

The T21
Difference

Learning and Development in People with Down Syndrome

A Time for Advocan

Let's Talk Down Syndrome

One Parent's Perspective

A WORLD of Possibilities **Globetrotting with Elyse**

Spring 2020







Société canadienne de la trisomie 21

Welcome to Issue Two of 3.21: Canada's Down Syndrome Magazine!

The feedback from our inaugural issue was absolutely incredible. Thank you to everyone who reached out to us, and even more importantly, thank you for sharing with others the magazine to further expand the reach of our inspirational and educational messaging.

Our second issue shines a light on advocacy. Whether you are a parent, teacher, sibling, friend, colleague, or person with Down syndrome, we hope you make a conscious decision to advocate, especially on March 21 - World Down Syndrome Day. Advocacy comes in many unique forms: from voicing needs and concerns at the government level, to simply living your life in a positive and impactful way. In this issue we choose to celebrate all forms of advocacy. We hope you enjoy reading about people's journeys in travel and in life throughout this spring issue.

We really do love your feedback! Please drop us a line at 321DSMagazine@gmail.com with your thoughts, story ideas and opinions.

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AWORLD of Possibilities

Globetrotting with Elyse

by Adelle Purdham



e are standing on a beach somewhere along the infamous North Shore of Hawaii, on the island of Oahu. I have my toes tucked beneath the sand and I'm feeling nervous. One hand rests on my hip while the other cups my forehead, shielding my eyes from the blinding sun that bleaches everything white. I'm scanning the waves, sizing them up; the waves are what the beach is famous for. These are the ocean waves we will be riding.

Standing nearby is my husband, Dan, and our three young girls, Ariel, Elyse and Penelope. We are on a forty-five-day

family trip around the world, taking us from Toronto, ON to San Francisco, CA and the Hawaiian Islands, then onward to Japan, Thailand, and finally a week in Portugal to complete the trip before heading back home.

Surfing in Hawaii is one of a handful of experiences we have been looking forward to for years. The waves are intimidating, but there's no backing out now.

Our eldest daughter, Ariel, is eight years old. She took skateboarding lessons and was the most enthusiastic about surfing beforehand; now, taking in the dramatic scene of the surf, she's less sure. Penelope is three years old and our

youngest child. I didn't think it was possible to take a three-year-old surfing, but with the help of expert surfers and a tandem method, Penelope will also be out catching waves — she just doesn't know it yet. I later learn from our photographer that even babies surf in Hawaii: he took his firstborn out at six months old, which he admits may have been "pushing it," but I digress.

Then there's Elyse, our middle daughter, who is on the cusp of seven years old and has Down syndrome. There was a time before she was born when I questioned what she would be able to do. *Know your child*. Elyse is not the wild, adventurous type.

She is not the steadiest on her feet at the best of times. She does not particularly enjoy standing on top of moving objects, is often resistant to change, and takes a while to adjust to new experiences. To say surfing on the North Shore would be pushing Elyse's boundaries is an understatement.

Oh, and neither Elyse nor Penelope can swim. When I wrote to the surfing company we eventually hired to inquire, I expressed my concerns about our younger two. In response, the owner – a veteran surf goddess – assuaged my doubts about safety and sealed the deal with her final comment. "I think it's going to be super fun."

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So here we are, practising our surf moves atop surf boards on the sand. We are wearing long-sleeved rash guards with bathing suits underneath. Elyse is really enjoying the warm-up. She is laying down atop her board on her stomach, imitating the cupped hands, arm swinging movement we will need to use to propel ourselves forward through the water. Now she's crouched down low, arms out for balance, feet apart, knees bent, standing sideways, looking like a real surfer chick. I feel a degree of anxiety lift as I see her attempting each movement on dry land. We look the part, but I can't help but wonder what is going to happen when we actually get out on the water.

The moment of truth. The time has come to get our feet wet, and all three kids look like they want to bolt. Penelope and Elyse do actively run away. With a big crew of helpful adults, our convoy convenes toward the water and what happens next is hard to explain. Like a car accident, everything happens fast. The next thing I know, all five members of my family have been towed out and we're bobbing in the ocean. Dan and Ariel, each on their own board, are being led away to be pushed into their first wave. I'm craning my neck to try and keep my eyes on them, but with the distraction of my youngest two and the rise and fall of the waves, it's near impossible. I just have to trust and keep my fingers crossed that our instructors know what they're doing and that everyone is going to be okay.

Elyse, Penelope and I are in the holding area, a safe place to wait until it's our turn to surf. Penelope has been moved onto my surfboard for safe keeping and she's clinging hard to my neck. Elyse is lying flat out on her surfboard

and it's pretty clear that she's terrified and wants her daddy. Both of them are wailing. I see Ariel in the distance; she makes it to her knees then crashes hard from the force of the wave. I can't see her resurface.

In moments like these, you start questioning the parenting decisions that have led you to this point. Why did I think it was a good idea to take our kids surfing in the Pacific Ocean? What if something bad happens? Why am I putting them through this?

Eventually, as the calm of our instructors rubs off on them and they habituate themselves to the movement of the waves, the younger two settle down. The owner surf goddess scoops Elyse up onto her board and away they go, off to catch her first wave. Surf goddess even gets Elyse to stand up on her first attempt.

I wish I could say Elyse loved surfing, but truthfully, she didn't. She found the experience to be scary and overwhelming. But would I change what we put her through? Absolutely not. Elyse hung in there for a second surf attempt, this time on her stomach facing the shore, and there's an incredible shot of her crashing through a wave, face first, eyes wide open with a hint of realization of what she has achieved. She did it. She conquered that wave. And if she can conquer her fears and a wave off the North Shore of Hawaii, what else can she do?

While surfing wasn't Elyse's first choice, we planned other excursions we hoped would be more her speed. True to character, in new situation after new situation, Elyse struggled to a degree, at least initially.

At the start of our rainforest hike through the jungle in Thailand, Elyse refused to budge. Arms crossed, she stood firmly in place. "I want food." *Know your child*. Luckily, I came prepared with snacks and so did our guide who not only provided fresh coconuts from his family's farm, but he also packed some of Elyse's favourites: chips and Oreo cookies.

Elyse found the several kilometre walk in the blanket of heat to be challenging, as we all did, so Dan carried her most of the way. When we chanced upon gibbons, tree dwellers for life that live in the rainforest cover, I encouraged her to crane her neck to look up and see them, but she wasn't interested – not in that moment. Near the end of our hike, Ariel spotted a vine

in our path, and that caught Elyse's attention. She monkeyed around with her sisters and was compelled to hang around, just like those gibbons she supposedly wasn't paying attention to.

