

3.21

Canada's
Down Syndrome
Magazine

Summer 2020
ISSUE #3

Mental Health and Aging:

Dr. Brian Chicoine

The Health Issue

**DOWN
SYNDROME
& THE
DENTIST**

**HOME
SWEET
HOME:**

Your Summer Staycation

**OUR
COVID
WORLD**





3.21 is a joint publication of



Canadian
Down Syndrome
Society

Société
canadienne de la
trisomie 21



**Down Syndrome
Resource Foundation**

Together. Hand in Hand.

Welcome to the summer issue of 3.21: Canada's Down Syndrome Magazine!

The first half of 2020 has not been what any of us expected it to be. The COVID-19 crisis has turned our lives upside down and brought health issues to the forefront. So, we thought it only appropriate to turn our attention to health and wellbeing for this, the third edition of 3.21.

As we write this, it is impossible to know what the situation will be by the time you read it. Hopefully, the worst will be behind us and we'll be tentatively poking our heads out for a taste of summer. Regardless, the topics covered here, including physical and mental health, dental hygiene, sleep, aging and more, will remain of utmost importance to all people with Down syndrome.

We would love your feedback! Drop us a line at 321Magazine@gmail.com with your thoughts, story ideas and submissions for consideration.

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DSRF.org
or CDSS.ca

Cover Model: Kenzie Copping is a recent graduate in Newmarket, Ontario who turns 21 this summer.
Cover Photo: Hilary Gauld-Camilleri of One For The Wall
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OUR COVID WORLD

The big question on many people's minds in the early stages of the COVID-19 story was whether or not people with Down syndrome are more at risk when it comes to exposure and becoming infected with the virus. Consistently, medical professionals have stated that while Down syndrome in itself does not make one more susceptible to contracting the virus, health issues that are more commonly seen in people with Down syndrome can make the virus more serious and challenging to recover from.

It is important to stay abreast of the most up-to-date and accurate information about COVID-19 to help you and your family respond to the demands of the situation. Below are some links to recommended websites about COVID-19 and Down syndrome. Some of these sites include links to easy-read resources and French resources. We encourage you to also visit your provincial health authority websites for the latest updates in your community.

COVID-19 RESOURCE LINKS:

Mental Health Commission of Canada COVID-19 resource page

<https://www.mentalhealthcommission.ca/English/mhcc-covid-19-resources>

Health Care Access Research and Developmental Disabilities: How to stay safe, well and connected

<https://www.hcarddcovid.com/info>

EASY READ : Green Mountain Advocacy ENGLISH: COVID-19 Information By and For People with Disabilities

<https://selfadvocacyinfo.org/wp-content/uploads/2020/03/Plain-Language-Information-on-Coronavirus.pdf>

EASY READ: Green Mountain Advocacy FRENCH: Informations sur la COVID-19 créées par et pour les personnes handicapées

https://cdss.ca/wp-content/uploads/2020/03/COVID-19_Self_Advocate_Easy_Read_FRENCH_resource.pdf

Council for Intellectual Disabilities: Look After Your Mental Health During Coronavirus

<https://cid.org.au/our-stories/look-after-your-mental-health-during-coronavirus/>

Government of Canada COVID-19

<https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection.html>

Down Syndrome International DSI: Down Syndrome and COVID-19

<https://www.ds-int.org/down-syndrome-and-coronavirus>

Global Down Syndrome Foundation: Everything You Need to Know About COVID-19 and Down Syndrome

<https://www.globaldownsyndrome.org/covid-19/>

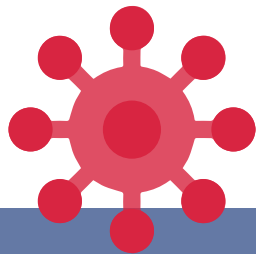
FRENCH: RT21 Resources sur de la COVID-19

<https://trisomie.qc.ca/ressources-sur-la-covid-19/>

Ally and good friend of the Down syndrome community and CDSS, Dr. Brian Skotko, MD, MPP, often shares valuable information pieces like this one:

https://www.dsagc.com/_dsagc/assets/File/Dr%20Skotko_COVID19.pdf. Give him a follow @drbrianskotko on Facebook.

Moving beyond the medical facts and statistics that doctors might discuss with you and that you may find online, the practical advice about handwashing, social distancing and healthy lifestyles are all key prevention measures. It is also important to ensure that mental health is cared for. Below are COVID-19 blogs from young adults with Down syndrome, discussing the impacts that COVID-19 has had on them, changes to their schedules and lives, how they keep themselves busy and connected, and how they stay in shape during self-isolation.



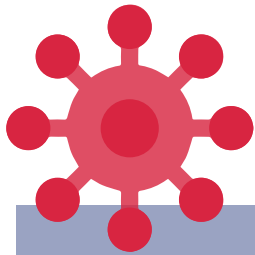
Question: How did you first learn about the virus and how are you hearing about what is happening in Canada daily?

I go to worldometers (<https://www.worldometers.info/coronavirus/>) to see where in the world it is and how many people have it. - *Natalie*

I visit the local radio station website on Facebook to get the latest news update in the newspaper on the coronavirus. I also watch the news for the updates in my area and for Canada. I listen to our city mayor's updates and I listen to our local Public Health Unit updates. - *Julia*

I don't go to websites or listen to the news. It is too upsetting. I talk to my parents and VATTA and my dance troupe about updates. - *Jessie*

I watch the CBC news almost every evening with my parents. They also read the newspaper in the morning and we discuss the situation over breakfast. - *Paul*

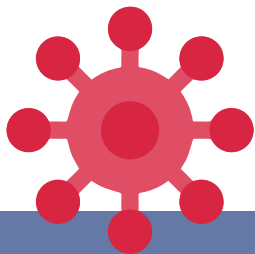


Question: What are some things you are doing to keep yourself and others safe?

I'm washing my hands a lot. I've used FaceTime to see my brother and my boyfriend. I keep myself safe by staying at home and avoiding any crowds. When I go for walks, I make sure to keep our distance if we talk with people on the street. - *Julia*

To keep safe I practice physical distancing, wash and Purel my hands, I shower, wash all our groceries, I don't see other people except who I live with. I am washing my hands, spraying down door handles with Lysol and wiping down areas where I touch with the Lysol wipes. I use hand sanitizers when I do go out, and follow instructions to stay at home as much as possible. The way I keep myself safe going place to place is that I bring things with me like hand sanitizers all the time. When I do get back home I make sure I wash my hands and wipe down my wallet and keys and phone. - *Matt*

I had to move home with my parents, because my roommate's co-worker got sick and they sent her home to self-isolate. - *Paul*



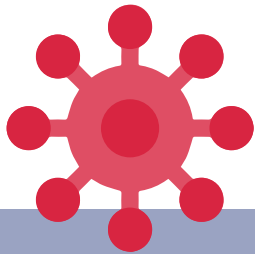
Question: Do you find it hard to follow the rules about distancing?

I find this very difficult. I miss my roommate, my co-workers, my friends and all of my activities and routines. - *Paul*

I find very hard because that's how I show affection and because I am very affectionate person. - *Alana*

I find it easy to follow the rules about social distancing. I know how important it is. I do miss seeing my brother and my boyfriend in person. - *Julia*

Not too hard to follow rules, except not touching your face. That's hard! - *Jessie*



Question: Are you worried about anything? If so, what are you worried about and how are you going to solve that worry?

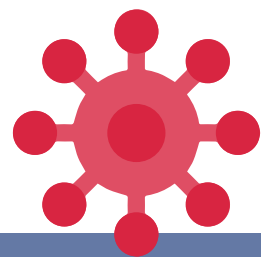
When I first heard about the Coronavirus I was worried about how this was going to affect me, but I learned how to stay safe and protect others by following the rules. I was also worried about not seeing my family, my boyfriend and my friends. I solved that problem by using FaceTime and texting. - *Julia*

I am worried about how long this will go on. - *Jessie*

There are always things to worry about, like wondering if everyone you know is safe and what activity got cancelled because of the virus. - *Matt*

I am worried about when or if I can get back to work and back to my activities and seeing my friends. Mom is worried about me getting sick because I have had pneumonia and been in the hospital twice, so we don't want that to happen again. - *Paul*





Question: What was cancelled because of COVID-19 that you enjoy?

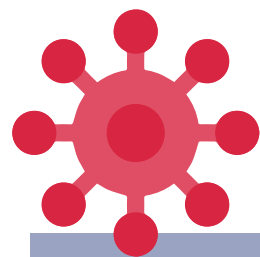
My job, workouts at the Y, my karate training, all of my competitions this year, choir practices, church. Everything! - *Natalie*

Everything has been cancelled! Movie theatres are closed, there's no more swimming, no more Mount Royal university classes, no more Special Olympic activities, no more meeting friends and just hanging out. No family gatherings. - *Paul*

I had a very busy life before the virus. In March I stopped working because it was unsafe for my health, but I will be rehired when it is safe for me. I miss my skating friends and all the kids I help coach. My figure skating banquet and Special Olympics Annual Sports Awards banquets have been cancelled. The monthly dinner/dances that I attend have been cancelled to keep everyone safe. I can't go to the mall, or the movies with my friends. - *Julia*

EVERYTHING has been cancelled! Where I was living, rehearsals, my gym, dance and fitness classes, date night, going out for tea, visiting friends, the art studio. But now people are trying to figure out how to do stuff online. - *Jessie*

Special Olympics, sports and hockey on tv. - *Matt*



Question: Your schedule has changed a lot because of the virus. What has changed the most? Are there some things that have not changed?

