system, but Catherine explains that every connection with friends and community means a great deal to them.

"I look at our life as an ocean. It can be rough, and wavy and stormy and, you know, big waves, and we are in the middle of it. An island is nowhere to be found. I see support from strangers, friends, and community as small ships with some nice people in the boat that can give us floaters, lifesavers, a buoy that

According to the Canadian Institute for Health Information, "Providing care to a family member or friend can be demanding, with profound emotional, mental, financial, and physical impacts."



we can use to rest on, instead of treading the whole time. What a relief. You enjoy, you appreciate that someone gave you a small floater to rest for a while before you have to swim further." Their religious faith and connection with others are what gives Catherine, Marcel, and Adrianna the raft they need to keep going.

Registered Psychotherapist Linda Burdett, who has provided therapy to parents who've had children in hospital with medical complexities, offers helpful advice on how to support these families. "First and foremost, try to understand what they may be going through." Others sometimes don't understand that having a child in the hospital can be traumatic and overwhelming. "Parents don't need things to be solved, necessarily. They just need to be heard." Support depends on a family's needs and wants, but there are practical needs such



as sibling childcare, making meals, laundry, grocery shopping, and house cleaning that can be addressed. But mostly, Burdett says, it's lending an ear, taking mom or dad out for dinner or coffee, and just connecting that fulfills the need to be heard and understood.

If a family finds themselves in the position of having a child in hospital, whenever possible, Burdett recommends getting good sleep, eating well, and exercising, which can help burn off anxiety and help with processing. "Gather the troops," she says. Reach out to your people and relatives for help and support. In addition, and especially if these aforementioned strategies and supports are simply not possible, citing and applying the work of Dr. Amelia and Dr. Emily Nagoski in their book "Burnout," Burdett explains there are seven things you can do to cope and get to the light at the end of the tunnel in a stressful situation: move, breathe, talk to people, laugh, speak to loved ones, cry, and do something creative.

When I asked Catherine what advice she has for other families in similar situations to help them cope, her response was resolute: "Acceptance, I think that's the key. When you accept (your circumstances), you start loving what you have and being grateful for what you have. Acceptance and a grateful heart."

Adrianna is recovering from her latest surgery and her family was overjoyed to be able to spend the holidays at home. Last

year they were in the hospital. The longest time their family has spent in hospital is over a year. The longest they've been home? "That's the question, I think," Catherine joked. Her answer: six months. Mostly they're home for two weeks to two months, and then back to being in the hospital again. "It feels like we're on vacation (now) being at home and being together," she explains.

Even with all that she and her family have gone through, Catherine and Marcel have learned to be grateful and appreciate all the things that they and Adrianna can still do together, and the quality time they have with one another. "At least we are together, doing things. I wouldn't exchange that (time) for anything else," she says.

Catherine maintains a positive outlook. "The way we perceive circumstances in our life is a choice and a decision whether to be happy or get overwhelmed. We also have to remember that how we perceive life is what they (our children) perceive as well. I choose to be happy in life." While Catherine has known life before Adrianna's medical complications, Adrianna does not know any other life than the one she is living. "If we feel bad about life, no matter where we are, whether they're sick or not, if we think it's not good, they will think life isn't good. So, I think, be creative wherever we are, in a hospital or at home, and enjoy the life that was given to us as a gift. It is a gift. And a gift needs to be celebrated and enjoyed."


Acceptance,  
I think that's  
the key.



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# WORLD DOWN SYNDROME DAY!



## March 21


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# Medical Advocacy & Covid-19 in Canada

A 3.21 Interview with Yona Lunsky and Robert Balogh

**Dr. Robert Balogh** is an Associate Professor at Ontario Tech University. He graduated with a Physiotherapy degree from McMaster University in Hamilton, Ontario in 1993 and has used his health professional background in clinical, research and teaching environments. He received a Master of Science in Epidemiology from Queen's University in Kingston, Ontario in 2003 and a PhD from the University of Toronto in 2008. He completed a postdoctoral fellowship at the Centre for Addiction and Mental Health and at the Institute for Clinical Evaluative Sciences, both located in Toronto, Ontario. His primary research interest is in the area of health and health services among people with developmental disabilities.



**Dr. Yona Lunsky** is a Psychologist and Professor in the Department of Psychiatry at the University of Toronto. She directs the Azrieli Adult Neurodevelopmental Centre at the Centre for Addiction and Mental Health (CAMH) and the Health Care Access Research and Developmental Disabilities Program (HCA RDD). She is passionate about mental health and working together with people with disabilities and their families to design supports and services to better meet their needs.





