

Spring 2021
ISSUE #6

Canada's
Down Syndrome
Magazine

3  21

**IRONMAN:
An Interview
with Chris Nikic**

*Workout
Inspiration
for Everyone*

**WORLD DOWN
SYNDROME
DAY 2021**

*Celebrating
our
Connections*

Plus: **Dual Diagnosis: When Down Syndrome and Autism Collide**



Welcome to the Spring 2021 Issue of 3.21: Canada's Down Syndrome Magazine.

Here at 3.21, as we discover and then dig deeper into the most current global topics about Down syndrome and work on the stories we will feature in our pages, a common thread typically presents itself. That thread becomes the issue's theme. Each theme helps us to stay focused on the goals of the issue, and we like to think that the theme ultimately gives stories more meaning. However, the theme for this spring issue didn't present itself gradually. Instead, Down Syndrome International announced a one-word theme for its highly celebrated World Down Syndrome Day 2021: CONNECT. Just like that, 3.21's Spring 2021 theme was born, quite literally overnight.

We embraced the theme of CONNECT immediately – and you should too. What better way to share stories and inspire the Down syndrome community right now, than through connecting? Connection is what we are all craving right now. Technology is helping our community too, bridging gaps to allow those with disabilities to connect.

People with Down syndrome are helping to shape the world. Through sharing their stories, these inspiring individuals can change lifestyles and create new routines for us. It requires some paying attention to notice and grow the positive habits that arise out of COVID times, but they are there, and we hope those habits will be long-lasting. We want this issue to inspire you to CONNECT. Find encouragement through these stories to try something new, learn and grow. CONNECT in meaningful ways. Keep taking care of one another, and yourself.

We're sure you all have a story about a single connection that turned the ordinary into extraordinary for you. We love hearing from you and sharing your feedback! Please drop us a line at 321Magazine@gmail.com

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IRONMAN

AN INTERVIEW WITH CHRIS NIKIC

Last fall, in the throes of a global pandemic, the world was captivated by a much happier story when Chris Nikic became the world's first athlete with Down syndrome to become an Ironman. Chris has inspired thousands of people – those with disabilities and those without – to get off the couch and reach for their dreams.

3.21 Magazine had a chance to chat with Chris and his father Nik. Below they tell us about their “1% Better” philosophy and all that went into Chris’ incredible accomplishment.

3.21: Let's start at the very beginning, Nik. Describe Chris' early development. What was it like teaching him skills like walking, swimming and riding a bike?

Nik Nikic: It was very difficult. Everything was so hard and took so long to learn, even the most basic things. He didn't learn how to ride a bike until he was 15 and that took six months of practice before he could balance himself.

3.21: What were your hopes and dreams for Chris as he was growing up?

NN: In hindsight, they were pretty limited. We had accepted the lie that our son could not achieve much. We wanted a normal life for him, but didn't believe it was possible. Now we believe anything is possible.

3.21: Chris, growing up, were you always interested in athletics? What sports did you enjoy?

Chris Nikic: Basketball. I love to play basketball. I don't know why; I just love it. Maybe because I watched my sister and I wanted to be like my sister Jacky. I beat my dad every day.

I also enjoy golf. One of my goals this year is to break 80 in golf. I'm practicing multiple times a week outside of my Ironman training.

3.21: For those who aren't familiar with the Ironman competition, what does it consist of?

CN: Ironman is a 140.6 mile, 17-hour event with a 2.4 mile swim, 112 mile bike ride, and you finish it off with a 26.2 mile marathon run.





3.21: Of the three components – swimming, cycling and running – which is your favourite, and which is the most challenging?

CN: My favourite is the run. The most challenging part is the bike. Sitting for eight hours makes my hands and butt hurt. I have to work extra hard for it because I have poor balance, and it is also hard to train for eight hours at one time.

3.21: Tell us about your progression towards becoming an Ironman. Did you compete in other events before entering the Ironman?

CN: In March 2019 I competed in a Special Olympics sprint triathlon and the gap between me and #1 was 75 minutes. I competed again in August 2019 at the state championships and I finished last, but the gap was only 25 minutes. In January 2020 I did a 33-mile Olympic distance, and on May 9 I did a half Ironman 70.3, which was my true test. The real race was cancelled because of COVID-19, so we just decided to schedule our own for that same day. I finished it in 8 hours 25 minutes.

3.21: You started out in Special Olympics, but eventually you also began competing in mainstream athletic events. Why was it important for you to take this step?

CN: It was important for me to take that step to show others like me that we can do the impossible one year, and then next year we can do something even more amazing. This will help them believe they can do it too.

The best thing I can do for others like me is be an example, show them that we can do anything if we are willing to work hard and get 1% better each day, and that we are capable of doing more than one thing.

3.21: What is it about the Ironman challenge that appealed to you?

CN: I wanted to be a world champ at something so on New Year's Eve, my dad asked me to write down my dreams. I wrote down that I wanted to buy my own car, buy my own house and marry a smoking hot blonde like my mom. I also wanted to show others like me that we can do anything as long as we focus on our dreams. So, my dad got me to focus on my dream and that has helped me to achieve my goal of doing an Ironman. I like triathlon events because they are fun, but Ironman was a way to get my dreams.

3.21: Describe your training regimen leading up to the competition.

CN: I train three to eight hours each day, six days a week. Over the course of those six days, I run three times, bike four times, swim four times, and do strength training three times. Plus, I do stretching and recovery every day.

3.21: Nik, how did you encourage Chris to keep up with this gruelling routine?

NN: By doing it with him and making everything fun. We found ways to make it fun, reward him for his efforts and help him keep growing.

3.21: During the race, were there times you felt like giving up? If so, how did you keep pushing forward?

CN: At mile-40 on the bike, I got attacked by fire ants. My leg swelled up and it was painful, but I kept going. Then on mile-50, I crashed my bike and I was bleeding and in pain but I kept going.

The hardest part for me was mile 10-13 on the run. The pain was really bad. Everything hurt. I was ready to quit, but my dad came, gave me a hug and asked me, what's going to win: my fake pain or my dream? I said, "My dream," so I kept going and my angels took me to the finish line.

3.21: Describe how you felt as you crossed the finish line.

CN: I was tired, in pain but happy it was over. I was excited to hear Mike Reilly say, "Chris Nikic, you are an Ironman." That was amazing.

3.21: Nik, what did it mean to you as parents to see Chris accomplish something so monumental?

NN: It means that he can live a life of independence, take care of himself, have a family and live an amazing life. It also means he can help others like him and other parents like us to believe in their children's future.

3.21: Chris, how did the other racers respond to you?

CN: They were so happy and supportive of me. They all came and hugged me and told me they were proud of me.

3.21: What personal qualities were most important in enabling you to achieve your goals?

CN: Being a boy with Down syndrome who had big dreams! Because doing Ironman means I can do anything, I can get my dreams, I can be included in everything.

I also love spending time with people and making new friends. The people and the races are so much fun that I will do the work.

My best quality is I don't quit. Other people quit when the pain comes; I don't quit. I keep going.

3.21: What does it mean to you to be the first Ironman with Down syndrome?

CN: It means that no matter the obstacles, you can accomplish your dreams if you're willing to work hard. It means proving to others like me that we can do what others can do, and being the first means showing them anything is possible.

