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Canada's
Down Syndrome
Magazine

Collaborative Care:
*Navigating Multiple
Caregivers*

SISTERS:
*A Lifetime
of Memories*

**Growing
Together:**
*A Sibling
Round Table*

**Who Will
Care for Me?**

The **Siblings** *Issue*

Plus: Siblings Share Lessons and Experiences in Q&A



Happy Holidays and welcome to the Siblings Issue of 3.21 Magazine! Join us as we explore the complex depths of sibling relationships and the unique evolution many people experience as they grow from childhood playmates into adult caregivers.

First, a community panel of adult sibling caregivers dive into the changes they had to make, the invisible responsibilities they did not expect, and the heartwarming moments and unforeseen benefits that keep them motivated when things get overwhelming. You'll also hear from three Canadian families who have multiple siblings and have each found their own unique way to divide caregiver responsibilities. Having multiple caregivers can be helpful for balancing schedules and skill sets, but it can also be a source of conflict when siblings do not agree.

Planning for the future requires some difficult conversations with your family. We have provided some practical advice on how to speak to your children about the future care of your child with Down syndrome once you are gone. What if you only have one child? What if none of your other children choose to become the primary

caregiver? These are the tough questions parents and families must not leave unanswered.

Finally, we sat down with Mary Ellen, one of the oldest living Canadians with Down syndrome, and her sister Barb to hear the unique life story of Mary Ellen growing up in the 1940's and '50s, finding a career with the Niagara Parks Commission, dealing with grief and the loss of their sister, and still thriving today in BC at the age of 77.

We hope that the community advice and real-life examples shared within this issue will encourage and comfort you as you take the next steps on your own journey of planning for the future care of your loved ones.

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We would love to hear from you! Drop us a line and share your article ideas at 321DSMagazine@gmail.com.



4 10 20

4 Growing Together:
A Sibling Round Table

10 Who Will Care for Me?
Speaking with Your Children About the Future

16 Sisters:
A Lifetime of Memories

20 Collaborative Care:
Navigating Multiple Caregivers

24 Sibling Q&A

28 CDSS Spotlight

30 DSRF Corner



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Growing Together:

A Sibling Round Table

Becca and Lydia

This article is a lightly edited discussion from The LowDOWN: A Down Syndrome Podcast, led by Marla Folden and Hina Mahmood, hosts of The LowDOWN. To listen to the full conversation, visit DSRF.org/podcast.

Every parent desires their kids to have close, supportive relationships with one another, throughout childhood and as they grow together into adulthood. When one of the children has Down syndrome, there are some extra layers to the sibling dynamic.

In this panel discussion, we turn our attention to the often-overlooked member of the family: the sibling. Five women, each of whom is sister to a young adult with Down syndrome, share their experiences growing up and look ahead to a future in which they will take more responsibility for the care of their loved one.

Meet The Siblings

Amanda: My youngest brother Ian is 22 years old. He lives in Ontario with my parents. He's an active participant in Special Olympics; he loves playing basketball, floor hockey, and soccer, and watching hockey on TV. He's got a great memory for names and birthdays: he knows everybody's name, everybody's birthday, famous celebrities' birthdays.

Rachel: My brother is David, and he is 23. David is a fun-loving, humourous, kind guy. I just feel very fortunate to have built the relationship I have with him over the years. David loves sports and he loves to be active. He loves to dance and sing and entertain. He's such a special guy.

Lydia: I am the oldest of four siblings. Becca, who is 19, has a dual diagnosis of Down syndrome and autism. She's a huge people person; she makes friends wherever she goes. She likes to tell people that they are her boyfriend or girlfriend and be really buddy-buddy, even if they're a complete stranger. She's quite the character and brings a lot of joy to our family.

Sarah: My brother Andrew is 30 years old, and he's the youngest of us three siblings. He also happens to be the glue that holds our family together. He's caring; he's funny. He's the type of person who sees the best in everybody and, and brings out the best in everybody. He works at Nester's Market, and he's an ambassador for DSRF. He's also a proud member of a ball hockey team. He's a great uncle to his three nephews and his niece – and he's definitely more popular with my friends than I am!

Marla: I can relate to that one for sure. I also have a sibling with Down syndrome. My sister Carina is 20. She also loves a party and is an absolute delight – and also the glue that keeps our group together, so that might be a common theme.





David and Rachel

What do you enjoy doing together?

Lydia: Probably our favourite activity to do together is to go to the movie theatre. She loves having a girl's day out – no little brother tagging along. She also likes to help in the kitchen. For a while, she really wanted to be a chef, so we like to bake together. She's a lot of fun to do that stuff with.

Sarah: Andrew has decided that I am chopped liver and that my husband is actually the one that he wants to hang out with the most! But he is always happy to come over and just hang out with us, make dinner, watch a movie with my husband, read a book to his niece, and tell me that I don't need to be in the room! I know in the back of his mind that I'm still important, but he's definitely at that age where he wants to hang out with the guys.

Rachel: Dave is super social, and he just loves to entertain, loves to be out and about, and just be in the community. There's a five-year difference between David and I and I'm the oldest in the family, so he loves coming over to my place and having a sleepover. I live not far from White Rock Beach, so we enjoy going out to the beach for walks and just being outside. It's a really nice way to spend time with each other.

What did you find challenging about growing up as the sibling of a person with Down syndrome?

Marla: When my sister was really small, she was very medically complex and we spent a lot of time attending to her medical needs. And of course, I didn't understand it appropriately because I was a kid, too. There were a lot of birthdays in hospitals and stuff that seemed unfair at the time. Now as an adult, I'm like, well, obviously you're going to do the heart surgery or whatever it was that took precedence over the sleepover that I had planned. But at the time, it did feel challenging and unfair.

Amanda: I am almost eight years older than my brother, so I felt like I had a lot of added responsibility: things like having to come home after school instead of hanging out with a friend because Ian couldn't be on his own and both my parents worked. I felt like my friends didn't always understand, and I got frustrated at times.

Rachel: I think for me, the biggest challenge growing up was the negative stares from people looking at us in public. I definitely saw those side eyes, the stares, and the negative attention that was put on us just because David is different and people don't understand. Sometimes it was other kids, and other times it was adults. We still get that attention from time to time when we're out in the community just doing our thing.

Lydia: When Becca was 10, she was diagnosed with leukemia; I would've been about 14 at that time. Becca was in the hospital a lot and one of my parents was always with her. I also have a younger brother who has numerous disabilities, so the other parent often needed

to be very focused on him. As a result, I missed out on a lot of experiences that most teenagers have. I'd say I was very mature for a younger person, and I really cast aside my needs at that time. A few years later I really started to unpack all of that in therapy! But when you're the oldest sibling and you love your siblings, you want to do everything you can to help them and help your parents.