**“My name is Lou.** I am fully vaccinated for Covid-19 and had a booster shot in December. My favourite part of getting vaccinated is getting an iced cappuccino after. I like going to the eye doctor to get my eyes checked and going to the audiologist to get my ears cleaned. I enjoy spending time with my family, especially during holidays like Christmas and Halloween. I go for walks and go swimming in the summer. I also like playing the drums in a band.” - Lou (Rob’s brother)



**“I am Danielle.** I am 53 years old and live in Toronto. I like to go on the iPad. I also like to go singing and watch movies. I like to do things with my roommates and my staff. I also like to visit my family, and go for walks with them. I like to exercise. I do jumping jacks, I walk, swim, and dance. I like my doctor. She is a nice person. I have to sit and wait to see her. And then I go into the office. I talk to her and she helps me. I am vaccinated, it was good to get my shot, I was brave.” - Danielle (Yona’s sister)

**3.21 Yona and Rob, let’s start with the big picture. How would you evaluate the current state of Canadian health care for individuals with Down syndrome?**

**Rob:** It’s a tough one to say Canadian, because there’s almost nothing in terms of Canadian health care focus for people with Down syndrome. It really is a provincial issue, so we have to look at each province separately in terms of how they’re doing with people with Down syndrome, and each one has its positives and not-so-positives.

**Yona:** I agree we don’t have a national picture of Down syndrome, and we don’t have a national picture of developmental disabilities. We have pockets of research on adult health care issues, and population level data on what’s going on provincially. And we’re getting more clinicians trained and focused on this population, and more researchers. Our **H-CARDD Program** has been around now for over ten years, so we’ve got more of a group of people we can bring together, crossing research with clinical practice.

I think the push around vaccines, if you take something like *Ready For My Shot*, led by people in BC, that’s looking at what’s going on nationally. Except the rules varied by province or territory. So sometimes we do work and we think, how does this apply to everyone across the country? We’ve done some Covid-specific research working with people with disabilities, parents, and care providers across the country. But research doesn’t always happen that way.

**3.21: Throughout the pandemic, you have been at the forefront of research and advocacy for people with Down syndrome and other developmental disabilities to be recognized as uniquely vulnerable and treated accordingly. Why are you so passionate about this?**

**Yona:** We’re passionate about this population because they’ve been left out for so long of so many things, and we

see it in our research. We are both clinicians, so we see it in terms of the kind of clinical care that’s provided to this group. We live it, and you can imagine with Covid that my sister and Rob’s brother suddenly had no services and also had restrictions in terms of movement; you either stay at home and can’t go back to where you live, or, if you live in a group-based setting, you can’t be with the people from your family home. That happened immediately with very real risks around how they would navigate things, how they would manage with the pandemic restrictions and the risks around Covid.

We all feel very helpless during the pandemic, but I thought if I can do something to help, it’s a good place for my energy to go, instead of endless worrying. Turning bad situations into good ones by asking the right questions, turning it into action, finding answers, so we have numbers, facts, and information to go with. Research is our outlet. But we’re also in touch with what’s actually happening, because we’re watching the people we love go through it.

**3.21: What shortcomings has the pandemic revealed about how people with developmental disabilities are viewed and cared for in our medical system?**

**Rob:** No one’s coming in to say, “We realize there’s this whole population we haven’t been focusing on in the medical community.” The message is coming from people with disabilities whose voices are not well heard, and families whose voices are also not well heard. So I think we just try to do our part in amplifying those voices.

**Yona:** One thing I think that may be a difference between, for example, a lung transplant patient and people with developmental disabilities, is that the person who does well with a lung transplant is able to advocate for themselves. And I think people with Down syndrome can advocate for

themselves, but they’re going to need a bit of help to get to the podium. And that requires the support of other people, often their families. But those families have been lacking in support for so long, they barely have the energy to just do what they need to day to day.

Also, I think all the people making the rules are healthcare people who’ve been trained to focus on particular issues. We don’t train healthcare providers a whole lot on Down syndrome or on developmental disabilities, so no one at the table making national decisions had a disability focus. I think that really hurt us when we had to pull information together very quickly during Covid. Our country was not

collecting data on these issues. We use an expression: If we don’t count, they don’t count. So if we’re not counting them, then they’re not going to count when we make our decisions.

**3.21: Have you seen any positive changes or encouraging signs during this period?**

**Yona:** I’d like to flag *Ready For My Shot*, especially as it relates to social media. I think social media can at times be really toxic, but it’s also a way to help people connect with each other. When my sister was really little, my mom went to a playgroup in a church with other parents who had kids with disabilities, and they supported each other. If you live in a smaller community, or it’s really hard for you to get out of the house, that might not be easy to do. And certainly during Covid, it’s suddenly hard for everyone.

So there’s a lot of good in social media, and in the ways we can share information rapidly and connect with each other. Rob and I haven’t seen each other or given each other a hug in a couple years now, but we’re right beside each other in terms of things that are going on. And we can also be right beside our siblings or family members, and people with disabilities can be right beside each other as well.