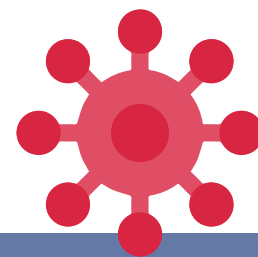
I am not working anymore, so I get to sleep in a little more. I have so much more time. For me what changed the most is that I love to show my family and my boyfriend how much I love them by giving hugs. I'm dealing with this change by showing them I still love them in different and creative ways. For me the things that have not been changed in my schedule and routine are working on my independent skills in my home, staying active and staying connected. I am cooking more with my family and helping more with family chores. - *Julia*

Although it is different I still see my support workers on FaceTime as well as my friends. I still keep in touch with people through texting and phone calls. - *Paul*

I have a new schedule in place of my old life. Now, I exercise in the morning, I write stories in the afternoons, or watch a movie, or shows. I help with supper sometimes. After supper every night I do yin yoga. Then I go to bed and listen to audiobooks before I go to sleep. I used to exercise before, now I exercise here. That has not changed. I used to do more cooking at home with my support worker. Now I enjoy baking with my mom, bread and stuff. I love my new life. - *Natalie*

We have things we do everyday: shower, go for a walk, go on the internet, read, a family game, be social (call/video chat) with three people every day, record Pandemic Picks - the video me and my dad post every day. We have lots of people watching and following! And we do a short mindfulness thing together. Oh and highs and lows at the end of the day! - *Jessie*

This change did not change a lot but it opened my schedule more and I found new activities that keep me busy at home and staying active. What I keep the same in my routine is my morning coffee! - *Matt*



Question: How are you staying active?

I go on the treadmill. When it gets warmer out, I will do more walking outside. I'm keeping up with my karate training, and piano practising. - *Natalie*

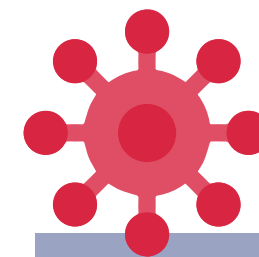
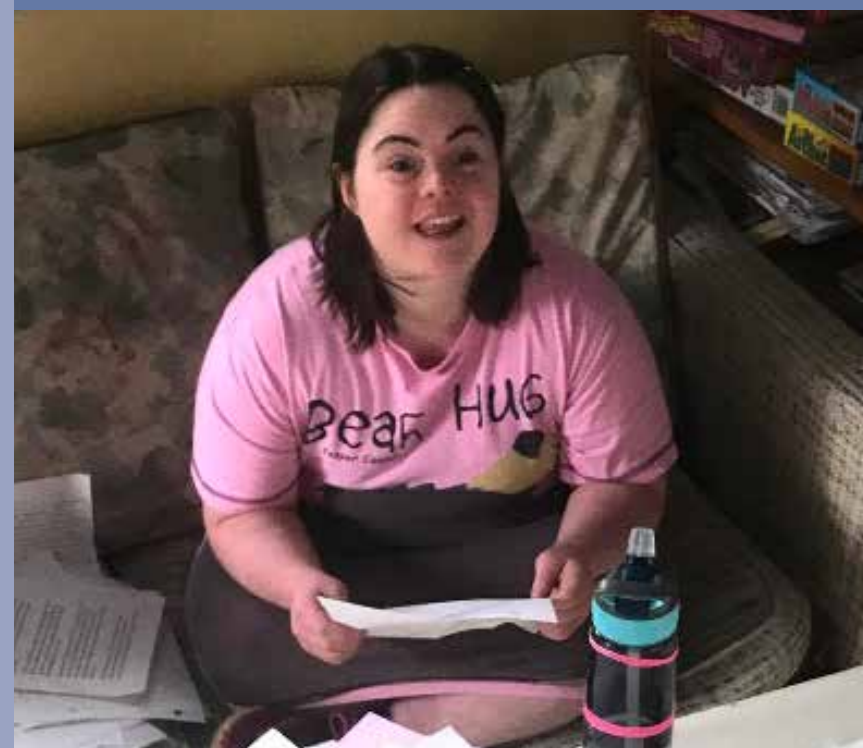
I do my dancing for my exercise. - *Alana*

I'm staying active using the Special Olympic Wellness Challenge everyday and using the Special Olympics Fit 5 Program and exercise cards. I have been dancing on my Nintendo Switch and going for walks to stay active. - *Julia*

Active walking, dancing with my headphones on and trying online classes. - *Jessie*

If I need some air I go outside. I go for a bike ride and do a run around the block and sometimes I do some new activities like yoga and workout that is visual online. - *Matt*

Special Olympics Calgary has some daily exercise sessions that I follow along with. They keep me active. Sometimes I go for short walks with my parents. I am baking more with my mom. I am also helping with the cleaning. We download audiobooks from the library that I am enjoying as well. We are looking into downloading some computer games for me to play. In the evenings we watch some of our favourite movies together. - *Paul*



Question: Are there any projects you will work on while you are at home more?

My dad and I enjoy woodworking and are building a new night table for my room in the condo. It is a good project and is taking lots of time. We also hope to put together a photo book from our vacation in the Dominican Republic. That will be an interesting project to work on. - *Paul*

The biggest project I'm working on at home is to work on my yearly project for the Special Olympics Ontario Leadership group that I am a member of. I will be creating a monthly calendar of events for our local Special Olympics. I am also working on creating a slideshow presentation on Healthy Lifestyles. The slideshow is based on my Healthy Lifestyle presentation I gave last fall for the Prince Edward Island Special Olympics Health Forum. I will also be including my experiences from the Health Forum. - *Julia*

The centre for the arts has been sending out art challenges. I do them then I send them back to them. - *Alana*

I am doing some projects. I am recording more phrases with Project Understood (www.ProjectUnderstood.ca). - *Matt*

I will work on my new dance piece—Puff of Smoke. I got an Ontario Arts Council grant for that!!!! And figuring out how to work with my dance mentor over Zoom. - *Jessie*





Down Syndrome & the Dentist

From Fairytale to Possible Reality

by Kristen Halpen

A date is circled on your family calendar, marked with a drawing of a perfect molar tooth. Your child eagerly crosses off each day of the month as it passes, counting down the days to the one with the tooth, with as much excitement as an approaching trip to Disneyland. It's finally here. They can't get through their breakfast fast enough. By mid-morning they are jumping up and down at the front door begging you to leave the house. Everyone loves the dentist!

If this doesn't mirror your family's dental reality, we're here to help with some tips, tricks, and advice from professionals to change what may be comparable to a dark scene from a horror movie into a slightly more manageable - maybe even happy - reality.

For Young People with Down Syndrome

It starts with one piece of consistent advice from experts across the board: *Impress healthy dental habits upon young people*. From a very early age teach your child to 'do what I do' when it comes to all aspects of personal care: take good care of yourself. Talk to them about how you take care of your teeth, and make it a key part of your AM and PM routine.

A masked stranger donning gloves and working away in your mouth for a potentially long period of time is, to most children, a strange and overwhelming concept. So be understanding of real fears, and *accept the fact that that this will likely be a scary event for your child* with Down syndrome. Keep in mind that almost half of the overall adult Canadian population strongly fears the dentist. According to Statistics Canada (2013), over 40% of people actually avoid dental care because they are afraid of the poking, scraping, gagging and choking that occur during dental treatments. Rest assured that you and your child have nothing to be ashamed about when it comes to any anxiety, and that *you can help ease those feelings with the right planning*.

Research and ask lots of questions of dental service providers, to *make sure you find the right fit for your child*. This includes the dentist, dental assistants, office staff, and dental hygienist(s). If the office doesn't have time for your questions, then they probably aren't the right fit for any client with a disability. Professionals should make time to get to know clients; they too should be asking the right questions about what fears or anxieties exist, and what would work to make kids more comfortable in the dentist chair.

Laura LaChance, Interim Executive Director with CDSS, who has worked as a Registered Dental Hygienist for over 40 years, stresses the importance of *building a level of trust*. "This is true of almost all health providers – doctors, dentists, ophthalmologists, etc. As a caregiver you should bring children from a very young age (many suggest as young as one year) to your own appointments for checkups. This will help them get used to the dental office, the people, equipment and the routine of it all." The dental team can give you tips for providing good care for their teeth and gums and what problems to watch out for.

Laura also suggests knowing your child and sharing that information: "Book appointments at a good time of day for the child, whenever that is that works with the dental office schedule. *Tell the dental office about your child*: what motivates them, the fears and anxiety they may be facing, if it is better to have you in the room or not, how well they can express themselves with language, etc. Don't hold back here – the more information you can share, the more helpful an advocate you become for your child."



Try to avoid making a huge deal out of the dentist visit; after all, this is something that everyone does, and is part of healthy habits. Laura advises to *keep things light*: let kids brush your teeth and gums if they want to, tie in a fun song as part of the teeth brushing routine, get fun toothpaste that they like, have two toothbrushes on the go – one yours and one theirs so you can ‘take a turn’ after they brush. Keep it happy and remember that young kids with Down syndrome usually love routine, and as they age, dental care is a great topic to help promote independence. Don’t forget to clean between teeth that touch each other with floss.

If your child is an absolute ‘no way, no how’ when it comes to dental care, and won’t even let you see the inside of their mouth unless they are screaming at the top of their lungs, Laura says to start by speaking with your dental team and also your Occupational Therapist, who will probably have some good advice. She also suggests approaching with baby steps, but always consistently in those baby steps get across the message that this is not an option – we will take good care of your teeth and gums. As a last resort, she adds with a laugh, “get yourself some good earplugs and use their screaming as an opportunity to get in there easily with a brush if you can do it safely.” With these more challenging dental care patients, remember to have plenty of ‘snappy’ foods like apples and celery on hand, says Laura, indicating that sometimes eating these foods in addition to reducing sugary drinks, sticky candy and sugar can go a long way to preventing dental decay.

Emergencies Happen

If you’ve ever dealt with a true dental emergency (think trauma involving blood and/or pain), even the most caring and comforting relationship with your dentist can go straight out the window. If you find yourself in this situation, Laura’s best advice is to “Just get through it. In this situation you have to take the dentist’s lead and work as a team. The dentist you have chosen to work with should have the right processes and tools in place to help in a safe way.”

For Adults with Down Syndrome

In a *group home environment*, care can be hit or miss. Ask questions of the care facility to understand what dental care practices consist of, ensure supplies are kept in a safe and clean area, and replaced as needed. And of course maintain regularly scheduled appointments with dental professionals for checkups.

