

*21 Welcomes



Canadian
Down Syndrome
Society

Société
canadienne de la
trisomie 21

*21 Welcomes

21 Welcomes is a collection of real stories from parents, siblings, grandparents, self-advocates, and others who love someone with Down syndrome.

Inside these pages, Canadian Down syndrome community members share their honest perspectives on welcoming a baby with Down syndrome and their journey as they joined this new community.

Toll-free: 1-800-883-5608

Phone: 403-270-8500

Email: info@cdss.ca

Website: www.CDSS.ca

Charitable Registration: 11883 0751 RR 0001



@cdndownsyndrome

2023

This booklet may only be copied or reproduced with the permission of the Canadian Down Syndrome Society (CDSS). Photography by Hilary Gauld of One for the Wall.



“The majority of parents felt that their outlook on life is more positive because of their child with Down syndrome.”

- Dr. Skotko et al.



Canadian
Down Syndrome
Society

Société
canadienne de la
trisomie 21

Welcome

We're So Happy You're Here!

Congratulations on the arrival or expected arrival of your new baby! Having a baby is exciting, but it can also be overwhelming and even frightening to find out your child has Down syndrome. The Canadian Down Syndrome Society (CDSS) is here to support and encourage you through all of the ups and downs of having a loved one with Down syndrome. We hope *21 Welcomes* supports you through the beginning of your journey and that you find inspiration, hope, and guidance in these stories.

Throughout this book you will find helpful information about:

- ▶ Adjusting 8
- ▶ Down Syndrome 12
- ▶ Talking About Down Syndrome 16
- ▶ Sharing the News..... 26
- ▶ Siblings..... 32
- ▶ Family 33
- ▶ Feeding Your Baby 40
- ▶ Early Intervention..... 44
- ▶ Self-Advocates..... 54
- ▶ Promising Futures 56
- ▶ Next Steps..... 62
- ▶ FAQ 63

If you read through this booklet and still need more information, please contact our team at 1-800-883-5608 or email info@cdss.ca.

Additional information is also posted on the New Parents section of our website at www.CDSS.ca/Resources/New-Parents/

We are happy to welcome you to the community!

Dear New Parents

By Paul Sawka

Congratulations on the birth of your baby! It is okay to be a bit sad and scared, but I hope by telling you about my life, you will feel better.

My name is Paul and I have Down syndrome and I am the Awareness Leader at CDSS. I have a great life and I feel very proud of it. It is important as a parent to have high expectations and to give lots of support to your child. Growing up, I had a lot of support and love from my family.


When I was young, I played sports and went to school. I learned math, reading, writing, and singing. I had a lot of fun learning and growing. I went to many schools and enjoyed them all. After high school, I went to Mount Royal University and Columbia College. I went to university because I wanted to learn the things that I would need to get a job in the future. I did learn many important skills that helped me get many different jobs. I was also valedictorian at my graduation from Columbia College.

I live in an apartment with a supportive roommate. I am able to get to work on my own. I am independent. I have some help, but I'm able to do lots of things on my own. Having Down syndrome did not stop me from doing all the things I have wanted to do. If you want to know more about me or have any questions about people with Down syndrome, please check out my blog at www.CDSS.ca/Awareness-Leader-Blog.

All the best,

Paul Sawka

CDSS Awareness Leader



*It's okay to be sad or scared,
but I hope by telling you about
my life, you will feel better.*

- Paul Sawka, CDSS Awareness Leader

Take Him Home

Love Him and Spend Time Getting to Know Him

By Sarah Kocher



Congratulations and welcome to the best, most inclusive club around!

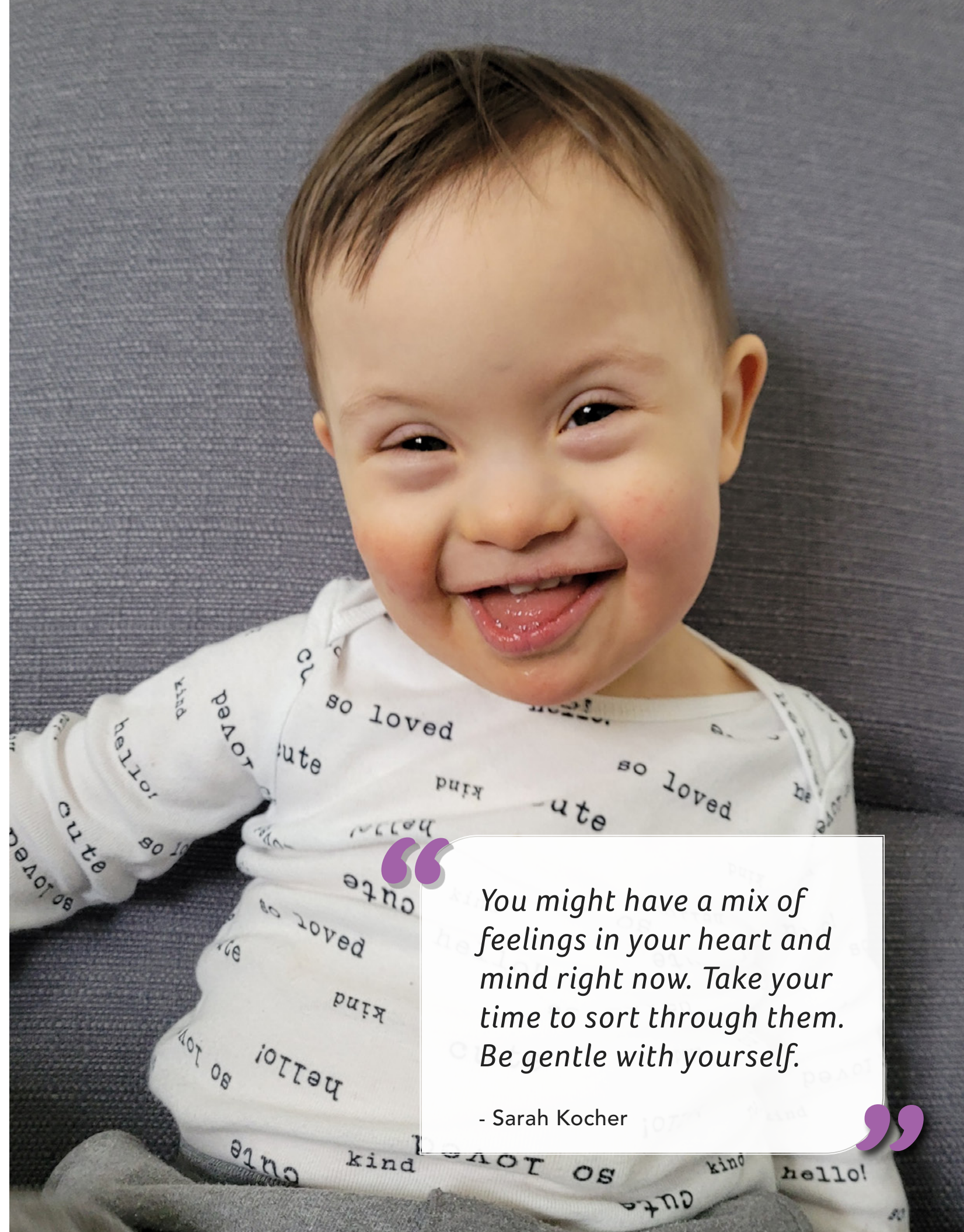
If you're reading this, it is because you have just welcomed a child with Down syndrome into your life. You might have a mix of feelings in your heart and mind right now. Take your time to sort through them. Be gentle with yourself. And get to know the new person in your life, with all of the qualities they possess.