Marla: I think surrogate parenting is a big theme, particularly for older siblings: the need to be responsible and also to defend your sibling. There is often a bit of caretaking involved. I remember keeping an eye out for my sister at school to make sure that everything was going down smoothly and that there wasn't anything that looked like mistreatment. I also remember getting called in for a completely different person with Down syndrome who was having a crisis, and they were like, "Who knows what to do about this? Oh, probably Marla!" I did not know.

Sarah: I am also eight years older than my brother, and when my brother was born, I thought my parents had given me a baby. I thought this was purely for my enjoyment! Only now that I have a child of my own do I realize how much additional support Andrew required. I think one of the times that I really realized that Andrew was "different" was when people started staring at him, because I didn't see the differences; he was just my brother. But going out and feeling like I had to defend Andrew and defend our family was difficult. And yet I realize it was even more difficult for Andrew, because he was the one they were staring at. Through these experiences, I think I became mature faster than my friends, at least in some ways, and as a result we didn't fully understand each other. There was nobody else to really talk to about it amongst my friend group. They knew and loved Andrew, but they could never really understand what it was like to be a sibling.

Marla: Did anybody else have to develop a hostile look just to give people the message, "No, you don't get to stare at our family. No, you don't get to make a comment right now. Yes, my sister is laying on the ground, but that's not your problem." I see a lot of smiles and nods from that one!

Sarah: I was thinking about this the other day. I distinctly remember walking down the street one day with Andrew, holding his hand, and people were openly staring. Andrew

squeezed my hand and said, "It's okay." And the realization hit me, that he was seeing this more than I was. But he deals with it every day and has sort of developed this hard skin about it. And he's also managed to develop this counter reaction, like, "You can stare at me, but I'm going to say hi and try to make you my friend, and make you realize that I'm a person too." I think that really shaped the way that I perceive it. But I still give the death stare when needed, don't worry!

What advice do you have for parents who are trying to promote a happy, healthy sibling relationship?

Amanda: One thing I really appreciated from my parents was their openness and their honesty. I remember when he was born, they sat me down with a book and explained, "Ian has Down syndrome, and it doesn't change much about him. He might need a little bit of extra help and he might learn to do some things a little bit slower; we just have to be patient." And as we grew up, they didn't hide the struggles. They encouraged us to talk about our feelings and ask any questions we had. And they took me to my brother's speech appointments; they didn't force me, but I wanted to, so they took me and let me be involved in everything.



Carina and Marla

Sarah: I remember on the way to the hospital, my dad picked us up and said, “Your brother has Down syndrome.” I had no idea what that meant, but from day one my parents were really open about what Down syndrome was, what that might mean for the family, what that might mean for Andrew and Andrew’s future, and our future. At the same time, my parents really got us involved in Andrew’s day-to-day care. I used to dress up Andrew in my doll clothes. I don’t know if my mom knew about that, but they let us grow that typical sibling relationship. We didn’t always get along, and it was okay to fight. It was okay to treat Andrew like any other sibling, and that included getting frustrated when he was taking up too much attention. So, not anything different from my sister and I.

What advice do you have for other siblings of a person with Down syndrome?

Marla: I have a piece of advice that I often give to families on this one, and particularly to younger siblings: it’s okay to take up space. You’re a kid too and you shouldn’t give up your childhood or be really torn between the needs of your sibling and what will be easiest for your parents. One thing that I often recommend to parents is to pull their typically developing children out of school every once in



Andrew and Sarah

a while, for some one-on-one time. It’s not the end of the world if they miss a day of school every semester to have focused attention from a parent that they might not normally get because their sibling with Down syndrome needs constant care. It’s a great way to connect with your other children, and you know that your child with Down syndrome is safe and secure.

Lydia: That’s definitely something I really struggled with as a kid. I was very excited to be kind of the third caregiver in the family. And I think I made some sacrifices that my parents didn’t even ask me to make, just because I really wanted to be the best sibling I could be. And as a result, I didn’t enjoy my childhood in certain ways that I think I could have otherwise.

Rachel: Over the years I’ve tried to find things to do with David that meet him where his needs are. I think that’s been really helpful over the years in building the relationship. Start from a place of love and respect for each other, and be patient when those harder moments come your way.

Amanda: If you can find other people who are siblings, that’s really helpful. One of my closest friends to this day is somebody who has a sibling with a disability and I met her much later on, in grad school. It’s a bond like no other: somebody who understands the joys, but also the fears and the challenges and can relate to your experience. Because as much as people try to understand, sometimes they just can’t. I wish I’d had her a lot earlier on in my life.

What are your hopes for your relationship in the future?

Marla: Well, I am one of the options for my sister’s care for the long-term future, so I anticipate always having a large role in her life. I think we’ll keep jamming on ukulele; we’ll keep talking about musicals. We will keep dancing and having spa dates. I just can’t wait to see her grow into an adult. She’s well on her way now, but I’m super excited to see her have a job and have some great adult friendships and just be out living her best life. Like she says, her lipstick is popping, so she’s ready!

Sarah: I am also the ultimate care plan. Part of that is continuing to be part of Andrew’s life as he evolves.



Ian and Amanda

I know that my role in Andrew’s life is going to be different than my husband’s role or my other sister’s role. Whatever Andrew needs, I hope he always knows that we are going to find a way to provide it for him. I have really enjoyed seeing the relationship that he has with my daughter and all the things that Andrew teaches her, and she’s going to start to realize what a special person Andrew is.

Amanda: Despite my physical distance from Ian, I hope we can continue to have our FaceTime chats and that he will feel like I’m someone he can confide in; someone who is always there to listen. I can’t wait to see what kind of job he ends up taking and just where the future takes him.

Rachel: I am really excited to see what the future holds for David as far as employment. He’s super eager to find a

job, whether it’s a paid or volunteer role. And then figuring out his living situation as well; that’s something that our family is working towards. Mostly, I just look forward to building on what we already have.

Lydia: Becca is looking to move into an assisted living situation in the next few years. She’s just finishing up high school now, so I’m really excited to continue to develop our more adult sibling relationship. I think we’ve only really started developing that in the last couple of years. I’m finally able to have a full conversation with her and go out and do things, just the two of us. And she’s just so much fun. I’m sure eventually – way, way in the future when my parents are no longer around – I will also have a big role in her care. But for now I’m looking forward to just having fun with her. That’s the good stuff.



Who Will Care for Me?

Speaking with Your Children About the Future

By Courtney Cassel

Thomas couldn't wait for his brother and sister to come home for the holidays this year; it had been quite a while since the whole family could get together. He had always been close to his siblings when they were kids, but as they moved out and started families of their own, visits home became reserved for special occasions.