At a professional level, we’ve done projects bringing people together across Canada, and we’ve been able to quickly compare notes and connect with people in other parts of the world. The fact that we could learn so quickly from other provinces and from other countries meant that we could advocate differently. Some of the earliest Covid resources came from Australia. Rob and I are part of **T21RS**, a group of scientists from around the world who are focused on Down syndrome, who’ve been meeting and sharing information with each other since the start of the pandemic.

AARON JEEVAN DARRYL EMMA SANJIV

**READY FOR MY SHOT**

**GET YOUR COVID SHOTS**  
LIVE YOUR BEST LIFE

ReadyForMyShot.ca

READY FOR MY SHOT IS A GRASSROOTS GROUP OF SELF-ADVOCATES, FAMILIES, FRIENDS, RESEARCHERS AND CAREGIVERS.

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Government of Canada, Gouvernement du Canada, Canadian Down Syndrome Society, Société canadienne de la trisomie 21, Azrieli Foundation, Health Data Action Research and Developmental Disabilities, PLAN, and others.

PRODUCED BY BIRD COMMUNICATIONS



### 3.21: What lessons would you draw from the pandemic to healthcare in general as it relates to people with Down syndrome and others with developmental disabilities?

**Yona:** First, we have to prepare for two things at the same time. We want to prevent Covid, and we also need to know how to deal with Covid when it happens. We want to prevent going to the emergency department, but some of us might end up at the hospital or in the emergency department anyway. So, we need to be planning health care around how not to wind up in a difficult situation, but at the same time, knowing that those healthcare situations may happen, there are ways we can be more prepared to make those experiences go better. One really important area would be thinking about how we communicate healthcare needs: what a person's needs are, how they communicate, what makes them afraid, what makes them happy and comfortable, who needs to be involved in their care.

Second, when we're in the midst of a really stressful health care situation, it can be hard to process in the moment. You may need to hear something twice, or you may want to write things down, or have someone sitting beside you to hear what's going on, because you can't process it all yourself. That's even more important for those with Down syndrome. We're very used to families of young children having parents make healthcare decisions. As people get older, we want them to make as many health care decisions as possible on their own, but they might need support. So we all need to think about who those key support people are. And how do you make sure that person is included in all communications, be it in the face-to-face room, in a virtual room, in written communications?

Third, recognize that we have all different kinds of health. We have mental health issues, physical health issues, lifestyle factors, as well as the illness of Covid itself. We need to think about all aspects of a person's health, now and after the pandemic.

### 3.21: At the patient-doctor level, do you have any tips for how individuals with developmental disabilities and their caregivers can advocate for their needs?

**Rob:** For me, the first step is trying to find a family physician who is an advocate themselves, and who has done the expert training. Those are really hard to find, but they do exist. Even my brother doesn't have somebody who has that extra training in the area of developmental disabilities, but that would be the first step, to try to find somebody who does have that extra training.

**Yona:** I don't know if I would go that route. I would say find someone who is willing to learn; teamwork makes the dream work. Find someone who wants to be part of your team because this kind of work around navigating healthcare is a lifelong thing. It takes cooperation and collaboration. You want people who are willing to learn and work together.

**Rob:** It can be touchy at times. When you come to a doctor or specialist with information on whatever your family member is dealing with, hopefully they don't take it as an offense or feel like you are questioning their expertise. For instance, I brought the Down syndrome health guidelines to Lou's family physician. It's important that you're able to talk about these things.

### 3.21: What would you say to families who may be discouraged by having to fight to have their loved one's needs met?

**Yona:** It's a great skill set to work on. It will come in handy in a number of other situations. It may not be obvious at the time, but having advocating skills makes a big difference and really improves and extends the life of the people we love.

**Rob:** Each generation is doing their advocacy work. My sisters and I look at people with Down syndrome now and are amazed at the things that they can do. You might not be able to quantify the improvements because of the advocacy, but it's there. Each generation seems to be making some really awesome contributions in terms of the life and quality of life of people with Down syndrome.

**Yona:** The other thing is that if you look at this current generation of health care providers, the things we're experiencing today are changing how we see the world. We're talking so much more not just about Down syndrome or developmental disabilities, but about equity and inclusion and diversity. And I think that this next generation of health care providers is going to be very different than the last generation, and the one that comes after them is going to be even more different. That's another reason for all of us to keep going; don't give up. Change is happening, even when you can't see it.

### 3.21: Do you have any suggestions for how families and people with disabilities can contribute to advocating for systemic change?

**Yona:** I think it's always important for us to understand our history. Historically, disability was medicalized and viewed as a problem. That's why, for example, we had institutions and we gave particular kinds of treatments to people with developmental disabilities. That created a lot of distrust. But people with disabilities are entitled to excellent health care,

just like everyone else. It's not that their disability is necessarily a problem that needs to be fixed or treated, but they need support to live their lives with their disabilities as best they can – and that includes health care.