Our family officially received Everett's diagnosis when he was 9 days old, but our pediatrician took about five minutes after his birth to broach the subject. Her first sentence was - "I see some signs that suggest he has Down syndrome" - it felt like someone had pulled the rug out from under me.

I was in a freefall away from the life I had imagined with our family of 5. Her next sentence caught me mid-fall and gently set me back down - "so we have some things to figure out about him, but the most important thing is that you will take him home and love him and spend time getting to know him." That would set the tone for how we would embark on this journey as a family.

I wish that things had unfolded quickly after that, but it took nearly 6 weeks to leave the hospital. Like approximately 50% of babies with Down syndrome, Everett was born with a congenital heart defect. Finding the right balance of medications to allow him to comfortably breathe and grow to a size large enough for surgery was like doing a back-and-forth dance when you don't know the choreography. Eventually, we got to a place where everyone was comfortable seeing Everett leave for home.

That first year and a half was a whirlwind of appointments, surgery, and therapy. But we quickly adjusted, and it simply became a part of our daily lives. We read children's books about Down syndrome and inclusion to our older children, who find pride in happily announcing that their brother has Down syndrome, and that it's pretty great. They are learning to celebrate the differences that make us unique, and that is a quality that they will carry with them throughout their lives.



You might have a mix of feelings in your heart and mind right now. Take your time to sort through them. Be gentle with yourself.

- Sarah Kocher

Adjusting

Resource Section

You have just had a new baby and that is something to celebrate! Your newborn needs to be loved like any baby does.

After finding out your new baby has Down syndrome, you may be feeling many emotions at once. This is normal. There is no right or wrong way to feel.

Receiving the news can be shocking. It may take time to adjust to having a child with Down syndrome. This is okay. Your journey will be unique to you.

All parents have different feelings when they find out they have a child with Down syndrome. Some parents feel happy and excited about the birth of their baby, while some experience feelings of shock, sadness, guilt, or disappointment. Many feel a lot of uncertainty and doubt regarding their child's future. You should know that there is absolutely nothing that you did to cause your child to have Down syndrome.



You already see the ability in your child, you just have to see it in yourself.

- Crystal Trumper

“Can we all please stop pretending that we’re all ‘doing great’ all the time and actually say ‘I’m miserable’ sometimes and then get on with our day anyway?”

- Anonymous Parent

No matter how you feel, remember that you are not alone in this journey. Right now, you probably have a lot of questions and concerns. Try to surround yourself with friends and family who will support you through this time. Finding a strong support system will help you with some of the challenges that are associated with raising your child.

Your partner, other children, and other family members may be experiencing feelings and emotions similar to yours. If you are comfortable with it, sharing your feelings together may be helpful for everyone.

Adjusting takes time. The adjustment process is different for every person. You should take as much time as you need in your journey. If you feel like you are not able to cope, seeking help from a professional may be beneficial.

When you are ready, we suggest that you contact a Down syndrome parent networking group in your area where you will meet other parents and families who have a child with Down syndrome. You will also learn about useful local resources. Many parents find connecting with other parents of children with Down syndrome an excellent way to gain confidence by sharing their feelings and concerns. Talking to other people who have gone through similar experiences might help you feel less alone and give you hope for the future.

If you are not ready to connect with other parents, that is okay too. Feel at peace with your adjustment process. If you would rather read about others' experiences, a blog might be a good place to start. There is a huge Down syndrome community online. The CDSS website has some great recommendations and lists of parent groups, visit:

www.CDSS.ca/Resources/New-Parents/

She is Your Baby First

By Megan Croteau

In September 2021, our daughter Winn was born. I had a home birth, and it was my midwives who, upon examining Winn, explained to us that there are some physical features that she has that indicate she may have Down syndrome. It was a couple of weeks later that we received the confirmation of Trisomy 21 after having bloodwork done through SickKids hospital. But back on the day of her birth, at home, my husband Henry and I processed the information we were given a bit differently.

I received the possibility of Down syndrome calmly and matter of factly, knowing that Henry and I are incredibly capable people of caring for this child and giving her exactly what she needs. What scared me was the unknown of what that meant, not knowing what the future would look like.

When Henry received the information, at first he was quiet, taking it all in, but then he proceeded to panic. Looking back now, he says that the panic that came upon him in those early moments were directly related to the unknowns. All of the unknowns made him feel completely out of control and ultimately his fear made him feel that he didn't know what to do to help Winn.

In my husband's panic, he called my mom (Karen) who was anxiously awaiting our update. He explained to her what was going on and quickly followed it up with "What do we do Karen, how do we help her?" In my mom's natural and beautiful way that she approaches almost all situations in her life, she took a moment to absorb what Henry told her, took a deep breath, and said "Henry, you have to remember that Winn is your baby first. She needs you to love her and care for her exactly the same way Rosie (our first daughter) needed you and still needs you. She is your baby first. And everything she needs in her future will fall into place because I know you and Megan are more than capable of raising this beautiful child."

The words "she is your baby first" put everything into perspective for us in those very early and fragile moments of receiving the possible diagnosis. It calmed us down and made us connect back to the beautiful moment of Winn entering this world and choosing us as her parents. Those words, hands down, were the best piece of advice that we received. Because once you continue on this journey, you do quickly realize how actually "normal" it is. Any challenges that Winn will face in her future can be supported. But remembering that she is our child first and not defined by her diagnosis is what guides us along this journey.