In Japan, we stayed in a traditional Japanese Inn, a ryokan, where it was customary to wear a robe called a yukata and slippers for the duration of your stay. Unlike her sisters, Elyse initially refused the yukata, which was fine. When she attempted to wear the slippers, our flat-footed girl whose feet turn outwards sent them flying off with each step.

Then there was the food. Elyse, typically a hearty eater, was beside herself. On the eve of our first dining experience, tired and jet lagged from travel, decadent course after course was delivered to our table, a gastronomic feast and pleasure for the senses – but completely foreign and mostly unidentifiable to our Canadian eyes. Elyse was having none of it. "Pizza," she moaned, "I want pizza." Penelope, for her part, curled up in a ball and fell asleep on the floor while Ariel poked questioningly at her plate. Elyse did eventually find her staple food in Japan; rice and fried chicken is a common dish and Elyse had her fill.

In Northern Thailand, I organized an excursion to an elephant nature reserve. I didn't realize we would be face-to-face and without enclosures amid the giant beasts, but was delighted to discover this would be the case.

Animal encounters for Elyse are hit or miss; sometimes she coos, other times... she screams. One day she might purr at a

cow and get dangerously close, the next she might wail at the sight of a kitten. It just depends on the day.

I was nervous about how our morning with elephants would play out, but having already survived surfing in Hawaii and eating in Japan, Elyse seemed to draw some confidence from her newfound worldliness. She was enthralled by the educational video that played in the car ride on the way to the reserve, and helpfully repeated every line.

Elyse isn't quiet about her fears, but she's honest about them, and the people we've traveled with seem to appreciate that about her. She clung to her dad when we first saw the elephants, but eventually became relaxed and comfortable enough to rest her hand atop of an 86-year-old gentle giant. She pet that grandma elephant and told her she was a good boy.

Our elephant encounter taught our girls about real, unrehearsed danger. When the elephants back up, you get out of the way – quickly! When her sisters fearlessly leaned in to feed the elephants pumpkins with their bare hands, Elyse eventually got in there too, choosing instead to toss the food in the elephant's direction. Those morsels did not go unappreciated.

The focal point of our six-week trip was a lantern festival in Thailand called Loy Krathong. We signed up for a boat ride that departed from our riverside hotel and carried us into the





heart of the festival in the old downtown of Chiang Mai. In retrospect, this is the only way our family could have safely enjoyed the experience, as we could see the crowded streets and packed bridges from our boat ride and our little family would have been engulfed by the masses.

Knowing my middle daughter, I knew the evening of the festival would be particularly challenging for Elyse for several reasons: the late night, the bright sights, the loud and unexpected sounds, the shiftiness of the boat moving through the water, and the novelty of the situation all

spelled potential disaster. I cringed at the thought of the stress I would be putting Elyse through. But when weighing the pros and cons, I decided the experience of thousands of floating lanterns in the water and sky would be worth it.

To mitigate the overwhelm in g sensory experience, we did something we never wanted to do—we brought earphones and an iPad. While I could have allowed myself to feel shameful about this parenting move, instead I felt relief. After showing signs of distress, we gave Elyse the device and she was then able to experience the festival at her own level. Know your child.

Our boat reached its destination and we were thoroughly enchanted by the experience of thousands of glowing lights rising in unison. At the height of the beauty and chaos, Elyse chose to take off her earphones and she came to join me, putting her little hand on my shoulder. Together, we released a krathong, a candle-lit banana boat, into the water on behalf of our family. It was a beautiful moment, and if I had insisted Elyse do things my way, it would never have happened.

Now we're on the shores of Koh Samui, a tiny island surrounded by jellyfish-infested waters. Elyse and I are sitting just the two of us, reading books in sling back chairs facing the ocean. Elyse loves looking at books.

I have asked nothing challenging of my family at this stop. No ocean surfing or strenuous hikes. We are purely on a beach vacation.

A lone tropical bird flutters in and settles itself close by on the chair in front of Elyse and me. The bird's startling tune, both haunting and lovely, catches my attention, and when I look over at Elyse, I see she's also watching the bird with interest. I'm watching the little bird closely now, drawn in by its song, which once upon a time I may have been too busy or too distracted to

hear. I am enjoying the bird's song immensely; its melody is intermingling with the soothing sound of the breaking waves and sweet blowing wind. While travel is about going places and doing things, it's also about being in the moment with the people you love.

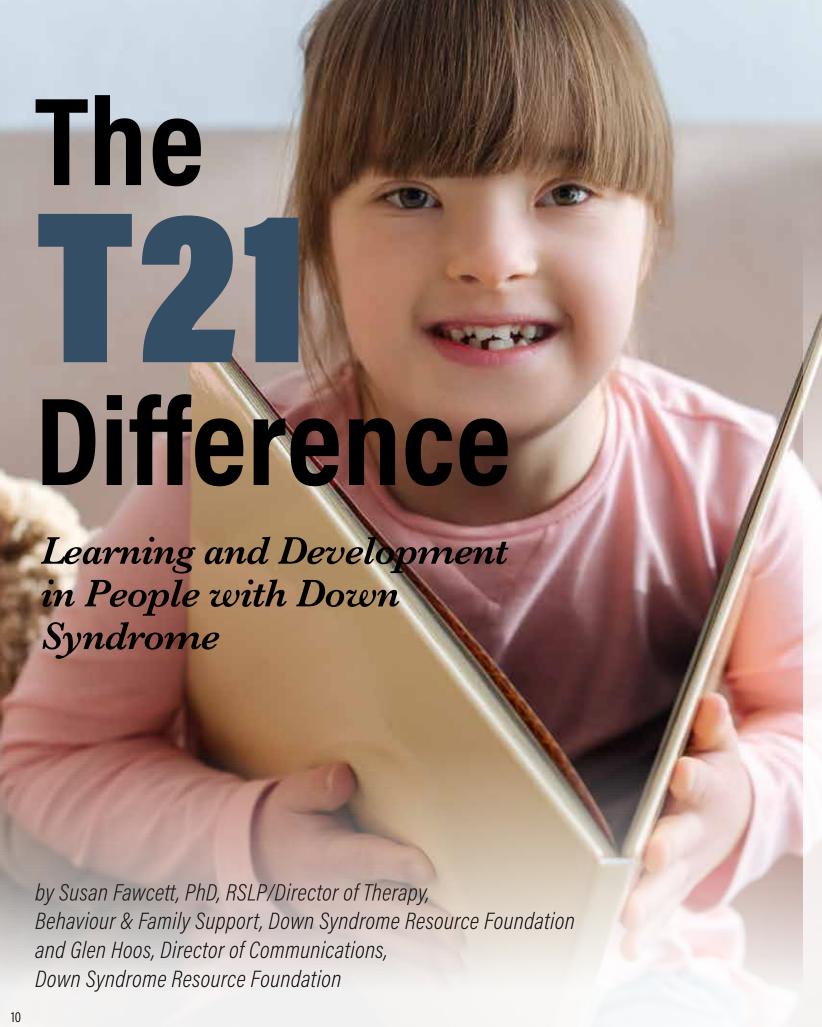
Now that our trip is over, I look at each of my children differently. I am in awe of their accomplishments; in the face of hardships and obstacles to overcome, they persevered. I'm more ready to let them be the ones to show me what they can and cannot do because out in the real world, unrehearsed, that's how it all played out.

