

Summer 2023

ISSUE #15

3.21

Canada's
Down Syndrome
Magazine

**THINKING
CLEARLY ABOUT
DOWN SYNDROME
AND ALZHEIMER'S:**

*An Interview with
Dr. Elizabeth Head*

Here I Am
**Exclusive
Interview and
Photo Essay**

**Practical
Preparations
for the Aging
Caregiver**

Aging with Down Syndrome

Plus: Self-Advocate Q&A on the Joys of Getting Older



Over the past four decades, people with Down syndrome have achieved an astonishing increase in life expectancy, rising from just 25 years in 1980 to over 60 years today. Thanks to improved awareness and medical advances, more and more individuals with Down syndrome are living long, healthy, and rewarding lives.

It's a development worth celebrating, and we do just that within this issue of 3.21 Magazine. The centrepiece is the heartwarming photo essay *Here I Am*, which dispels the misconception that people with Down syndrome do not live into their adult and senior years. The project showcases a powerful series of portraits featuring Canadians 40 and over with Down syndrome alongside their childhood selves. We dare you to try not to smile as you see the joy captured on these beautiful faces!

Of course, getting older brings its own set of challenges for all of us. Within these pages, we examine a pressing concern for people

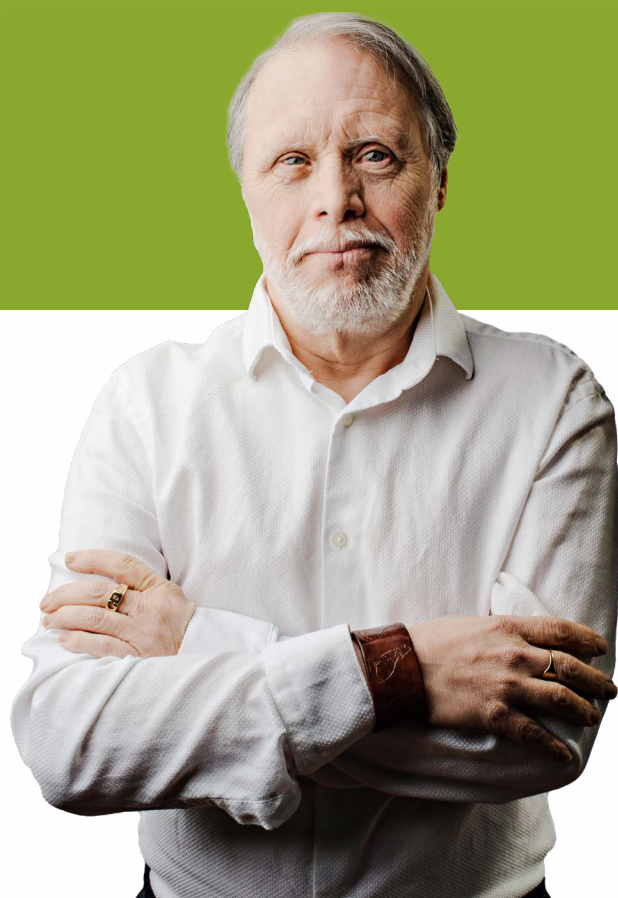
with Down syndrome and their loved ones. Dr. Elizabeth Head has dedicated over 25 years to the study of aging and Alzheimer's disease with a focus on people with Down syndrome, and she helps us think clearly about this widespread condition.

Also in this issue, we consider the complex subject of transitioning care as caregivers age and we share the stories of older adults with Down syndrome and what they love about life. We hope this edition of 3.21 expands your horizons as you and your loved one with Down syndrome look ahead to their golden years.

Glen Hoos
Director of Communications
Down Syndrome Resource Foundation

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



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Here I Am

Photo Essay & Exclusive Interview with Photographer Hilary Gauld of One for the Wall

Life expectancy for Canadians with Down syndrome has more than doubled over the past 40 years—from 25 years in 1983 to over 60 years today. Yet many people still have the false assumption that individuals with Down syndrome do not live into their senior years.

This photo essay, “Here I Am” by CDSS and photographer Hilary Gauld of One for the Wall, refutes this misconception with a powerful and indisputable series of portraits featuring seniors and adults with Down syndrome over 40 years of age.

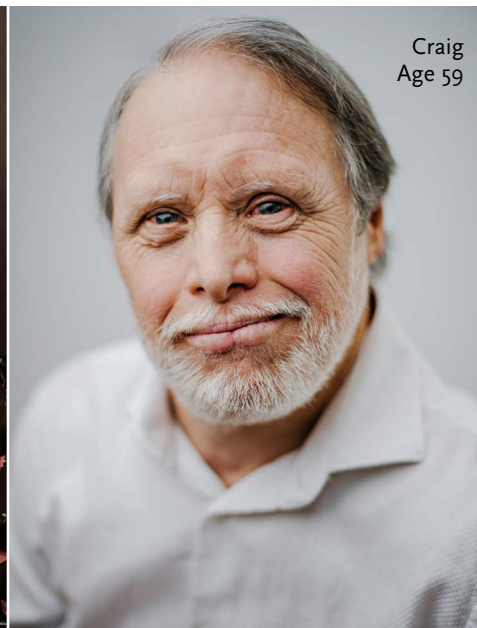
The portraits featured here are previously unreleased and can be only seen in this issue of 3.21 Magazine. You can view the complete photo essay online at CDSS.ca/Here-I-Am.