Rosie, Henry and I adore Winn more than words can express. In the 12 short months that we have known her, she has added so much love and joy to our family. We would not change one thing about her.

“

You have to remember that Winn is your baby first. She needs you to love her and care for her exactly the same way Rosie needed you.

- Karen, Megan's Mother

”



About Down Syndrome

Resource Section

Down syndrome is a naturally occurring chromosomal arrangement that has always existed and is universal across all race, ethnic, gender, and socio-economic lines.

Down syndrome is associated with having an extra and/or rearranged copy of chromosome 21. One in every 781 babies born in Canada have it. There are three different types of Down syndrome: Trisomy 21, Translocation, and Mosaicism.

TRISOMY 21

95% of people with Down syndrome have Trisomy 21.

Cell division results in three copies of chromosome 21 instead of two.

TRANSLOCATION

2-3% of people with Down syndrome have a translocation pattern.

Part of chromosome 21 breaks off and attaches itself to another chromosome.

Two-thirds of translocation occurrences are spontaneous, while one-third is inherited from a parent.

MOSAICISM

2% of people with Down syndrome have Mosaic Down syndrome.

Cell division occurs in one of the early cell divisions after conception, resulting in some cells having three copies of chromosome 21 instead of two.

The effects from the extra genetic material vary from person to person, and the degree of resulting developmental delay also varies.

No matter which type of Down syndrome your child has, the effects of the extra genetic material will be unique to them. They will have their own strengths, likes, dislikes, talents, and temperament.

Although people with Down syndrome often share some features such as a smaller stature, almond-shaped eyes, a single palm crease, and smaller ears, this varies greatly between individuals.

People with Down syndrome are not all alike. A popular generalization is that people with Down syndrome are always loving, smiling, or happy, but just like the general population, they experience a full range of emotions.

People with Down syndrome have:

- ▶ Some characteristic physical features, including some degree of recognizable facial appearance and a smaller stature
- ▶ Some degree of intellectual disability
- ▶ Delays in development including delays in speech, gross motor skills like sitting, crawling, walking, and fine motor skills

With appropriate medical interventions and treatment, most people with Down syndrome can have healthy lives. In 1983, people with Down syndrome lived to about age 25, now the average is 60 years old. However, as with anyone else, there is no definitive life span and some people with Down syndrome have lived into their 80's.

Health concerns for people with Down syndrome may include:

- ▶ Vision and hearing issues
- ▶ Congenital heart conditions
- ▶ Gastrointestinal issues, including gluten intolerance
- ▶ Respiratory infections
- ▶ Sleep issues
- ▶ Thyroid problems
- ▶ Increased risk of developing childhood leukemia



I Wouldn't Change A Thing About Him

By Jennifer Crowson

In 2011, I was expecting a baby. My two previous children had been born prematurely – between this and my age, I was deemed high risk for potential complications during this pregnancy and birth. My pregnancy was being monitored and supported closely by a high-risk obstetrician. I remember her saying to me early on, “if there is anything going on with this baby, they would find it.”

I did not seek any prenatal testing. Yet, at early appointments, I recall being encouraged to do the screening given my age and the likelihood that the baby could have a genetic disorder. I was in fact told that my baby could have Down syndrome. This didn't cause me to change my mind. I was comfortable with the idea of having a child with Down syndrome (or so I thought) and I also just didn't believe “it would happen to me”. I had two boys, and this third baby was going to be the girl I had longed for.... or so I thought.

Fast forward to my 20-week ultrasound. I lay quietly staring at the screen in awe of this little one growing inside of me. Despite knowing this was a longer appointment, I grew a little worried at just how long it was taking, and I could sense that she was focusing on one part of my belly. I asked, “Is everything okay?” – to which she responded with a question – “Are you seeing your doctor after this appointment?” I replied “Yes, I am”, and, at that moment, my heart sank. What did this mean? Her tone had changed, her demeanour had changed, and she said little else for the remainder of the appointment.

I quietly walked to my doctor's office feeling worried and uneasy, but I could feel my baby move so it must be okay. I tried to convince myself everything was fine, but the sense of something being wrong that I'd felt from the technician's reaction was strong. When the doctor came in, she sat down and without hesitation calmly said, “Your baby is showing some soft markers for Down syndrome.” Despite my sense she was going to say something was going on, this hit me like an unexpected punch. After much debate and discussions with her and my family, I did have an amniocentesis which confirmed our baby was a boy who had Down syndrome.

I was stunned, sad, confused, and scared. I did not really know or understand what all this meant – for me or for this baby growing inside of me. As a parent, you want your children to grow up, be healthy, and live strong, happy, and independent lives. The little knowledge I had of Down syndrome suggested this

was not going to be the reality for my son. But I also knew that I needed to find a way to have those same hopes and dreams for my unborn son that I had for his older brothers .

The hospital put me in touch with another parent who was happy to speak with parents who also had a child with Down syndrome. I felt raw and vulnerable, but knew I would find it helpful so I made the call. She was immediately warm and friendly and invited me to her home to meet her son. When I walked in her front door, I was greeted by her generous smile and one of the most beautiful little boys I have ever seen. She beamed with pride over his many accomplishments in his first two years but was honest with me about the emotional roller coaster she and her partner had been on and the challenges they had faced. It was an emotional visit, but I left her home feeling uplifted and inspired.

Every parent needs to figure this one out for themselves. Learning your baby is not going to be what you expected – and you are going to be fearful of what the future holds for your child and your family. But through reading books and blogs, speaking to other parents, becoming friends with other parents, leaning on friends and family, and becoming actively involved the Down syndrome community, I came to embrace the fact that our son would have Down syndrome and prepared myself for how this would change my world in so many new and wonderful ways.

Our son, Owen, is now 10 years old and I wouldn't change a thing about him. When I am asked what he is like – I am always quick to say he is everything I was told he would not be. He is active, he is chatty, he is bright, he is kind, he gets sad, and mad, and giggles with great joy. He loves to learn, he loves to read, he loves to swim, and ride horses, and he loves to play with his friends and brothers. He loves his family and our love and respect for him, and his life, is immeasurable.

With love,

Jennifer

Proud Mother of Owen and his brothers Max and Ruairidh



Talking About Down Syndrome

Resource Section

It is important to use appropriate language when referring to any group of people. Correct language helps reduce prejudice, misconceptions, and stereotypes.

This guide will help you when talking about Down syndrome.

IT IS DOWN SYNDROME

Down syndrome is named after Dr. John Langdon Down, the first person to identify it. He did not have Down syndrome, therefore it is not possessive (as in Down's).