There was a time before she was born when I questioned what Elyse would be able to do. Perhaps a better question to consider these days is what *won't* she be able to do?

But why ask that? The possibilities span the globe. I cannot wait for our next family adventure, wherever it may be. I know it's going to be super fun.

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he 21st chromosome is small, but powerful. Having an extra copy of this tiny slice of genetic code, as people with Down syndrome do, can impact an individual in a plethora of ways.

Physically, people with Down syndrome may exhibit a variety of characteristics, such as a flat bridge of nose, a simian crease on the palms, extra space between the big toe and its neighbour, an extra fold of skin around the eyes, widely spaced and upward-slanting eyes, straight hair, structural differences in the mouth and ears, short stature, and more.

Healthwise, individuals with Down syndrome may be extra susceptible to a whole range of health problems, including heart defects, hearing problems, sleep disorders, gastrointestinal issues, dental problems and many other comorbidities.

Developmentally, people with Down syndrome exhibit neurological and cognitive differences, intellectual delays, behavioural and mental health issues, speech deficits, memory impairment and more.

It goes without saying that all these issues will have a major impact when it comes to learning. As parents and professionals seeking to help our daughters, sons and students reach their full potential, it is incumbent upon us to understand how each of these factors impacts their learning and development – and then craft our approach to fit how they learn best.

As we consider the learning strengths and challenges of children with Down syndrome, we will admittedly be forced to generalize. Never forget, though, that every person with Down syndrome – just like every other person – is a unique individual. Down syndrome impacts each individual differently, and any given person will have their own strengths and weaknesses that may or may not align with what we would expect. The number one rule is know the child.

Strengths of Children with Down Syndrome

In the Hebrew language, there is a pessimistic equivalent to the phrase "rose-coloured glasses": black-coloured glasses.

Though we would hope this is beginning to change, when it comes to Down syndrome, much of the world sadly views the condition through black lenses. It's so easy to focus on the negatives and only see the challenges. All too often, parents find themselves leaving doctor's appointments and teacher meetings feeling discouraged and defeated.

However, those of us who know and love people with Down syndrome know that there are many strengths and positives associated with Down syndrome. So, let's start there!

In fact, every IEP or learning plan should begin with a list of the student's strengths. Success in learning isn't just a product of overcoming or compensating for perceived weaknesses; it also requires understanding the learner's strengths and teaching in such a way as to maximize and build upon them.

With respect to learning, people with Down syndrome often have the following strengths:

- Empathy and social motivation
- Musical/dance ability
- Gesture use
- Visual learning
- Receptive language, particularly vocabulary
- Certain aspects of literacy development

When we start from a place of strength, it will help us figure out what to do about the challenging stuff!

Challenges for Children with Down Syndrome

That extra 21st chromosome has a long reach, touching virtually every aspect of a person's being including health, physical and sensory issues, cognition, behaviour, mental health and communication. Each of these areas has a significant impact on a child's ability to learn academic and life skills, and to participate fully in a classroom amongst peers.

Health

Often when a child struggles with learning, we assume it's a cognitive or behavioural issue. In many cases, however, there's a health challenge at the root of the problem. Addressing any underlying health concerns can work wonders for a child's ability to learn and develop.

Medical issues to be aware of, check regularly, and act upon quickly include:

- Vision problems
- Hearing difficulties
- Sleep disorders
- Ear and/or respiratory infections
- Nutrition deficiencies
- Gastrointestinal issues
- Dental problems
- Thyroid abnormalities
- Anemia or low iron
- High red or white cell counts
- Atlantoaxial instability

Hearing is a huge issue for kids with Down syndrome. They are very prone to ear infections, as well as fluid buildup in the middle ear. This can result in fluctuating hearing loss, which can appear an awful lot like selective listening and make it very difficult to learn.

Sleep disorders such as sleep apnea and restless leg syndrome are extremely common in individuals with Down syndrome. In fact, upwards of 80% of children with Down syndrome have at least mild sleep apnea (stoppages in breathing throughout the night, depriving the brain of oxygen and preventing the person from entering into the crucial deep REM sleep). Poor sleep affects not only the next day's behaviour, but it also has cumulative detrimental effects over years.

It is strongly recommended that all children with Down syndrome be assessed for sleep apnea via a polysomnogram (sleep study) by the age of four. There are effective treatments, and they are easier to implement when the child is young.

Parents must be proactive about health issues. Many young people with Down syndrome can't express when they aren't feeling great because of communication difficulties. Visit DSRF.org for links to the Canadian Healthwatch Table and the American Academy of Pediatrics health guidelines for individuals with Down syndrome.

Physical and Sensory Challenges

Factors that affect development of gross and fine motor skills include:

- Low muscle tone
- Decreased strength
- Hypermobile joints
- Decreased activity tolerance & endurance
- Difficulty maintaining postural stability (may fatigue more quickly due to the extra effort required)

Even something as seemingly effortless as sitting takes more effort for a person with low muscle tone and a weak core.

In addition, many individuals with Down syndrome face complex sensory issues. Approximately 49% of individuals with DS experience sensory processing difficulties compared to approximately 5-16% of the general population.

Sensory processing refers to the ability to take in, organize and make sense of the sensory information received by the brain from the sensory systems, and to respond appropriately. There are six sensory systems, five of which you are no doubt familiar with: sight, sound, touch, taste, and smell. The sixth is our proprioception and vestibular sense: how our body is positioned in space, and our sense of balance.



A child can have sensory sensitivity (an over-sensitivity to specific sensory input), or they can be sensory seeking (undersensitive to specific sensory input). In the first case, they may be fearful or avoid certain sensations, and become easily alarmed by unexpected loud noises. In the latter case, the child will require more intense sensory input to be regulated and will seek out greater than average amounts of sensory input. For example, they may intentionally fall or bump into objects or people.

In either case, sensory processing issues are a barrier to inclusion. The child may have trouble staying in the classroom with lots of other students around.