As everyone laughed and chatted together over drinks and snacks, Thomas could see his sister glancing at their mother in the kitchen - she was moving a little slower these days and second guessing some of her tried-and-true recipes. "What's the matter?" Thomas asked, but when his sister noticed him observing her, she shook her head and changed the subject. "How is your new job going, Tom?"

We took our seats together to enjoy our favourite tradition - holiday dinner. Smiling at each other across the table, we passed dish after dish of way too much food and waited to begin. Finally adding the last dish to the table, Dad sat down and groaned dramatically, "I don't know how many more years we can do this!"

Awkward laughter echoed around the table followed by a bit of a silence; Thomas noticed his siblings were avoiding each other's gaze.

"What is it?" Thomas asked them.

"Oh nothing! Nothing, just happy we could all be here," his sister remarked while his brother started eating quietly. Thomas could tell there was something that needed to be said, but he was happy to have his siblings at home.

"I'm happy you're here, too."

Leaving the future undiscussed is never part of the plan for any family, but the reality is that often these difficult conversations are put off until it is too late to have them.

Fear of the unknown, uncomfortable questions, and avoiding conflict are very persuasive reasons to avoid the elephant in the room - who is going to care for your child with Down syndrome once you are gone? Leaving that question unanswered is not really a luxury that primary caregivers have, and past studies have even shown that a lack of formal planning for the future can sometimes lead to rushed or inappropriate care when a family member is no longer available. Older Carers of Adults with a Learning Disability Confront the Future: Issues and Preferences in Planning, 2007.)

“Parents not being ready or avoiding the conversation has been identified by Sibling Caregivers in Canada as one of the most common barriers to planning for the future.” Siblings Canada Survey, 2021.

Although you may have an idea of what that future care plan looks like in your mind, your child with Down syndrome (and any other children you may have) deserve the chance to ask questions and provide their thoughts as well.

“There’s an important need for sibling caregivers to be recognized or be included in conversations among caregiving,” Dr. Yona Lunskey, Senior Scientist at Toronto’s Centre for Addiction and Mental Health, Why Siblings Are the Forgotten Caregivers, Chatelaine March 2023.

Having “The Conversation”

How are parents supposed to overcome their natural apprehensions and make time for these uncomfortable conversations? In A Guide to Communicating with Family for Adults Who Have Siblings with Disabilities, Siblings Canada (formerly The Sibling Collaborative) recommends two approaches, depending on your families preferred style of communication:

- 1. **Little and Often.** This approach works well if your family responds better to shorter, more casual conversations



about specific questions or details. Instead of having one big conversation or planning session, you have several conversations over time. Being open about these topics with your children from a young age allows your family time to get comfortable with the subject matter and plan in a pressure-free way.

- 2. **Direct and Planned.** This approach is ideal if your family doesn’t often see each other or if people tend to avoid questions about the future. You can pick a date and time where the family agrees to sit down together and discuss details and make some decisions about future care. You can give your family members questions and prompts ahead of time to allow them time to think over their answers and anticipate any emotional subject matter.

“We’re encouraging people to talk to their families over time, and not just once there’s a crisis.” Helen Ries, co-founder of Siblings Canada

“The future” is a pretty broad expanse. Try making a list of the different conversation topics that need to be covered to create a complete care plan. Shannon McCrae, Independent Financial Advisor specializing in estate planning for families who have a family member with a disability, recommends covering these topics, among others:

People with Down syndrome are now outliving their parents. This letter captures their instructions to the people who will care for them: **their siblings.**



Dear Clare,

I have written a few words for you to hold in preparation for a time when your dad and I are no longer here.

I know Evie will take care of you in her own way, but it is weighing heavy on my heart that caring for a sibling with Down syndrome is going to require energy that may be hard for you to find at times.

As Evie’s sister, you will be the one to be the deep listener, the interpreter, the sensory diet therapist, the one to nudge her when something new is required of her. So much falls on you at a time when you need to grow and nurture your own precious and beautiful life. Your compassion and your ability to read people and your deep devotion to living in a just world will help you.

With love beyond measure,

Mama

Care Instructions from Wendy.
Mother of Clare & Evie.

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- **The Will.** Review your will with your children and let them ask any questions about why decisions were made and what will happen when you are gone. Keep your will up-to-date and make notes of why any changes were made and when.
- **Financial Security.** If you have set up a trust for your child, explain to them what a trust is and how it works. It is there to protect assets that may eventually go to your loved one to ensure their inheritance will not be impacted by receiving funding, government or otherwise, that they will depend on.
- **Life Insurance.** Speak to them about any life insurance policy you may have which will pay an amount to your children when you pass away to provide financial resources for ongoing care.
- **Legal Matters.** Discuss and decide who will act as the Power of Attorney for Personal Care and for Property. Always include your child with Down syndrome in these decisions and all future care planning.
- **Living Arrangements.** If your child lives at home with you and their living arrangements are going to change

upon your passing, that needs to be discussed. Many options exist, including government subsidized community group homes, a pay out-of-pocket community group home or independent living with shared accommodations, shared accommodations with one or more roommates, moving in with a new family member or caregiver, or a homeshare where a family or couple is paid to accommodate your child and assist with day-to-day tasks.

- **Dealing with Grief.** Understanding death and methods for coping with grief is often a challenging concept for individuals with Down syndrome, but it is an important one. (Several resources exist about facilitating and understanding death and grief, please visit CDSS.ca/Healthy-Aging for more information.)
- **Day-to-Day Support.** Who is going to assist with daily activities such as cooking, cleaning, transportation, managing appointments, social activities, and other daily life activities? Every person with Down syndrome is different and will need different types of support - create a care plan that works for your family.

Asking the Hard Questions

Understandably, there are some very hard-hitting questions brought about when planning for the future care of your child. If you are finding it difficult, try looking over these commonly asked questions from other parents to help ease your anxiety.

What if none of my other children are willing to become the primary caregiver?

No one should be forced to take on the responsibility of primary caregiver. One of your children may offer or want to naturally, and that's okay - they just need the space to make the decision without guilt. If none of your children are capable or willing to take on that role, then it makes planning for future care even more urgent. Several options exist for paid caregivers and community living situations.

What if I only have one child?

Developing a microboard and a circle of care with a minimum of five members is a good place to start. People in the circle of care should be active in your child's life, such as friends, cousins, coworkers, past school friends, as well as professionals. Each person has a self-appointed role on the board to make sure all needs are met, such as social activities, living situation, employment, recreation, and holidays.

What if the discussion is getting heated?

Stay calm, it is going to be an emotional experience discussing the future and unknowns. Allow room for patience and expression. If you're disagreeing on several topics, choose which ones are the most important and pressing and discuss them first. It can be emotionally and mentally draining to have these discussions, especially if someone is already feeling stressed and tired. Try to limit the discussion time and focus on a specific topic or decision.