It is important to recognize that *it’s never too late to start a regular dental routine* with a loved one. If you find yourself in a circumstance where you are suddenly caring for an adult with Down syndrome who may not have been diligent with their dental practices, start one as soon as you can. Keep in mind the importance of accessing health records and sharing medical history with dental professionals. If no records are available a baseline may be required.

Don’t be surprised if your dental provider asks very detailed questions and there is a lot of *paperwork to complete*. Heart defects, antibiotics, sleep apnea, and a long list of other topics may come up. This is a sign that you have come to the right dental office, and it is your responsibility to give full disclosure on the patient to ensure proper, safe care.

The Flipside of the Chair: Advice for Professionals

As Laura puts it, “the best care, be it for an adult or a child with Down syndrome, starts with how you as the professional *manage the environment* and the client’s fears. Be proactive with the client, tell them what you are doing before you do it, what instruments are used for, what they will see, feel, and hear.”

More tips LaChance offers dental professionals:

Always have at the ready the small, cheerfully coloured *tooth ‘piks,’* for kids to floss with. This can also (bonus!) help develop fine motor skills. Laura’s son Kevin, now 27, mastered this skill at age three after a quick introduction and lesson, and the desire to mimic his three siblings.

Keep in mind that children and some adults with intellectual disabilities *may require more than one visit to become comfortable*. This is a good discussion to have with your entire office team; start by simply sharing this article and the associated links.

Generally speaking, children and some adults with Down syndrome like to mimic what others do, so when young people visit with caregivers, *interact at every opportunity*. Condition them to dental care and to you. Ask to count their teeth while

Looking for the right dentist?

If you are connected to a local Down syndrome or disability group in your area either in person or online, ask around! A personal recommendation to a friendly office from someone who’s ‘been there’ is often worth its weight in gold.

Sometimes provincial support programs will cover basic dental services. Talk to providers in advance to make sure their fees are a good fit with whatever coverage you have so you aren’t surprised with fees you will be personally accountable for. If you are under a provincial plan, make sure the provider accepts that form of coverage.





they hold a mirror, ask them to smile and if they want to watch you 'take care' of their parents' or even older siblings' teeth. Keep in mind this concept will likely backfire if your procedure is intense or pain is involved. You will also want to keep this in mind if there happens to be another child screaming in the next room... keep your pulse on the office happenings as best you can.

Be prepared for a wide variety of concerns: Some people with Down syndrome have sensory issues, and may be hypersensitive to power toothbrushes for example. Having Down syndrome often also involves having unique facial features. But similarly to the rest of the population, all faces are different in size and shape. Some will have smaller jaws, and tongues may appear larger due to smaller mid-face features present in people with Down syndrome. Some patients with Down syndrome may have trouble breathing while lying down flat. Educate yourself and staff on these topics.

Special Circumstances

Sedation: Sometimes, if a required tooth repair will take a long time while lying very still with local anesthetic, the dentist may recommend various types of sedation. Be sure to discuss any questions that you may have, share medical history and any diagnosed health issues for the patient with the dentist in charge.

Specialists: A visit to the orthodontist may be recommended as many children with Down syndrome have missing permanent teeth, an unusual eruption sequence, or sometimes teeth growing in out of line. In these cases the bigger and longer term plan needs consideration. Discuss what options there are now, what's reasonable for long term management of the situation and lifelong dental health. Perhaps procedures and devices are not started now,

and together you decide to let nature take its course and follow up in six months to a year.

X-Rays: These are of course often advised by professionals to obtain a clearer picture of potential future developments and to plan ahead where necessary. X-rays are a part of routine, standard care. If the patient is very resistant to x-rays, speak with your dentist to come up with a plan.

Being proactive and having a positive attitude when it comes to dental health is key. We hope the ideas outlined here will help you put the right strategies in place for your loved ones, resulting in a positive impact not only on their oral health, but overall quality of life.



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Our Paperless Efforts

With much of the world 'going digital' in the midst of the COVID-19 crisis, CDSS is asking our community to join this movement.



There are many benefits to switching to paperless, including:

- As a non-for-profit CDSS will save on printing and mailing costs, putting those savings towards resources and other critical administrative projects.
- Donors and supporters will receive their receipts and other mailed resources faster.
- It goes without saying that the reduction of paper usage will have a positive impact on Mother Nature.



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This interview is adapted from Dr. Brian Chicoine's April 29, 2020 appearance on The LowDown: A Down Syndrome Podcast, produced by the Down Syndrome Resource Foundation. Dr. Chicoine, Medical Director at the Adult Down Syndrome Center just outside Chicago, has provided medical care for adults with developmental disabilities for more than 30 years and has written extensively on caring for adults with Down syndrome. In addition to his duties at the Adult Down Syndrome Center, Dr. Chicoine serves as a faculty member at the Family Medicine Residency Program at Advocate Lutheran General Hospital.

Our interview with Dr. Chicoine touched on several topics related to optimizing the physical and mental health of adults with Down syndrome. In this lightly edited excerpt, we delve into issues surrounding mental health, aging, dementia and Alzheimer's.

3.21: Dr. Chicoine, can you tell us a little bit more about yourself and your professional journey?

Dr. Chicoine: I'm a family physician by training. I trained here at The Advocate Lutheran General, and then I practiced in a small town in the northwest corner of Illinois. Two 16-bed residential facilities for people with intellectual disabilities, including several people with Down syndrome, opened while I was there, and I became their Medical Director.

When I came back to join the faculty here at the hospital, a local parent group came to the hospital asking us to start a clinic for adults with Down syndrome. I had the most experience, having worked with those 32 people in the residential facilities. So, I eagerly grabbed that opportunity and we started two mornings a month, but it has become a full-time operation. We now have two physicians and a nurse practitioner, and we have seen over 6,000 adolescents and adults with Down syndrome since we opened in 1992. We have about 7,000 patient encounters a year. It is a busy place!

3.21: Through these experiences, you have become one of the world's leading experts on medical issues for individuals with Down syndrome, and particularly adults with Down syndrome. What is it about this population that made you want to specialize in it?

Dr. Chicoine: It's just a wonderful group of people, which makes the day a lot of fun. The thing that has been so interesting is that life expectancy for people with Down syndrome, when I graduated from medical school, was less than 30. Now it's about 60. It has been a very interesting opportunity to participate in helping a population double their life expectancy in the course of my career. I don't know how many providers have the opportunity to participate in such an incredible change in a relatively short period of time for the patients they serve.



An Interview with Dr. Brian Chicoine

Mental Health and Aging

3.21: One area that has been receiving increased attention is mental health care for adults with Down syndrome and other disabilities. Why do you think this area has been neglected for so long?

Dr. Chicoine: Well, I think probably for two reasons. Firstly, I think I think it has been undertreated and underappreciated in all of us across the board. People with Down syndrome then just sort of get lumped into that lack of treatment, if you will, that so many people have experienced over the years.

The second is more specific for people with Down syndrome. I think there is a lack of understanding. One thing that is very different is that, because of communication obstacles, physical health problems and pain that someone cannot express verbally end up being displayed in a behavioural or mental health fashion. If you don't appreciate that and just sort of treat it as a behavioural or mental health issue without going back to evaluate for the underlying physical health issue, you're not only going to miss a lot of things, which is unfortunate, but you're also much less likely to have success in treating the mental health or behavioural issues. If someone is having pain from something that is causing them to have a behavioural change, and you just treat the behavioural change without addressing the underlying painful issue, you're not likely to be successful.

3.21: We have seen this with some our adults where they tend to internalize that feeling of depression or anxiety. Outwardly it seems like they are functioning fine, but it is just all so internalized, and they have no way of really expressing what they are feeling.

Dr. Chicoine: I would agree. Our sense is, even those folks that have good verbal skills may have difficulty verbalizing mental health stress. Actually, in some ways, it's the people with good verbal skills that get in the most trouble, because we anticipate that they would be able to tell us if something is wrong, but they're actually not able to do so because they don't have the language for it. So, they get overlooked.

3.21: What should a parent or family member to do if they are noticing something that they think is a mental health related change?

Dr. Chicoine: First and most important, take your son or daughter to your primary care physician and have them checked for the medical issues. It is important to particularly consider the health issues that are more common in people with Down syndrome. These include things like thyroid problems, sleep apnea, celiac disease and more. These issues affect how people feel physically, which ultimately can affect how they feel mentally as well, or how they display mentally. It's helpful to have a provider that has some experience with people with Down syndrome, to make sure that we're looking at those underlying issues and not just treating the mental health piece, but also addressing physical problems as well.

Second, you want to look at what is going on around the person, socially and environmentally, that may have a detrimental impact upon mental health. I suspect that, perhaps because of their very strong memories, people with Down syndrome may be a little more susceptible to some post-traumatic stress issues because they have such strong visual memories of things that have happened. But the problem is, we often do not understand what the trauma was. We tend to think of PTSD as being tied to things like war or a horrific car accident. But trauma is really in the eye of the beholder. So, what I

may think is stressful, you may not and what you do, I may not – and that is true for individuals with Down syndrome as well. So, we want to see if it could be something in school, or something at work.

We also need to consider sensory issues. For a long time, we thought of sensory issues as something you either had or did not have. In reality, it's probably a bell curve like most things in life. Most of us are somewhere in the middle, and people with Down syndrome can be in the middle or at one end or the other. And I think there are some sensory issues that do contribute to some of the behavioural changes. There are some sensory strategies that would benefit people even if they don't have extreme sensory issues, just to help them relax and get through tough situations.

3.21: As adults with Down syndrome move into their forties and beyond, we unfortunately continue to see a high incidence of early onset Alzheimer's and dementia. What can families do when their loved one with Down syndrome is younger in order to try to prevent this or at least slow down the onset?

Dr. Chicoine: Unfortunately, we still have limited information on that. We know that for people with Down syndrome, as well as the general population, exercise is important in helping either prevent it or slow it down. There is some discussion about whether insulin resistance related to being overweight contributes to Alzheimer's disease. I don't think we have a final answer on that yet. But there are lots of good reasons to be physically active, eat healthy and try to stay at a good, healthy weight. If there's a possible benefit to reducing or preventing Alzheimer's disease, that's an added bonus.