Thank you to all 13 of our participants and their caregivers who so graciously allowed us this window into their lives. (You can learn more about our participants in this issue’s Self-Advocate Q&A!) Bringing attention to our aging community members and their needs is important to us all, and will continue to be a pillar of our efforts moving forward.

Do you have a photo or story about a loved one over 40 with Down syndrome you’d like to share? Please send it to CourtneyC@cdss.ca - we have received many submissions already and would love to see more!



Maryann
Age 60



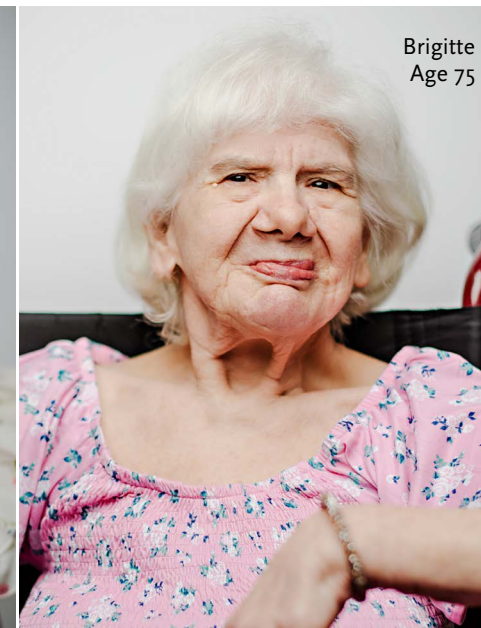
Craig
Age 59



Chrissy,
Age 45



Lynn,
Age 58



Brigitte
Age 75



Michael
Age 58



Owen
Age 56



Brandon
Age 46



Melissa
Age 46



Allan
Age 44



Gus
Age 49



Myron
Age 52



Sean
Age 49

EXCLUSIVE INTERVIEW WITH HERE I AM PHOTOGRAPHER HILARY GAULD

By Courtney Cassel

COURTNEY:

How did you feel meeting with people in their homes and hearing their life stories? Was it an emotional experience for you?

HILARY:

Although this latest project was much more challenging to execute because of accessibility to our participants, I was happy to meet them in their homes. It gave me a chance to see where they call home, to be surrounded by the things they love, and to meet the people who care for them. Their lived experiences were most important to me; how they spent their birthdays, what they were most proud of in life, what activities they enjoy doing, and who they like to spend time with.

Seeing the participants with their families was most emotional for me. There was so much love!

COURTNEY:

You mentioned that one of the participants had a funny response to the question ‘Do you think you’re old?’ Can you tell us that story?

HILARY:

Many of us seem to be more aware of the people aging around us than ourselves - as though somehow aging does not apply to us! Many of the people whom I photographed felt that they were young and those around them were old. When asked if he thought he was old, Gus said to his sister, “I’m not old. You’re old!”

COURTNEY:

Can you comment on the challenges you experienced connecting with seniors with Down syndrome?

HILARY:

Although we had a great number of participants reach out to be a part of this series, some of the challenges were connecting with their caregivers. Some participants had multiple caregivers that needed consent given, others had caregivers that only used the phone for communication. As people with Down syndrome are aging, so are those around them, and that made scheduling more challenging.

COURTNEY:

Were there any interesting lessons that came out of your experience?

HILARY:

I have found over the years that the one common element to all of these photo sessions and how they go is the music. Music calms. Music excites. It elicits a response. This project was no exception. For the adults with Down syndrome in the project that were non verbal - this was a huge way to connect during our sessions.

COURTNEY:

You have dedicated a great deal of time in your career to improving the representation of people with Down syndrome. What do you hope the impact is in our community and beyond?

HILARY:

When I first started these projects almost a decade ago - very little imagery existed. And certainly not imagery that was of good quality. I knew there was a gap in representation within this community on a global scale and I wanted to change that. I wanted to contribute to more accurate imagery of people with Down syndrome and images that were of better quality that really showed the world who these people are.