We need to know our audience and think, what would be the best way to communicate with them? Maybe there are gaps in their knowledge. So how can we provide them with that information so they can make wise decisions? I try to approach the doctor with the same gentleness that I would want someone to approach my sister with. Now, sometimes you have to be more than just gentle when dealing with the system, but thinking about that collaborative team-based way of working is one important piece.

**Rob:** I always think of that expression: You've got to kick at the darkness until it bleeds daylight. It gets a little frustrating because at the systemic level, it's sometimes hard to see any changes happening, but they are happening and they're incremental. My impression is that they happen, especially at crisis times. It seems to me that when a crisis happens, that's when data becomes really important and people go looking for it. It sounds kind of strange, but I think at the systemic level, sometimes you have to take advantage of the crisis that happens.

**Yona:** It's a terrible thing when there's a crisis. Absolutely. But there are lessons that can be learned, and people can come together very quickly to make changes. ●



## Resources & Related Stories

- ✓ Covid-19 Vaccine Story, Featuring Lou
- ✓ COVID-19 positivity rates, hospitalizations and mortality of adults with and without intellectual and developmental disabilities in Ontario, Canada
- ✓ Blog: 'A Sister's Reflections' by Yona Lunsky, on her sister Danielle and Covid-19
- ✓ Global Medical Care Guidelines and Checklist for Adults with Down Syndrome





# THE JOURNEY:

## Health Stories from the Community

### LEUKEMIA

**Name, current age, and location of individual with Down syndrome:** Eli, 8 years old, Prince George, BC

**Age at diagnosis of leukemia:** 8

**A brief summary:** Eli has bloodwork every six months to monitor, among other things, kidney function. The day after this routine bloodwork we received a call first thing in the morning to take him to the hospital where our pediatrician was waiting. We were told there were abnormal blood cells; he was flown to BC Children's that afternoon where the leukemia diagnosis was confirmed, and treatment started on Monday. His official diagnosis is DS-B-ALL, which has a well-established course of treatment. This involves multiple rounds of

chemotherapy; due to increased risk of secondary issues, kids with Down syndrome spend more time in hospital as a precaution. Because we live in Prince George, this has meant only two week-long visits home over the past 11 months. The outlook has been very good, with this treatment having a very high success rate and the fact that it was found very early. There is ongoing study into developing better treatment options, and Eli is a part of a study that includes immunotherapy. This did lengthen the overall timeline a bit, but has shown very positive results and lowers the overall toll treatment will take on his body. The team at BCCH has been incredible and we are so grateful. Ronald MacDonald House and all its supporters have been a huge blessing as we will be well past the 300-night mark there.

**Where is the person now in their journey with this health issue?** In mid-February, nearly a year after diagnosis, Eli started the maintenance phase of treatment. This will involve trips back to BCCH most months for about two years for additional checks and treatment.

**Can you share any resources that you found valuable?** Ronald MacDonald House has been an absolute lifesaver for our family to have a place to stay. There are many businesses and organizations that

support families through RMH and the Hospital. BC's At Home Program was a support we were not enrolled in at the time of diagnosis but we were connected with it by the hospital social worker. At Home provides support with travel to and from appointments as well as help with prescriptions and home supports such as housecleaning. West Coast Kids Foundation has also been invaluable, as they provide many supports including the provision of both in hospital and at home meals and snacks for families.

**What advice do you have for patients who may face this health issue?** It's a hard thing to go through for anyone. Those who love you will do everything they can to help you through this.

**What advice do you have for those supporting this individual with this health issue?** It's hard, there's no getting around that. Take all the help you are offered. If you're not the direct caregiver, know that at times, we don't know what we need. There is a lot of trauma in this journey, from a phone call that has you drop everything to go to the hospital, to seeing your kid get weak and sick, to throwing up, to climbing the walls because they can't leave their room. Our son has been pretty good at taking things in stride, but certain procedures are causing more stress the further down the road we get.



### KERATOCONUS

**Name and current age of individual with Down syndrome:** Lou, 55 years old, Oakville, ON

**Age at diagnosis of keratoconus:** Approximately 38

**A brief summary:**

Lou had vision problems since he was young for which he wore corrective lenses prescribed by an ophthalmologist. When Lou was 38 years old, the ophthalmologist that was caring for him informed us that Lou had keratoconus and was legally blind. We had to act quickly to get Lou on a waiting list for a corneal transplant as soon as possible. The waiting list to get such a procedure can be years long.

After the first corneal transplant (each eye was done separately) Lou was upset, because he thought he now "can't see" (he had to keep his operated eye closed during recovery). Luckily the recovery time was short and Lou soon realized that he could now see out of the operated eye better than before the procedure and

no longer needed glasses! He was much more cooperative and understanding about what to expect when he had the procedure for the second eye.