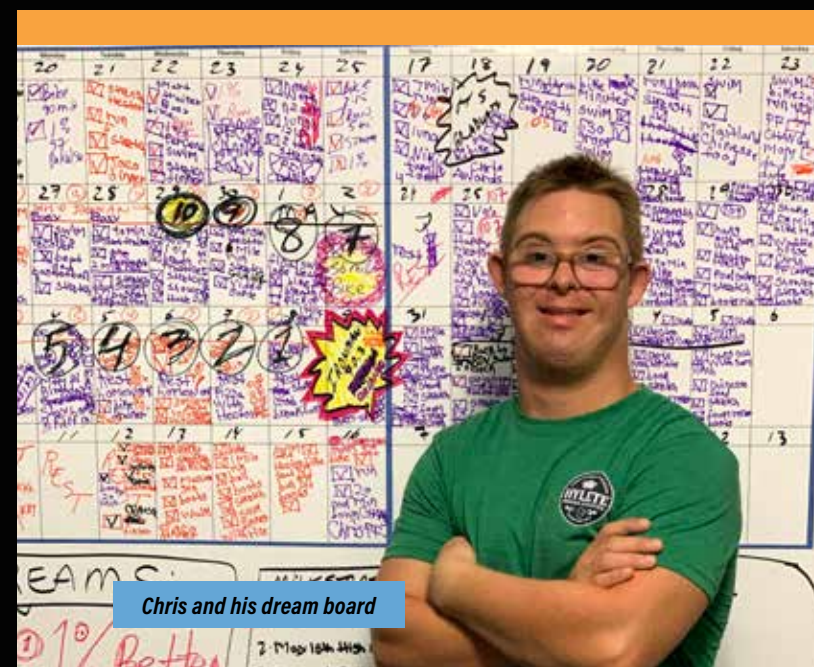
3.21: Do you plan to compete in more Ironman events in the future?

CN: Yes, I am competing in the championship Ironman in Kona Hawaii in October 2021. I will also do some other events to prepare for that race like half marathon, a full marathon, and half ironman.

3.21: Your story has generated international interest. What kind of opportunities have come your way since the race?

CN: It's been freaking amazing since the race, I'm so blessed.

Special Olympics has been amazing. They made me a Champion Ambassador and gave me the Florida Hero award. They invited me to the USA Games and I got to meet Governor DeSantis.



Chris and his dream board



Ironman has also been amazing. They offered me a global ambassadorship and invited me to compete in Hawaii. Plus, they did an NBC documentary about me.

Disney gave me a hero's welcome, and Universal gave me a private VIP tour. The Tampa Buccaneers gave me a special football, and Orlando City Soccer gave me special recognition. Sports Illustrated nominated me for Inspirational Story of the Year. I got a book offer and a sneaker deal – and Guinness gave me a new world record!

This has also given me the opportunity to become a motivational speaker. I can now use my story and speaking ability to share a message of awareness and inclusion and hopefully help make the world a little better by being a good example of what is possible.

3.21: You are an inspiration to so many people, and especially to others with Down syndrome. What would you say to somebody who is working to achieve a major goal?

CN: I did not do anything spectacular. I just got 1% better every day for two years and I went from couch to Ironman. So, anyone who wants to accomplish something great, you just have to be willing to be consistent for a couple of years and you can do amazing things. The easiest thing to do is quit. The hardest thing to do is just keep improving every day. I used my dream to keep me going. If you want to do something big, then start by writing down a BIG dream and look at it every day. Never take your eye off your dream.

3.21: Nik, what have you learned as you have seen Chris achieve his dream?

NN: We learned that individuals with Down syndrome can achieve amazing things but their potential has been locked by the world's perceptions and limitations. We have learned that anything is possible for someone who is willing to get 1% better every day and work hard for their dreams.

3.21: How have your hopes and expectations for Chris' future changed as a result of his Ironman journey?

NN: We now believe that there are no limits to what Chris and others like him can achieve. Chris is 21-years-old and has already created more opportunities for himself than most of us can ever imagine. We are excited to see what he can truly achieve over the next 5-10 years as he continues to change perceptions for others like him.

3.21: Last word to Chris. Now that you've proven that you can accomplish anything you set your mind to, what are your goals for the future?

CN: This year I will learn to drive my own car, but my next big goal is to do Ironman Hawaii. I also want to break 80 in golf. In 2022, I want to do the Special Olympics USA games. In 2023, I want to do the World Games in Germany.



Chris Nikic will serve as Race Ambassador for the Down Syndrome Resource Foundation's Run Apart for Down Syndrome presented by Euro-Rite Cabinets. Join Chris in empowering people with Down syndrome to make their own dreams come true by joining the virtual run at DSRF.org/RunApart.

A large promotional poster for a virtual event. At the top left, it says "A Virtual Event" in white. The main title "RUN APART FOR DOWN SYNDROME" is in large, bold, white letters with a red outline. A red banner with "APART" in white is slanted across the top of the title. To the right of the title is a starburst graphic that says "100% COVID-19 Protected!". Below the title, it says "presented by EURO-RITE CABINETS" with the tagline "European Styling. Built Right!". In the top right corner is the Down Syndrome Resource Foundation logo with the tagline "Together. Healthier. Happier." The background features a large photo of Chris Nikic, a young man with glasses wearing a blue tank top with the "kiwami" logo. In the bottom left, there is a smaller photo of Chris Nikic wearing a red and black athletic shirt with "SUGOI" and "IDS" logos. At the bottom, there is a dark red banner with white text that reads "JUNE 6, 2021 WHEREVER YOU ARE REGISTER AT [DSRF.ORG/RUNAPART](https://DSRF.org/RUNAPART)".

GET FIT WITH CHRIS

by Kristen Halpen

Most of us have the usual reasons for not exercising on a regular basis: “I don’t have time, I can’t afford a gym membership, I’m too tired, I can’t stick with a program...” The list can be lengthy. But what if the reason for lack of exercise was less of a convenient excuse; what if it was a real, existing barrier?

While Chris Demchuk didn’t face a physical barrier to the world of fitness, it certainly bothered him that when he brought home the latest issues of his favourite popular fitness magazines, he struggled to read many of the articles. They were written too

scientifically, too technically; they were high-level and confusing. Chris describes his reading frustrations: “Some of the words were just TOO BIG.” His difficulties had him considering barriers for others, so after some thinking he decided to do what he could to help.

Chris’ idea was pretty simple in the beginning: He would create a book about fitness, specifically for people with intellectual disabilities. He wanted it to be easy to read, simple to follow, with clear pictures. From there, he and his parents added more ideas to further improve accessibility for all: a colour-coded

system would identify the level of difficulty for each exercise. Also, 75% of the exercises would be performed using the athlete’s own weight, no equipment necessary. The remaining exercises would require very basic workout equipment. “Nothing fancy,” Chris notes.

But creating a book is of course easier said than done, and soon the family had a mountain of work ahead of them. There was the planning, the writing, the testing, safety considerations, photography, design, and promotion of the book to consider. The group enthusiastically put together a plan, and a solid team, including a professional trainer who would ensure each exercise’s effectiveness and overall safety.

Many jobs were taken on by Chris personally, including helping with the design of the book. Chris had recently graduated from Mount Royal University’s Inclusive Post-Secondary Education Program in Calgary with an Information Design Certificate, where his classes focused upon poster making, signage, and other projects. Chris uses a pared-back version of Adobe programs such as Illustrator and Photoshop to bring his design projects to life. For his book *Get Fit With Chris*, he helped to lay out the pages and select colours for the book, and worked on his website design. To Chris, “It was important (for me) to make a lot of the decisions.”