THE CONNECTION

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Thinking Clearly About Down Syndrome and Alzheimer's:

An Interview with Dr. Elizabeth Head

The LowDOWN: A Down Syndrome Podcast recently welcomed Dr. Elizabeth Head to discuss Down syndrome and Alzheimer's disease. Dr. Head earned a Master's in Psychology and a PhD in Neuroscience at the University of Toronto. She received postdoctoral training at the Institute for Memory Impairments and Neurological Disorders at the University of California – Irvine. Dr. Head moved to the University of Kentucky in January of 2009 and served as a Professor and Associate Director of Education at the Sanders-Brown Center on Aging. Now at the University of California – Irvine, she is a Professor and Vice Chair for Research in the Department of Pathology & Laboratory Medicine. Dr. Head has dedicated over 25 years to the study of aging and Alzheimer's disease with a focus on people with Down syndrome. She has published over 200 papers and her research is supported by the National Institutes of Health. The goal of her research is to contribute to the development of interventions that will promote healthy aging in people with Down syndrome. This article is a lightly edited transcript of a portion of The LowDOWN Podcast episode, produced by the Down Syndrome Resource Foundation. The full conversation can be found at DSRF.org/podcast.

The LowDOWN: Can you begin by defining Alzheimer's disease and dementia, which are often used interchangeably?

Dr. Elizabeth Head: Like you say, a lot of people interchange Alzheimer's disease with dementia. Dementia is a clinical set of signs including a loss of memory and a loss of function, such as forgetting where we parked the car. These symptoms can happen for a number of different reasons, but the most common cause of dementia is Alzheimer's disease, in which people have plaques and the tangles in their brains. But there are other kinds of dementia that are caused by other diseases in the brain. For example, Lewy body disease looks slightly different. It certainly is dementia, but it's caused by a different set of proteins that are abnormal in the brain. So, dementia is the umbrella term, and underneath that you have specific types of dementia like Alzheimer's disease, Lewy body disease, and frontotemporal dementia.

LD: With respect to the Down syndrome population, when they develop dementia, is it always Alzheimer's, or have other forms of dementia also been observed?

EH: In my personal opinion, it's almost always Alzheimer's disease. I believe there are a few case reports out there suggesting that one person with Down syndrome had Lewy body disease. If that happens, it's incredibly rare. I think we can be pretty confident when we think about what interventions we are going to design for the future.

LD: What are some of the symptoms or characteristics that you see in Alzheimer's disease, and are they different for people with Down syndrome?

EH: In the general population, usually the earliest sign is memory loss, although there can be other profiles or variants of Alzheimer's disease that show up early,

looking a little bit different. But memory loss is the key thing. That then progresses to language problems and difficulty with objects in space and placement of things, before transitioning into more behavioural and psychiatric problems. It just gets progressively worse, until the person really can't take care of themselves.

For people with Down syndrome, it's essentially the same pattern. Families will report memory changes, but the most common thing we hear from families is a change in behavior. The person becomes very withdrawn, not interested in the same hobbies and activities as they used to be. That's often what really triggers families: something's changing. What we're looking for is change over time. A single visit to a clinician may give them a good guess at what's going on, but we really firm up that diagnosis when we see that person again after a period of time, and there's been a decline.

LD: We should note, for families who are seeing behavioural changes, there could be many other causes besides Alzheimer's, some of which are temporary and very treatable. It's important to see your doctor before assuming that you're dealing with Alzheimer's.

EH: I'm really glad you mentioned that because I am seeing more discussion of regression, which typically happens in younger adults. If it's not in the age range where we start to think about Alzheimer's disease, there are likely other explanations, and it could be something as simple as environmental changes.

LD: Speaking of which, what is the age when Alzheimer's becomes an issue for people with Down syndrome?

EH: 40-years-old is a pretty comfortable cutoff. However, we're starting to see the age shift later, more towards 50. That's fabulous, because it means people are better managing their health and lifestyle which may reduce their risk of Alzheimer's.

LD: What are the current incidence rates? Can we expect all individuals with Down syndrome to develop Alzheimer's as they age?

EH: Unfortunately, the cumulative risk for people with Down syndrome 65 and above is 90% with signs



of dementia and Alzheimer's disease at some point. When we look back at all the different studies of groups of people around the world, it never quite reaches 100% even in the oldest people with Down syndrome – there are 10-15% of people with Down syndrome who get into their sixties and even early seventies without showing change in cognition. This happens in the general population as well, of course: certain people live to be very old, and though they have a lot of the risk factors, they don't develop dementia. We are very hopeful that we are going to get a better handle on this and see those numbers go up.

LD: There must be some things we can learn from those who don't develop it, to advance prevention and treatment.

EH: That's what's so fascinating. Individuals with Down syndrome are a gateway to learning more about Alzheimer's in general. We are working to determine the genetic and physiological components of Down syndrome that contribute to the development of Alzheimer's, which helps everyone – people with and without Down syndrome.