There's a relationship between sleep apnea and Alzheimer's disease, so certainly we want to make sure people are getting tested for that condition. If you notice that a person's ability to function or mental health is changing, look at getting a sleep study.

3.21: At DSRF, we are telling parents that their kids need to get tested at a young age because it can be very difficult to get compliance with the CPAP mask as they get older. Getting them accustomed to using the mask is tricky, so if you can start earlier it makes a big difference.

Dr. Chicoine: Absolutely. Also, I hear a lot of concern that “this person could never comply with a study or use a CPAP.” I would encourage people not to give up until it has been tried, because we do have a lot of people where we think “this will never happen,” and then they do it.

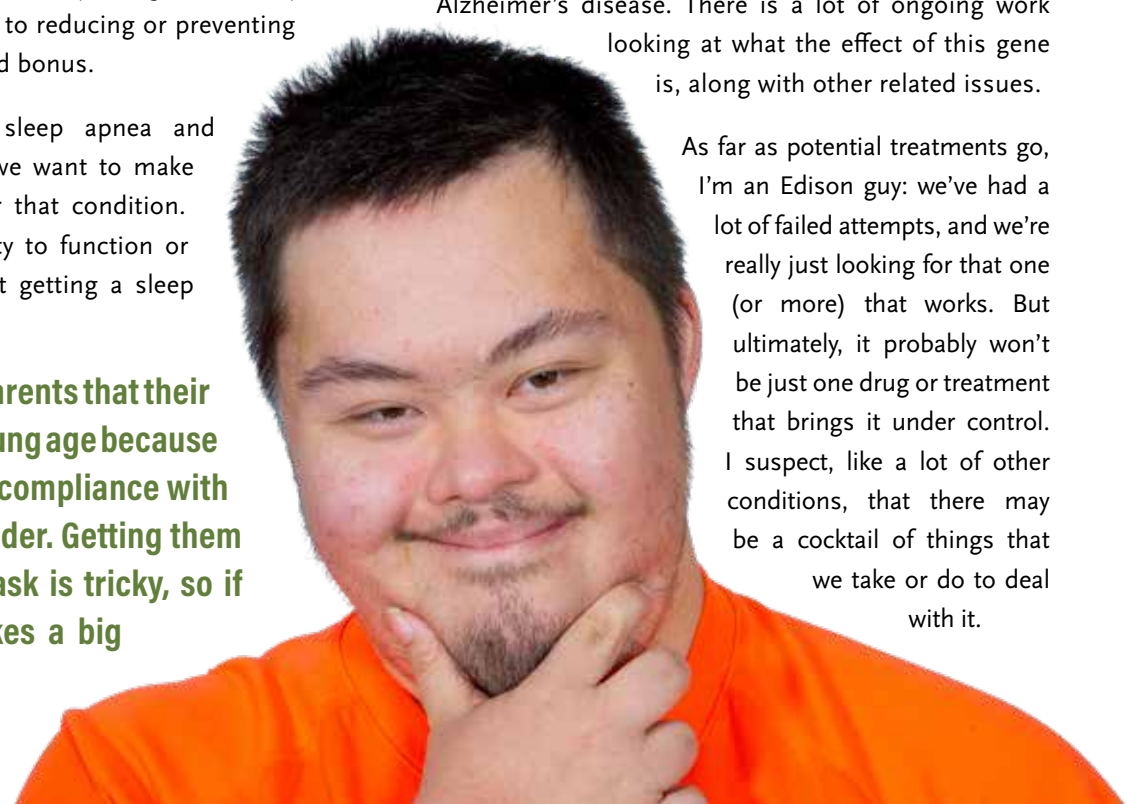
3.21: In our experience, almost all our clients who get referred for a polysomnogram end up getting diagnosed with sleep apnea – and often quite severe.

Dr. Chicoine: It's not known to be 100% among people with Down syndrome, but it's pretty high. And it is not always connected to weight problems. Certainly, obesity increases your chance of developing it, but a lot of folks with Down syndrome who are a good, normal weight still have sleep apnea.

3.21: From time to time, we read exciting reports of research around dementia. Can you tell us what progress is being made in identifying why so many people with Down syndrome develop dementia relatively early and some of the efforts that are being made to address this issue?

Dr. Chicoine: We do see that Alzheimer's disease does occur at a younger age and more frequently in people with Down syndrome. The APP gene is on chromosome 21, and it is thought that because people with Down syndrome have three copies of chromosome 21, there is more of this gene expression. This seems to contribute earlier and more frequent Alzheimer's disease. There is a lot of ongoing work looking at what the effect of this gene is, along with other related issues.

As far as potential treatments go, I'm an Edison guy: we've had a lot of failed attempts, and we're really just looking for that one (or more) that works. But ultimately, it probably won't be just one drug or treatment that brings it under control. I suspect, like a lot of other conditions, that there may be a cocktail of things that we take or do to deal with it.





The LowDOWN: A Down Syndrome Podcast brings a professional perspective on issues facing individuals with Down syndrome and their loved ones. Hosts Marla Folden and Hina Mahmood of the Down Syndrome Resource Foundation welcome North America's leading Down syndrome experts, parents and self-advocates to cover topics from across the lifespan including health, physical and intellectual development, advocacy, employment and much more.

Season One Episodes

1. Dr. Susan Fawcett, M.Sc. RSLP: Learning and Development in Individuals with Down Syndrome
2. Sue Robins, Author: Advocacy and Ableism
3. Dr. Brian Chicoine: Optimizing Physical and Mental Health for Adults with Down Syndrome
4. Hina Mahmood, M.OT.: An Introduction to Occupational Therapy
5. Sam Leach, LSS Teacher: Thriving in Elementary School
6. Jillian Baldwin, M.Sc. RSLP: Early and Higher Level Communication Skills
7. Mark Wafer, Disability Rights Activist: Why Hiring Individuals with Down Syndrome is Good for Business

DSRF.org/podcast

These guys know Down syndrome! I am really impressed with how knowledgeable the hosts and guests are about the unique world of Down syndrome. It's clear they have a special understanding and connection to DS and love what they do. Lots of wonderful nuggets of information in this episode alone. Looking forward to listening to each episode. So glad I found this podcast!

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When I was in medical school, we first started to hear about AIDS and HIV, and at that time it was a terminal illness right from the beginning. Now it is treated very much like a chronic disease, almost like you would treat hypertension or high blood pressure. There is a cocktail of medications and healthy activities that patients can take or do to address it. My hope is that we will see something similar where people with Down syndrome or Alzheimer's in general may be able to take something and do things to manage it. Or it may be something that can be taken or done at a young age to prevent it from becoming a problem, perhaps in the twenties to forties when the brain is beginning to develop these plaques and tangles. There could be medications that people take at that time to kind of clear that out, if you will.

Some people think that with regards to the ultimate cure for Alzheimer's, or the control of Alzheimer's disease, some significant breakthroughs will come through studying people with Down syndrome. Some researchers are studying Alzheimer's disease in people with Down syndrome for the benefit of the general population, and, to me, that is okay. Ultimately, people with Down syndrome are going to be well served by this.

3.21: Is there a relationship between the buildup of plaques and tangles in the brain and sleep quality?

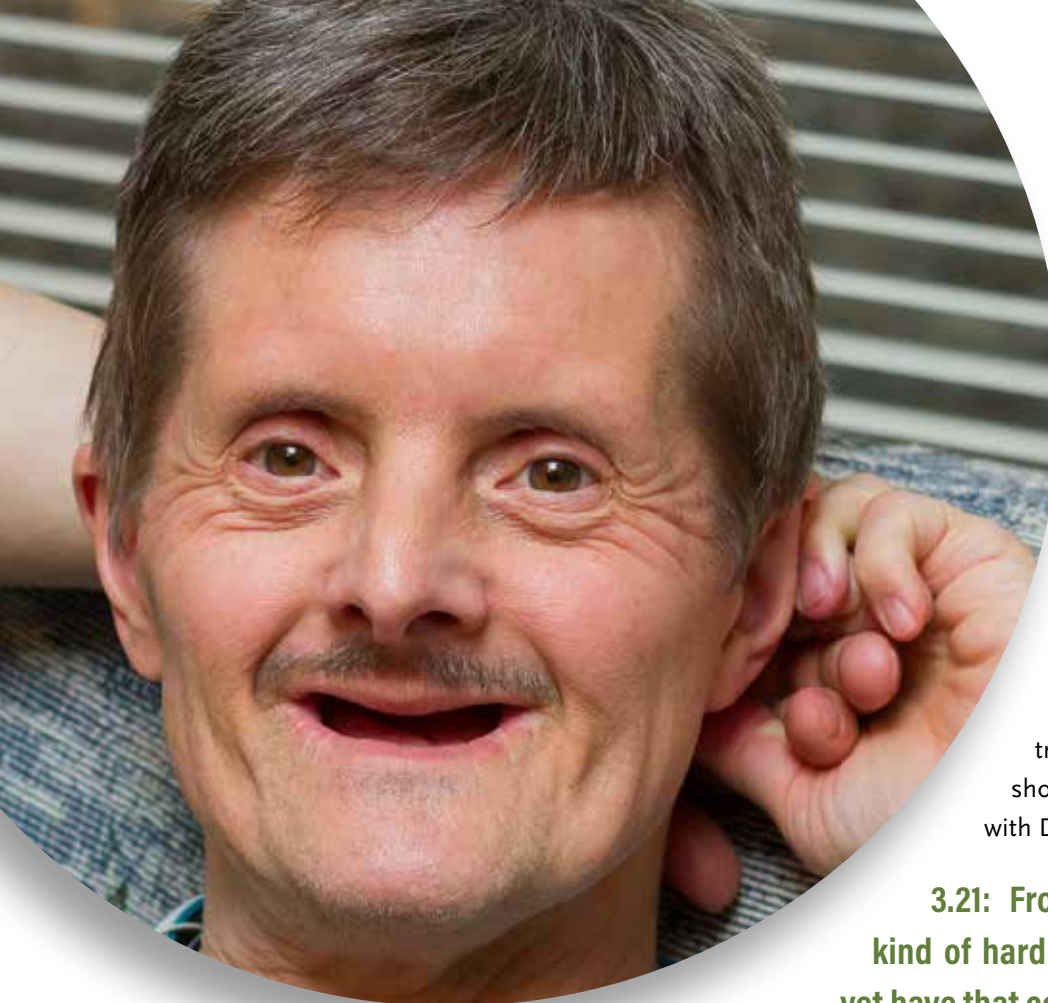
Dr. Chicoine: This has not yet been definitively proven, but it does seem there may be a link. The chronic oxygen deprivation or low oxygen levels that are seen in people with sleep apnea certainly could be a contributor. Our brains need to have a regular eight-hour sleep cycle with REM sleep and non-REM sleep. And if we don't have that, our brain does not get the restoration that it needs. Ultimately, good sleep is like healthy eating and exercise: there are many good things that come from good sleep. If it happens to be that it also helps prevent Alzheimer's, that is an extra plus.