Above all, Chris insisted that each and every exercise, page, and word was easy to understand. The team would meet and carefully dissect each page, decoding the instructions to make them easy to read and follow.

There were days and days of photo shoots, which Chris enthusiastically describes: “It was a lot of fun and there was a LOT of joking around.” One of his favourite memories of working on the book took place at one of these shoots. Chris was holding a plank pose in perfect form at the photographer’s request. “It was a long time,” he recalls. “They forgot about me.” With the trainer and photographer looking at the camera to assess one particular image, they had forgotten about Chris in his pose! By the time the pair looked up, Chris was shaking and dripping in sweat. He isn’t really sure how long he held that plank, but guesses that over a full two minutes had passed! The group laughed at the gym, and Chris “laughed again when I told my parents at home.”

All in all, it took six months for the book to come together. Now, Chris helps on the administrative side to process book orders, and is proud that books “have gone to a lot of

How does exercising make him feel? “Happy,” says Chris. “I feel different, I feel good. I look forward to it.”



Does he ever not feel like exercising? Chris gives that a hard no. "That would be rude," he says, adding, "I exercise because I want to. I want to stay healthy and strong, and to keep a schedule. I know that I am going to work out every day."



Chris' inspiration: His brothers Alex and Daniel, left, and Matthew, below, who mean the world to him, enjoy each other's company and are always there for him.



Special Olympics athletes, to people all over Canada, and to England, Australia and Germany."

COVID-19 has been challenging for someone as active and social as Chris. He comes from a family of four boys, where physical activity was always a part of their daily lives. What COVID has not changed is Chris' unwavering commitment to physical fitness. He has a gym at home, and can do his entire workout there while gyms are closed in Alberta. When those gyms reopen, look out, says his mother Linda. "He will go to any gym that he can get his hands on." Chris also looks forward to golfing again, seeing friends, enjoying his photography hobby even more, and working more on finding a job - he hopes to become a personal trainer someday soon.

Chris has used the quiet, somewhat isolating times during COVID to think about what he wants to do when this is all over. His future plans are many. First, he wants to write a healthy eating book. The family already has a nutritionist lined up to work with. Second, on social media, he wants to post a workout once a week for his followers. His brothers help on the technical side, with Instagram posts and blog ideas. Third - and what we enjoyed hearing the most about - he has an idea for a mental and emotional wellness project. Chris understands that exercise is just one part of the complete wellness equation, and he wants to address the mental wellness side of being healthy. The concept is in its preliminary stages, but we suspect that Get Fit With Chris will be just one inspiring story among many from this amazing Canadian.



"Chris' fitness book is very well illustrated, making it easy to follow along with and implement into warmups for our floor hockey team."
- Joan

"Chris' book is easy to read. The exercises are demonstrated very well and easy to follow." - Justin

"I was thrilled to be one of the first people to get a copy of Chris' exercise book! It's a great book with pictures and easy to follow instructions for the exercises. It has helped me to get into better shape and I love it!" - Darby

1 cup strawberry yoghurt
1 cup frozen fruit
1/2 banana
1/2 cup milk
5 - 6 ice cubes
Add protein powder if you like!
Mix all together in a blender, and serve!

Chris' Favourite Protein Smoothie



Get Fit With Chris is available for \$29 Canadian plus shipping, on his website Get-Fit-With-Chris.ca

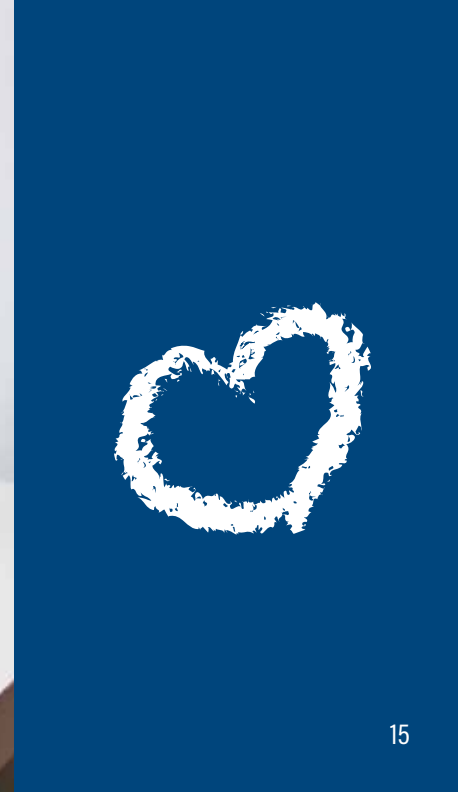


WORLD DOWN SYNDROME DAY: CONNECTIONS



This year's theme for World Down Syndrome Day is "CONNECT." We all know it's been really hard to connect with others during the pandemic, and we've had to get creative. Here is some important advice from myself and other young adults with Down syndrome about ways to connect with others, and ways to reconnect when we come out of the pandemic.

- Self-Advocate, Matt MacNeil



Who are you looking forward to reconnecting with as we begin to come out of the pandemic?

- > My whole extended family and hugging everyone that I love! I have also missed going to book signing events – I love them because I meet new people and get to stay in hotels with pools! – **Lauren**
- > I look forward to reconnecting with people when I compete in sports again, and being with my family, going back to my work and also going on trips. – **Matt**
- > I am looking forward to seeing my brother and sister. They live in different provinces. – **Janet**
- > EVERYONE. My dance company peeps, my friends at my art studio, my friends in the U.S. who I didn't get to see last year. Also, the people I meet in coffee shops, and my support people. – **Jessie**
- > I am really looking forward to reconnecting with my athletic teammates and coaches, my local Down syndrome group, friends, old community supports and my CDSS co-workers. I really do miss them all so much and thinking about seeing them all again gives me strength to get through this pandemic and return to our normal lives. – **Paul**
- > My friends, my roommates and life coaches. Also, my work life, my social life and family members including my sisters. – **Alana**
- > I'm looking forward to getting back to work and seeing all my co-workers. I want to meet up with friends for dinner and a movie, bowling, or just hanging out. I can't wait to see my cousins and family for get togethers. – **Chris**
- > Mostly my friends. I miss seeing them at hockey, or soccer or book club. I like people and I want to give everyone I know a hug when this is all over. – **Andrew**
- > I'd like to see a lot of my friends and coaches from Special Olympics and reconnect again. I'm looking forward to seeing people at the senior centre where I volunteer. – **Jodi**
- > I'm looking forward to starting up my sports and seeing my friends again at Special Olympics, and working more hours again so I can see my coworkers more often. – **Danielle**
- > I want to spend more time face-to-face with my best friend, instead of being in front of the computer screen using Facetime. – **Julia**



Are there activities that keep you connected with others who have Down syndrome, or who have disabilities?