In the general population, people develop Alzheimer's disease anywhere between 65 and 125 – that's kind of a made up a number, but there's a huge age range for when a person might begin to decline. Plus, that decline could be Alzheimer's, it could be Lewy disease, there could be many things contributing. So, when you are trying to understand biomarkers such as fluid measures or interpret neuroimaging brain pictures, it gets really complicated.

In contrast, for people with Down syndrome, because of their genetics and the extra copy of chromosome 21, the changes in their brains reflecting Alzheimer's disease are strongly age dependent. By age 40, we typically see full-blown Alzheimer's disease in the brain, but that isn't necessarily reflected in their change of function. In their thirties, they're starting to develop the earliest signs, but in their twenties, they seem to be okay.

As a result, we can better understand what's coming first in the order of events that leads to disease, which is really hard to do in the general population – in fact, it's almost impossible. These age-related changes in people with Down syndrome tell us a huge amount about how Alzheimer's disease develops, and which markers in the blood or in an MRI signify that a person is on that trajectory. That's why we can take a lot of what we learn from people with Down syndrome and not only use it to help find ways to prevent Alzheimer disease in Down syndrome but also apply it to the general population.

LD: Do you have any advice for families who are navigating an Alzheimer's diagnosis now with their loved one with Down syndrome?

EH: The advice I would give is to always keep a positive attitude. I'm sorry if that's a little Pollyanna, because I know for families going through this process, it's incredibly hard. There are going to be behaviours that are hugely challenging to deal with, and there are not a lot of resources out there. But don't give up on trying to manage those behavioural changes, which can be aided by medication. Keeping up with the person's routine is very valuable. And of course, it's never too late to introduce healthy lifestyle habits, even though it may be challenging. Take walks; try new foods. Engage in social activities as much as possible, and make sure the person is getting enough sleep.

Finally, don't neglect caregiver respite, which should be part of the treatment plan. A break for the person taking care of a family member with Down syndrome is critically important. We're treating the whole family, not just one person.

Resources

[Down Syndrome + Alzheimer's Disease Information Page \(DSRF\)](#)

[Mental Health and Aging: An Interview with Dr. Brian Chicoine](#)

[Down Syndrome and Alzheimer's Disease: Supporting Communication \(Video Presentation\)](#)

[National Down Syndrome Society: Alzheimer's Disease and Down Syndrome](#)

[National Task Group on Intellectual Disabilities and Dementia Practices](#)



Practical Preparations for the Aging Caregiver

By Adelle Purdham

We all require varying levels of support throughout our lives, and this is especially true for individuals with Down syndrome. Eventually for all of us, the question becomes: who will look after your loved one once you're no longer able to?

There are all kinds of other questions hidden within that one. Where will they live? What if they don't have family

willing or able to step in as caregivers? What decisions need to be made early on and what steps can parents and guardians take to both protect their loved one and ensure the continuation of a meaningful and fulfilling life? How do we set our child up on a trajectory that will lead to an enriched future built on community and the sense of love and belonging that every person deserves?

Evie Allgeier and her mom Wendy Newbery

A Supportive Community

Preparations can begin as early as prenatally or as late as today. A great first step is to build connections and foster existing relationships.

Many people with Down syndrome require a caregiver, which mom and support group facilitator Wendy Newbery describes as "someone who holds important pieces either in a direct way (personal care, homemaking, coordination, and planning), or in a facilitative way (double checking money management, keeping a watchful eye on healthy living skills, being responsible when something tanks), or both." But a caregiver doesn't have to be only one person or a couple; having others who support the primary caregiver is hugely beneficial. This is where the notion of Support Circles comes in.

Circles of Support are a way of conceptualizing an individual's support network. They are comprised of a dedicated group of individuals who care for and are present in the life of a vulnerable individual. Based on a person-first approach that centers on the individual's talents, gifts, dreams and circumstances, members of the Circle foster meaningful community participation.

Circles of Support are not a one-and-done exercise; they must be nurtured and maintained over time. Members often spend time with the individual doing mutually

enjoyable activities, such as going to the movies, taking a walk, or grabbing a coffee. (For more detailed information and resources to create your own Circle of Support visit www.inclusion.com and www.plan.ca.)

Legal and Financial Considerations

From a legal and financial perspective as a caregiver, three essential pieces should be considered: creating a will, buying a life insurance policy, and opening and contributing to a Registered Disability Savings Plan (RDSP).

The ideal time to get a will is "as soon as you have children, especially if you're a single parent," says Shannon McCrae, an independent financial advisor who specializes in estate planning for families who have a family member

with special needs. “You don’t want someone else taking that decision from you when you’re not around.” Some families purchase a Life Insurance Policy which will pay an amount to their child when the parent(s) dies to provide financial resources for ongoing care.