3.21: We can start to see some of these symptoms of early onset Alzheimer's and dementia in adults with Down syndrome when they are in their thirties and forties, and this population does age at an accelerated rate. Could you explain why these symptoms come on so early for them?



Recommended Reading:

A Guide to Aging with Down Syndrome (CDSS; available in English and French)



Dr. Chicoine: The onset of symptoms before 40 is actually thought to be fairly uncommon. The youngest person we have diagnosed with Alzheimer's was 38. The average age of onset of symptoms is about 54, and it is often later than that. But the thing with Alzheimer's disease is that the changes in the brain start occurring long before the symptoms present themselves. Some studies have found people with Down syndrome, even in their twenties and certainly in their thirties, who already have some of the changes in the brain. That is not unique to Down syndrome; all people can have the changes in the brain long before they actually begin exhibiting the symptoms. But the timeline is shifted to younger ages in people with Down syndrome.

3.21: In recent years, life expectancy for individuals with Down syndrome has increased dramatically. What needs to happen to continue this trend – and not just to help people live longer, but live longer with good health and a good quality of life?

Dr. Chicoine: I had a great uncle that had Down syndrome. He was born in 1907 and he lived to be about 40, which was very unusual in those days. His life expectancy when he was born was only nine. When I graduated from medical school in 1984, life expectancy was about 28. Now it is about 60. That is a dramatic change. If the rest of us had increased by the same percentage, we would all be living to be about 350.

Unfortunately, it does seem to be plateauing around 60 at this point, and Alzheimer's disease is the big issue that is causing that. So, the next big step is to figure out how can we prevent and treat Alzheimer's disease successfully. That should have a significant benefit for people with Down syndrome.

3.21: From a parent's perspective, that's kind of hard news to hear, because we do not yet have that cocktail of drugs that would help see adults through it. But in terms of what is within the control of individuals with Down syndrome and their families, it sounds like just the regular preventative health measures that all adults, with Down syndrome or not, should be doing: exercising, eating well and sleeping well. Is that really all that families can control?

Dr. Chicoine: I think at this point, those are the things that we know. The other thing I would encourage people to consider is participating in a research study. There are more and more of these studies being done around the world, including Canada. I would consider participating in a study because the more we can learn about this, the better chance we have of preventing and treating it.

For years, I looked at it like, this is a whole chromosome. This is going to be such a such a huge problem to try to fix an entire chromosome. But now researchers have narrowed it down to certain likely genes; maybe it is multiple genes, but it's no longer the whole chromosome. It is certainly not going to be easy, but we're getting closer.

Support CDSS Today

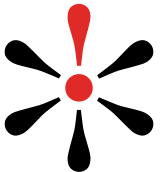
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Your donations provide life stage resources to new and expectant parents, medical professionals, teachers and families. You also support important work in areas such as human rights, health, social programs, inclusive education and employment, and help to strengthen the voice of all Canadians with Down syndrome in Federal and Provincial Government matters.

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All Through The Night

A Family Sleep Story

by Christie Hoos

In 1949 the Geneva Convention condemned sleep deprivation as a cruel and illegal form of torture. Right up there with waterboarding and starvation, it will cause all sorts of physical and mental damage. And crankiness... so much crankiness.

My oldest daughter settled into a sleep schedule with the greatest of ease. By six weeks she was sleeping through the night. Naturally, I chalked it up to superior parenting skills on my part, smug in the way only a first-time parent with an easy baby can be. I had Opinions. Theories and Opinions and a list of the Best Books to be read on the topic.

When her sister came along two years later, she put a dent in my confidence. She refused to sleep in her crib. At all. Or in the bed beside me - something we swore we'd never do, but in our exhaustion resorted to trying. The only place she would fall asleep, and stay asleep, was in her infant car seat. We used to strap her in and swing her back and forth through the air with all our might. If the Olympics had added an infant tossing event, we would have been serious contenders. By eight months old, we were putting her car seat into her crib each night, and eventually she began to sleep like a normal baby. And not a moment too soon, as the child we had affectionately dubbed “Buddha Baby” was far too chubby to swing through the air anymore. My strong-willed second child took all the air out of my smug.

But it was our third daughter who really taught me the meaning of exhaustion. Not right away; in fact, our initial trouble with her was excessive sleepiness. It wasn't Becca's diagnosis of Down syndrome, but persistent jaundice that kept her in the special care nursery those first three weeks. She just couldn't wake up long enough to eat. Breastfeeding was not happening either, because she lacked the strength. Each mealtime would begin with us stripping her down to her diaper and callously wiping her with a cold cloth... poor little peanut. And still she would drift off after only a few ounces. We had to add a booster supplement to her breast milk just to help her gain weight.

The next three years were a constant struggle to get her to consume enough calories to thrive. But she was adorable, easygoing and slept more than any of my other kids. It wasn't until Grade two that she was able to make it through an entire school day; until then, I picked her up early each day for her afternoon nap.

Most children are finished with their afternoon nap by age two or three,

so our pediatrician suspected that her quality of sleep might not be adequate. Sleep apnea is a very common problem for children with Down syndrome, due to a crowded upper airway. The treatment is removal of tonsils and/or adenoids, and if that doesn't work, the use of a CPAP machine. We were referred for a sleep study to get to the bottom of it.

The polysomnographic (PSG) evaluation started with a questionnaire and examination by a respiratory doctor, and then a few weeks later Becca and I trekked out to Children's Hospital for the night. By now, my easygoing baby had grown into a feisty preschooler, and she had absolutely no intention of cooperating with the strange lady in blue hospital scrubs. Despite the comforting presence of her very own pillow and her favourite tattered teddy, this was NOT her room and NOT her bed, and putting stickers on her arms, legs and head was NOT her idea of a good time. In the end we waited until she had fallen asleep to put the band around her chest and stick the sensors on with a thick putty. Several times she woke up and pulled them off, and we'd wait until she fell back asleep to put them on again. She eventually slept for a long enough stretch to get the results we needed.

Our next appointment was an extended Q&A session with our charming sleep specialist. Dr. Ipsiroglu is one of those rare professionals that seems unrushed, like he has all the time in the world to get to know his little patient and figure her out. The sleep study results showed no sign of apnea, but clearly something was going on. It turns out that Becca, myself and both of her sisters have a hereditary form of Restless Legs Syndrome (Willis-Ekbom Disease). The brain creates a sense of discomfort when legs are kept still, making it hard to fall and/or stay asleep. The doctor prescribed an iron supplement, as well as plenty of exercise and fresh air.

At this point we'd filled out checklists, sleep logs, and answered so many probing questions about our bedtime routines that I felt like a bug under a microscope. A diagnosis felt like a gift. A really crappy gift that I'd love to return, but at least it explained our ever-sleepy Becca, not to mention my own insomniac tendencies. And we were finally done with it. Or so I thought.

Fast forward about a decade - through the nightmares of childhood cancer, leg surgery, and puberty. Becca had a rough few years, to say the least. We added an autism diagnosis to her list, which has helped us understand her and her behaviour much better. Her cancer is in remission, her legs are straightened out, and she's settled firmly into adolescence. But her sleep is worse than ever.

On a good night she's up at least three or four times; on a bad night it can be six or more. Lack of quality sleep affects emotional stability, the ability to learn and remember, fine and gross motor skills, alertness, immunity to illness, and can even cause premature aging. Which is why I feel about 87-years-old most days.

Some nights she comes into our room, puts her nose a millimetre away from mine and stares silently until I wake up. It's as creepy as it sounds. She's been known to cover her dad's mouth and nose until he wakes up gasping for air. Other nights she employs the poke-and-whine method: Mom-Mom-Mom-Mom-Mom-MOOOOOOOOOMMMMM! If we lock our door, or hers, she'll pound on it and throw her body at it and scream until everyone in the family (and likely in our townhouse complex) is thoroughly awake. And, since it's the question we get most often, she can keep it up for hours. The word in the autism community is “perseveration,” and it's her super-power: she is obsessively persistent.

Instead, we clamber dead-eyed out of bed and run through her going-back-to-bed routine over and over again. “It's bedtime, time to go back to sleep.” We tuck her in, sing her a lullaby, and promise to tell her little brother that he's not allowed in her room. No, she can't have another drink of milk until morning and yes, she has school tomorrow, and goodnight.

“GOODNIGHT. Yes, I love you. For Pete's sake, just go to sleep!” Rinse and repeat until she's quiet. I take the first shift, until 3 a.m.; Dad has 3 a.m. on. She's up for the day by 5 a.m.

She loves to wander the house at night. Strange things are done for midnight fun in our house. One night we woke up to the sound of giggling, only to find Becca and her little brother, TV blaring at full volume, stripped down to their pull-ups, soup spoons in hand, preparing to share a bowl full of Flintstones vitamins. Childproof does not equal Becca-proof, as we have learned after many rounds of child locks and high cupboards and hiding treats.

It's not all naked drug parties, either. Her signature move is to eat an entire carton of ice cream, leaving the empty box in the freezer with only a spoon at the bottom, as if to taunt us. Since she's lactose intolerant and not toilet-trained, the consequences of this binge are usually... quite... unpleasant.