My children are still fairly young. How do I start these conversations with them, without giving them cause to worry?

The earlier you start the conversation about the future, the easier it will become for your family to discuss it. So while you might think that your pre-teens or teenagers are too young to be thinking about becoming a second-generation caregiver, there are other question prompts that can get them thinking about it on their own in a positive way:

- What are your dreams for the future?
- Do you ever feel anxious about the future?
- What are you most excited about when you grow up? (career, big dream, travel)
- Where would you like to live when you're older?
- What kind of job would you love to have? Where would you work?
- Where do you see yourself in 10 years? 20 years?



SISTERS: A LIFETIME OF MEMORIES

Interview by Glen Hoos



Mary and Barb

At a healthy and vibrant 77 years, Mary Ellen Somerville is thought to be one of the oldest living Canadians with Down syndrome. We recently sat down with Mary Ellen and her sister Barb to hear about Mary Ellen's life and their special family bond.

Growing Up

Barb: Mary Ellen was born in Niagara Falls, Ontario on September 21, 1946. We grew up together with our sister Roseanne. Mary Ellen was the youngest.

When Mary Ellen was born, they called her a Mongoloid. That was the official diagnosis. It was a different time. Later, when the terminology changed, they changed it to Down syndrome in all the doctors' reports.

Our parents were very protective of her and very loving right from the get-go. Our mom was manic depressive, so she was in and out of a mental institution many times when we were children. And of course, it was suggested numerous times that Mary Ellen should be put into an institution. But that was an absolute non-starter. Our dad and our mother stood their ground and said, "She's our child. She's in our home, and we will take care of her."

As sisters, we were part of that; we protected her and watched out for her at school. She went to the same schools as us, in regular classrooms for elementary and in special education for high school. The teachers always loved her because she wasn't disruptive. They never worried about exams; she just did what she could do. She absolutely loved school and was very well behaved.

Mary Ellen: I remember going to school, but I didn't particularly like it.

Barb: That statement could be because she was teased by other students. She hit a roadblock in the ninth grade. She repeated grade nine three times, then we received a letter from the Board of Education saying that you can only repeat a grade three times and then you're out. They wouldn't let her come to school the next year.

She cried that whole year. By that time, I was working at the school as a secretary. Her teacher, Mrs. Arnold, absolutely loved her and she fought hard for them to let her come – but they wouldn't allow it. I would be in the office and I'd see these rebel kids skipping school and

causing problems being sent to the principal's office. And I would think to myself, "All she wants to do is come to school and they won't let her."

Outside of school, there were no supports. No speech therapy, no occupational therapy, no respite. Just your family. Fortunately, our extended family – aunts, uncles, grandparents – were extremely supportive. Mary Ellen was always loved by all the family. We advocated for her and included her in everything, and it shows in the fulfilling life that she has led.

Career Woman

Barb: Mary Ellen lived in Niagara Falls on her own for 31 years in a Kiwanis village apartment complex. There was an overseer and my sister and brother-in-law brought her meals and did her laundry. She was an immaculate house keeper, and was self-sufficient otherwise.

Once we realized that Mary Ellen couldn't go to school, we knew she couldn't sit at home all the time and we needed to find something for her to do. I started making connections with people that I knew, including someone at the local hospital. I contacted them and they said they would be glad to hire her for the cleaning staff. They called when Mary Ellen was home alone, and she answered the phone and they said, "Mary Ellen, we have a job for you. You can start work on Monday!" And she said, "Well, what am I going to be doing?" And they said, "Well, you know, you're going to be cleaning under the beds, mopping, and things like that."

She said, "I do enough housework at home. I'm not doing that." And she hung up the phone.

Our next attempt to find her employment went much better.

Mary Ellen: I got a job with the park, at the restaurant.

Barb: She got a job with the Niagara Parks Commission. She worked there for 34 years, going every day and never missing a shift.

She started out as a bus girl. One day her supervisor said to her, "We're going to close off the section by the windows that overlook the falls, and I want you to fill the salt and pepper shakers."

Now, when the supervisor tells Mary Ellen to do something, nobody else can come behind and change that. If you tell her to do something a certain way, that's the way it's going to get done. But a young couple came in, jumped the rope, and sat at a table by the windows. And Mary Ellen became very upset. "You can't sit there! Get out of here!"

That's when they moved her to the kitchen, which worked out really well. She worked a split shift, lunch and dinner, putting the silverware into the napkins.

Mary Ellen: I was a jack of all trades. I liked folding the napkins, clearing dishes, and talking to the customers.

Barb: The chef absolutely loved her. But in the summertime, they would bring in teenage kids as summer staff, and they loved to tease her because if they got her going, she would get angry and swear a blue streak. And so the chef would say, "You know, Mary Ellen, I think we've done enough work for today. Why don't you just go home and relax?"

The staff had lockers next door to a meeting room, and one day there were government dignitaries in there having an important meeting. She was getting her stuff to leave because the chef had sent her home; the kids had really got her goat and she was quite angry. She was slamming the locker door and swearing up a blue streak and of course, they could hear her in the meeting. So they called my sister Roseanne that weekend and said, "We think it's time that Mary Ellen retired." By that point she was in her fifties. They had a retirement party for her and gave her a service award, and she was excited. She had an incredible career.

Staying Healthy

Barb: Throughout her life, Mary Ellen has always kept busy. She used to go to the community centre where she had an annual pass. She would take the bus that stopped right in front of her place and go swimming on her own. Travel has also been important in her life.

Mary Ellen: I like to travel. I went to Disney World in Florida, and to the Rose Parade in California in 1983. I went to New York, and the place with gambling – Las Vegas. Also, Reno. I won 60 bucks!

Barb: That was her bus trip with our niece Julie. She was 18 at the time, and she took Mary for a whole month on a bus trip. They went down through California to Disneyland

and the Tournament of Roses parade. Then went back up through Vegas.

Mary Ellen: My favourite was Hawaii. I saw the Arizona, the one that they bombed at Pearl Harbour.

Barb: She has been exceptionally healthy for most of her life. She gets good, solid sleeps, and she's always enjoyed a variety of foods.

Mary Ellen: I like eating ice cream. And pizza. No salads. If I knew how I've stayed healthy, I would tell you. I go for walks over to the Chinese Garden.

Barb: Mary Ellen has stayed very sharp into her late 70's. I attribute this to the level of care she has received from her loved ones. Earlier in life, she had mastoid surgery in one ear, which caused total deafness in that ear. She's lost hearing in the other ear over the years, but not completely. She also had hip surgery in 2006. It wasn't due to a fall; the hip just wore out and she had it replaced.