- > I participate in virtual programming very regularly through Extend-A-Family. I also participate in other virtual programs in my community through Bridges to Belonging, Our Studio, Mighty Hawks through Wilfrid Laurier University and Light House Programs. I have learned so much and met many great people and have new friends. – **Lauren**
- > There are lots of activities on the computer, for example virtual dance parties and online workouts and also yoga, to name a few. – **Matt**
- > I have things like virtual social hour, virtual dances and challenges like scavenger hunts. Also, I am a representative for Down Syndrome International and we have monthly Zoom calls and work to do like preparing for webinars. – **Janet**
- > My Ups and Downs group and my role as Awareness Leader for CDSS keep me connected. I was doing an online joke night with Ups and Downs in the fall. Normally I would be swimming and doing my other sports. These things are still cancelled due to the pandemic but I hope to return to them as soon as I can. – **Paul**
- > Yes, there is my local Down syndrome group and Special Olympics, and my circle of friends. – **Alana**
- > I Facetime at 7pm with a couple of friends from DSRF. I also continued taking DSRF's yoga and taekwondo classes on Zoom. – **Chris**
- > Sports and social activities are my main avenue of connection. I play basketball and floor hockey weekly with special needs teams. I have a group of friends within these sports and we go out for dinner together (pre-COVID) and to the pub. Like most of my age group, I also spend (according to my family) too much time messaging my friends. – **Andrew**
- > I connect by using Zoom, and texting on my phone. – **Jodi**
- > My Bollywood dance group has continued every week since the beginning of the pandemic but on Zoom. I also Facetime with groups of friends and I have gone for some walks outside with a friend. – **Danielle**



What would you say to someone with Down syndrome who may be hesitant to connect with others?

- > I think it is normal to be a little hesitant but do not let it stop you from connecting with others. Do not forget that you know yourself best, just remember to think positive things about yourself - and always keep cleaning your hands! – **Matt**
- > It is important to connect with other people. Get help to use a computer and connect using Facetime chat or Zoom, or just an old-fashioned phone call. – **Janet**
- > No one should be without friends or be hesitant to connect with others. – **Paul**
- > I understand we are in the middle of a pandemic and I understand you might be scared. It's okay if you feel uncomfortable. – **Alana**
- > Get a routine so that people get to know you and you can meet more people and feel more comfortable in your community. Go on outings on transit, shop local, visit local cafes and restaurants so that you become well known in your community. – **Chris**
- > The hardest thing for me is to initiate an activity and then to invite other people, but my family helps me with this. Look for something that interests you, either a sport or a social activity, and then find access for people with special needs. – **Andrew**
- > Keep up your friendships by using social media or phone so you don't get lonely and feel left out or bored. – **Danielle**
- > My advice is to let them know that we all need a friend. Reaching out to others is a great thing to do because connecting with others helps us feel a part of something, so you don't feel alone, or depressed. You can start by connecting with one person at a time. When you feel comfortable, then you can expand your circle. – **Julia**



Danielle



Janet



Julia



What activities keep you connected to your wider, local community, family, friends and others?

- > I like to draw, colour, paint and read. I share my work when we do Zoom calls with family and friends and through my virtual program. I also love to cook and do so every week online with my friends. – **Lauren**
- > I stay connected with my community, family and friends by going for walks, running and cycling. – **Matt**
- > In PEI we are lucky that we are not in a lockdown, and I have my work two days a week. I can also go to the gym and yoga and church. I can visit my friends and family here. I also have some speaking engagements. – **Janet**
- > Every weekend my family and I get together. We bake, go on very long walks and have dinner together every Sunday night. I am very well connected with old roommates. We don't see each other anymore but we stay in touch on the phone. – **Paul**
- > I normally stay connected through my work, indoor and outdoor soccer, and my busy social life. – **Alana**
- > I walk the neighbourhood and chat with people I know. I also walk to the golf course once a week to see the people I worked with there and stay connected. – **Chris**
- > My jobs play a large part in this. I have worked for Lush, Wild Birds Unlimited, the Salvation Army and Nesters. It's amazing how often I get recognised on the street or in a bus. I like to go out for meals with friends or my family and have gotten to know the staff at my favourite restaurants and other patrons. Most people are very friendly and we chat. – **Andrew**
- > I do musical theatre on Zoom, and also work with DSRF as an Ambassador. – **Jodi**
- > I go walking in the forest and neighbourhood with my mom and see people in my community. I have been swimming two times a week with my mom at the rec centre. My mom and I also do Pilates on Zoom with a group. I recently started working again at the grocery store but only one day a week and I started working again at DSRF. – **Danielle**
- > Almost everything I do is inclusive – it includes people with and without disabilities. All my classes now are online. Propeller Dance, BEING studio, and an improv class with the Improvaneers out of the U.S. I even got to do classes with Zach Gottsagan from The Peanut Butter Falcon! I also do voice lessons with a friend who's an opera singer. – **Jessie**

Share your favourite story about connecting and inclusivity.

- > Right as the pandemic hit, I was graduating from high school to begin my new life as an adult. The pandemic changed almost everything. Then Extend-A-Family Kingston reached out and asked me to read my books virtually to participants. Since that day, I am a regular participant in their online programs and connect with them daily for learning, teamwork, fitness, friendship and skills building. I feel motivated, connected and included. Bridges to Belonging is also working with me to help one day have a place of my own to call home! – **Lauren**
- > My favourite story about connecting and inclusivity happened right before the pandemic started. I went to Toronto to perform with Propeller. After the performances we partied! We went out and danced, the band couldn't believe how wild we were. I also rocked my solo in the dance piece Spasticus! It was a great comeback for me after my stroke. – **Jessie**
- > Our church was able to start up again but needed volunteers to make it work. So, I volunteered and am a greeter and hand sanitizer. – **Janet**
- > During the pandemic I started up a WhatsApp and Skype group chat. It's a great way to stay connected to people that you can't see right now. – **Chris**
- > This is a love story of how I met my girlfriend. It started in 2019 at an ugly sweater Christmas party. I asked her for her phone number and I put it in my phone. We met again and we talked about our interests and we have been dating ever since. Our relationship is going very well. We will keep on dating until we get to the point of getting married but we don't know when that day will be. Now, we stay very connected to each other by calling on Facetime and Zoom. – **Paul**
- > For me it's being around the people I connect with, and also being included in different places and situations. It's really important to feel connected, like when I volunteer at the senior centre: they help me, and I help them. – **Jodi**
- > I have two! As a Special Olympics Health Messenger, I worked to create a tutorial to help others learn how to stay connected using Zoom. The other story is about my acting career. I took an online acting course and I even did a few jobs for my acting. I did a background voice for a ParticipACTION commercial and I had a part in a Disney movie called SPIN, coming out this year. This was the first movie I have acted in. I was on the movie set for three days and it was so much fun being included with all the lead cast members. In the future, I hope to see more "differently-abled" people included in film, movies, print and TV. I am glad the movie casting director and my agent were able to SEE MY ABILITY. – **Julia**



Chris



Lauren



Jodi



Matt



Jessie

photo credit: Doublespace Photography

DUAL DIAGNOSIS:

When Down Syndrome and Autism Collide

By Susan Fawcett, PhD, RSLP and Glen Hoos

Susan Fawcett is Director of Therapy, Behaviour and Family Support at the Down Syndrome Resource Foundation. Glen Hoos is Director of Communications at the Down Syndrome Resource Foundation, and the father of Becca.

“I’m just Becca!”



When Becca was born, we had a whole lot to learn about Down syndrome. Like most parents of a new baby, we never imagined our child would be anything other than typical and healthy. And so, we embarked upon a journey of discovery, guided by a team of doctors, specialists, and support workers.