Cognition

People with Down syndrome actually have structural and functional differences in the brain compared to typically-developing people. For example:

- Decreased growth in frontal lobes. This is where our ability to plan and organize takes place. The Marie Kondo types out there have lots of neurons firing in this region! The frontal lobe is also responsible for our ability to control our impulses.
- Decreased volume in brainstem and cerebellum
 These parts of the brain control basic functions of life support, as well as balance and coordination.
- Differences in temporal lobe and hippocampus structure and function. The temporal lobe controls the ability to process auditory information (what comes through theears), including language.
 The hippocampus is responsible for memory.

These brain differences have significant consequences. They result in a reduced ability to process information, particularly auditory information. If a child doesn't understand what's going on, this may increase the likelihood of noncompliance — a very common issue for kids with Down syndrome. In a typical school day, teachers may give upwards of 300-400 questions and directions to students. That is a lot of auditory information! Add in fluctuating hearing loss and you can see the problem.

People with Down syndrome often have lower levels of intrinsic motivation. They are simply not as motivated to learn or do things. Think about your own level of intrinsic motivation. It varies; sometimes it's low. How much harder would life be if it was low all the time? Children with Down syndrome are

perpetually low on that internal drive, that "get up and go" factor. It's on us to find ways to motivate them.

Another common issue is problems with executive functioning. People with Down syndrome may be more impulsive and may lack the ability to plan their behaviour or think through consequences before acting. This may manifest as bolting, hitting, kicking, or saying "no" every time someone asks you to do something. Kids with Down syndrome are experts at living in the moment, for sure!

Memory problems certainly contribute to learning difficulties. The differences in the brain lead to reduced encoding and consolidation of new information. Encoding refers to the process by which new information gets written into our brains; consolidation is the process by which it stays there. This explains why kids with Down syndrome need a great deal of repetition and review.

People with Down syndrome are also often hyper-aware of other people: They can be oversensitive and easily distracted by people and their emotions, making it harder to focus on the task at hand. But this last brain difference has an upside, too. Their heightened empathy may help counteract the intrinsic motivation problem; at DSRF we often find that our students are highly motivated by the approval of others.

Behavioural Challenges and Mental Health

We're going to tackle behavioural challenges and mental health together because the two subjects are very closely linked. It is estimated that up to 38% of individuals with DS may have an additional mental health diagnosis, most of which have significant behavioural implications. Common diagnoses include:

- Autism
- Disruptive behaviour disorders
- Attention Deficit Disorder or Attention Deficit
 Hyperactivity Disorder
- Anxiety
- Social anxiety
- Selective mutism
- Obsessive compulsive disorder
- Depression
- Major depressive episode

When addressing problem behaviours, it is crucial to identify the root cause to determine the best approach. If there is an underlying physical or mental health issue, this needs to be addressed first. Sometimes it can be difficult to determine whether a behaviour should be attributed to Down syndrome or to some other cause, such as autism, as there can be a great deal of overlap. If you suspect that there may be something more going on than just Down syndrome, it is very important to consult with a mental health professional.

That being said, sometimes problem behaviour really is just problem behaviour. During cognitive work, many children with Down syndrome exhibit lower levels of task persistence, higher levels of off-task behaviours, and overuse of burgeoning social skills. This last one can be very fun, as a child may resort to the use of party tricks — what we call the "ham effect" — in order to distract from what they are supposed to be doing. Don't let them see you laugh!

Communication Challenges

People with Down syndrome can have challenges in almost every area of speech and language development. In fact, communication may be the most universal area of difficulty, and the toughest one to address. Specific problem areas include:

- Cognitive skills (e.g., attention, memory, problem solving) – This includes deficits in auditory processing, verbal short-term memory, attending skills, reasoning and problem-solving abilities, sequencing and organization, and generalization and maintenance of learned skills.
- Expressive language Children with Down syndrome will be delayed in their development of speech and language; development will occur more slowly. They may encounter difficulties with both individual words and sentence structure, including decreased use of function words, increased number of omitted morphemes (e.g. [-ed], plurals), decreased MLU (mean length of utterance), decreased production of connectives (e.g. and, or), and decreased production of verbs. Learners with Down syndrome particularly seem to have trouble going from the 1-2 word stage to combining words into longer sentences.
- Speech sound production and general intelligibility –
 Speech sound production is difficult due to the
 shape of the oral cavity and hypotonicity, which make
 some sounds harder than others (the toughest
 sounds are s, th, sh, ch, j, r and l). Speech
 intelligibility is typically moderately to severely
 reduced, continuing into adulthood. Longer words

- are harder than short ones. Hearing loss is common, which can result in characteristics of deaf speech (e.g. leaving off ending consonants as in "ca" for "cat").
- Social communication Though people with Down syndrome are perceived to have strong social skills, social communication is actually a major area of concern for many. Early on, young children with Down syndrome have trouble with taking turns, interacting appropriately with peers, and greetings. Later, children may continue to have difficulty with eye contact and greetings, and earlier deficits in turntaking now surface as inappropriate conversational behaviour. Older children with Down syndrome have trouble repairing communication breakdowns, which can make it hard to make and maintain friendships or other relationships.

Using Strengths to Address Challenges

Let's think back to the learning strengths we identified at the beginning of this article. How can we utilize those strengths to help people conquer their challenges?

For example, we saw that individuals with Down syndrome are often highly socially motivated. I have used this to my advantage many times in my work with adults. For example: "We need to keep working on your speech sounds so that your friends can understand you! Or so that you can get a boyfriend! Or a job!"

Sometimes, it's as easy as reframing the negative. "Stubborn" is a word that gets thrown around a lot with respect to people with Down syndrome. But stubborn sometimes translates into a good work ethic. How might it change things if we thought of it as "persistence" instead?

The key is to stay positive — especially on the hard days. Remember that just about everything is harder for kids with Down syndrome; considering all the challenges they face, they are doing exceptionally well! Always start from a place of strength, and you can help them become the very best version of themselves.



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y son Aaron, age 16, stumbled into an acting career a year ago. After being discovered when we were on holidays, he signed with a local Vancouver talent agent. Aaron then auditioned for a number of roles and secured his first acting gig last fall. In November he appeared in a Nintendo Switch commercial that has been shown worldwide.

I've been asked by other families how to get their kids into acting. The first step is to listen to your child and let him or her take the lead. It is important that your child has a natural love of performing and that they are not pushed into a career.

Our whole family is learning as we go. Here is my advice about helping your child build a career in the dramatic arts. I also interviewed Aaron about his experience as an actor, and his comments are included in italics.

I felt super-incredible when my commercial came out. And I like getting paid. -AW

Being cast in the Nintendo commercial was a big deal for Aaron and our family. It started with Aaron auditioning for the part just like everybody else. The casting director was specifically looking for an actor with a visible disability and Aaron is clearly recognizable in the 30-second spot. What is awesome about the scene is that Aaron was playing Nintendo Switch with three typically developing teenage boys. He was just hanging out with them and it wasn't a commercial specifically about kids with disabilities. This is what I'd call inclusive writing and casting – Aaron was just one of the guys, playing video games.