She always loved swimming in the lake, so I took her to the beach yesterday. It's tough now for her to walk on the sand because her stability isn't there anymore. And now when she gets in the water, she's more fearful of it than she ever was. She said to me afterwards, "I wish I was younger again and could do that. I guess I just can't do it." But she's doing remarkably well. She says she's never going to die – and to be honest with you, she might live well beyond me!

Heading West

Barb: Our sister Roseanne passed away in January 2023, and that's what prompted Mary Ellen to move out here to BC. I had been paving the way for a couple of years because Roseanne had cancer. I would tell Mary Ellen, "You're going to move out west with me one of these days, you know?"

It hasn't been an easy transition. I initially thought she would do okay in Niagara for a little while, giving me more time to set things up here in BC. But when she has grief like she does now, or like she did earlier when our father passed away, she gets angry. She misses that step of grieving and crying, and goes right to anger. Our cousin Gail and our brother-in-law Tom were bringing her meals and stopping in for a cup of tea once in a while, but

it became too difficult to deal with. I had to fly in three times; finally I just said, "It's time, we need to bring her out." So, she moved out here in March.

Mary Ellen: I wasn't sure whether I'd wind up here. But I'm a Westerner now. My sister got me this place. It's okay.

Barb: She lives in an assisted living home. It's not a care home, but she may need that soon. I set her up in a beautiful little apartment. She has a nice little kitchenette; she gets her meals brought to her with meal assistance.

The dining room was difficult because of her hearing. I come twice every day to bring her meals at 11:30 and 4:30. I make sure that her meat is cut up and her bib is on, and then she's fine. She takes two hours to eat, but then she cleans up her own dishes and puts them on the tray for me to take down when I come back to the next meal.

Mary Ellen: I like to watch videos, especially the old westerns, like West Wagon Train.

Barb: We used to watch them when we were kids, so she remembers them now. They're familiar to her. Any of the newer shows confuse her.

She could basically just sit in that room, I think, and watch TV for the rest of her life, but I'm trying to enlarge her world a little. I take her out to the beach and to picnics and for ice cream. I bring her downstairs so she can see people, and she's very

sociable. She goes up to them and says, "Hi, I'm Mary Ellen." And she always says, "What's your name?" If they don't know that they have to talk directly in her ear, it becomes a hoot, because I'll say into her ear, "That's Margaret," and she'll say, "Oh, Marjorie." And they say, "No, Margaret," and around and around we go.

I also set up Zoom for her, so now she's seeing more people – our nieces, my daughter and sons, great nieces, nephews, and cousins. She adores her family.

A Good Life

Barb: The world has changed now. Yesterday, we met a young couple at the beach. They asked how old she was, and I told them she's going to be 77. And I said, she has Down syndrome. And they said, "Wonderful!" They were so attentive to her and helped me get her to a chair.

When I told her about this interview, Mary Ellen didn't know why you would want to talk to her. I said, "Well, you know, Mary Ellen, you have Down syndrome, and you're one of the older people with Down syndrome in the entire country. You're very special."

She has been blessed to live such a long, good life. And that's all our parents ever wanted for her. With their loving care, and then that of our sister Roseanne and brother-in-law Tom, she is now here and able to enjoy life with me and my husband Jack.



When our dad passed away, my older sister Roseanne and I were on either side of the bed. His last words were, "Take care of Mary Ellen." You asked Mary Ellen for advice for parents of children with Down syndrome, and she said, "Live a good life." That's what we have done. It's good advice!



Collaborative Care: Navigating Multiple Caregivers

By Sarah Caraher

Every family's caregiving plan is different. Sometimes one family member, often a sibling, becomes the primary caregiver for their loved one with Down syndrome as they grow older. In other families, professional carers play a major role. Another common scenario is sharing caregiver responsibilities in different ways among multiple family members or setting up a circle of care.

For the McKay family, Marriah's two older sisters Vanessa and Cassandra have both been actively involved in her care since their mother passed away. The sisters knew from a young age that they would look after Marriah in the future. Growing up, their mother taught them to care for Marriah, and as adults, their chosen careers also make them uniquely qualified for the task.

Cassandra, who works as a nurse, manages her sister's physical needs, like ensuring Marriah maintains a healthy lifestyle. Vanessa, who is a social worker, takes care of administrative tasks like booking Marriah's medical appointments, completing applications for funding, and managing finances.

The two other McKay siblings also lend a hand by being an active part of Marriah's social life. Marriah's younger sister Daniella, who lives in the United States, likes to take her sister on shopping trips, and the eldest McKay brother hosts Marriah for sleepovers with his family.

Caring for Marriah hasn't always been easy. Stepping into her role as caregiver when she was only 24 years old, Vanessa found it difficult at first not to compare herself to others her age who had more freedom.

"It was a massive adjustment, a complete 180," Vanessa said, "I was also grieving my mom so that was really hard."

Taking on the responsibility of caring for a loved one often means big life changes for caregivers. In a 2018 study, Statistics Canada found that 75% of caregivers who provided 20 or more hours of care per week had less time to relax and engage in self-care. 78% of these caregivers also spent less time with friends and participating in social activities.

McKay Siblings



This was certainly true for Vanessa. Once she was a caregiver, most of her social plans needed to involve Marriah. Some friends weren't thrilled about always including Vanessa's sister, and Vanessa quickly realized that those friendships weren't feasible to maintain.

Although caregiving as a team means having a built-in support system, navigating the division of care among siblings can also be a challenge. According to one study, families who saw themselves as having conflict over coordinating the care of a loved one were also more likely to report depression, anxiety, limited social activities, and feeling the weight of responsibility as a caregiver.

Marriah's care often unfolded in a natural, co-operative way, but there were still times when the level of responsibility became overwhelming. For both Vanessa and Cassandra, there have been moments where each of them has felt like the primary caregiver for Marriah, or that they had to prioritize Marriah's needs over their own more than the rest of their siblings.

Although caring for her sister has been difficult at times, Vanessa has found a balance between Marriah's needs and her own. She realized that she could still pursue the things she wanted in life, it just might look a bit different than it might for others her age.

"I let [caregiving] become part of my life," Vanessa said, noting that gratitude helped her to shift her perspective. "Marriah became one of my best friends. I wouldn't change it."



For Laura Marin, her husband and children are important collaborators in the care of her sister Ruthy. As the younger sibling, Laura's role in her sister's life has changed a lot over the years. Initially, it was Ruthy who looked after Laura, but

now Laura has gone from being Ruthy's "chiquita" (little one) to being her caregiver. Ruthy sometimes even refers to Laura and her husband as her parents, telling Laura "Thank you for being my mom."