The system just loves to categorize kids – even those who defy the usual categories. As the experts set aside the growth and development charts they use for typical children, they introduced us to the norms and expectations for children with Down syndrome. She should be this size by this age (Becca is off the bottom of the growth charts). She should be crawling by one and walking by two (Becca never crawled, and walked at four-and-a-half). She should be potty trained by the age of seven (at 16, it’s still a major work in progress).

It’s all been incredibly discouraging. Every step of the way, Becca has seemed to be behind her peers – not just typical children her age, but also many other children with Down syndrome.

It’s not just her physical development, either. We started noticing some odd patterns of behaviour that didn’t seem to

fit with the Down syndrome profile. As a young child, Becca’s favourite playtime activities were tiling her entire bedroom floor and bed with board books, and taking all her Little People figures and lining them up in one long, straight line.

She was also a major stasher. She would remove the grates from floor vents and stuff the vents with toys and food. She would hide everything, including the shoes of visitors we invited over. Often, she would even hide her own favourite toys and then forget where she put them, causing great upset when she then had to make do without them for weeks or even months at a time. Even today in her mid-teen years, she hides food all over the house. We find dried out tortillas in between the LPs in our record collection, wieners between the couch cushions, and boxes of long-thawed frozen food in all sorts of creative places.

The stereotype of people with Down syndrome being easy-going and happy-go-lucky is questionable to begin with, but Becca is on the extreme opposite end. Her need to be in control is so strong that she often gets stuck, refusing to move and therefore missing out on things that she herself desires to do because an unspoken precondition has not been met in just the right way.

The professionals on her team noticed the differences as well. She was diagnosed first with anxiety, and later with OCD. However, it wasn't until her early teens that it became clear something more was at play. Finally, at the age of 14, Becca received a dual diagnosis of autism. It was "a slam dunk" case, said the developmental psychologist who made the final call.

Why then did it take so long to diagnose?

PREVALENCE OF AUTISM IN DOWN SYNDROME

Traditional thinking held that autism was rare in people with Down syndrome, but that is far from the case. In fact, it is estimated that autism in individuals with Down syndrome is 10-25 times more common than in the typical population. At the Down Syndrome Resource Foundation, our prevalence rate is in line with these studies, with approximately 12% of our students having a dual diagnosis. However, this diagnosis often comes much later than it would for an otherwise typical child.

In fact, Becca's case is quite common. In one study of subjects with a dual diagnosis, the mean age of autism diagnosis was 14.4 years – this despite the fact that, as with other children,

autistic symptoms are present much earlier in life (rarely do they emerge in kids after the age of three, whether or not they have Down syndrome).

This delayed diagnosis creates many problems. Clearly, children with a dual diagnosis are at a real disadvantage in their development and education, even relative to children with only one of the disabilities. Even more problematic are the faulty expectations that may be placed on the child where the autism has gone undetected. As one study concluded, "inconsistent or poor social relating in a child expected to be 'charming' or 'outgoing' may create some frustration for all concerned and may lead to a poor fit between the child and the expectations in the environment."

Parents, many of whom report that the symptoms associated with autism are more difficult to deal with than Down syndrome, can feel that their child's slower development is their fault; that they haven't done enough to help their child with Down syndrome. They notice that other children with Down syndrome are more advanced and exhibiting less severe behavioural problems, leading to feelings of frustration and inadequacy. These parents need extra support, but they may not feel like they fit in well with other Down syndrome families.

Beyond this, there is the practical matter of funding for therapy services. In British Columbia, for example, a Down syndrome diagnosis does not automatically give families access to funding for intervention, even though all children with Down syndrome can benefit from speech therapy, occupational therapy, specialized education services, and more.

On the other hand, the autism diagnosis opens the door to a significant amount of funding for such services: \$22,000 per year through age five, and \$6,000 per year from ages 6-18. The delayed autism diagnosis for children with Down syndrome, then, results in them receiving far less therapy than those with autism alone, despite facing double the challenges. All told, a child diagnosed at three will receive \$144,000 for therapy and supports throughout their childhood. A child with Down syndrome who is diagnosed with autism at 14 will receive \$30,000 – all of it coming after their most crucial developmental years have passed. It's not about the money, it's about the lost opportunity to build skills necessary for independence.

WHY IS DIAGNOSIS SO DIFFICULT?

Unlike Down syndrome, which is conclusively diagnosed via a simple blood test, Autism Spectrum Disorder is a subjective diagnosis based upon observed behaviours and social communication patterns. In order to be diagnosed with autism, a person must meet all four of the following criteria:

A: *Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all three of the following: social and emotional reciprocity, nonverbal communication behaviours, and developing and maintaining relationships*

B: *Restricted, repetitive patterns of behaviour, interests, or activities as manifested by at least two of the following: stereotyped or repetitive speech or movements, excessive adherence to routines, highly restricted/fixated interests, hypo- or hyper-reactivity to sensory input*

C: *Symptoms must be present in early childhood*

D: *Symptoms together limit and impair everyday functioning*

Parents of children with both Down syndrome and autism will often say that they "knew something was different." It's often just a matter of degrees, because part of what makes autism so difficult to identify in children with Down syndrome is that many of the characteristics are common to both conditions, particularly in the area of communication. And, although there are a lot of bits and pieces that make up autism, it is primarily a disorder of social communication.

Students with Down syndrome can have challenges in almost every area of speech and language development, including:

- **Underlying cognitive skills**
- **Expressive language**
- **Speech sound production/general intelligibility**
- **Stuttering**
- **Voice**

Social communication is an area of increasing concern among students with Down syndrome. Early in life, many young children with Down syndrome have trouble with differentiating emotions shown on the face, taking turns, interacting appropriately with peers, and greetings. Later, children may continue to have difficulty with eye contact and greetings, and earlier deficits in turn-taking now surface as inappropriate conversational behaviour (asking partner-directed questions, topic maintenance, elaboration of topic, etc.). Still older children and adults with Down syndrome may have trouble repairing communication breakdowns.

If you think this all sounds like autism, you're right! That's part of what makes dual diagnosis so tricky.

On the other hand, despite these shared characteristics, there are other traits common to children with Down syndrome that may seem incompatible with autism. It's a stereotype, yes, but it's a stereotype because there is some element of truth to it: many people with Down syndrome do have a perceived strength in social abilities. While children with Down syndrome are often seen as friendly and sociable, children with autism can present as socially impaired, aloof and isolative. What we're learning, however, is that children with both Down syndrome and autism may actually be more social than children with autism alone.

Yet another obstacle to an accurate diagnosis is the nature of the testing itself. The assessment team consists of the same professionals who diagnose any child with autism, which may include a developmental psychologist or psychiatrist, paediatrician, and/or a speech-language pathologist. They use the same assessment measures that are used with all other children who are suspected of having autism. This creates measurement issues with kids who are nonverbal or low-verbal, and/or severely intellectually impaired.