All the actors on the shoot were under 18 and needed to have their guardians on set with them, so I was there along with the other parents. The director took me aside at one point and asked a question about Aaron and what he could understand. "Everything," I said. He understands everything if directions are explained to him in short pieces.

The modifications for Aaron at the shoot for the commercial were simply for the production crew to be patient and to repeat instructions a couple of times. It did not take more effort to have Aaron there. It is important to note that all actors need support to give their best performance.

Aaron explains what it was like to shoot a commercial:

I drank some iced tea. I got my hair done and got dressed in a big trailer. They also covered up my zits! For the commercial I had to play video games with three other boys. The director told us what to do. There was tons of food at lunch. -AW

Importantly, Aaron was paid for his time at the wardrobe fitting, rehearsal and shoot and he received a residual cheque after the commercial was aired. He received the same rate as everybody else. And while opportunities for actors with disabilities are rare, he will get paid well when he works. If all goes well, he will be able to make a living being a film and TV actor (supplemented with a day job as so many other actors

Acting has opened up a whole new world. This is the first time I've thought about my son's future without feeling fear. Working and being paid a decent wage also leads to a sense of meaning and value in Aaron's life. Plus, he has expensive taste and can save up to buy that Lamborghini he keeps talking

I bought a Nike Apple Watch with my own money that I made from the commercial. -AW

I've learned that it is hard work to be an actor. We are lucky to live in Vancouver, where there is a happening entertainment industry. But Aaron himself has to put in the work to be ready to go to auditions. This means attending high school drama class, summer acting camps, acting school classes and working with an acting coach. His Grade 11 IEP changed this year to focus on what he needs to learn to be a successful

"Drama keeps me happy. In acting you have to work with people. And Ilike people."

actor, which includes leadership courses, public speaking opportunities and English class to work on his literacy skills so he can read lines.

At auditions I have fun. I have to keep the words in my brain and say them out loud. -AW

Having fun remains a crucial factor for Aaron to live a good life. He does get nervous before auditions (just like all the other actors) and his acting coach is working with him to practice breathing exercises to calm his nerves. As long as Aaron continues to have fun, we will do whatever we can to support his acting career.

Acting is now part of my life. I work on my acting. I took TheatreSports Improv camp and acting classes. I am still in drama and I work with an acting coach twice a month. It is work but it is fun. -AW

We need more roles written specifically for people with disabilities, and to cast real actors with disabilities. Inclusion means that differently-abled actors have the opportunity to try



Aaron's agent has put him forward for both types of parts.

There are other actors with Down syndrome, like in Stumptown and the movie The Peanut Butter Falcon. I wish I was in a film with Dwayne Johnson. That is my dream. I want to be the guy with Down syndrome on the big screen! -AW

Representation does matter. Non-disabled actors have won many Oscars over the years playing disabled roles – think Tom Hanks in Forrest Gump or Jamie Foxx playing Ray Charles. Organizations like the Ruderman Family Foundation advocate for auditioning actors with disabilities.

The media, whether it is film, TV, commercials or print, should be a snapshot of the real world. That means writing roles and casting people who have disabilities. Cole Sibus (Stumptown) and Zachary Gottsagen (The Peanut Butter Falcon) are two actors with Down syndrome who were cast in high profile roles last year.

The world is slowly changing as more opportunities become available for actors with Down syndrome. When roles come up, Aaron will be ready.

Drama keeps me happy. In acting you have to work with people. And I like people. -AW

If you'd like to follow along with Aaron's career, he's on Instagram @aaron.waddingham.

Sue Robins is a health administrator and author of Bird's Eye View: Stories of a Life Lived in Health Care, available through suerobins.com. Sue's writing has been widely published, including in The New York Times, The Globe and Mail, the Canadian Medical Association Journal, the Journal of Family Nursing, the Journal of Paediatric and Child Health and the Journal of Medical Imaging and Radiation Sciences.

Ten Tips to Start an Acting Career

To start:

Go to lots of movies! Aaron loves going to the movie theatre and we actively encourage his love of film.

For motivation, watch the performances of actors who have disabilities. Speechless, Stumptown and Atypical are examples of television shows featuring actors with disabilities. Aaron also is inspired by watching the A&E show Born This Way.

Watch for theatre companies that feature actors and writers with disabilities and attend performances if you can.

Sign up for drama classes or clubs in school settings. (Bonus – this is a free way to see if your child has the performing bug).

If the acting bug bites:

Contact acting schools and camps to ask if they have inclusive programs. The majority of schools we have approached have said yes to Aaron (with only one saying no, which was discouraging – but we did not give up!).

Find a Facebook group for families of child actors.

Invest in professional photography to get head shots done.

The way to find out about auditions is to sign with a talent agent. Contact your local agencies through their websites to find one that is a good fit for you. It is important to work with an agency that believes in your child and aligns with your own values.

Invest in a small audition wardrobe, which includes plain clothes with no patterns or logos on them.

Be available and willing to respond to audition calls at short notice, practice lines and do a lot of driving and waiting around.

Please support organizations who cast actors with disabilities by buying their products, watching their shows, sharing their work on social media and writing letters of encouragement. If we all cheer and advocate for actors who have disabilities, it will mean our kids will turn on the television and see someone who looks like them. That is validating and allows our children to dream big dreams, just like every other kid. Don't settle for anything less.

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ADVOCACY

Are You Up For The Challenge?

t may seem like March 21 has been an important date on our calendars for generations, but World Down Syndrome Day (WDSD) has only been officially observed since 2012. The United Nations General Assembly declared its observance, and the 3/21 date was selected to signify the uniqueness of the triplication of the 21st chromosome which causes Down syndrome. What began as a date on a calendar has now become an international day of celebration and awareness, with campaigns reaching millions of people around the world. And what really started it all was advocacy.

According to the Down Syndrome International (DSi) website: WDSD was first (unofficially) observed in 2006 in many countries around the world. Down Syndrome Association Singapore launched and hosted the WDSD website from 2006-2010, on behalf of DSi, for global activities to be recorded.

The resolution was adopted by consensus in 2011, stemming from an original request by the Brazilian Federation of Associations of Down Syndrome, who worked with DSi and its members to launch an extensive campaign to generate international support. The resolution was eventually co-sponsored by 78 UN Member States.

Down syndrome groups and associations around the world campaigned for their governments to co-sponsor the resolution. In addition, DSi launched an international petition for the adoption of WDSD by the UN. This received more than 12,000 signatures in a two-week period and was presented to the Chair of the Third Committee.