**Where is the person now in their journey with this health issue?**

It has been almost 20 years since Lou had the surgeries and he continues to have yearly appointments with the eye surgeon. These are always very positive experiences for Lou. The surgeon and staff at the eye surgeon's office have always been extremely understanding and caring. The same surgeon has performed cataract surgeries for Lou.

**Can you share any resources that you found very valuable?**

This is a little dated and uses some archaic language, but the information was useful at the time: <https://pubmed.ncbi.nlm.nih.gov/11782228/>

**What advice do you have for patients who may face this health issue?**

As soon as you get the diagnosis, attempt to get the individual on a waiting list for a corneal transplant. The procedure is invasive and a bit scary, but made a marked difference in Lou's quality of life.





# HEART SURGERY

**Name, current age, and location of individual with Down syndrome:** Ellie, 7 years old, Surrey, BC

**Age at diagnosis of heart issue:** We had a pre-birth diagnosis of Down syndrome with Ellie and were therefore examined closely every month prior to birth. Despite all the looking, she was not diagnosed until she was born.

**A brief summary:** On the day of her birth, Ellie was moved to Surrey Memorial's NICU (neonatal intensive care unit). I believe she was diagnosed with her VSD (ventricular septal defect) that first day. The hole in Ellie's heart was 5mm in diameter at birth, which is quite large, and this hole, which was between the two lower chambers of the heart, was causing already oxygen-rich blood to be pumped back into her lungs. Ellie also had an ASD (atrial septal defect), which was a small hole between the chambers in her upper heart. Both of these conditions are quite common in all newborns and, if small enough, will close up on their own. Ellie's was too large and so had to be closed with surgery.

We were told to watch for signs of the condition such as blue lips or fingertips, fast breathing, and lethargy. Due to Ellie's condition, the pressure in her lungs was kept quite high, which masked all these symptoms. To us, she seemed fine until they called us on a Tuesday and told us they wanted her in for surgery that Friday. She was only five months old at the time. The team at Children's Hospital was very good at getting everything arranged and we met with the surgeon a day or two before the operation. The surgery went fine, although for her parents it



was one of the longest days we've ever experienced. Ellie was in the ICU for three days afterwards, and that was extended only because one of her lungs collapsed, which is a fairly common post-operative complication with this sort of surgery. They took care of that and then moved her into a room with her mom, where they stayed for the rest of the week before coming home.

**Where is the person now in their journey with this health issue?** Today Ellie is fully recovered from her heart surgery. She had a few follow-up visits so they could monitor the patch, but after the last one when Ellie was five, they gave her a clean bill of health and sent us on our way. Her scar has faded quite a bit by this point.

**Can you share any resources that you found valuable?** Since the surgery happened with almost no warning, we really didn't take advantage of any resources. Children's Hospital was the only place we relied on

during this time, and they were terrific. I would also like to say that it is fantastic that they run a satellite heart clinic at Surrey Memorial so parents out here in Surrey and further out into the Fraser Valley don't have to drive into Vancouver.

**What advice do you have for those supporting this individual with this health issue?** I can only say that this is a scary thing to have happen to your child. For us, Ellie was very young and today she doesn't remember the experience, unlike her parents. Cry when you need to. This is not something normal to deal with; you need to let it out. There will be more than enough to deal with without bottling it all up inside. Also, keep in mind that our children are amazing at healing and bouncing back from things that would take adults much, much longer to recover from. Ellie was out of the hospital a week after open-heart surgery. I can't imagine the same could be said for her dad!

There's not much I can say regarding supporting a child with this condition. Ellie was very young and not showing any of the symptoms normally associated with a VSD. After the surgery, she needed more comforting for sure. There were some rough nights when she got home from the hospital, but after the first week, she was pretty much back to normal. Our main concern was infection and so we isolated her from everyone and pretty much kept to ourselves until the wound had completely healed.

If you're interested in hearing more about our experience, I discussed it on the **T21 Mom Podcast, episode 34.**

# GASTROINTESTINAL ISSUES - PART ONE

**Name and current age of individual with Down syndrome:** Paul, 35 years old, Calgary, AB

**Age at diagnosis/discovery of gastrointestinal issues:** No formal diagnosis of a specific gastro-intestinal problem, but exhibited bowel-related issues starting approximately age 28.

**A brief summary:** The issues were intermittent, making diagnosis difficult. Paul was tested for Celiac disease (negative). The doctor could not identify any specific cause and encouraged us to investigate diet triggers via a daily food log. We suspected insufficient fibre intake, so Paul started Metamucil, which helped somewhat. Next, we cut out dairy, and many problems resolved. We switched to lactose-free products, and when that is not available, Paul takes Lactaid tablets. We have also found that more regular exercise, plus planned bathroom stops helps.