Formally assessing a child with a developmental disability using a standardized test is incredibly difficult – not to mention extremely discouraging for parents who have to see their child's scores plotted at the very bottom of the chart. The child may have difficulty with the test due to overall low functioning, poor attending skills, high variability from day to day, environmental

The advertisement features a background image of a modern conference room with several black office chairs around a long wooden table. Two pendant lights hang from the ceiling. The text is overlaid on this image. On the left, the logo for the Canadian Down Syndrome Society (CDSS) is displayed, consisting of a stylized figure with arms raised, next to the text "Canadian Down Syndrome Society" and "Société canadienne de la trisomie 21". The main headline in large, bold, red font reads "We are seeking candidates to join the CDSS Board of Directors!". To the right, in white text on a red background, it says "WE WANT TO HEAR FROM YOU." followed by "Requirements, role details and responsibilities are available at: cdss.ca/about-cdss/board-of-directors". At the bottom right, it says "Apply online by March 31, 2021."

factors, or challenging behaviours. Many studies have noted the tendency for autism to be more commonly diagnosed in children with Down syndrome who are functioning at a lower cognitive level.

This is where a lot of challenge with assessment arises: Does a failure to show a particular communication or social skill arise due to an overall low level of intellectual functioning, or is it because of a specific, qualitative deficit?

WHAT TO WATCH FOR

We are often asked by parents whether we think their child may have autism, or whether they should be assessed. We have broken down the most common warning signs into two categories: grey flags and red flags.

Nevertheless, it is possible to distinguish between low intellectual functioning and autism. Several studies and researchers in this area refer to an “autistic flavour,” “autistic quality,” or “autistic-like condition” rather than clear-cut criteria. Assessors have mentioned that their final decision is a “gut” one. It’s far from ideal, but this is the current reality.

Grey Flags

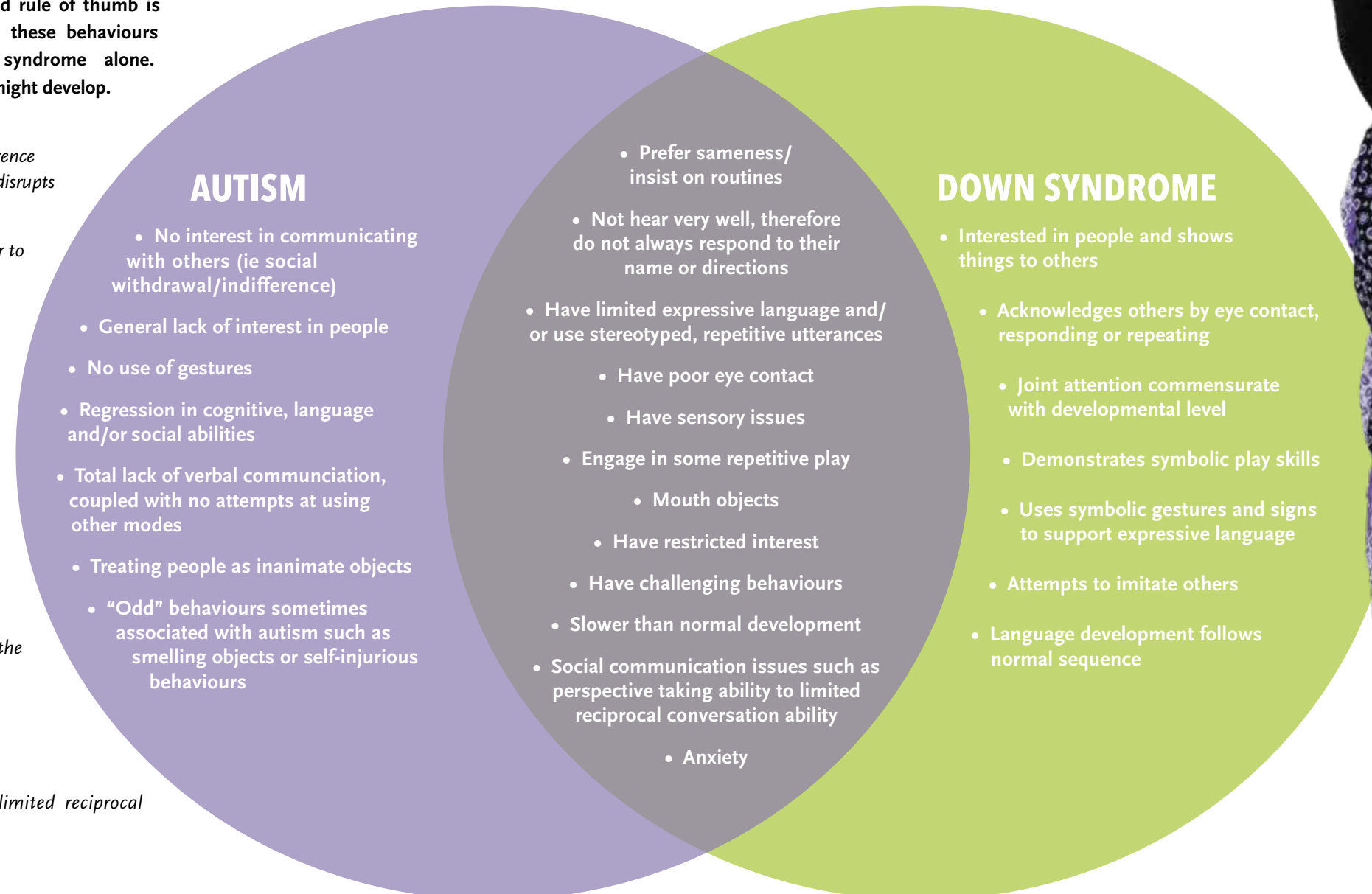
With regard to these grey area characteristics, a good rule of thumb is not to worry about isolated items from this list, as these behaviours are relatively common for children with Down syndrome alone. However, the more you see from this list, the more concern you might develop.

- prefers sameness; insists on routines (must remember degree here – there is a difference between a general preference for sameness and a rigid insistence that significantly disrupts life on a daily basis); note: this is also a characteristic of OCD
- does not hear very well, and as a result, does not always respond to their name, or to questions and directions
- has limited expressive language; and/or uses some stereotyped, repetitive utterances
- has poor eye contact
- has sensory issues (e.g. finicky eaters)
- engages in some repetitive play
- mouths objects
- has restricted interests
- has challenging behaviours
- slower than normal (for Down syndrome) development (i.e. functioning in the moderate to severe range of intellectual disability)
- anxiety
- repetitive, stereotyped behaviours
- social communication issues such as: limited perspective-taking ability or limited reciprocal conversation ability

Red Flags

The red flag characteristics are more concerning, as these behaviours are not typically associated with children who just have Down syndrome.

- no interest in communicating with others (i.e. social indifference/withdrawal)
- general lack of interest in people
- no use of gestures
- regression in cognitive, language, and/or social abilities
- total lack of verbal communication, coupled with no attempts at using other modes
- Treating people as inanimate objects i.e. using someone’s hand to get desired object
- ‘Odd’ behaviours sometimes associated with autism (e.g. smelling objects) or self-injurious behaviours



WHAT TO DO IF YOU SUSPECT AUTISM

If you suspect your child may have autism, the first step is to consult with one or more members of your professional support team, such as your pediatrician, speech therapist, or child psychologist. If they share your concerns, they can provide you with a referral for a formal assessment.

For many parents, another label for their child (and another long series of assessments) is the last thing they want, and that is totally understandable. However, an accurate diagnosis is important for truly understanding your child and getting

the best possible support to help them achieve their fullest potential – whatever that may look like.

Whether your child has one diagnosis, or two, or many, their conditions do not define them. They are who they are, in all their strengths, challenges, and quirks of personality. Or as Becca (who hates it when anyone calls her by anything other than her name) says, “I’m not (sweetie/honey/beautiful/sister/daughter/Down syndrome/autism), I’m just Becca!” That she is... and Becca is awesome.