This resolution was a major step forward towards DSi's goal for WDSD to be observed and celebrated by persons with Down syndrome, their families and friends, those who live and work with them, and all persons who wish to promote and ensure quality of life and human rights for all people with Down syndrome.

The last fifty years have seen tremendous strides: awareness, advocacy, inclusivity, medical advances, educational systems enlightenment, employability, and general acceptance. People

with Down syndrome are not just hopeful for the future, they are excited about the future. According to Helen Powell, Policy Development Manager at Down Syndrome International, "the number of celebrations and events grow in number year on year with more countries getting involved, all helping to raise greater awareness about Down syndrome internationally."

Still, sometimes others see March 21 approaching on the calendar and face anxiety. The widely successful and very public stories of advocacy work are at times overwhelming to hear, and leave some wondering how they'd ever achieve something so monumental and far-reaching. But it is important to remember that advocacy is very broadly defined. It is not always about influencing public policy, it is also about influencing public opinion, and can be simply any act that raises the public's awareness about Down syndrome.

Down Syndrome International's 2020 theme for World Down Syndrome Day is 'We Decide.' The theme was inspired by the United Nations Convention on the Rights of Persons with Disabilities, which "supports effective and meaningful participation as a core human right." The We Decide theme can also be adopted into everyday actions that support and inspire advocacy. Here are some ideas to get started:

How Can 'You Decide' in 2020?

Reach Out & Team Up

Join your local Down syndrome group and ask what others may be doing to help inspire change and awareness. Are there others in your community who have a disability different than Down syndrome? They may have ideas and inspiring success stories to share with you, or want to advocate as a team.

No Experience Necessary

Just by sharing your story you can become an advocate. Is your story about something you have changed, or want to change? Is it about you, or someone else? There are no hard and fast rules when it comes to sharing stories of advocacy.



Once you've written your story, share it on social media, a blog, or if you are feeling really ambitious, call or email your local media outlets to see if they want to feature your story.

Host an Awareness Event

This is a good one to work on as a group. Start by setting some goals for the group — do you want to boost awareness about Down syndrome, do you want to raise money for a specific need, or is the event simply to celebrate being you? Give everyone involved a specific job, and communicate regularly to make sure everything stays on task. Share your event on social media to boost awareness even further.

Get In Front of People

Lots of people choose to advocate where they are comfortable – this can be setting up a table at your school, your workplace or community center. Bring books, photos of you enjoying life and showing what you have accomplished, and make sure people who pass by can ask you questions about your life and having Down syndrome.







Join CDSS!

Help make our country
a better place for
people with Down syndrome
through all stages of life.

Receive a

FREE CDSS MEMBERSHIP

for the calendar year with all donations made until March 21, 2020.



Société canadienne de la trisomie 21

CDSS.CA/DONATE

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I gently responded, "Please don't feel badly, it's really okay. Let me tell you why having a child with Down syndrome is a little different, yes, but in so many wonderful ways is just the same as having a child without Down syndrome."

Now, let me help you understand how I got to that place and how my passion for advocacy has grown over the past seven years.

When we learned that our third child was going to have Down syndrome, I was 20 weeks pregnant. It was a steep learning curve for us and one of the things I agonized over was how I should tell people. What should I say? What would they say? Would they be afraid to say anything at all when they saw that our baby looked a little different? I didn't want people to feel sorry for me - and certainly didn't want them feeling sorry for our child. I didn't want any of that. I made a decision: I would understand everything there was to understand about Down syndrome and I would share it all with pride. I wanted family, friends and strangers to feel comfortable in asking me anything.

That was my plan. But as many find, in my search for information, I found so much negativity. My unborn child was ONLY being described as someone with a "condition," "genetic error," "disorder," "abnormal cell division," or "the most common birth defect." The overwhelming message was that I should lower or even have no expectations for my son's future. This didn't feel good, didn't feel right, and was not how

I wanted the world to see and understand my child. I wanted to change people's outlook and reaction, for people to see my baby and not a condition. But I felt like I was up against a mountain of negativity, thanks to the world wide web and outdated stereotypes.

Yes, it is true that people with Down syndrome have some common physical characteristics and there are some health conditions that a person with Down syndrome has a higher chance of having; people with Down syndrome will have varying degrees of intellectual delays; some are non-verbal and some have unique social and learning difficulties. I came to understand, accept and embrace all of this. But why was the dominant narrative always so negative, why did it seem like my son's life had less value than those without Down syndrome, and why did it seem like his life was not going to be as fulfilled as his brothers or peers?

I was in love with Owen at first sight, the same way I fell in love with his older brothers. All my personal worries about what he would look like, would I be afraid to hold him, would he be okay were quashed the moment he was put in my arms. We had a new baby! And just like we did with our other children, we were going to hug him, sing to him, feed him, change him, bathe him, read to him and we were going to celebrate everything about him. We were also going to provide him with all the supports he needed to be the best that he could be – just like our other children.

Let's Talk Down Syndrome: One Parent's Perspective

by Jennifer Crowson

was once out for coffee with a group of women, some I had just met that very morning. Most of us were over 40. I don't remember exactly how it came up, but the subject of having babies was raised. I mentioned that I'd love to have another baby, to which someone I didn't know well responded, "But you could have a baby with Down syndrome, would you really want that?", to which I quickly replied, "Oh that's okay, I already have a child with Down syndrome, and two would be just fine with me." Cue, very long, awkward silence, and a horrified look on everyone's faces. It was clear that she felt awful, and the others were visibly uncomfortable.

I am not going to lie, that comment hurt and my initial response perhaps sounded a bit cynical. I paused before further responding and thought, I could be offended or I could use this as an opportunity. Immediately, my budding resolve to become the best advocate I could be for my son and for all people with Down syndrome became a personal necessity. In that moment, and in the countless that have followed, I chose to advocate positively and to make those around me comfortable with the "uncomfortable," and to always encourage a positive and informed conversation about Down syndrome.



LET'S CHANGE THE STIGMAS

With accessible and comprehensive health care, many children and adults with Down syndrome can thrive and live long, healthy lives. And with solid, accessible and inclusive supports, some people with Down syndrome can learn to read, write and do arithmetic. They can graduate and find meaningful employment. The world has changed for people with Down syndrome.

Owen now attends a school with his brothers, has wonderful friends, is invited on and hosts his own play dates, and has tried soccer but found his greater passion in horseback riding and swimming. He loves art classes, reading, telling stories and great jokes. He challenges his family to a trivia game almost every day. He is sharp and witty and brings joy to our family and all those who meet him. His future is bright, and he'll tell you all about it and his dream to become a police officer. You get it... Owen is his own person, and he's not defined by Down syndrome.