**Where are you now in your journey with this health issue?** With good meal planning, Paul's issues have largely been resolved. However, there have still been a few instances which have caused us to do further investigation. Recently, we met with a Dietician, who suggested that sugar could be a problem. Paul switched from fruit juice to vegetable juice, and avoids pop, which has also helped.

**Can you share any resources that you found very valuable?** Family doctor – they can do a preliminary investigation, rule out major problems and provide referrals to other health professionals such as Dieticians or Gastro-Intestinal specialists.



Dietician – they can offer food-specific advice and information and can direct you to other resources such as other health professionals or information resources.  
Online information – credible sites can offer further information to help with diagnosis/resolution, and online discussion groups can help as well.

Other families in your network – others may have already faced these issues and may offer advice or links to other resources. It is also very helpful to know you are not the only one facing these issues.

**What advice do you have for others who may face this health issue?** Consult your child's doctor right away to rule out major issues quickly. Food-related G-I issues can be difficult to diagnose and will require active involvement by the parents and other health professionals.

For Paul this will likely be a lifelong issue, and he will need to continue to make good food choices and adjust his diet as necessary as circumstances change.

**What advice do you have for those supporting others who have this health issue?** First, it is important to recognize that G-I issues can have a major impact on your child's life and ability to enjoy activities.

Keep a food log and log when bowel issues occurred.  
Involve the child's doctor and other health professionals in the investigation. There is lots of suspect information on the internet and it is important to rely on credible sources to get the most appropriate information.

It is important to look at product ingredients (in Paul's case we look for dairy) to determine whether they may cause a problem.

Here we are covering two individual stories: one featuring a medically-diagnosed issue, and one with a self-diagnosed issue.



# GASTROINTESTINAL ISSUES - PART TWO



**Name, current age, and location of individual with Down syndrome:**  
Colin, 33 years old, Calgary, AB

**Age at diagnosis/discovery of gastro-intestinal issues:**  
Diagnosed at age 23 with ulcerated colitis.

**A brief summary:**  
It started after a bad case of the flu. Colin was losing weight and started having bowel movements after every meal. He would complain that his waist was hot. This triggered us to research further medical advice and we were referred to a gastroenterologist who immediately sent Colin for a colonoscopy. Colin had quite a number of ulcers in his colon and was put on prednisone for two weeks to help clear up the ulcers. After that we had a sigmoidoscopy to see how things were healing. The diagnosis was positive, and Colin was prescribed a new and lifelong medication of Mezavant (four pills daily), and a follow-up, complete with blood tests every six months. Colin also reduced his caffeine intake considerably and was already eating a pretty healthy diet, so that didn't really change.


Things were going very well so his doctor reduced his medication to two pills per day in January 2018.

In November 2018 Colin started to experience another flare-up as well as vomiting. He had another colonoscopy as well as an endoscopy for his upper tract. Ulcers were found in both areas, and he was prescribed medication to clear them up and increased the Mezavant back to four pills per day, and added a second prescription, Pantoloc, taken daily.


**Where are you now in your journey with this health issue?**  
As long as Colin is taking his medication and eating a healthy diet, he can control his colitis.

**What advice do you have for others who may face this health issue?**  
I would say it's very important to seek professional advice if your son or daughter are experiencing issues with bowel movements, vomiting or stomach aches. It can go on for some time before you even realize there's a problem. •

# RUN UP




## For Down Syndrome

*Presented by:*  **EURORITE**  
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**BC's BIGGEST Annual Down Syndrome Event Returns!**

**June 5, 2022**  
**Swangard Stadium**  
**Burnaby, BC**



**Supporting the Down Syndrome Resource Foundation**

**DSRF.org/RunUp**



# CDSS SPOTLIGHT

## Fundraise My Way

Are you an individual or group considering holding an awareness and/or fundraising event this spring? Check out CDSS's **Fundraise My Way** platform page for some inspiration and to see just how easy it is to create your own fundraiser. Get creative with a sports theme, a birthday or milestone celebration, a school-wide event, a company fundraiser, anything goes! Contact us at [Events@CDSS.ca](mailto:Events@CDSS.ca) to learn more about this simple five-step-to-event process.

## CDSS's Bridge the Digital Divide Campaign News

Thank you to those who submitted applications for our tablet and app program during the month of February. Stay tuned for further details as applications are reviewed and we begin to deliver tablets to successful applicants in the spring. Learn more [here](#).



## Have You Checked out our New CDSS Socks?



Order by March 3 in time to receive your limited-edition World Down Syndrome Day socks from CDSS and our generous partner Friday Sock Co. Our striped socks sold out in a few short weeks, so don't miss out on this fresh new dot design to add to your collection! See our ad on the back page and [order here](#).