Shannon suggests being overprepared and keeping your will current following any major life changes. Additionally, she recommends setting up a trust to protect assets that may eventually go to your loved one to ensure their inheritance will not impact receiving funding, government or otherwise, that they will depend on. “And not just any trust,” she says. “The right trust.” Your Will should direct any inheritance for your child to an Absolute Discretionary Trust, sometimes referred to as a Henson Trust. Shannon urges families to review their provincial and territorial regulations and to hire a lawyer who specializes in assisting families who have children with disabilities with their estate planning.

Being prepared also involves choosing Powers of Attorney for Personal Care

(health) and for Property (financial), for you and for a child once they reach the age of majority, either 18 or 19 years of age depending on where you live. If a child over the age of majority is able to provide their input, and meets capacity requirements for signing legal documents, they should be supported to do so.

“We’re more likely to be medically incapable before we die,” says mom, author, and disability advocate Lucinda Hage, whose adult son Paul has a developmental disability. Paul accompanied her to meet with a lawyer and offered his consent in response to the family members that were chosen as his Powers of Attorney that will cover his property and personal care. In this way, Paul is being given agency over the decisions that impact his own future, and having a say means he’s more likely to be happy with those choices when the time comes.

A Registered Disability Savings Plan (RDSP) is another consideration. Amongst saving tools, an RDSP is an excellent tool where one receives federal grant amounts on setup at a financial institution. A Disability Tax Credit Certificate is required to open a RDSP. Shannon emphasized that while opening a RDSP may be the easiest to do, a will and purchasing life insurance are the most important. Shannon also points out that leaving things until the last minute “is going to cost you more in the end.”



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+ Hina Mahmood, OT

The LowDOWN
A Down Syndrome Podcast





Mary Lynn Cassels and Scott Fattedad

Housing

Housing and living arrangements are another big consideration. Several housing models exist, depending on where you live, including: moving to a government subsidized community group home, a domiciliary hostel, a pay out-of-your-pocket community group home independent living with shared accommodation, a shared accommodation with one or more

roommates, or moving in with a new family member or caregiver, a “homeshare”, where a family or couple is paid to accommodate the individual with Down syndrome in their home and assist with their shopping, cooking, and other daily activities (e.g. travel to employment, programs, Special Olympics). Based on experience, Lucinda Hage cautions against shared living with only one other person in case the arrangement doesn’t work out.

Mary Lynn Cassels, mom to 41-year-old Scott, had her son go through a experience with independent living. Mary Lynn is now embarking on a model with one other parent called ‘Reverse Home Share,’ whereby a caregiver, or caregiving couple, will pay part of the rent in the house or apartment that her son Scott co-rents and lives in with a friend. Scott has built a life in his small town, and this forward planning will allow for the continuity of his job, social life, and his place in a community that celebrates him, and that he knows how to navigate. Lucinda is planning to adopt a similar model and has purchased a home that is 99% in her son Paul’s name, under trust.

How to pay for housing? No direct funding for housing currently exists, but in some provinces funding may be available to assist with the cost of housing through Community Living and requests to the Ministry of Social Services. Costs related to supporting daily independent living, however, may be offset by funding through your local or regional agencies.

Suzanne Zwara, single parent to 27-year-old Brenden, urges other parents to submit housing plans to their respective Ministry of Social Services to show the government there is a need. Without a plan in place or family to intervene, individuals with Down syndrome are often placed in government subsidized group home scenarios. According to Suzanne, the yearly cost to maintain a young adult in a group home is six times more expensive than the roommate housing model she priced out for her son.

Microboards

Brenden is an only child. With the support of an independent facilitator, Suzanne set up a ‘microboard’ that will ensure Brenden’s caretaking and housing needs are looked after. Microboards are formalized Circles of Support comprised of a small group of family and friends (a minimum of five) who join with a person with a disability to create a non-profit organization. The legal fees associated with setting up Brenden’s microboard totalled about \$2,000, but the cost of microboards varies greatly and can be done for less in some situations.

Brenden has fourteen people on his microboard. These are people “who are in the picture,” says Susan, and who keep in regular contact with Brenden in his daily life—people with whom Brenden has a meaningful relationship. Members include friends, cousins, and past school friends, as well as professionals. Each person has a self-appointed role on the board to make sure all of Brenden’s needs are met, including his living situation, social activities, recreation, and holidays. For more information about microboards, visit: www.planningnetwork.ca/resources/microboards-safeguarding-the-future-for-our-loved-ones

Foster Independence

“We do a disservice to our loved ones with disabilities by always being there for them,” says Wendy Newbery. “We need to practice being apart so that we can all enjoy our lives and so that when we die, our kids know that their care needs can be met by others.”

Investing time in social interactions and building relationships with others will help make the individual’s transition to an eventual new living situation smoother. Debbie Boycott, mom to 39-year-old Emily, plans to set up rotating weekends away for Emily to stay with other families in her friend circle. Each family will take a turn, allowing the other families respite while the adults with Down syndrome benefit from coping with new situations and being away from home—without family. Inclusive summer camps and respite care, accessed through Community Living, are also great options to foster independence and adaptability.