It is always spelled with an upper case "D" and lower case "s" when used in sentences (Down syndrome, not Down Syndrome).

USE PEOPLE-FIRST LANGUAGE

When someone has a disability and you are talking about them, always say WHO they are before anything else. You want to focus on the person, not the disability. This is called people-first language. For example, it is not a Down syndrome person, it is a person with Down syndrome.

BE POSITIVE

A person is not suffering from or afflicted with Down syndrome. A person has Down syndrome. People with Down syndrome can lead fulfilling lives, including attending post secondary school, having careers, and getting married.

END THE R-WORD!

The R-word is often used in everyday speech in a derogatory, offensive, and hateful way. Never say the R-word and help eliminate this hurtful word by encouraging others not to use it too.

“

My sister Adele has Down syndrome. It was scary at first, but it gets better and better. When we play together, I sometimes have to help her, but it feels good that I get to teach her new things. I'm grateful that she's my sister.

- Brinley Collins

”



She is Our Little Rainbow

By Candice Simpson

Had I been asked a year ago to write about my feelings towards having a child with Down syndrome, it would be filled with disbelief, sadness, fear, and worries; I know this because that is how I felt the second half of my pregnancy once we found out.

How do you tell someone their child wouldn't be what they dreamed of or imagined? How do you properly grieve the child you thought you were going to have? The life you were going to have?

I began googling for answers, trying to figure out what our life was going to look like, what our child would or wouldn't be able to do, what people would think. Would they pity us? Feel sorry for us? Would Josh resent me or our child when life got hard?

When they lifted her for us to see, I knew right away and with a heavy heart I said, "Babe...I think she has Down syndrome." He replied "I know, something about her eyes," but we were smiling, and the smiles grew bigger as we held her.

It wasn't until the next day that I cried messy, uncontrollable tears. I didn't quite have the words to explain just how sad I was that I ever thought for one second that I wouldn't want her.



The thing about Down syndrome I have found is that more often than not, you are given a list of all of the "possible" things that can go wrong for your child, but these "possible" outcomes apply for any child. Yes, it is true that Piper takes a little bit longer to meet milestones, but when you are told not to expect them anytime soon, they become that much more exciting and special.

At only eight months old, Piper's smile can light up an entire room and make someone's bad day better in the matter of seconds.

People gravitate to her in a way I've never seen. She is the biggest cuddle bug, she loves splashing around in the water during her baths, and will spend all day floating around in the lake during the summer if you'd let her. She loves rolling around and trying to crawl on her play mat, prefers to sit up on her own and is happiest in her jolly jumper hopping up and down. She is great at traveling, not only to her many appointments but also on all kinds of family adventures.

We do not let Piper's diagnosis limit her and most days we forget that it's there at all. She is our little rainbow with an extra colour and we can't wait to see what she will do with her sweet life - we truly are the lucky ones, so much so, that Piper does not have any health concerns at this time.

We are happier than we've ever been now that we have Piper, we couldn't imagine life any other way and we are surrounded by an amazing community that has so much love and support to offer us that it has been overwhelming.

I only wish I could go back to my pregnant self last year with just a glimpse of it all and hope that somehow this letter sparks excitement and happiness for you!



"I didn't quite have the words to explain just how sad I was that I ever thought for one second that I wouldn't want her."

– Candice Simpson

Taking Things Day by Day

By Collette Beneteau Renaud

Welcome to the beginning of your journey of adapting to life with a little one with Down syndrome. For most of us, this is unknown territory and it's difficult to picture what your future now has in store for you.

I was at the beginning of my third trimester when we received the news that our baby had Down syndrome. Almost simultaneously, the pandemic began taking hold and our day-to-day world was shutting down around us. My husband and I dealt with this news in very different ways, all the while having to transition to working from home and helping our other two children navigate online learning.



“Hope, worry, happiness, and guilt, were just some of the initial emotions pulling me in completely different directions.”

– Collette Beneteau Renaud

To add to the stress, we found out our new baby had a congenital heart defect that would require immediate care at birth and surgery soon afterwards. I was still hoping for a miracle, and in denial at this point, hoping that none of this was true. Hope, worry, happiness, and guilt, were just some of the initial emotions pulling me in completely different directions. Once our daughter was born and we settled in at home, I found time to read about the experiences of others and discovered that this paradox of emotions I had been feeling was normal.



When I met my daughter Théa for the first time in May 2020, I felt this primal desire to protect her for the rest of my life and yet some faint disappointment that she wasn't going to be the typical child I had expected. I think it's important to know that whatever you are feeling is okay, you do not need to feel guilty.

Initially, we were not able to meet in person with our local Down syndrome community and even though we were provided with great reading material and books, other people's experiences are what really got our family excited about the future with Théa. We explored Down syndrome content on social media like Chris Nikic, a young Ironman triathlete with Down syndrome who posts his accomplishments online. Knowing what is possible led our family to take up running, and my husband even completed his first half Ironman this summer. I started listening to podcasts and as a teacher have been inspired by the work of Dr. Vaish Sarathy, who demonstrates that there really is no limit into what our children can learn. Théa's sister and brother think the Safier brothers' videos on TikTok are hilarious, often re-enacting their favorite parts. Eventually we were able to meet other families and quickly realized that we are not alone.

Almost two and a half years later I can say that I am one proud parent of a child with Down syndrome. Théa is a beautiful, smart girl who loves music, dancing, and waving to everyone at the grocery store. She is still working on walking, talking, and eating solid foods, things that would have bothered me at the start of this journey, but I have realized that it will be accomplished on her own timeline. I still don't know exactly what our future has in store for us, but I know that with Théa in our family, it will be wonderful.

A Bit of Hope

By Sasha Makkinga

After several months of trying, I discovered I was newly pregnant in the early months of 2011. I had just turned 35 and was excited to welcome our second baby. We did the nuchal translucency (NT) screening without a single thought as to why we were doing the test or what we would do when the results came back. I just wanted to have the early ultrasound and see my baby. At the ultrasound, everything was different than it had been three years earlier when I was pregnant with my daughter. My husband was not allowed in the room for the screening,

the tech was almost silent, and they refused to print our ultrasound photos. We went home a little deflated, but I was excited that we had seen the tiny baby.

A day or so later, we received the call that would shake up our hopes, dreams, and expectations. My midwife said that the nuchal translucency measurement was so high, I would be flagged regardless of what was found in the blood test.