## CDSS Board of Directors Recruitment

Requirements, role details and responsibilities are available [here](#).



## SAVE THE DATES

**MARCH 3** Free CDSS Webinar: *Employment: The Gold Standard for Inclusion*

**MARCH 3** is the shipping deadline for official CDSS WSD socks, see our ad on the back page and **order TODAY!**

**MARCH 3** is the deadline to participate in our World Down Syndrome Day **#InclusionMeans video!** Email [events@cdss.ca](mailto:events@cdss.ca) for details.

**MARCH 21** is World Down Syndrome Day! See our ad on page 21 and follow @CdnDownSyndrome for ways that YOU can get involved in 2022 and be heard!

**APRIL 5** Free CDSS Webinar: *Supported Decision Making & Guardianship*

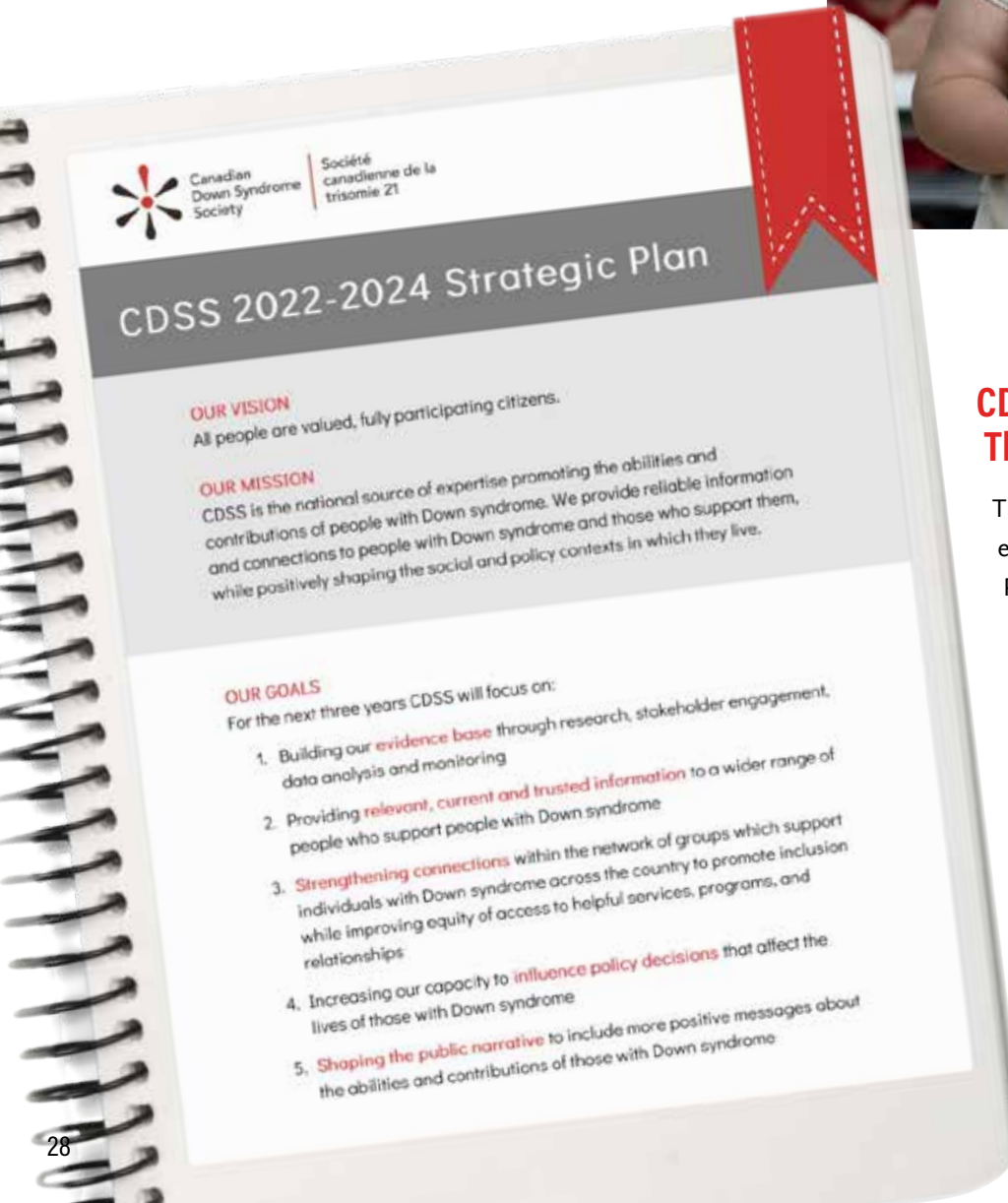
**APRIL 8** CDSS's Annual General Meeting, memberships are available [here](#).