Laura always knew that she would take care of her sister, and her parents had discussed Ruthy's care with her since she was a teenager. Because Laura moved from Mexico City to Canada as an adult while Ruthy remained in Mexico with her parents, Laura's transition into the role of primary caregiver was one that had to be carefully planned. Ruthy came to visit her sister in Canada while Laura worked towards obtaining Permanent Residency for her sister.

Laura's husband Gerardo has also been involved in Ruthy's life for many years, as he and Laura started dating when Laura was just sixteen years old. Even then, Laura knew that any potential romantic partner had to be excellent with Ruthy, and she would use her dates' interactions with her sister to gauge whether the relationship might work. When Laura and Gerardo started talking about marriage, Ruthy and Laura's father made sure that Gerardo understood that Laura would one day be Ruthy's caregiver.

Laura's husband is now an important support for Ruthy. The couple aligns their hybrid work schedules to ensure that someone is always able to be with Ruthy. Gerardo also sometimes brings Ruthy to his office, where she likes to say that she works as an architect just like him.

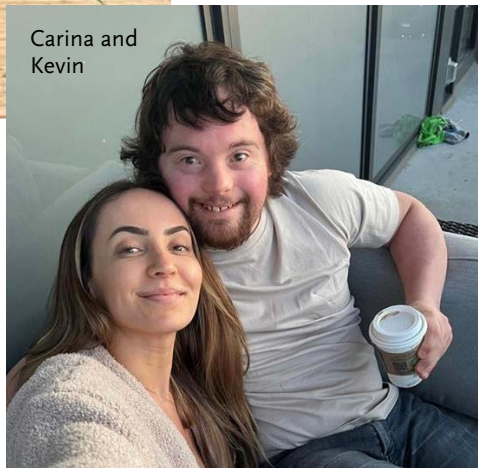
An important part of Ruthy's caregiving plan was set out in Laura's mother's will, which clearly stated that Laura would be Ruthy's caregiver and that Gerardo would care for Ruthy should anything happen to Laura. It was essential that these roles were clearly identified because Laura and Ruthy's brother, who lives in Mexico, did not want to be involved in Ruthy's care and the family wanted to ensure that Ruthy would always remain with Laura or Gerardo.

Laura's two daughters, who are 17 and 19, love to spend time with their aunt and often drive Ruthy to her day programs when Laura and her husband are busy. This helps to offset the family's biggest caregiving challenge - juggling two full time work schedules with Ruthy's care.

Despite the complicated logistics at times, Laura's experience caring for her sister has been a positive one. Everyday moments like driving somewhere with Ruthy and playing some of their favourite music in the car are full of



LaChance Siblings



Carina and Kevin

joy for both sisters. This is a sentiment that is echoed by many caregivers - 61% of those who care for a loved one for 20 hours or more per week found their experience rewarding.

The LaChance family is in an earlier phase of their caregiving journey. Kevin lives with his parents, who are his primary caregivers, and the family has started to think about who will care for him in the future.

Kevin and his parents recently went to a lawyer and with consent from Kevin completed Power of Attorney documents that allow Kevin's older brother Frazer, in consultation with his younger siblings Carina and Derek, to make decisions along with input from Kevin about his healthcare and financial affairs, should his parents be unable to do so. But devising a caregiving plan for Kevin is easier said than done. Two brothers currently live in Europe, and without knowing where each of Kevin's three siblings will be living decades from now and what their situations will be when he is in need of a caregiver, it's difficult to plan for the future.

Kevin's sister Carina doesn't think it's something the family will be able to exactly plan for; they'll have to figure out the details when the time comes. What they do know is that all three of Kevin's siblings feel the responsibility and desire to look out for him, and Kevin himself will continue to be actively involved in decisions about his care. Their hope is that the responsibility of caregiving won't fall solely to one person and taking care of Kevin will be a collaborative effort.

Their mother Laura feels she and her husband can't make the decision whether Kevin's siblings should care for him one day. "It's not their birthright to be caregivers," Laura

said, "It's a decision that they make on their own."

Carina could see Frazer managing the administrative parts of Kevin's care because he's the oldest sibling and he's adept at planning and organizing. She is nervous at times about her own potential level of involvement, as the sibling currently located closest to Kevin. In her 20's, it's difficult for Carina to imagine what her role as caregiver might look like, as there are a number of ways the LaChance siblings could be involved in Kevin's care.

In a 2021 survey of sibling caregivers by Siblings Canada, 20% lived with their sibling with a disability, 41% anticipated living with them in the future, and 89% said they had a supporting role in their siblings' lives.

Carina feels that the beginning of the caregiving transition will be the most challenging as Kevin adapts to lots of changes in his routines, however, she thinks those changes have the potential to bring a lot of personal growth by forcing him outside his comfort zone.

Although the idea of becoming a second-generation caregiver can be daunting, Carina is confident that the four LaChance siblings have a solid relationship and that they will be able to collaborate and figure things out together.

Kevin agrees, saying "Teamwork is important."

For siblings like Carina who might care for a family member with Down syndrome in the future, Vanessa and Laura offered a few suggestions. Both women advised relying on programs and supports that are available like Community Living, local Down syndrome groups, the Disability Tax Credit, and provincial funding. They also stressed the importance of having a strong support system of family and friends.

Perhaps their most important piece of advice? Practice self-care.

"Take some deep breaths, take care of yourself, and don't be hard on yourself," said Vanessa "Don't compare yourself to others."

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Sibling Q&A

- ★ What is one thing you want people to know about living with / having a sibling with Down syndrome?
- ★ What have you learned from your sibling? What lessons have they taught you?
- ★ What activities do you like to do together?
- ★ What is your favourite memory that you have together?
- ★ Have you talked about living together in the future?

What is one thing you want people to know about living with/having a sibling with Down syndrome?

Carina: It is important to know that having Down syndrome means you can have confidence. My best advice is to be respectful, have fun, and remember we are all in this together.

Marla: The most important part is the sibling part, and the Down syndrome stuff is secondary in the relationship. We like to be funny and joke around!

What have you learned from your sibling? What lessons have they taught you?

Carina: She always helps kids to do special activities. She shares toys and love.

Marla: Carina is really good at keeping a positive attitude, and she can find the silliness everywhere. In a really serious world, this trait is so refreshing! Carina does not hesitate to share kind words with people.

What activities do you like to do together?

Carina: We like to paint rocks on vacation, that was fun.

Carina and her sister Marla



We also do swimming. The best part is the holidays. We can do a really nice ukulele duet, that is fun.

Marla: I would add that we like to do art together, and we are pretty great at decorating Christmas cookies!

What is a favourite memory that you have together?

Carina: I remember when you graduated from high school. I am so happy to see you working so hard.

Marla: Carina is a fantastic Auntie, and we are making new memories all the time with her nieces.