The following week we met with a geneticist. She was gruff, cold, and full of worst-case scenarios. She listed the various chromosomal abnormalities we could anticipate given our results and scheduled

our chorionic villus sampling (CVS) test within the next few days. The staff at the CVS test were very warm and kind and my husband and I floated through the day in a fog. Within 48 hours we had the news that our baby would have Down syndrome. I received the news at work, called my husband, and left early in complete shock. That night, my husband and I were fortunate enough to speak to another mom who had two children with Down syndrome. She told us, “it may not feel like it right now, but you have just won the lottery. Your child will bring you immeasurable joy and you will never doubt that your child loves you!” She offered us a bit of hope as compared to what all of the doctors were saying.

Another appointment with the geneticist was made. We met again and she described, in excruciating detail, the process of termination. She showed us black and white photocopies of photos that were 30-40 years old and said, this is what Down syndrome looks like. She painted a bleak picture. My husband and I had to repeat several times that we did not want to terminate, and even had to tell the doctor to stop asking.



At first, we only told a handful of people while we processed our own feelings of grief for the child we had expected. We had originally selected the name Jacob, but given the new diagnosis, changed it to Zachary. I remember washing all the baby clothes and putting them in the dresser. With each article of clothing I thought to myself, this was for Jacob, but now it's for Zachary, trying to reframe the visions of the future we had for our little guy and our family. It was a period of darkness. We didn't know what to expect. I was most concerned for my daughter; would this be a burden on her? Would she be teased or bullied? Would she wish she had a different sibling? My husband wondered if our son would ever ride a bike or enjoy camping and the outdoors. Would we still be able to travel and go to Disney?

As we settled into our new reality, we told our extended family through an email. We provided some websites and information and we were clear to say that we could not answer any questions at the time as we were still processing.

I woke up one morning at the end of my pregnancy and knew something was wrong. I took my daughter to daycare, packed my hospital bag and camera in the car, and headed off to the midwife. The midwife sent me for an ultrasound and there they found a fetal heartbeat, but saw no movement. I was given a letter and told to go directly to the hospital. Once at the hospital, I was quickly assessed and whisked off down the hall for an emergency C-section. My husband made it just in time.

Zachary was here! He needed oxygen and we spent 2.5 weeks in the NICU. He was a whopping 7 pounds 5 ounces and looked twice as big as the other babies. After coming home from the hospital, he caught a cold and landed back in the NICU for another 3 weeks. The time he was in the hospital was the hardest of my life. Not having our family all under one roof and not knowing if he was going to make it was sad and terrifying. By the time he came home, just in time for Christmas, the Down syndrome didn't seem to matter anymore. We just wanted our baby to be healthy and our family to feel whole.

Looking back, I sometimes feel that the prenatal diagnosis robbed us of the excitement and anticipation of my last pregnancy. But, on the other hand, I felt like my husband and I needed that time to grieve, process our feelings, and be ready to welcome the baby we were having with open arms.

Today, Zachary is 11 years old. He rides his two-wheel bike and loves to camp and hike. He has a fairly typical relationship with his sister: they love each other and fight and call each other names and miss each other fiercely when they are apart overnight. We have travelled to Disney World, Disneyland, multiple road trips, and to Europe. Not every day is sunshine and roses, there are challenges and bumps in the road. He is human after all, and so am I. I've learned to be his advocate and cheerleader. We don't know all that lies ahead for Zachary, but he makes me laugh every single day and I have never doubted that he loves me.

Elyse The Star

By Adelle Purdham

Tell a story to new parents of a child with Down syndrome that is honest, heartwarming, and real, they say. I have ten years of material, where to begin?

Honest.

If I tell you I never wanted to give birth to a daughter with Down syndrome, that I grieved the loss of normalcy I experienced in my first pregnancy - would you still want to read on? If I recount fist-pounding-pillow-tears of rage; that I howled to the moon, cursed the stars when we found out - would you judge me? And if I told you that I rode the highest of horses and thought somehow that having a child with Down syndrome was beneath me - will you hear what I'm really saying, how wrong this feels to me now? However you receive the information that your child will be born with Down syndrome, however you feel about that information - I will not judge you. I will not tell you how to feel. I will only tell you that for me, once I accepted that Elyse would be born with Down syndrome and there was nothing I could do to change that fact; when I realized what I could do, what was in my control, my perspective shifted. I began to see the world differently, to inhabit the glorious space of those standing next to me, a dazzling array of human diversity.



"I will not judge you. I will not tell you how to feel. I will only tell you that for me, once I accepted that Elyse would be born with Down syndrome and there was nothing I could do to change that fact; when I realized what I could do, what was in my control, my perspective shifted."

– Adelle Purdham

During Elyse's pregnancy, I called my mom. Moms know best. She picked up the phone and I let out our news with a sob. "Down syndrome?" my mom repeated. "Oh good! I thought the baby had died or something. Oh honey, it's going to be okay. Down syndrome's okay." I don't know who needs to hear those words right now, but my mom was right, Down syndrome is okay.

Heartwarming

Three years after Elyse's arrival, I gave birth to our third daughter. The years pass. We are riding in our minivan, our little family of five. Elyse is regarded as the comedian of the family. My husband pulls up to a red light and let's out a small toot. Her two sisters snicker, but Elyse drops one of her favourite Minion movie lines, "You've been a bad boy!" The van erupts in appreciation of her joke. I can't breathe kind of laughter. We dab at the corner of our eyes. We may have to pull the van over. I glance in the rearview mirror. Elyse, my star, is glowing.

Real

One day after school, I open the door to Elyse's room to find her sitting on the bottom of her hand-crafted bunk bed from grandad. She looks lonely tucked under there, not doing anything that I can understand. Before I can say anything, she turns to me, "I want to be left alone." "Okay," I say, "no problem." I shut the door behind me. My daughter recognized her need for silence after a busy day, and even though it was not what I wanted in that moment, I honoured her by giving her what she needed.

Empower. Bring hope. Welcome. Embrace.

The Down syndrome community is strong. If you ever want to talk to another parent, I'm here for you, as are many others. I once asked Elyse, who had been happily taking big bites out of my breakfast sandwich, if I could have a handful of her blueberries in exchange. Blueberries are her favourite and a big bowl sat filled in front of her. She eyed me sideways, then using her dainty pointer finger, slowly rolled one blueberry over to my side of the table. I pursed my lips and thanked her. Because you know, she has given me infinitely more.

Sharing the News

Resource Section

After learning your baby has Down syndrome, one of the hardest things can be telling your friends and family.