1 Capone, G. T., Grados, M. A., Kaufmann, W. E., Bernad-Ripoll, S., & Jewell, A. (2005). Down syndrome and comorbid autism-spectrum disorder: Characterization using the aberrant behavior checklist. *American journal of medical genetics Part A*, 134(4), 373-380.

2 Rasmussen, P., Börjesson, O., Wentz, E., & Gillberg, C. (2001). Autistic disorders in Down syndrome: background factors and clinical correlates. *Developmental medicine and child neurology*, 43(11), 750-754.

3 Howlin, P., Wing, L., & Gould, J. (1995). The recognition of autism in children

with Down syndrome-implications for intervention and some speculations about pathology. *Developmental Medicine & Child Neurology*, 37(5), 406-414.

4 (Capone et al. 2005)

5 (Capone et al. 2005)

6 Starr, E. M., Berument, S. K., Tomlins, M., Papanikolaou, K., & Rutter, M. (2005). Brief report: autism in individuals with Down syndrome. *Journal of autism and developmental disorders*, 35(5), 665-673.

7 (Capone et al. 2005; Starr et al. 2005)

8 Capone, G., Goyal, P., Ares, W., & Lannigan, E. (2006, August). Neurobehavioral disorders in children, adolescents, and young adults with Down syndrome. In *American Journal of Medical Genetics Part C: Seminars in Medical Genetics* (Vol. 142, No. 3, pp. 158-172). Hoboken: Wiley Subscription Services, Inc., A Wiley Company.

9 Ghaziuddin, M., Tsai, L. Y., & Ghaziuddin, N. (1992). Autism in Down's syndrome: presentation and diagnosis. *Journal of Intellectual Disability Research*, 36(5), 449-456.

Visit our website for **FREE** downloads of all CDSS life stage resources!



Canadian Down Syndrome Society

Société canadienne de la trisomie 21

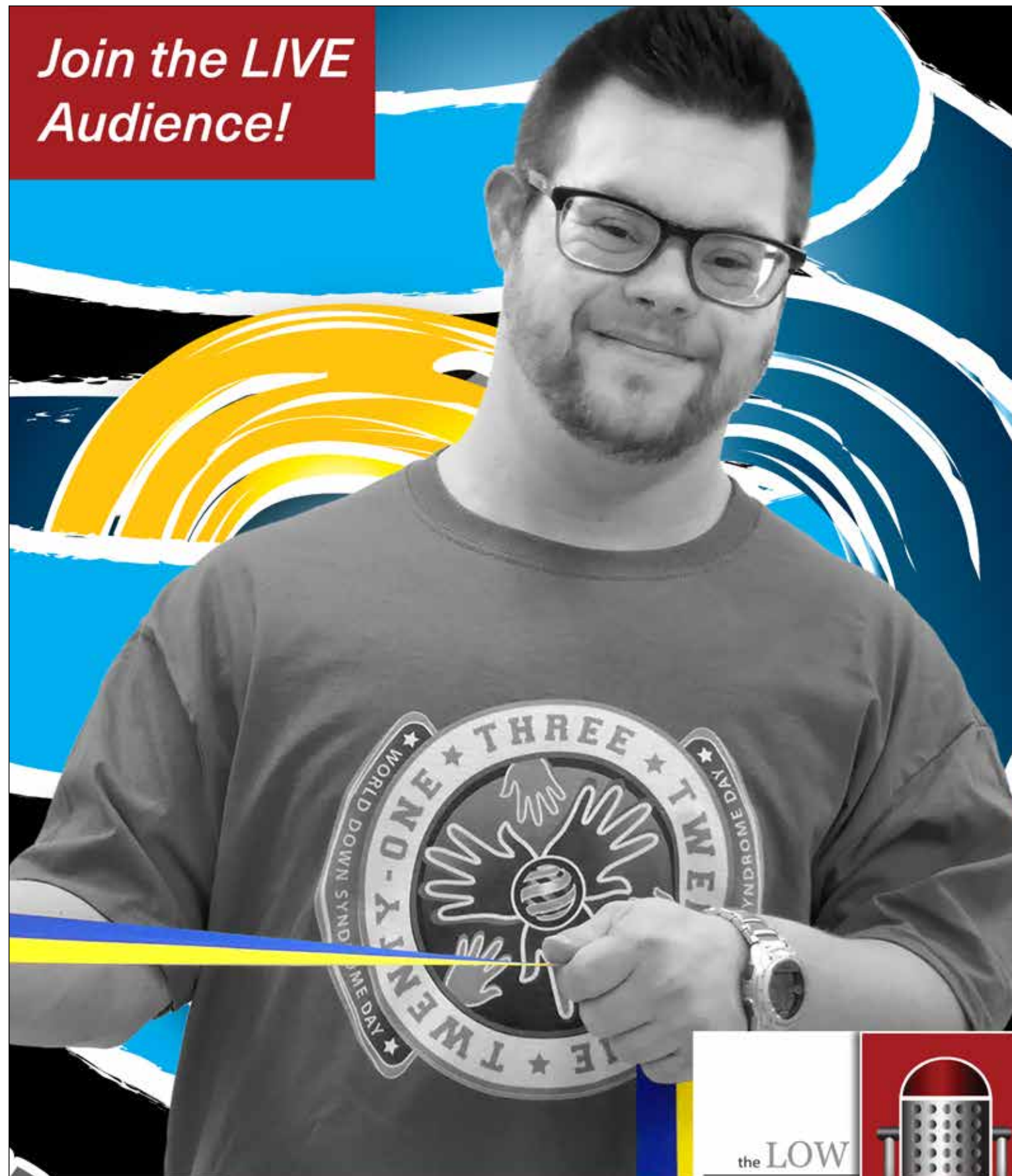


Information for individuals when they need it most: from prenatal to aging.
CDSS.ca



Thousands of downloads by new and expectant parents, families, support persons, teachers, medical experts, therapists, and those with Down syndrome.

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TICKETS:
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/WSDS

**Andrew Bingham, Danielle Juilfs
Jodi Klukas and Chris Sayer**
**CONNECT With Us: A World
Down Syndrome Day Panel**

the **LOW**
DOWN



A Down Syndrome Podcast

CDSS SPOTLIGHT

Spring and Summer Event News

Is your group considering holding an awareness and/or fundraising event this spring? CDSS has exciting new ways to fundraise for individuals, teams and organizations. We are saying goodbye to GO21 and bringing you an exciting new fundraising platform! "Fundraise My Way" will allow you to create your own fundraiser, whether your way is sports themed, birthday, music, garage sale or any other: we've got you covered. If you are an individual or group who is planning a spring or summer event, contact us at events@CDSS.ca to learn more.



COMMUNITY SURVEY 2020 HIGHLIGHTS

Thank you to all who participated in our November 2020 survey. Highlights from the CDSS Community Survey coming very soon. It was clear from the survey results that the most pressing issue within the Down syndrome community in Canada is about planning for the future, or in one survey respondent's own words: "When my mom and dad are no longer living...I worry about living on my own." Supporting families and individuals' futures are an even stronger priority for CDSS in our planning.