Have you talked about living together in the future?

Carina: I think we did. We see each other a lot. We live together for the holidays, that is the fun part. We see each other a lot, and my nieces and family, of course.

Marla: We live in different countries, so that is a bit tricky. We make the most out of our visits together, and we try to see each other as much as we can.

Zamaan and his brother Keyaan

What is one thing you want people to know about living with/having a sibling with Down syndrome?

Keyaan: I want people to know that people with Down syndrome are just like everyone else. They are not limited in any shape or form and have the same capabilities, feelings, and abilities as everyone.

What have you learned from your sibling? What lessons have they taught you?

Keyaan: Zamaan has taught me to work hard, never give up and be kind to others. Zamaan has also taught me some important lessons. These include hard work pays off and keeping going even when things get tough. Zamaan has illustrated these lessons with his business and when he completed a 4 hour literacy exam in high school. I use this as motivation in my everyday life when I'm running track & field or studying for an exam.

Zamaan: Keyaan taught me how to play basketball with him. He also came up with the name for my business, the Granola Kid.

What activities do you like to do together?

Keyaan: Zamaan and I enjoy playing golf together. We try to play once a week and we have a lot of fun. Some of our favorite locations to play include Northlands Golf Course, Northview Golf Course and Burnaby Mountain Golf Course.

Zamaan: We like to go out for lunch and go for walks and runs. We just like to hang out.



What is a favourite memory that you have together?

Keyaan: My favorite memory that I've shared with Zamaan was when we explored the city of Vancouver together. During the summer of 2023, my father was forced to attend a meeting in Downtown Vancouver. This is when Zamaan and I decided to spend the day together. So, we decided to go to an Italian restaurant, but this idea soon changed when

Zamaan told me, "Let's go on an adventure, Keyaan!" I responded and said, "Sure, let's do it." So we decided to walk across the Cambie Bridge and eat a delicious lunch at Earls restaurant. After this we decided to get a coffee at Starbucks and sit by the water in peace. I started to appreciate how mature, smart, and funny Zamaan is and I will never forget this experience.

Zamaan: One of my favourite memories is playing sports together, like basketball. And we get to play golf!

Have you talked about living together in the future?

Keyaan: Yes, we have talked about living together in the future. We have planned our future and what we would like to do and I aspire to become a Sports Medicine doctor while Zamaan continues with his 'Granola Kid' business. We will hopefully be rich enough to buy a mansion in Hawaii and play lots of golf.

Zamaan: We're going to live in a big house - a mansion. We're going to invite all the DSRF students over to visit.

What is one thing you want people to know about living with / having a sibling with Down syndrome?

Sofia: One thing I want people to know about having a sibling with Down syndrome is they bring out the best of you through their constant joyful presence and they shine a whole new light into life. Living with Gianpaul, and his constant joking and loving personality has made me more appreciative of our differences and helped me to realize it's individuals like him that you want around you all the time.

Gianpaul and his sister Sofia



**What have you learned from your sibling?
What lessons have they taught you?**

Gianpaul: What I have learned from my sister, Sofia, is how to do Math, how to kick a soccer ball, how to throw a 3-pointer in basketball. The lessons she has taught me is whatever I am doing to keep trying and don't give up.

Sofia: Through Gianpaul I've learned to be more patient with others. It can take him a little longer to process certain things or complete different tasks but he's taught me that good things take time and we can accomplish great things by being patient with not only others but ourselves too.

What activities do you like to do together?

Gianpaul: Play basketball, soccer. I like making videos on TikTok, watching movies, play video games.

Sofia: Together we like to play sports like basketball and soccer, we enjoy making TikToks, we enjoy going to TFC games together and we enjoy doing car karaoke when we are on drives.

What is your favourite memory that you have together?

Gianpaul: Going to Miami Beach with my sister and spending time with her and playing the pool.

Sofia: My favourite memory that we have together is watching Messi play live on our vacation to Miami, it was a very exciting moment for the two of us and one that we will definitely remember forever.

Have you talked about living together in the future?

Gianpaul: No not yet.

Sofia: Since my brother is 13 and I am 16 we haven't discussed living together in the future yet as it's still early. However it is something I could see us doing when we are older.

What have you learned from your sibling? What lessons have they taught you?

Laura: Ruthy taught me to sing and dance. She taught me what pure love means because she is pure of heart and doesn't have any malice. I have learned how to have patience and how to see things. Every day there's something that teaches me to be better and more pure of heart.

Ruthy: Laura has taught me good things. I do meaningful things with her and my family. We are very close. My family is loving and caring and they give me advice and I listen to them. I like helping my family.

What activities do you like to do together?

Laura: Walking the dog, playing basketball in the park during the summer, going to concerts as a family - Ruthy loves the Jonas Brothers and my daughter recently went with her to one of their performances. Ruthy loves all things music and dancing - sometimes we'll put music on and dance together. We also enjoy going to visit friends together; we have a close network of friends who are family to us.

Ruthy and her sister Laura



Ruthy: I like going out, going to restaurants, shopping, and I love our walks. I really enjoy being with my sister, singing and dancing. She is very loving with me.

What is your favourite memory that you have together?

Laura: Ruthy has an ability to know exactly what needs to be said during difficult moments. After our grandmother passed away, the whole family was very quiet and sad. Ruthy said she wanted to speak to everyone. She told us "Our grandma was always happy and always singing, laughing, and making jokes. I don't think she would want any of us to be like this. She would want us to celebrate her life and how she loved us." That was a special moment.

Ruthy: Being with my sister, singing, dancing and doing everything with her. My sister is a really good mother-figure to me and I love her so much.

CROSS ROAD

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Meets Autism



FEATURING

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Faith Gazzola
Nikhil Ekanayake

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CDSS SPOTLIGHT

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This holiday season, give a gift that gives back! In partnership with local Canadian businesses, we present the CDSS Holiday Gift Shop. Proceeds from the sale of every item go towards essential programs and initiatives for Canadians with Down syndrome and their caregivers. Browse for great gifts today at CDSS.ca/Gift-Guide



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Introducing the Ds Collaborative



We are proud to announce that we have successfully received federal funding for a 3-year project from Employment and Social Development Canada (ESDC) to create the first Ds Collaborative in Canada, a groundbreaking initiative designed to drive positive change and impact within the Canadian Down syndrome community.

The Ds Collaborative will be a network of organizations and self-advocates, united by a common goal – to share, support, and impact the lives of those with Down syndrome and their families. Our objectives are to foster collaboration, facilitate resource-sharing, and create a collective voice that will have a greater impact, working together to transform the landscape for individuals with Down syndrome.

We are actively engaging with Down syndrome organizations to be part of the Phase 1 planning and capacity building. Please stay tuned on social media for updates and new information.