You may still be adjusting. You may be worried about how others are going to react to the news. It is normal to feel nervous about telling your friends and family that your baby has Down syndrome. You might get mixed responses from them. Many will be in shock and will grieve the same way you did. Tell them that this new baby is something to be excited about and to celebrate. It is important to remind your friends and family about the joy of having a new child.

Some people do not have a good understanding of Down syndrome and they may see Down syndrome as a sad and negative thing. Before sharing the news about your baby, it is helpful to have an understanding of Down syndrome and the positive things that people with Down syndrome can accomplish. Take a look through the New Parent Resource Hub on the CDSS website at www.CDSS.ca/Resources/New-Parents/ and help to educate your family by sharing the website and this *21 Welcomes* booklet with them.

Many of your close friends and family will want to support you. Invite them to learn along with you. Remind them that you are learning and you may not have all the answers to their questions. It is okay to be honest about the worries that you have and your uncertainty of what the future will hold. Telling others can help you create a good support network. Educate others about having a child with Down syndrome and all of the good things that your new baby will bring to your family.



“

When your baby grows up, support them and teach them to be their own advocate one day.

- Dewlyn Lobo

”



Your Little One Will Show You the Way

Just Love Them and Let Them

By Laura Anderson

Our son, Archie, was born earlier than expected and we spent ten days in the NICU before we learned he had Down syndrome. I remember trying to decide how to tell our people about his diagnosis. We wanted to be sure they knew we weren't ashamed of him and were open to talking about it, so waiting wasn't an option. We told our whole world right away. It was healing to talk and be open about his diagnosis.

We were feeling all of the things; sadness, fear, uncertainty, excitement, joy, acceptance, and disbelief. There were moments we grieved the son and the life we had imagined for our family; wondering what he would and would never do. Not wanting a child with a disability but a "normal" child. In hindsight, it's hard not to be critical of ourselves for those thoughts but it's important to forgive yourself and have grace.

From the moment Archie was born, we were surrounded by NICU staff telling us how strong and capable he was - his diagnosis didn't change that. I spent some time on Instagram watching other families with a child with an extra chromosome doing life, and it was very therapeutic. We felt supported by our family and friends who didn't hesitate to accept Archie.

We were thinking about therapy and all the things we could and would need to do to support Archie when the geneticist told us, "don't worry about therapies and all the things for now, just love your baby. He will do all the things, hit the milestones, it will just be on his own timeline." He was right.

Archie gives hugs and kisses, he walks, he hops, he dances. He gets mad, he laughs, he loves making you laugh. He signs, he says words, he rides horses, he cleans up toys, he climbs the stairs, and he gets into trouble.

One day, when your little one is a few years old, you will look at them but you won't think, my child has Down syndrome. You'll just look at them and think they need a haircut, their nose wiped, their face washed, or their lunch packed.

Having a child with Down syndrome will be hard work at times, but your child is absolutely worth it. You will feel immense pride because you will know how hard they work in everything they do. Congrats, I'm excited for you! Take a deep breath. Your little one will show you the way, just love them and let them.

“

One day, when your little one is a few years old, you will look at them but you won't think, my child has Down Syndrome. You'll just look at them and think they need a haircut, their nose wiped, their face washed, or their lunch packed.

- Laura Anderson

”



She's Here and She's Perfect!

By Martha Walls

Not a single sad tear was shed the day our baby entered this world. Just after noon, in recovery following my C-section, I shared on social media that “she’s here and she’s perfect!” – a message I meant with every ounce of my being on a day that brought pure joy.

I wish I could say that our whole pregnancy felt that way. At our 12-week scan, a stern-faced doctor shared his belief that the baby had Down syndrome – all the markers were there. Further testing followed, and one day at work the phone rang. It was the genetic counsellor whose first words “are you sitting down?” were followed by “the baby has Down syndrome.” She kindly explained what this meant - and then offered to share with me the sex of the baby: “it’s a girl!”

Eventually we pulled ourselves together enough to reach out to a select group of friends: parents of children with Down syndrome.

Looking back, my call, asking them to share their experiences must have been incredibly stressful. But I’m forever grateful for the counsel of these generous parents who both knew precisely our fears and offered to us our first congratulations untinged by sadness. They did not shy from sharing their struggles and worries, but what stood out most was the profound love that had found their families in the form of an extra chromosome on the 21st pair. We came away from these calls greatly reassured.

The next few months were not easy. We learned that our baby had congenital heart disease that would require surgery. And then on my 40th birthday we were told she probably would not survive. What followed was a whirlwind of medical appointments and ultrasounds. We were blessed to have an amazing medical team – not one doctor or nurse suggested that this baby’s life was not worth fighting for. They all went above and beyond. We breathed a sigh of relief when we reached the 28-week milestone. Then 29, 30, 31, 32. At week 33 and 3 days, it was time for our baby to enter the world. Just before noon on March 20th (the day before World Down Syndrome Day) the nurse raised a screeching Quinn Elizabeth to my lips for a kiss – all 3 lbs and 7 oz of her.

Quinn, now nine years old, brings joy and light to our life every day. She is so funny, so caring – and so in love with life, that we can’t help but be too. Our worries have not all been erased, but they are eclipsed by the fact that she is here and she is perfect.

- Martha, Corey, and Quinn



I’m forever grateful for the counsel of those generous parents who both knew precisely our fears and offered to us our first congratulations untinged by sadness.

- Martha Walls



Siblings

Resource Section

After giving birth to a baby with Down syndrome, many parents are worried about how it will affect their other children. This is understandable. The good news is that a study done by Dr. Skotko and his colleagues found that an overwhelming majority of parents feel that their children with Down syndrome have a good relationship with their siblings. They also found that 94% of older siblings to a child with Down syndrome are proud of their brother or sister.¹

The vast majority of people describe their relationship with their sibling with Down syndrome as positive and enriching; some even say their sibling is the best thing that ever happened to them. It is important to keep in mind that your children will have their own unique journey, full of the typical friction, learning, and love that embodies sibling relationships.

Some siblings will take on the role of caregiver, but others may find it difficult to understand why their sibling with Down syndrome seems to get extra attention. This may make the sibling feel resentment or embarrassment toward their brother or sister. Some will also have questions and concerns for their sibling, making it important to communicate openly and often.

Depending on the age of the sibling, you may have to share more information with them to help them understand Down syndrome. Keeping your other children informed about their sibling with a disability can help them feel included and important. To help you facilitate these conversations, visit the General Information page on the CDSS website for FAQs and information about Down syndrome: www.CDSS.ca/Resources/General-Information

Dr. Brian Skotko is a Board-certified medical geneticist and Co-Director of the Down Syndrome Program at Massachusetts General Hospital.