Yet, he and we have experienced odd stares, hurtful and uninformed comments, sometimes bizarre questions, people feeling sorry for us, and assumptions about what people think it is like to have Down syndrome, or to have a child with Down syndrome. This does not come from our family and friends, who have come to understand and love Owen like we do. Owen and the positive Down syndrome community have taught us all a new and informed understanding of Down syndrome. The misunderstandings and sometimes negativity come from those who have perhaps never met a person with Down syndrome, or who hold dated stereotypes to be the truth, or are influenced by the dominant narrative we continue to read online and see and hear in the media.

Owen is a very chatty, articulate boy and yet some people we meet are often surprised that he even talks. In fact, I am often asked if he only has a "little bit of Down syndrome." He's also quite tall for his age, and people have told me that seems "odd"

to them, as people with Down syndrome are "always" short. I have read and been told that people with Down syndrome have poor memories, yet Owen knows the name of every child at his school and most of their parents — a skill his mother does not share.

I recognize that many comments and actions are not intended to offend me or my son and I am grateful that they've brought them up, as it opens a door and presents opportunities for us to advocate and be part of changing the narrative. I encourage people to speak directly to Owen. For example, when we are in a restaurant, they often to look to me to order for Owen. Owen actually takes great pride in reading menus and ordering his own food. I hope that he is modeling for waiters who may not have served a person with Down syndrome, to ask each of us at the table what we want first and not assume some can't order for themselves. We need to presume competence in everyone we meet. When I am asked why Owen is "so tall," I share how his mother and father are both tall, so why would he also not be tall? Here, I emphasize how although Owen may have Down syndrome, he is his own unique self and he takes after his family first. Any child or person with Down syndrome is an individual first with their own strengths and unique characteristics and we must encourage the focus to be on this, not on Down syndrome. Yes, we must help others understand Down syndrome, but it does not define who they are or who they can become.



HELP SPREAD THE WORD

On the CDSS website you can find links to printable resources that support talking about Down syndrome. The posters are geared to school-aged children, but also can be posted in libraries, grocery stores, doctors' offices, anywhere where people will stop and read. Advocacy does not always have to take the form of discussions and presentations. We can all play a part in educating others and making people more comfortable talking about Down syndrome.

One of the many things about being an advocate I enjoy most is talking to school children. For the past few years, along with a fellow parent, I have had the pleasure of going into many classrooms to talk about Down syndrome. We have used Lego figures to foster a conversation on how people with Down syndrome are more alike than different, but how there are also some important things to understand about classmates and future colleagues with Down syndrome (or indeed other learning differences). Children have asked us, "Can I catch it?" "Is your son sick?" "If it is an extra chromosome, why can't they just take it out?" "Will your son get better?" "Were you sad when you had your son?" And equally we are asked, "Do you have a dog?" "Does your son like dogs?" All wonderful questions that each allow for conversation and greater understanding and importantly, shows us all how we are more alike than different. My favourite question of all, and the one that made this all worth it, was from one of Owen's classmates: "After everything you have said, how can we help Owen?"

Owen is everything I was first told or read he would not be. He and many other people with Down syndrome have changed my narrative and understanding of Down syndrome. I feel privileged to join the many parents, caregivers and self-advocates in forming a powerful and persuasive voice — a voice that has changed the story of Down syndrome over the past fifty years and will only continue to push boundaries. I am confident that my son will graduate from high school, will attend college or university if he chooses that path, that he will be meaningfully employed, will get married if he chooses to, and that he will live a fulfilled life where he contributes to his community and family. Isn't this just what we want for all our children? Why should it be any different for our children with Down syndrome? We know it, we just need make sure the world knows it!

LET'S TALK! Simple Rules to Follow and Share with Others

- As with any disability, always use people-first language that describes who the person is first, not their disability. Instead of "a Down syndrome child," it should be "a child with Down syndrome."
- A person "has" Down syndrome; it is not a disease or illness and they do not "suffer from" or are "afflicted by" Down syndrome.
- Don't use the terms "retarded," "handicapped" or "challenged." These inappropriate words create barriers. Use the terms "intellectual disability," "cognitive disability" or "Down syndrome."
- Avoid using stereotypes and generalizations when referring to people with Down syndrome. For example: "People with Down syndrome are always happy." It is important to remember that people with Down syndrome, just like everybody else, experience a wide range of emotions.



Jennifer Crowson is mother to Max, Ruaridh and Owen. She is a passionate advocate for people with Down syndrome, and is the current Chair of the Down Syndrome Association of Hamilton. She sees it as her obligation and privilege (alongside Owen) to educate, advocate, challenge and change the dominant story of Down syndrome. She already sees Owen becoming his own best advocate, but in the meantime, she takes pleasure in sharing him with the world and contributing to a different and positive story of what it is like to have Down syndrome, and to raise a child with Down syndrome. Follow Jen and Owen on Instagram — @jenandowen21

Thanks to all who signed up for Project **Understood!** We are delighted to announce

that we have surpassed our initial goal of 500 participants! Google AI is analyzing the voice data received to date, and some participants were sent a second set of recording data to advance the research study further. Follow @CdnDownSyndrome for further updates throughout 2020.

If you are 18 years of age or over, have Down syndrome and speak english, there is still time to participate! Visit ProjectUnderstood.ca for all the details and sign up today!



Interested in Joining the CDSS Board of Directors?

We have a deeply committed and talented volunteer board with a wide variety of professional and personal experience. We are currently seeking new board members to help us achieve our mission and vision.

While no experience serving on a Board of Directors is necessary, applicants must be residing in Canada, and must commit to serving a two-year term. Details about the roles and responsibilities of the CDSS Board of Directors, and a fillable application form is available on the CDSS website.



Paul's Blog!

March 21 is circled in red on Paul's calendar! In his latest blog CDSS's Awareness Leader Paul Sawka writes about the importance of advocacy and awareness. Paul likes to advocate through "sharing the story of his life so that people can understand who he is and learn more about Down syndrome." Read all about ways Paul shares his story and how it has helped others on the CDSS website.

G021 in 2020

Go21 is an event model created by the Canadian Down Syndrome Society to help communities celebrate and raise funds that support individuals with Down syndrome in Canada. We have recently revised the Go21 information package and processes to streamline the online creation of Go21 events. Our informational package details the many benefits of using the Go21 platform, and clearly outlines the program fees to community hosts.

For more information about our Go21 program, please reach out to Deb at Go21@cdss.ca.



Membership News

Donate Today to help make our country a better place for people with Down syndrome through all stages of life. All donations made until March 21, 2020 entitle the donor to a FREE CDSS membership for this calendar year.

Join CDSS and be part of a movement which focuses on making the lives of all people with Down syndrome the best it can be. CDSS provides information and resources to individuals with Down syndrome, their families and the people who support them. Families have a lifetime connection with CDSS as our resources cover every life stage.