Learn more about the Ds Collaborative at CDSS.ca/Ds-Collaborative

You're Making a Difference!

- 8,000 21 Welcomes Booklets were produced and are being distributed across Canada to help new parents in the Down syndrome community.
- A new Multilingual Caregiver Network was established representing 17 different languages, facilitating more peer-to-peer connections in our community.
- Here I Am brought international awareness and recognition to the aging population in our community, improving representation for seniors with Ds.
- Today & Tomorrow: A Guide to Aging with Down Syndrome was revised to include recent studies, updated health information, and more community voices.
- Inclusive employment resources were developed for new employers joining Inployable to support them during recruitment, hiring, and onboarding.

Important Dates For 2024

| | |
|----------------------------------|-----------------------------|
| <div>March</div> <div>21</div> | World Down Syndrome Day |
| <div>June</div> <div>15</div> | Down Syndrome Walk |
| <div>October</div> <div>20</div> | Canadian Down Syndrome Week |
| <div>October</div> <div>26</div> | |

THANK YOU REXALL CARE NETWORK

We would like to thank the Rexall Care Network for their ongoing support of Caregivers in the Down syndrome community. The tireless efforts of caregivers are essential to our community, and we could not support them without the support of businesses who share our goals and commitment to equality.

OVER 15,000 PEOPLE JOINED THE OFFICIAL CHICKEN PREMIERE

Thank you for your support of the Official Chicken Premiere during Canadian Down Syndrome Week! We are proud to be the sponsor of this award-winning story of sibling relationships. Learn more about the short film and where you can watch it at ChickenFilm.ca.



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If there is a DSRF student who embodies the word achievement, it is Trevor Bush.

Trevor has been a familiar face at DSRF for over 10 years, having attended many of our adult programs as well as speech therapy and one to one reading. But it has been in the past two years that all of Trevor's efforts have really paid off.

In the spring of 2022, Trevor went from severe hearing loss that was managed with a hearing aid in his right ear, to becoming fully deaf. With this sudden change in his hearing profile, Trevor was no longer able to rely on his hearing to understand others.

As a result, he had to learn to use a combination of sign, spoken, and written language to communicate, along with visual aids. The improvements in Trevor's reading comprehension and writing skills, which he

Trevor Bush Honoured with George Klukas Achievement Award

developed over the past decade, proved crucial as reading and writing became his primary forms of communication.

Trevor also began using a variety of communication devices, including a book filled with pictures and information about his life. He is constantly adding new pages to his book so he can share about himself and learn about others.

Trevor did not skip a beat in the face of his big life change. He continued doing all the things he loves, including socializing with his friends and family, and taking programs at DSRF.

In September 2022, Trevor underwent surgery for a unilateral cochlear implant. He took to his cochlear implant from the start, which is no easy feat considering it takes lots of dedication and practice to adjust to hearing through this device.

Trevor has met every challenge head on with a resilient and positive attitude. He has an infectious zest for learning and is always up to trying new things. His warm spirit is welcoming and generous, and we are grateful to have him as part of the DSRF family. Congratulations, Trevor!



DSRF Launches Down Syndrome Academy Mobile App

In September, the Down Syndrome Resource Foundation introduced the Down Syndrome Academy, an online education portal offering self-paced multimedia courses on a variety of topics related to Down syndrome, along with a private Down syndrome community.

Now, the Academy is more accessible than ever with the launch of DSRF's first-ever mobile app. The Down Syndrome Academy app is now available for free download from both the Apple and Google Play stores.

The Down Syndrome Academy app provides on-the-go access to all Academy Courses, including Down Syndrome 101, Mental Wellness for People with Down Syndrome, Supporting Learners with Down Syndrome + Other Developmental Disabilities, and more.



The app is also the ideal way to engage with the DSRF Circle of Support, a private Down syndrome social community that is included for free with enrollment in any Academy course.

In its first month, the Down Syndrome Academy attracted over 200 users. One parent said, "I'm so excited for the Academy. This is an AMAZING resource! Wow! Thank you!!" Another user exclaimed, "The inception of the Down Syndrome Academy is not just a leap, but a boundless flight into the world of inclusivity and empowerment! It's about time we had accessible, specialized resources for individuals with Down syndrome and those who wish to understand more about it."

Visit DSRF.org/app to download the Down Syndrome Academy app, and be sure to leave us a rating and review!

CrossRoad: Where Down Syndrome Meets Autism (Short Film)

In late October, DSRF celebrated Canadian Down Syndrome Week by releasing the latest in our series of short films.

CrossRoad: Where Down Syndrome Meets Autism features three families whose child has both Down syndrome and autism. The families open their lives to let us see both the joys and the challenges they experience as they navigate multiple disabilities.

DSRF speech therapist Liv Meriano explains the similarities and differences between the two conditions, why it can be difficult to identify autism in a child who has Down syndrome, what to do if you suspect your child might have autism, and how to support a child with Down syndrome and autism.

It is estimated that 16-18% of people with Down syndrome also meet the criteria for autism. *CrossRoad* dispels some of the mystery behind the dual diagnosis and celebrates those who are on this complex journey. Watch it now at DSRF.org/CrossRoad.



Down Syndrome
Resource Foundation



FRIENDS OF DSRF

DSRF's signature fundraising event Up the Down Market returned this fall to Vancouver, Calgary, and Toronto. Over \$350,000 was raised at the three dinners, with all proceeds supporting DSRF's pre-employment programs for adults with Down syndrome. Special thanks to National Sponsors the Air Canada Foundation, the Answer Company, Phillips, Hager & North, MAWER, SLC Management, CIBC Asset Management, Connor, Clark and Lunn, Jarislowsky Fraser, PIMCO, and WTW; Local Sponsors LiUNA, Aviso Wealth, Fiera Capital, Klukas Investments, QV Investors, RP Investment Advisors, Bloomberg, Concert Properties, Lincluden, Loomis Sayles & Company, Mercer, Odlum Brown, Steadyhand, and Lawson Lundell; and Media Sponsor CTV. You have made a lasting investment in people with Down syndrome.

Longtime supporter the Ames Family Foundation has generously donated \$32,000 in support of several projects including DSRF's Down Syndrome Academy and mobile app, our employment support service, the purchase of assessment and learning tools, and training for family caregivers. We are deeply grateful for the Foundation's commitment to helping people with Down syndrome and their families flourish.

UPCOMING AT DSRF

Flourish for Life Campaign: *Throughout December*

DSRF's Magical Morning: *December 15, 2023*

Down Syndrome Film Festival: *March 16, 2024*

World Down Syndrome Day: *March 21, 2024*

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

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A Guide to Aging with Down Syndrome

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