¹ Skotko BG, Levine SP, Goldstein R. 2011. Having a brother or sister with Down syndrome: Perspectives from siblings. *Am J Med Genet Part A* 155:2348–2359.

Family

Resource Section

Having a child with Down syndrome will affect everyone in your family: parents, siblings, grandparents, and extended family. Everyone processes information differently; allow time for every family member to adjust. By supporting family members in learning and understanding Down syndrome, you will help them learn about your new family member and all the possibilities that the future holds for them. Together you and your family can support each other, and a great place to start is sharing this booklet with them so they can learn with you.

Concentrate on your entire family and not solely on one child. Although a child with a disability often needs more attention for healthcare needs and advocacy, it is important to view a family as a team and see that everyone has a role.



As a primary caregiver, you need to take care of yourself - your child needs you to be healthy. There are many ways to reduce the stress that can be associated with raising a family, choose something that works for you:

- ▶ Take time for yourself when you can
- ▶ Allow friends or family members to help when they offer
- ▶ Ask for support when you need it. Your child will need you to support them through any health challenges and to be involved in their therapy and early intervention programs

What It's Like to Have a Brother with Down Syndrome

By Max Crowson

My brother Owen has Down syndrome. It is the most wonderful thing you could ever imagine. Owen is very funny and picks up on things very quickly. For example, if we even go anywhere near Waterdown (which has a Dairy Queen we frequently go to), Owen will assume we are going to a Dairy Queen, even when we aren't even thinking about the fact that we are near a Dairy Queen. He is very focused on ice cream!

Another thing that makes Owen so lovely is that he always displays very rich emotion. He never will just say "meh" he will always be very vocal and honest about what he wants. When you give him what he wants he will hug and kiss you, but when you don't - well he can get a bit moody to say the least.

The same carries over to his hobbies and really anything he does for that matter. For example, when Owen plays frisbee with you he will always try his best to make the perfect throw. Owen is like this with everything. He will never just go 50% on something. If Owen says he is going to do something he will do it. Owen loves things to the extreme, does things to the extreme, and is loved to the extreme. So yes, living with someone who has Down syndrome is awesome.



We Are All Different

By Ana Maria MacKeigan

As kids, sometimes we do not see the difference between others. We just see another friendly face.

We found out I was having a sister. My parents sat me down at the table and told me she would have Down syndrome. They said she would be different. I said "So what? We are all different!" I didn't fully know what that meant, my mom would read me books and explain what it would be like. The doctor told my parents she would learn slower, not be able to dress herself, feed herself, and not even be able to talk.

We went to meet my mom's friends and their kid had Down syndrome. When we were walking out to the car, I told my parents I wanted a sibling just like her.

Once she was born, I found out she had to have heart surgery. I was so worried. I couldn't believe my little sister had to have surgery. I was so scared. After the surgery I couldn't even visit her in the NICU because it hurt me to see her hurting. I was so stressed out because I had always hoped for a sister. Once she was able to come back home, it felt so good to have her safe and healthy with us.

We worked hard and taught her so much. She can do everything the doctor said she couldn't do and more. She skis with me, she bakes with me, she sings, and dances with me. She loves school, we read together, and she always makes me laugh. She is unstoppable.

I want others to see that she may look different, but we are all different and beautiful in our own way and there is nothing "down" about Down syndrome.

I see my sister as a brave, kindhearted, lovable, funny girl that no one could ever replace. She inspires me to love a little more, smile more often, and live life to the fullest. She teaches me how to be more patient, kind, and loving towards others. I can't even put into words how much I love her and wish her the best because I know that she can change the world.



Smile!

By Lisa LaRosa Lledo

Lucas is everything that is right with the world bundled into an underestimated package full of wonderful surprises. When we found out that our baby had Down syndrome early into pregnancy, we were scared to say the least! What should have been such a happy and joyful time was clouded by worry and concern. We had met some adorable children and adults with Down syndrome, but all we heard about were the difficulties we would face, the medical concerns, and the limitations of his future. When the genetic counsellor called me, she stressed the urgency to confirm the diagnosis so we could DECIDE. No one mentioned the joy he would bring, the talents he would have, and the gift he would be!

“Only Lucas knows what he will be capable of, and he will let us know what that is in due time.”

- Lisa LaRosa Lledo



Lucas has taught me so much! He repeatedly reminds me to stay in the moment with him. When I am sad or overwhelmed, he looks at me with his incredibly cute face and says “Mommy, happy face!” as he uses his fingers to pull the corners of his mouth up, reminding me to smile because it’s all ok.

He has taught us all valuable lessons. His brothers, his father, his grandparents, aunts, uncles, cousins, friends, we are all continuously learning from Lucas!

The support we received from some was veiled by underlying stereotypes of the limitations of a Down syndrome diagnosis. I found myself having to tell many support workers that only Lucas knows what he will be capable of, and he will let us know what that is in due time.

I’m happy to say that those supporters were far fewer than the many, many more TRUE supporters. They were the ones who understand that we are not here to teach people with Down syndrome, they are sent here to teach us!

- The Lledo Family

You May Not Know It Yet

By Ashley Bowerman

You may not know it yet, but you’ve just become a part of a much larger, loving, and accepting family than you ever could have imagined!

When my daughter Lyla was born on Christmas Eve in 2020 during a global pandemic via emergency C-section - my life changed forever. I remember laying in the recovery room when the pediatrician and her team informed us that Lyla had undergone an HIE (hypoxic ischemic encephalopathy) event before or during birth and could possibly have brain damage, and she was also showing signs of Down syndrome.

In that very moment my whole world shattered into a million pieces. Why did this have to happen to us? What did I do to cause this? What would our future look like now? And how did our doctors miss this during our routine prenatal checks? There were no signs of anything out-of-the-ordinary on any of our ultrasounds. And yet here we were in the recovery room, baby-less, with all these doctors telling us how sick our baby was and that we could have lost her had we not come in when we had.

Tears started to flow. There was so much medical jargon I didn’t understand. So many questions I wanted answers to. So many tests to be done, and our baby girl needed to be transferred to SickKids hospital for treatment. All my hopes and dreams for her and the future I had imagined were replaced with grief, anger, and fear.

After 19 days in the NICU, we were finally able to bring Lyla home. At first, we only shared her diagnosis with close friends and family. I spent hours researching and educating myself on Down syndrome so that I could share my knowledge and teach others. I connected with local supports for developmental services and joined many groups on Facebook. It was in those groups that I found connection and comfort with others who had lived a similar journey and had come out stronger on the other side. Some of those connections have become friendships that I would have otherwise missed out on.