**JUNE 11-19** The second annual CDSS Walk for Awareness takes place. In 2021 the walk raised over \$65,000 to support our national literacy program. Stay tuned for 2022 registration and team details @CdnDownSyndrome.



## CDSS Announces Three-Year Strategic Plan

The Board of Directors and staff at CDSS are very excited to present our new 2022-2024 Strategic Plan. This will guide our continued awareness and advocacy work, our research, resources, partnerships, policy influence and programs over the next three years and beyond.



## FIND US / TAG US

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# DSRF CORNER

## What Does Inclusion Mean to You?

This year on World Down Syndrome Day (March 21), people with Down syndrome and their loved ones from around the world will come together to celebrate under the theme #InclusionMeans. Inclusion means different things to different people, and we want to know what it means to YOU.



DSRF is producing a community video to debut on World Down Syndrome Day in which every person with Down syndrome is invited to tell the world what inclusion means, and why it matters. Please visit [DSRF.org/WDSO](https://www.dsrf.org/WDSO) to find out how you can participate. The deadline for submissions is March 6.



Also on World Down Syndrome Day, we invite you to join us for a live (virtual) recording of The LowDOWN: A Down Syndrome Podcast. DSRF Ambassadors Andrew Bingham, Jodi Klukas, and Chris Sayer will share their thoughts on inclusion and take questions from the audience for the Season 5 premiere of The LowDOWN. Book your free ticket at the link above and listen to The LowDOWN through your favourite podcast app starting March 23.

And our World Down Syndrome Day celebrations don't end there! We also have our 3-2-1 fundraising campaign, a WDSO 50/50 draw, lots of socks and local landmarks being lit up in blue and yellow. Details on all the World Down Syndrome Day festivities can be found at [DSRF.org/WDSO](https://www.dsrf.org/WDSO).

## New Behaviour Service

DSRF is continuing to expand our programs and services for individuals with Down syndrome and their families with the introduction of our first full-time Behaviour Consultant, Sara Peralta.

Problem behaviour can negatively impact a child's and/or family's life in many ways. Families may start to avoid certain activities (e.g., going to stores, swimming, eating at restaurants) due to their child's behaviour. It can also impede the child's personal development in other important areas.

Family-Centred Positive Behaviour Support Service is designed for families who would like to learn strategies to address behaviour challenges and/or would like to support their children in learning new skills. Positive behaviour support services can help to enhance both child and family quality of life and increase the range of activities a family can enjoy together. Positive behaviour support services are

individualized and will be designed to focus on each family's unique concerns, with a particular focus placed on positive reinforcement.

DSRF is now accepting requests for one-time consultations for our Family-Centred Positive Behaviour Support service. Register for your consultation at [DSRF.org/OtherServices](https://www.dsrf.org/OtherServices).

## Everything's Changing

Shhh... come close. Can you keep a secret?

*\*whispers\** Everything is about to change at DSRF.

Okay, not *everything*... but a lot. A whole lot.

That's all we can say right now. But you'll definitely want to tune in to @DSRFCanada on Facebook, Twitter, Instagram, and YouTube over the next two months as the Down Syndrome Resource Foundation enters a new era. Much more to come!



## UPCOMING AT DSRF

**World Down Syndrome Day – March 21, 2022**

**Run Up for Down Syndrome – June 5, 2022**

## FRIENDS OF DSRF

2022 got off to a flying start at DSRF thanks to our generous supporters, who UPended all the expectations for our DownSide UP campaign. Our year-end campaign raised more than \$52,000, exceeding our goal by over 30%.

Social Venture Partners Vancouver, which has been a major funder of DSRF over the past three years, has made another significant investment in children with Down syndrome. SVP has committed \$26,000 per year for the next three years to fund the creation of a Kindergarten Readiness program. The Kindergarten Readiness Program is designed to help individuals with Down syndrome ages 3-5 years and their parents/caregivers prepare for the transition into kindergarten. This new program is a collaborative effort between the DSRF program team, which includes teachers, speech language pathologists, occupational therapists, behavioural consultant, and mental wellness expert.

The Jarislowsky Foundation has generously donated \$7,000 in support of DSRF's educational programs and health services for people of all ages with Down syndrome.

The Adera Foundation Society has generously donated \$5,000 in support of DSRF's programs and services for children, youth, and adults with Down syndrome.

Long-time supporter the Hamber Foundation has granted \$2,000 in support of DSRF's programs for youth with Down syndrome.

Thank you very much to the sponsors of DSRF's Winter Festival Express holiday event: the Neil Squire Society, Vancity - Brentwood Community Branch, Borden Ladner Gervais LLP, CIBC, The Answer Company, LiUNA Western Canada, Phillips, Hager & North Investment Management, and BlueShore Financial.



**Down Syndrome Resource Foundation**

Together. Hand in Hand.

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**World Down Syndrome Day**

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