Find Your Village

You are not alone in preparing for your child’s future, but you do have to put in the work. “The onus is on the caregiver,” says Lucinda Hage.

Consider joining or forming a support group for parents and caregivers to adults with developmental disabilities in your area. Retired Independent Facilitator Wendy Newbery, who is also a parent to thirty-year-old Evie who has Down syndrome, helps facilitate one such group in the Waterloo Region (ON) called A New Chapter. She is part of a team of seven parents who coordinate monthly meetings, with topics such as grief, self-care, planning for the future, building networks of support, Individualized Funding, and local recreation resources. Each meeting covers a topic related to supporting the caregivers or learning about ways to support their loved ones with disabilities. “The work of a caregiver is all encompassing,” Wendy says. “Meeting with others who love and provide care for their loved one with disabilities is normalizing and reassuring.”

While the task of planning ahead can feel overwhelming, there are comprehensive resources that can help. Families

can find out more about building networks by connecting with Planned Lifetime Advocacy Network. You can also find free online webcasts, action guides, networks, federal and provincial supports, and a wealth of knowledge at the P4P Planning Network. Every resource is designed specifically for the relative, friend or caregiver of a person with a disability. We recommend the popular book Safe and Secure: Seven Steps on the Path to a Good Life for People with Disabilities by Al Etanski. Additionally, reach out to Community Living and your regional Developmental Service program, which may offer workshops and housing navigator sessions that teach parents how they can make shared living arrangements happen.

But what happens... after?

Following the death of her mother, fifty-six-year-old Ruth Marin moved from Mexico to Canada to live with her younger sister Laura and family. At the time, Ruth appeared older than her fifty-one years. She was overweight with rashes on her skin and disheveled gray hair she refused to style. Though Ruth demonstrated athleticism and artistic talent from an early age, as her parents’ health declined,

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Ruth Marin

they were no longer able to get her out of the house for activities and Ruth's life became sedentary.

Moving in with her younger sister gave Ruth a lifestyle makeover. They are an active family that get out for regular dog walks and plays in the park. "Being active," Laura says, "got Ruth into a different mindset, and she has flourished."

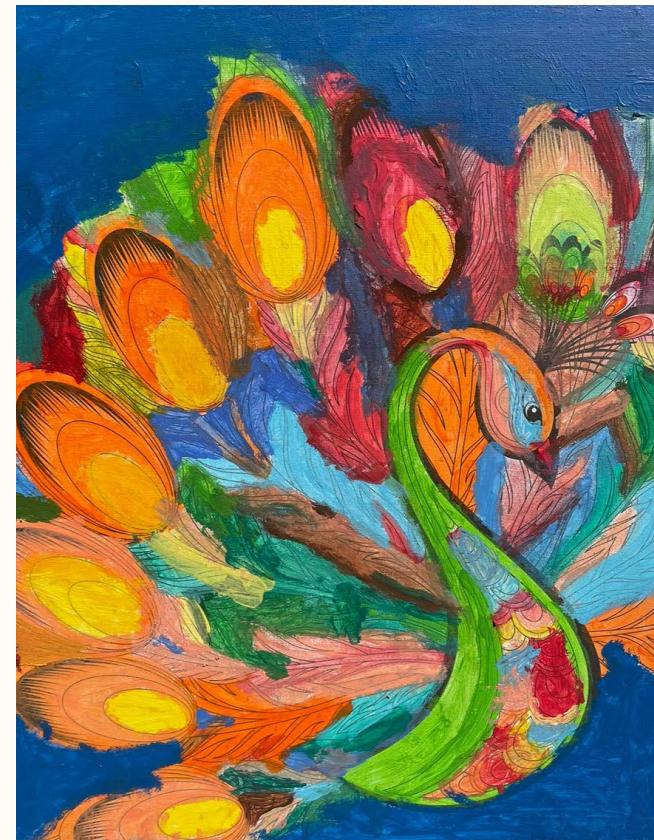
Ruth spends three days a week at a day program through Community Living. Laura's husband is an architect and Ruth enjoys copying her brother-in-law's house drawings. Ruth also paints and has her own dedicated space in the home for her art projects. One of her paintings—a peacock—recently won a provincial art contest for World Down Syndrome Day. Ruth enjoys girls' nights with her nieces, which they call Convivio. This weekly date is their chance to eat a few treats, watch a movie and laugh together.

As a new caregiver, Laura has found real community and support through her local and provincial Down syndrome associations. She says that Ruth has enriched the life of every member of her family: "She's my angel."