Remote controls often go missing, as do school supplies, toys, charging cords and occasionally a shoe. She likes to hide things, then forgets where she put them. Our heating vents were stuffed full of small items she managed to fit through the holes. When she figured out the deadbolt on the front door, she took it upon herself to trot down the block in her nightgown and fill the mailbox with “letters” – mom yelling behind her.

The scariest moment thus far has been the night she stuffed her brother's pictures and school papers into the oven (I'm not sure what he'd done to annoy her). She pushed some buttons and managed to turn the oven light on. I still have visions of a house fire if she had hit “bake” instead.



Safety is our biggest concern. It overrides all normal parental boundaries, something typical parents often find shocking. But our little Houdini is a problem solver, so our systems are constantly evolving. We had rigged up a sleep tent to keep her safely in bed at one point (with liberal use of sewing supplies, superglue, and safety pins), but she hid my nail scissors under her pillow and cut it to shreds. At this point we have an extra high baby gate installed at the top of the stairs, reinforced by 2x2s and locked with a combination bike lock each night. This way she has access to the bathroom and our room, but nothing that can cause irreparable harm.

My husband can't resist posting the latest hilarious Becca escapade on Facebook, and we do laugh – so much. But it's not really that funny in the middle of the night, or the next day when we have to pull over to take a nap while doing school drop-offs, lest we fall asleep at the wheel. Nor is it good for her, for us, or the rest of the family. Year upon year of sleep deprivation takes a toll behaviourally, cognitively and health-wise – for all of us.

I could write a book on everything we've learned about proper sleep hygiene (that's what the fancy professionals call bedtime habits). Fresh air and exercise during the day, then a consistent routine of calming activities before a set bedtime in a quiet, cool, dark room. The longer we struggle in this area, the more convinced I am that it is a crucial need. When sleep improves, everything improves – it is more powerful than all the other therapeutic, educational and medical interventions we have access to.

We have tried All. The. Things. We have seen doctors and psychiatrists and behavioural consultants and sleep specialists. We have done another round of sleep studies and appointments and tried a long list of drugs. We have tried suggestions from family and friends and social media and strangers. Most recently, we have ordered a very expensive Safety Sleeper Tent especially designed for youth with autism, thanks to an extremely generous family member.

I wish I could say we found a magic cure for sleep issues: that one special technique that made all the difference. But life is not that simple, especially for those of us who have children with developmental disabilities. Some days are pure survival mode, and I've stopped beating myself up about that. Because that's all I've got in me. Over the years, we've found a hundred little things that work for us, or work for a little while at least, and we just keep on trying.

That's all good parenting is, in the end: loving our kids and trying our best.

Recommendations:

Sleep Better: A Guide to Improving Sleep for
Children with Special Needs
by V. Mark Durand

Abram's Nation Safety Sleeper
(<https://www.abramsnation.com/>)

Canada's
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Home Sweet Home

PLANNING YOUR SUMMER STAYCATION

by Adelle Purdham

As a family who travelled the world together, we had further big travel plans this summer. The Yukon! The wild open expanse of the Yukon and the 2,000 km car ride there from Calgary, Alberta, starting with dinosaur bones in Drumheller and then making our way up through the Rockies and ending with a ferry ride to Juneau, Alaska for sightseeing and whale watching. Sounds like a grand adventure for a family of five, doesn't it?

As with the rest of the world, we have put our travel plans on hold, but that doesn't mean the fun has to end; it does not mean we have to lay our curious and adventurous spirits to rest. Perhaps we will dig up homemade dinosaur bones in our own sandbox? Or watch documentaries on whales and gain an appreciation for the issues threatening their extinction? There are a multitude of interesting ideas and means of exploration at our fingertips and in the vicinity of our own homes. First, let's take a look at outside activities close to home.

Outside Activities Close to Home:

Get active – If parks, beaches and pool facilities are open for summer, then dive right in; otherwise find a vacant green space or step into your backyard and pull out your sports equipment. Hula hoops (often available at dollar stores), a lightweight bouncy ball, or a soccer ball can provide hours of family entertainment. Kicking and passing a ball is great for improving gross motor skills, strength, balance and coordination. Turn physical activity into a game, with classic games such as Monkey-in-the-Middle (rotate after several tries), What Time is it Mister Wolf?, Tag and Hide-and-go-Seek. Set up simple obstacle courses for kids to enjoy or a scavenger hunt that gets kids reading clues (you can also use picture clues), problem solving, and running all around your property, or a nearby park or field.

Go for a walk – Take a stroll around the block. Younger kids will love to pull a wagon or push-toy, or even try a scooter. Pass through a forest to gain all the health benefits of trees, including boosting the immune system, reducing stress, improving mood, and increasing one's ability to focus. Collect what Mother Nature has discarded and use your findings to make nature crafts at home, such as pinecone animals, leaf pictures or stick people. And don't forget an icy treat to cool off after your warm-weather outing! Try a homemade popsicle recipe or make fresh lemonade.



Garden together – Whether it's an ambitious project such as a large outdoor vegetable garden, or something simple like repotting a flower outside, get little hands to work the soil. Afterwards, kids love to water the plants. Plants such as beans and tomatoes produce a good yield if given lots of water and sunlight and kids will rejoice at the opportunity to pick fresh produce. If you live in an apartment, why not start an indoor windowsill garden with herbs you can later use in your cooking? Think fresh basil in spaghetti sauce – yum! You can also learn more about where your food comes from by visiting a local farm, berry picking in June, and sampling fruits and vegetables on a trip to your local farmers market.

Make music – A classic Canadian rite of passage is sitting around a campfire toasting marshmallows and making s'mores while someone pulls out a guitar. If you have a guitarist in your family – great! – get singing. For the rest of us, pull up a playlist, lay out a blanket and sit under the stars for an evening concert in your own backyard. To formally teach your children music, consider an online teacher while social distancing remains in effect. Our daughter's piano lessons continue virtually, and that half hour becomes a family music moment, much to everyone's delight.

In-Home Activities:

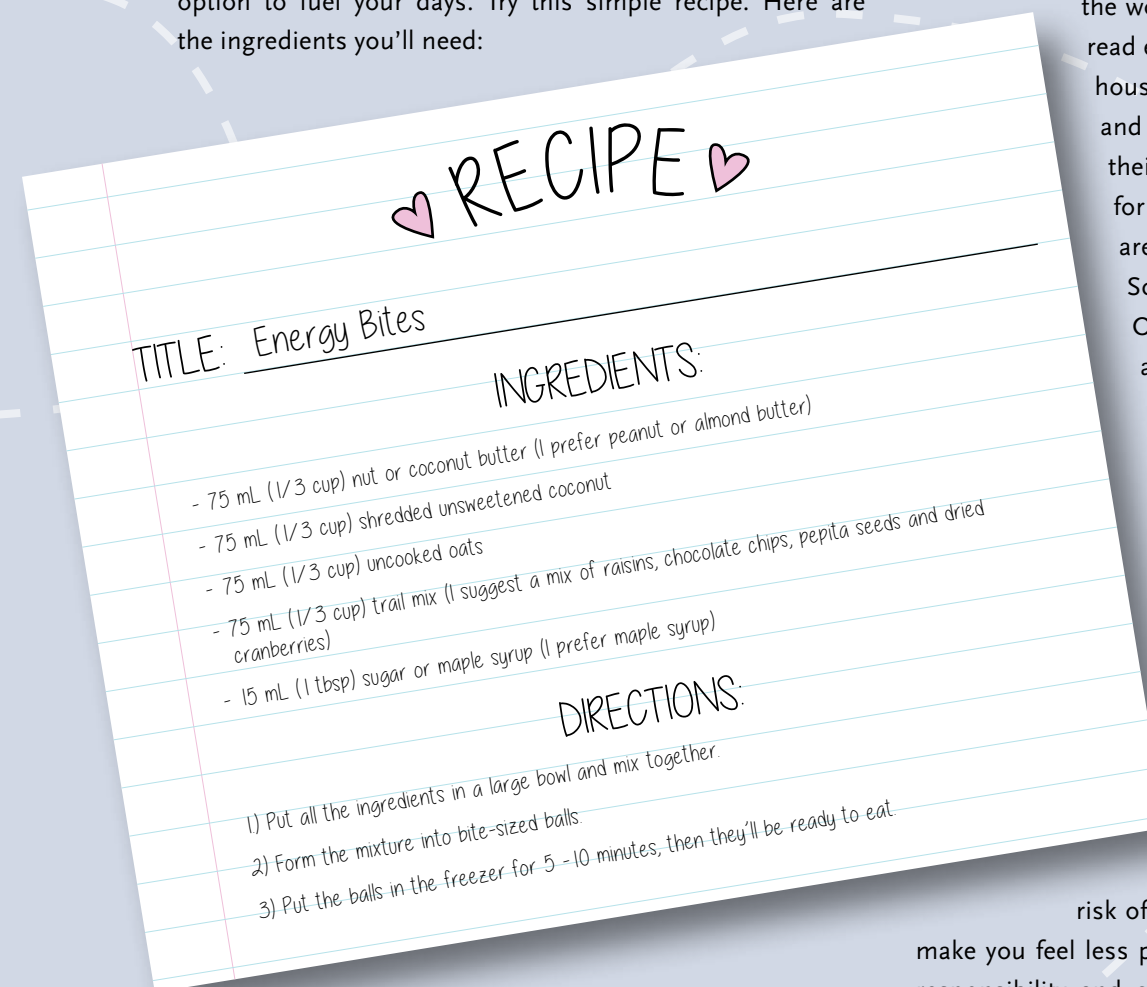
Dance to the music – Create a special playlist of your child's preferred music and throw a family dance party. This activity is an all-time favourite in our house.

Board games – Pretend you're at a cottage on a rainy day and pull out your favourite board games. Hungry Hippos, Checkers, Candyland, Trouble, Twister and card games such as Old Maid, Uno, Go Fish and Crazy 8's are all great for beginners and help develop social skills such as turn-taking, while fostering math skills such as counting and one-to-one correspondence. Kids old enough to spell may enjoy Boggle, Scrabble or Bananagrams. Most importantly, these games spell F-U-N.