Visit this link before March 21, 2020 to donate and activate your membership, or phone us toll free at 800-883-5608.

As a not-for-profit we depend on donations to allow us to continue working for you. Your contact information will not be given to any other organization by CDSS for solicitation





Let's Celebrate on Saturday, March 21!

See the back cover of this issue to learn how you, your workplace, teams, classroom and community can get involved.

NEW! We have improved our awareness resources to include French and English downloadable posters, a K-6 power point presentation and a lesson plan that focuses on starting the conversation around inclusion. Help us to build strong foundations within our youth so that everyone chooses to #SeeTheAbility in 2020 and beyond. Teachers: Due to March 21 falling on a weekend, we anticipate school celebrations happening in advance. After your school events, encourage children and families to continue

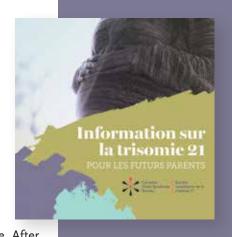


awareness activities over the weekend!

Société canadienne de la trisomie 21

NEW RESOURCE FROM CDSS

Our winter issue mentioned our latest resource for expectant parents. We are happy to now share this free informational prenatal package in both french and english at this link.



This publication is for expectant parents who are considering undergoing prenatal screening, or who have recently learned of the possibility of their child having Down syndrome, and are seeking more information. We also see this resource as a valuable tool for medical professionals, and are working to share with larger medical groups throughout Canada.

FIND US / TAG US

@CdnDownSyndrome on all our platforms













On March 13, 1995 DSRF's doors opened. Actually, it was just one door, swinging from a tiny trailer on the grounds of Vancouver's Sunny Hill Health Centre for Children.

The cameras have been rolling at DSRF. Last fall, we opened our doors to a local film crew shooting Raising Ava Rose, a documentary about one of our young students and her family. Keep an eye out for the premiere later this year.

Meanwhile in February, production began on an upcoming feature video on the topic of housing options for adults with Down syndrome. Four DSRF students and alumni in various semi-independent living situations will be spotlighted, showing off their homes and sharing their housing journeys. The video will premiere on DSRF's website and social media channels this spring. Stay tuned to @DSRFCanada on all platforms!

#DSRF25: Celebrating 25 Years of Caring for the Down Syndrome Community

For the Down Syndrome Resource Foundation, 2020 is an occasion a quarter century in the making.

DSRF (known then as the Down Syndrome Research Foundation) was the vision of Josephine Mills,

a strong advocate and passionate supporter of children with Down syndrome and their families. She devoted more than 30 years to improving the quality of medical care, education, and opportunities in the community for people with Down syndrome and their families, and was instrumental in founding three major organizations that address the needs of people with Down syndrome: Down Syndrome International, the Canadian Down Syndrome Society, and DSRF.

In 2002, Jo swung open another set of doors - these ones leading into DSRF's brand new centre in Burnaby. Designed first and foremost as a research facility, which at the time was our primary focus, DSRF quickly became home to hundreds of families in the Lower Mainland Down syndrome community.

Over the past 25 years, the organization has evolved away from research and towards service delivery, as it became clear that this is where we could make the greatest impact for our families. Today, the Down Syndrome Resource Foundation is Canada's leading provider of educational programs and

UPCOMING AT DSRF

DSRF's 25th Anniversary - March 13, 2020

WDSD and 25th Anniversary Family Skating Party Burnaby 8 Rinks, Burnaby - March 20, 2020

World Down Syndrome Day - March 21, 2020

Up the Down Market Toronto Arcadian Court, Toronto - April 23, 2020

BMO Vancouver Marathon #RUN4HOPE Vancouver, BC - May 3, 2020

Run Up for Down Syndrome Swangard Stadium, Burnaby - June 7, 2020

therapy services to people with Down syndrome across the lifespan, serving over 400 students annually.

As we considered the best way to mark our silver anniversary, we came to realize the best way to remember and honour the past is to build upon it. Expect a major announcement later this year!

DSRF Welcomes New Ambassadors

Over the past year, Danielle Juilfs has represented DSRF very well as our first ever Ambassador. She will continue to do so going forward – and in 2020, she's set to be joined by three new members of the DSRF Ambassador team!

Andrew Bingham, Chris Sayer and Jodi Klukas are all familiar faces around DSRF, having each attended DSRF programs from a young age. Now, they join Danielle as the public faces of the organization, demonstrating to the world all that people with Down syndrome can accomplish.

Watch for Andrew's new monthly DSRF news segment to premiere on the @DSRFCanada social media feeds in March. He'll keep you in the know about all the exciting happenings throughout our 25th Anniversary year. And while you're at it, check out his photographic card business, Through Andrew's Eyes, at DSRF.org/Andrew.



FRIENDS OF DSRF

The Lohn Foundation has been a consistent supporter for six straight years, investing \$18,000 in individuals with Down syndrome in that time. They are making a real difference through DSRF's educational programs, and we're grateful for their 2019 donation of \$3,000.

DSRF is lucky to call the City of Burnaby home for many reasons. We're extra grateful these days thanks to the City's grant of \$10,000 for educational programs and services for children with Down syndrome. It's wonderful to live in a place that recognizes the tremendous value that people with Down syndrome add to the community!

Throughout 2019, Mike Watson and Ignite Management spearheaded the Ignite the Future campaign, raising an incredible \$45,250, which was presented to DSRF in December at our Christmas Breakfast. Special thanks as well to Gerry Wood and Wood Automotive Group, who contributed \$10,000, and to all who donated to the Ignite campaign: BCMEA, Blueshore Financial, CIBC, Daytona Capital Corp., DP World Canada, Founder's Cup Charity Foundation, Richard and Carol Scott, Safe Step Tubs, Shea Weber, Stefan, Fraser & Associates, Valor Fireplaces, Virani Real Estate Advisors, and Western Stevedoring.

For the second consecutive year, George Klukas and Bill Longman have generously donated \$15,000 towards bursaries for families who cannot afford DSRF programs and services. We appreciate their commitment to ensuring that every child with Down syndrome receives the support they need to achieve their full potential.

The 2019 DownSide UP campaign (held annually in December) raised over \$44,000 in support of DSRF programs and services. Thank you to all who generously donated to UPend expectations, UPgrade quality of life, and UPlift individuals with Down syndrome.

FIND US / TAG US



WORLD DOWNSYNDROWE DAYS



March 21

So many ways to get involved in 2020:



blue & yellow lights
education
lots of socks
awareness activities

See our website for ideas and links to downloads.

#WDSD2020 #LotsOfLights #LotsOfSocks #DanceOn321 #WeDecide #DownSyndromeAwareness





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