The Heart of the Matter

While practical tips are important, the essential component of this entire process is the human being at the heart of these decisions. What are the wishes of the person with Down syndrome themselves? This question needs to be at the core of planning any version of their future, and they should be actively involved in that process. Discuss plans and have conversations early on to alleviate stress and guide expectations for the future.

In speaking with Emily Boycott, she is direct about not wanting to think about a future without her parents—



nobody does. Yet she is also clearheaded about where she might live and who will care for her when the time comes. Emily's four siblings have each expressed a desire for Emily to continue to be a part of their lives and homes, and Emily knows she will likely go live with her oldest sister nearby. But what is most important to her with regards to the future? Her relationships and connections to others.

"I like being with people," Emily says. "As long as I'm with company, nothing else matters."

Adelle Purdham can be found at www.adellepurdham.ca.



“Losing friends very, very close to me has been hard as I get older. Growing older means just enjoying life and being on earth and enjoy day by day.”

Sean. Age 49

Self-Advocate Q&A

“46 is still young! I am going to take care of my mom. I love my mom so much. She will always be my best friend.”

Brandon. Age 46

How do you feel about getting older?

“I am young at heart. I like to be on my laptop, my phone, colour pictures, go shopping with my mom, and go for walks.”

Chrissy. Age 45

“ Our parents told us that Brigitte wouldn’t live past 7 and now she is 75. She is thought to be one of the oldest living persons in Canada with Down syndrome. She complains a little bit of arthritis in her back and feet, and I tell her we’re just getting old! I’m very proud of her and shocked that she made it this long.

Mariana, Brigitte’s Sister ”



“ At age 44, Allan has grown to become a much more independent person and his family is incredibly proud of him.

Sonia, Allan’s Sister-in-Law ”



“ It is harder for Maryann to get around as she gets older. But Maryann doesn’t think she is old. She likes rock and roll, Sonny and Cher, and Kenny Rogers.”

Susan, Maryann’s Sister ”



Join the Down Syndrome Walk June 17th!

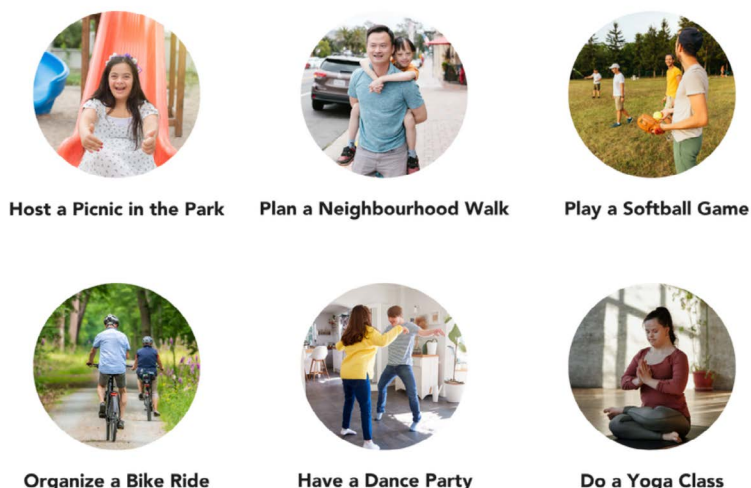
Show your support for the Canadian Down syndrome community and register yourself or your team for Canada's only national Down Syndrome Walk. You'll be making programs like Inplayable and awareness initiatives like Here I Am possible.

Invite your friends, family, coworkers, and classmates to join you - hundreds of people from coast-to-coast will be coming together in their local communities! To make the event more accessible for all, you can choose how you'd like to participate:



Register at
DownSyndromeWalk.ca

Don't forget to join the nationwide Virtual Celebration on our CDSS Facebook page on Saturday, June 17th at 7:00pm EDT co-hosted by Heather Avis of The Lucky Few. Other surprise guests, special announcements, and top fundraiser congratulations will be made during the celebration, so make sure you're following our Facebook page!



Meet Your Walk Ambassadors

This year's Down Syndrome Walk Ambassadors were chosen from across Canada to represent their local communities and lead the celebration for us! Thank you all for your leadership and dedication to our community.

- Krista Rowland-Collins & Family
- Ashley & Lyla Bowerman
- Breigha Wynter
- Paul Sawka
- Brittany and Henry Caffet
- Monika Myers
- Tara McCallum
- Nao Hatamochi and family
- Candice and Piper Sampson
- Arthur Carr & Family



Over 165 Million Views

As a community through your shares, comments, likes, articles, and word of mouth, we have now reached over 165 million people with our Here I Am photo essay awareness initiative. Wow! Just wow! Together our voices are so strong, we can make anything possible.

Thank you all for your support of this project - representation for the aging members of our community is clearly very important to us all. We ask for your continued support as we build new, meaningful programs and initiatives that continue to bring much-needed attention to aging issues, but also provide real-world support to improve day-to-day life.