Let there be art – Can't make it to the Guggenheim or the Louvre this summer? Many famous art galleries, museums and other tourist attractions are opening their doors for free digitally. Art doesn't need to be critically acclaimed or beautifully mounted to be worthwhile. Pull out a large roll of paper and create a scene with nothing more than a few crayons or markers. Reuse a large cardboard box by turning it into a storefront or puppet theatre. Grab some chalk and draw hopscotch or make a life-size version of Snakes and Ladders on your driveway. Pick an art project that's good for the environment, such as making a pinecone bird feeder. Appeal to the senses with homemade playdough, goop or magic sand. The messier, the better! And let there be drama: pick a topic to act out, such as animals, then go wild over charades as a family.

Bake it until you make it – Preparing a simple recipe such as oatmeal chocolate chip cookies teaches kids about fractions and measurement, as well as accomplishes the task of getting food on the table – or at least dessert! Pretend you are at a fancy restaurant and create a set menu the kids can help cook. Get dressed up and enjoy a candlelit meal at home.

Energy bites are a tasty, kid-friendly, no-bake healthy snack option to fuel your days. Try this simple recipe. Here are the ingredients you'll need:



Build a fort – Encourage your kids to pull the cushions off the couch and create an awesome reading nook or a castle fit for a queen. This might be a good time to vacuum under the couch, and who knows, maybe you'll find hidden treasure!

DIY and hands-on skills – As a kid, I once spent an entire week-long beach vacation sitting inside a cottage making bracelets – I was hooked! Never underestimate the value of teaching a new skill like bracelet-making or braiding hair; even simple household tasks like sweeping, doing the dishes, laundry, swiffering, windexing or vacuuming are enthralling to children who like to imitate their parents. Kids love hammering in a nail, so pull out those DIY projects and get the kids involved. Pretty soon, with your little helper, you might actually be able to kick your feet up and feel like you're on vacation.



Read together every day – Whether travelling the world or in our daily life, we make sure to read every day. After lunch is quiet time in our house, a chance for our kids to slow down and read and quietly or look at stories in their room. E-Books are available to borrow for free from your local library and/or there are some great resources online such as Scholastic Learn-at-home and Storyline Online. With a book in hand you can travel anywhere without leaving your room.

Consider getting a pet – Since you're going to be around anyway, you might consider getting a pet, which are associated with some major health benefits. According to the Centre for Disease Control (CDC), "Studies have shown that the bond between people and their pets can increase fitness, lower stress, and bring happiness to their owners." Dog owners, in particular, reportedly make more friends while decreasing their

risk of obesity and heart attack. Pets can even make you feel less pain and they can help teach kids about responsibility and compassion. Do your homework – they will be your newest family member, after all – and consider adopting a pet in need. *Meet our new pup, Louie, a vizsla, pictured on the next page.*

Useful Links for SUMMER STAYCATION ACTIVITIES

Make Your Own Dinosaur Fossil Dig Kit:

<https://parentingchaos.com/make-your-own-dinosaur-fossil-dig-kit/>

29 Incredible Nature Documentaries for Kids:

<https://kidworldcitizen.org/incredible-nature-documentaries-kids/>

22 Fun Scavenger Hunt Ideas to Keep Your Kids Guessing:

<https://www.goodhousekeeping.com/life/parenting/g32050844/scavenger-hunt-ideas-for-kids/>

Immerse Yourself in a Forest for Better Health:

<https://www.dec.ny.gov/lands/90720.html>

Easy Nature Crafts for Kids:

<https://www.redtedart.com/easy-nature-crafts-kids/>

Forty Popsicle Recipes that are Bound to Become Your Favourite Summer Snack:

<https://www.countryliving.com/food-drinks/g830/popsicle-recipes-0709/>

How to Plan and Plant a Garden for Kids:

<http://www.mykidsadventures.com/kids-gardening/>

How to Make a Play Dough Recipe Without Cream of Tartar:

<https://stayathomeeducator.com/absolutely-perfect-no-cook-scented-play-dough-recipe-without-cream-tartar/>

20 Virtual Field Trips to Take with Your Kids:

<https://adventuresinfamilyhood.com/20-virtual-field-trips-to-take-with-your-kids.html>

Scholastic Learn at Home:

<https://classroommagazines.scholastic.com/support/learnathome.html>

Storyline Online:

<https://www.storylineonline.net>

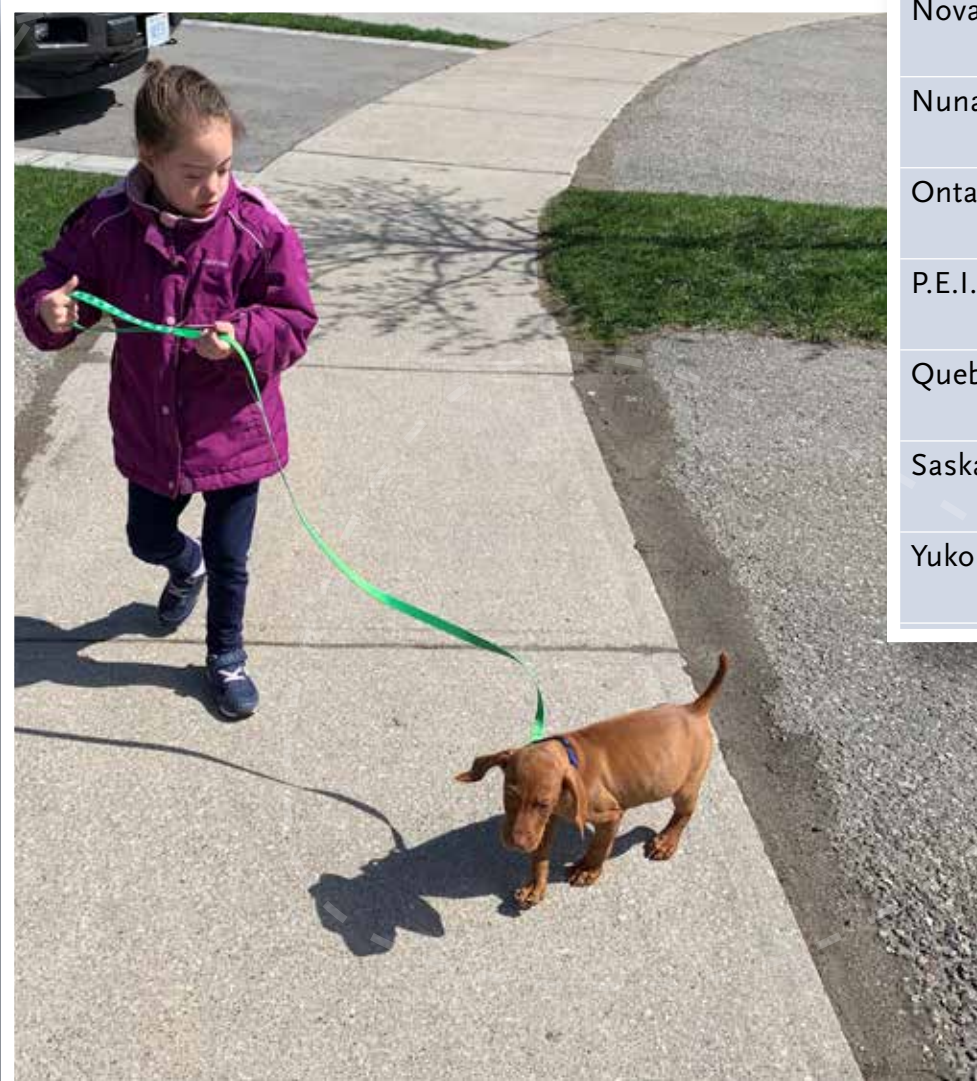
About Pets & People:

<https://www.cdc.gov/healthypets/health-benefits/index.html>

Self-Care for Parents:

Be sure to carve out some alone time for you and your partner after the kids go to bed, by ordering in your favourite meal or sharing a crossword puzzle. Find time to chat with friends over the phone or on Facetime, Zoom, Houseparty, Skype, WhatsApp? or your preferred platform. Kids can similarly stay connected with friends through Kids Messenger. When seeking out time for myself, I prefer to get up early and either write or work out. Make time for exercise and your creative outlet by either trading off with your spouse or making use of time when kids are engaged in an activity they can do independently, such as playing outside, looking at books, or playing games on a device. One couple I know parked their van in the scenic surroundings of the forest, then got into the backseat to snuggle and watch a movie for date night. Use your imagination!

The best vacation for me is one where I get to feel well-rested and relaxed, as well as engaged and stimulated. Find the right balance for you and your family by using the activities outlined above as your inspiration. Staying home may just become the next hottest destination – all the rage.



If social distancing rules relax enough to allow for short daytrips, consider an adventure close to home. Pack up a picnic and some hand sanitizer, and plan your 'escape for the day' through one of the PDF travel guides here:

PROVINCE	GUIDE NAME	LINK
Alberta	Travel Alberta	https://www.travelalberta.com/ca/
British Columbia	Travel British Columbia	https://www.hellobc.com/
Manitoba	Travel Manitoba	https://www.travelmanitoba.com/trip-essentials/visitor-guides/
New Brunswick	Travel New Brunswick	https://www.tourismnewbrunswick.ca/Help/ContactUs/
Newfoundland	Traveller's Guide - Newfoundland and Labrador	https://www.newfoundlandlabrador.com/trip-ideas/travellers-guide
Northwest Territories	Travel Northwest Territories	https://spectacularnwt.com/travel-info/order-guide
Nova Scotia	Doers and Dreamers Travel Guide	https://www.novascotia.com/travel-info/travel-guide
Nunavut	Travel Nunavut	https://www.travelnunavut.ca/
Ontario	Ontario Travel Guides	https://www.ontariotrail.net/en/plan/travel-guides
P.E.I.	Prince Edward Island Visitor's Guide	https://www.tourismpei.com/visitors-guide
Quebec	Tourisme-Centre-du-Quebec	https://www.tourismecentreduquebec.com/en/brochures.aspx
Saskatchewan	Tourism Saskatchewan	https://www.tourismsaskatchewan.com/about-saskatchewan/travel-guides-and-maps
Yukon	Travel Yukon	https://www.travelyukon.com/en/vacation-planner



DSRF CORNER

DSRF in the Time of COVID-19

Just as it has for every person, business and charitable organization in Canada, the COVID-19 crisis swiftly and completely changed the landscape for the Down Syndrome Resource Foundation. We take very seriously our obligation to protect the health and safety of our clients, families, volunteers and staff, and as such we were an early adopter of social distancing practices. Ultimately, on March 17, we closed our doors to the public and instructed all staff to work from home until further notice.