Next steps for CDSS are to:

- > Use survey results to guide project planning for 2021 and beyond
- > Enhance the link of participants to CDSS and regional Down syndrome groups
- > Encourage stronger following of CDSS social media channels for current and timely communication
- > Improve awareness of currently available French and English CDSS resources



See our ad on the back page for all the ways to get involved in World Down Syndrome Day! March 21 is a Sunday in 2021, so remember to share our presentations and resources with teachers early to help plan classroom activities as we lead up to the big day.

Blog News

In case you missed it, Awareness Leader Paul Sawka's latest blog is all about dating and relationships, sharing his thoughts on why all kinds of relationships are important, and advice for those curious on this topic.

CDSS's Mind & Body is a great resource to help inspire discussions about healthy relationships. Developed specifically for people with Down syndrome, you can find this resource in French and English here.



Feedback on our 2020 and early 2021 free webinars is outstanding! Make sure you are following CDSS on social media to stay up to date – we are working on more webinars to support the community!

FREE Webinars From CDSS!



Actively seeking candidates for the CDSS Board of Directors! See our ad on page 22 and apply by March 31, 2021.



FIND US / TAG US

@CdnDownSyndrome on all our platforms



DSRF CORNER

3/21/21: COVID-safe World Down Syndrome Day Activities in and Around Vancouver

World Down Syndrome Day (March 21) may be a little different this year thanks to the pandemic, but there are still lots of fun ways to celebrate. Here's a list of COVID-safe activities happening in and around Vancouver.

The "CONNECT with Me" Campaign

This year's theme for World Down Syndrome Day around the world is "CONNECT."

In 2020 around the world, we all had to adapt the ways we connect with each other. It was a big challenge and many people have been left behind. But it was an opportunity to find new ways to connect.

DSRF will promote this theme through a collaboratively-produced community video released on World Down Syndrome Day. Follow @DSRFCanada on Facebook, Instagram and Twitter to see and share the video.

The LowDOWN Podcast Live Recording: CONNECT with Us

The LowDOWN: A Down Syndrome Podcast will kick off its third season with a live episode recording featuring DSRF Ambassadors Andrew Bingham, Danielle Juilfs, Jodi Klukas and Chris Sayer. You'll be able to watch the panel interview and submit your questions for the Ambassadors via Zoom. The recording will take place on March 16 at 2:00 pm PT, and the episode will be available for download on 3/21/21. Visit DSRF.org/WDSO to register to be part of the live audience.

WDSO Socks and Merchandise

Each year, people around the world don funky socks on World Down Syndrome Day to show their support for those who are rockin' the extra chromosome. This year, DSRF is proud to partner with John's Crazy Socks to offer John's Down syndrome awareness socks and face masks. We also have exclusive World Down Syndrome Day t-shirts, buttons and other merchandise through our office and at DSRF.org/shop.

3-2-1 Campaign

Empower individuals with Down syndrome! Donate \$321, \$32.10 or \$3.21 on 3/21/21, at DSRF.org/321.

Lights of Vancouver

Vancouver's most famous landmarks will be aglow in blue and yellow (the official colours of Down syndrome) the night of March 21! Participating venues include BC Place, Rogers Arena, Telus World of Science, Canada Place, Jack Poole Plaza, Vancouver City Hall and Surrey Civic Plaza. Be sure to tag @DSRFCanada in your photos!

Official Proclamations

World Down Syndrome Day 2021 will be officially proclaimed by the cities of Vancouver, Burnaby and Surrey, and by the Province of British Columbia. Follow @DSRFCanada on all social platforms to see and share the proclamations.

Run Apart with Chris Nikic

In this issue of 3.21, we've gotten to know Chris Nikic, the world's first person with Down syndrome to become an Ironman. Chris is all about overcoming challenges, and now he's joining forces with DSRF to help people with Down syndrome conquer obstacles and achieve their dreams, just like he did.

Chris will serve as the official Race Ambassador for the 2021 Run Apart for Down Syndrome. Join Chris, and hundreds of supporters, as we virtually Run Apart for Down Syndrome

on June 6. Run or walk the distance of your choice, wherever you are, and raise money to empower individuals with Down syndrome to reach their potential. Learn more and register at DSRF.org/RunApart.

Listen for Chris on Season Three of The LowDOWN: A Down Syndrome Podcast later this spring!

FRIENDS OF DSRF

Employment & Social Development Canada, administered by United Way of the Lower Mainland, has granted DSRF \$30,000 from the UWLM Mental Health and Well-being Emergency Community Support Fund 2.0 in support of our mental health services for individuals with Down syndrome. This funding from the Government of Canada has played a crucial role in our ability to continue to care for families through the pandemic and we are deeply grateful for their support.

For the sixth consecutive year, the John Hardie Mitchell Family Foundation has made a generous donation in support of the Down Syndrome Resource Foundation's educational programs and services for youth with Down syndrome. The Foundation's \$3,000 investment will help students develop their speech, fine motor, reading and math skills. We are so thankful for their ongoing support!

Longtime DSRF supporter the Hamber Foundation has bestowed another generous gift upon us. Their \$2,000 grant will support children and youth with Down syndrome in speech therapy, occupational therapy, one to one reading and math. Thank you again to the Hamber Foundation!

The Beutel Goodman Charitable Foundation made a very generous donation in support of educational and health opportunities for children and young adults with Down syndrome. We appreciate their investment in our students.

The following individuals and organizations sponsored DSRF's holiday countdown calendar in December, contributing to the \$51,000 raised through this year's DownSide UP campaign: Phillips, Hager & North Investment Management, LiUNA, CIBC, the Vancouver Canucks Alumni Association, BLG, The Answer Company, Chris Forman, the Neil Squire Society, Blueshore Financial, George Klukas, Bill Longman, and Euro-Rite Cabinets. Thank you to each and every one of you.



UPCOMING AT DSRF

WDSO: CONNECT with Us Live Podcast Recording –
Wednesday, March 16, 2021

World Down Syndrome Day – Sunday, March 21, 2021

Up the Down Market Calgary – Thursday, April 22, 2021
(virtual event)

Run Apart for Down Syndrome – Sunday, June 6, 2021
(virtual event)

FIND US / TAG US

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WORLD DOWN SYNDROME DAY!



March 21

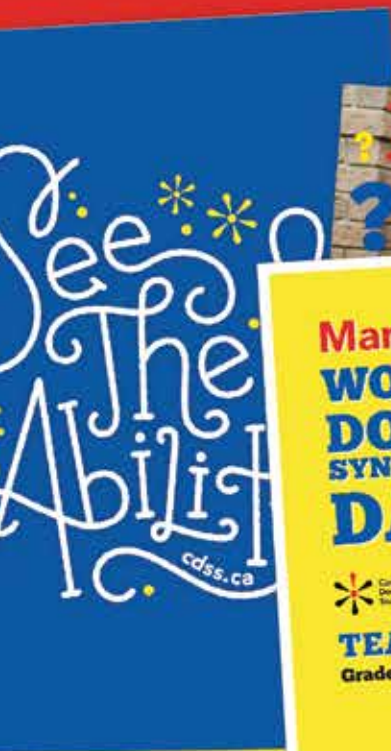
So many ways to get involved:

blue & yellow lights
education

lots of socks

awareness activities

See our website for
ideas and links to
FREE downloads.



#WSD2021 #LotsOfLights #LotsOfSocks #WSDConnect #DownSyndromeAwareness



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