NEW 21 WELCOMES



The newly revised 21 Welcomes booklet for new and expecting parents will be available June 18th! You'll find more stories, more lived experiences, and updated information for parents on pre and postnatal care.

It will be available for download in our resource library: CDSS.ca/Resources/

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DSRF CORNER

First Down Syndrome Film Festival Shines Spotlight on People with DS

All the stars came out to DSRF's inaugural Down Syndrome Film Festival in Burnaby on March 18. And by "stars," we mean people of all ages with Down syndrome and other developmental disabilities who lit up the red carpet with beautiful smiles and stylish outfits.

Over 235 people attended the festival, which featured the Burnaby premieres of three films starring people with Down syndrome who are students at DSRF: Raising Ava Rose, Minding My Own Business, and Lay Down Your Heart, along with the trailer for the upcoming short film Chicken. The event was hosted by DSRF Ambassador Danielle Juilfs, with other adults with Down syndrome introducing each film.

The enthusiastic audience was united in its praise for the films and their stars, with one parent sharing, "(The festival) was spectacular! Every film was so well done and I saw (my son) in those people. I looked over and he was crying. I think it was really moving for him to see and he could relate. It is wonderful what DSRF is doing!"

Caroline Coutts from the National Film Board of Canada, which produced Lay Down Your Heart, was equally effusive. "Congratulations to everyone at DSRF for such a wonderful event! I loved that you had set up the photo wall with a dedicated photographer and that everyone could get their photo taken. And your moderator for the evening and all the folks who introduced the films were such pros. The whole mood of the event was so celebratory and welcoming. Everyone obviously had a great time (including me!) and I was proud to be a part of it."

Thank you to everyone who joined us for the Down Syndrome Film Festival!



This is the Real Us: Born with Down Syndrome

In today's world, there is a lot to speak out about, and people with Down syndrome should have their voices heard on all issues that impact their lives. In DSRF's Speaking Out program, students learn about many of the important issues our community and our world is facing. More importantly, they learn how to share their thoughts on matters that mean a lot to them.

In the new video "This is the Real Us: Born with Down Syndrome," members of DSRF's 2022-23 Speaking Out class tell us what they want others to know about people with Down syndrome before showing off their unique talents. Watch the video here.

DSRF Advocates to Senate for Creation of Canada Disability Benefit

In late March, DSRF's Director of Communications Glen Hoos appeared as a witness before the Standing Senate Committee on Social Affairs, Science and Technology, calling for the establishment of the Canada Disability Benefit.

The Committee is currently studying Bill C-22, an Act to reduce poverty and to support the financial security of persons with disabilities by establishing the Canada Disability Benefit and making a consequential amendment to the Income Tax Act. The bill received cross-party support and passed third reading in the House of Commons in February 2023, and is currently before the senate.

Hoos, who in addition to his work with DSRF was able to provide a personal perspective as a husband and father to three immediate family members with disabilities, advocated for the swift passage of the bill and implementation of the Canada Disability Benefit before the end of 2023. Click here to read his opening statement to the Committee. To learn more about this important legislation, listen to the recent episode of The LowDOWN Podcast featuring Rabia Khedr, National Director of Disability Without Poverty.



FRIENDS OF DSRF

The Down Syndrome Film Festival was a huge success thanks in part to lead sponsor LiUNA Local 1611. Thank you to LiUNA for supporting this first of its kind event – it won't be the last!

LiUNA Local 1611 and the BC Maritime Employers Association each provided matching donations of \$3,210 for our World Down Syndrome Day 3-2-1 Challenge fundraiser. Thanks to their generosity and the many individuals who donated on March 21, we raised over \$14,000 – a new record for the single day campaign.

We are excited to introduce the new presenting sponsor of Run Up for Down Syndrome, Upper Canada Forest Products. We look forward to seeing the Green Team at the starting line on June 4th. Thank you for helping people with Down syndrome thrive!

UPCOMING AT DSRF

Run Up for Down Syndrome: June 4, 2023

Summer Camp: July 4 – August 11, 2023

Up the Down Market Vancouver: October 11, 2023

Up the Down Market Calgary: October 19, 2023

Up the Down Market Toronto: November 2, 2023

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DSRF.org

Down Syndrome
Resource Foundation





Join Us From Coast-to-Coast!

Down Syndrome **WALK**

Saturday, June 17th

Ambassadors across Canada are hosting local events in support of Canadian Down Syndrome Society programs. Get involved by hosting your own event, attending an Ambassador event, or making a donation. Learn more at:

DownSyndromeWalk.ca



Canadian
Down Syndrome
Society



Don't miss the Virtual Celebration on the Canadian Down Syndrome Society Facebook page at 7pm EDT co-hosted by Heather Avis of The Lucky Few!

Facebook.com/CdnDownSyndrome/