Within days, everything had changed for DSRF. We were fortunate in that the first two weeks of closure coincided with our scheduled spring break, giving us a couple weeks to envisage how we could continue to deliver our programs and services in the time of COVID. By the time spring break ended, we were ready to begin hosting our adult educational programs via videoconferencing. A week after that, we unveiled newly developed one on one teleservices, delivering both individualized therapy sessions and parental consultations to families in their homes – services that have been very gratefully embraced. One family confided that DSRF is “the most important element in their child’s life, even more so than school.” It’s a sentiment that seems to be shared by many of our clients.

Even as we pivoted our programs and services, our team also got to work developing a new resource: a “Learn At Home” section on our website (<http://DSRF.org/LearnAtHome>), where we post one or more home education exercises each day, including free downloadable materials so that parents can do it themselves. Our teachers and therapists have gotten very creative, filming demo videos for various skills. These posts have caught the attention of not only our current families, but the worldwide Down syndrome community and other homeschoolers, resulting in our highest-ever web traffic numbers.



While our program team reimagined their whole approach to caring for families, we also had to come to grips with our new financial reality. Understanding the strain and uncertainty many of our families are facing, one of our first decisions was to make all DSRF programs and services available free of charge to families in financial need for the duration of the COVID-19 crisis. We have expanded our bursary program to include more families facing more serious financial challenges including those at or below the poverty line (see <http://DSRF.org/funding>).

There remains a significant gap between the funds coming in from program funding and emergency government support, and the cost of maintaining our operations for the duration of the crisis. In order to meet this need, our fund development team – much like our programs team – has quickly changed course, making difficult decisions about some of our upcoming events and campaigns, and working to identify new funding opportunities.

In the short term, Up the Down Market Toronto was rescheduled to October, while Up the Down Market Calgary has been cancelled. Run Up for Down Syndrome - our biggest annual fundraising event - was reconceived as a virtual event: Run Apart for Down Syndrome (DSRF.org/RunApart). We were blown away by the generosity of our community, as over 760 people ran through their own neighbourhoods and collectively raised over \$155,000.

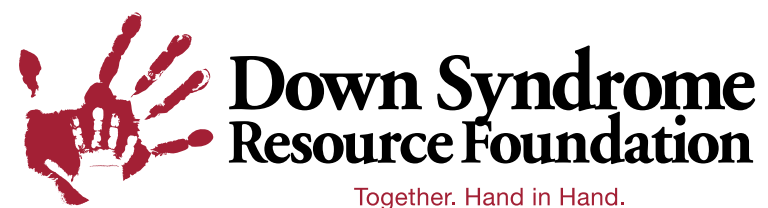
Looking ahead, we expect that COVID-19 will have a long-lasting and significantly detrimental impact on our fund development. Whether we are able to proceed with the three Up the Down Market Dinners scheduled for this fall is an open question at this time, and even if we can, it remains to be seen the extent to which the economic downturn will impact their success.



Once our centre reopens, we will face tremendous pressure to restore our fund development to meet needs amidst a very challenging economic environment. In the meantime, however, our focus remains fixed on caring for our families during this time when they need us most and ensuring that DSRF continues empowering people with Down syndrome through the COVID-19 crisis and beyond.

To do so, we need your help. We understand that these are difficult times for everybody, and not everyone can afford to give right now. But for those who are able, your support now means more than it ever has. You can rest assured that we are stretching every dollar for maximum effect.

If you can do so, this would be a wonderful time to become a Triple-21 monthly partner. Many people find it is easier to give a small amount each month than to make a larger one-time gift, especially during difficult times. Your \$21 a month will add up to a big impact in the lives of students with Down syndrome. Learn more and sign up at <http://DSRF.org/Triple21>.



FRIENDS OF DSRF

At DSRF, we are doing everything we can to continue caring for families and empowering people with Down syndrome throughout the COVID-19 crisis. This would not be possible without generous supporters like the Vancouver Foundation, which has awarded us a Community Response Fund grant of \$25,000. Thank you!

Our incredibly awesome and generous partners SVP Vancouver have done it again. They have awarded DSRF \$10,000 in emergency funding in support of our new virtual and adapted services designed to alleviate the isolation of children with Down syndrome and their families. Thank you!

Prior to the onset of COVID-19, two of our regular funders generously renewed their support for 2020. The Edith Lando Charitable Foundation, which has a special interest in building the self-esteem of young people, provided \$4,000 for DSRF’s children and youth programs. Also, the CKNW Kids’ Fund gifted DSRF \$3,000 for materials and supplies for our individualized therapy programs including speech therapy, occupational therapy and behaviour services.

UPCOMING AT DSRF

Up the Down Market Vancouver
A Virtual Event - date TBA

Up the Down Market Toronto
A Virtual Event - date TBA

Action 21 Montreal
A Virtual Event - date TBA

FIND US / TAG US

@DSRFCanada on all our platforms



CDSS SPOTLIGHT

World Down Syndrome Day During COVID-19

On March 21, 2020 we brought community awareness to the next level – all while staying safe at home.

CDSS's Matthew MacNeil and Board Chair Ed Casagrande presented Project Understood virtually on Friday, March 20. The update about this key research initiative was shared with the United Nations as well as with a live online audience. Thank you to Down Syndrome International for making the 2020 @WDSConference a wonderful success amid the travel restrictions and safety guidelines that were in place.



CDSS mailed out awareness packages containing information that would be shared with more than 18,000 children across Canada!!! Many of these presentations, educational and celebratory activities took place prior to the isolation guidelines most of Canada was following by March 21.

Supporters and self-advocates wore #LotsOfSocks, and many celebrated by dancing as a family, dressing pets up in socks, and decorating windows to share awareness about Down syndrome. Landmarks also lit up across Canada, many shared on social media by passersby with cameras.

Congratulations Canada on another successful March 21 – showing the world that Canadians can celebrate and #SeeTheAbility in many ways, shapes and forms.

Project Understood

Have you shared your voice with Project Understood? There's still time! Visit www.ProjectUnderstood.ca today.

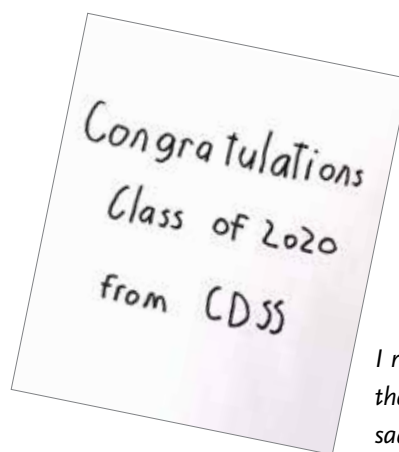
And if you've already started your recordings, please keep going to complete your phrases. Project Understood registrations and recordings are still being processed - the perfect activity if you are looking for a new project over the summer months.

PROJECT UNDERSTOOD.ca

Congratulations graduates!

For all of the graduates - you did it. All of the hard work and dedication you put in all of that paid off congratulations. Be proud of yourself. And now you can look back on your memory and now you can start on make thing happen for your future. So congrats!

-Matthew MacNeil, VATTA



I remember the thrill to walk across the stage and hear cheering. I'm sad a big crowd won't be celebrating this year. Celebrate however you can. Get together on ZOOM, have a dance party, have a special meal. Graduates will have to be creative. This was part of my valedictorian speech in 2013, for you now:

**You have brains in your head.
You have feet in your shoes.
You can steer yourself any direction you choose.**

– Dr. Seuss

-Paul Sawka, CDSS



Go 21

Extraordinary times call for extraordinary measures, and to help your group continue to raise money in the absence of the traditional large gatherings within our communities, our GO21 platform is here to support that!

CDSS will brand your event as GO21, and look after all electronic donations and receipting, all while staying safe and paperless for participants.

The GO21 model of fundraising can easily brand your virtual walk, run, dance party, dinner, or whatever creative and engaging event your group comes up with! One simple example is to continue your annual 'walk' or 'fun day' event virtually: have families walk and take photos of them out with fingers raised, showing how many kilometres they walked or ran, set a group goal of 21 kilometres, or 21 times three! Or do something great together as a family and share a photo for the group you'd normally be out celebrating with at 'fun day.'

Because events are online now, it is often best to promote a specific project, resource, or goal you are working towards as a group. Set a financial goal for a project and have everyone spread the word on social media about the fundraiser and virtual event.

Contact us at GO21@CDSS.ca for more information and ideas on hosting a virtual fundraiser this summer or fall.



ANNOUNCING THE CANADIAN DOWN SYNDROME SOCIETY RESOURCE HUB!

In an effort to help ensure the most current and accurate information is accessible to the Canadian community, and to help serve those who need assistance, CDSS has added a resource hub to its website. As part of our community engagement, education and resource activities, we have developed this collection of links organized by life stages, health topics, and common inquiries.

Link to these great new resources here, and check back for updates often: www.CDSS.ca/resources

Project 321 Peel Down Syndrome Association raised over \$6,600 at their spring PlayDay 2020 Space Jam!



Canadian Down Syndrome Society

Société canadienne de la trisomie 21

FIND US / TAG US

@CdnDownSyndrome on all our platforms



Learn At Home

Discover a world of home schooling resources at your fingertips! Throughout the COVID-19 crisis, DSRF's team of Down syndrome specialists is sharing all kinds of learn-from-home suggestions and DIY exercises to empower parents to work on essential skills with children and adults with Down syndrome.

Topics include:

- reading
- spelling
- printing
- math
- speech
- OT
- mental wellness
- behaviour

PLUS:

COVID-19
resources!

[DSRF.org/LearnAtHome](https://www.dsrff.org/LearnAtHome)