Lyla has taught me so much about determination and perseverance. We all develop at different rates and Lyla needs to work ten times harder to meet her milestones compared to her typically developing peers. Although it’s tough not to compare, we are learning to celebrate every milestone for the huge accomplishment that it is, whenever it happens.

No one said the journey would be easy, but they did promise it would be worth it, and let me tell you it is!



Nana's Precious Piper

By Shirley MacInnis



My sweet granddaughter Piper Rose came to us by storm, just like her mama did 29 years ago.

Candice and Josh (Mom & Dad) knew their darling child would be born with an extra chromosome. After months of preparing themselves for all the possible complications the doctors had advised them about, Candice insisted that she wanted to keep the sex of their baby a surprise and have a natural delivery. With such uncertainty throughout this pregnancy, this was the only control she could have. Unfortunately, that wasn't to happen either. Symptoms of preeclampsia started to develop as the due date neared. The doctor had warned us of symptoms that we shouldn't ignore because we were an hour away – “don't hesitate” he said.

On the morning of January 7th, 2022, Candice called me describing urgent symptoms. When we got to the hospital, I knew she was in good hands. Candice was to have an emergency C-section as soon as an operating room became available. But wait! Dad was at work two hours away - hurry Dad. Well, it's difficult to hurry when you're driving through two feet of snow and watching the snowplow you're following go into the ditch.

Finally Dad arrived, but because of Covid, the hospital staff asked me to leave. I left with a heavy heart and found a nearby hotel where I prayed harder than ever before. I prayed for my child and even harder for theirs. Please, I begged, don't let anything else go wrong, these parents have already withstood a lifetime of heartache. Candice and Josh had suffered through two miscarriages and had their three month old puppy die in Candice's arms as I drove her to the animal hospital.

In less than an hour, our precious Piper bounced into the world and stole the hearts of Mom, Dad, and of course EVERYBODY that would soon meet her. She is everything I promised Candice she would be - she's so happy all the time.

She sleeps all night, she rarely cries, and her smile lights up any room. Everytime I see pictures of her (which are posted daily, of course) they bring tears of joy.

Piper is our miracle child, she shows us daily that all we need is LOVE. Cuddling is her forte, but she is very quickly becoming the best dancer ever. I am beyond proud of Candice for working with her non-stop. If she is not on the floor playing and doing exercises, she is cuddling her. Although Piper is on solid foods now, Candice is still nursing and is not looking forward to weaning. Piper has been on more play dates at her young age than most five year olds. Mom and Dad are working very hard to build her social skills, which I believe is contributing to her increased abilities.

Josh is certainly raising the bar for other Dads; he is very supportive and jumps right in to help anyway he can. Piper is blessed to have such loving and patient parents. Piper has brought a huge community together, the outpouring of love from people who barely know us is mind blowing. Her online community of love is growing leaps and bounds with hundreds of comments from many, sharing their love and encouragement. Piper with the help of her parents, family, and friends, raised close to \$5,000 for the CDSS Walk for Awareness.

I am thrilled that both Candice and Josh did not focus on the “what-ifs” and became dedicated to creating a happy and nurturing environment for Piper and their new puppy Rusty Roo.

This proud Nana is looking forward to sharing the many moments of joy and laughter Piper brings as she grows and flourishes.

“Piper is definitely an angel of love, she came into this world to spread laughter and joy; her smile is contagious and I feel blessed that I get to see it every day.”

- Shirley MacInnis



Feeding Your Baby

Resource Section

The early days of feeding are a time for you and your baby to get to know each other and create a special bond. You must make some adjustments during this time because every baby is unique. As you get acquainted, you will discover that babies with Down syndrome have physical characteristics that may have an impact on feeding. You probably will not encounter all of the challenges discussed here, but understanding your baby's particular needs will help you to get feeding off to a good start.

Contrary to misconception, babies with Down syndrome can and do breastfeed. Keep in mind, no matter the feeding method you choose, it often takes time and patience to make sure your baby is feeding well. In the early days, you may need information, support, and/or practical interventions from a feeding specialist. The most important thing is that you find a way that works best for you and your baby.

For some mothers, breastfeeding simply doesn't work out - and that's okay. Your health care provider or doctor can provide information on all feeding options. You can also find more detailed information on our website at: www.CDSS.ca/Resources/New-Parents/

What is the La Leche League?

La Leche League (LLL) is a mother-to-mother, peer-to-peer support group. Volunteer LLL Leaders provide breastfeeding support in person, by phone, online, and at informal Group meetings. They provide evidence-based information on breastfeeding and human milk. They live and parent in the communities they serve and tailor programs to the needs of each community.



La Leche League Canada
www.LLLC.ca
289-660-5900



“Whether your baby is breastfed or bottle fed, remember that the most important thing you can feed your baby is love.”

- Anonymous

SIGNS OF EFFECTIVE FEEDING

Perhaps the most obvious sign of effective feeding is adequate weight gain in your baby. This should not be solely relied on, however, as babies with Down syndrome often gain weight at a slower rate than traditional milestones suggest. It is important to monitor your baby for weight gain.

Although you cannot actually see the milk going into your baby, there are signs you can check to ensure your baby is feeding effectively:

- Listen for sounds of swallowing coming from your baby
- Watch for milk spilling from your baby's mouth
- Your baby is gaining weight
- Your baby has 6-8 wet diapers and 2-5 stools every 24 hours



POSITIONING

As babies with Down syndrome often have low muscle tone, including reduced muscle strength in their tongue and lips, good head support is particularly important for your baby. Make sure that you hold and support their head, neck, and upper back during feeding.

If you find your baby seems to be drinking too quickly, position your baby more upright with their throat and neck up high and not lying down. You can lean your body farther back by sitting in a rocking chair or leaning on a supportive pillow, or have your baby sit up in a straddle position on your lap. This position will help avoid gulping and coughing, which may be a problem for some babies with Down syndrome.



SLEEPINESS

Many babies with Down syndrome are very sleepy for the first few weeks after birth, which can hinder their feeding routine. Stimulate your baby's senses by lightly touching the edge of their outer ear, stroking their arms, and talking to them during feeding. These touches and sounds will distract your baby from becoming drowsy and help them to focus on feeding.

TONGUE THRUST

Babies with Down syndrome may have a protruding tongue, which can pose a challenge as your baby may push the nipple out of their mouth. Don't be disheartened if your baby needs some initial encouragement to keep their tongue down while drinking.

Early Intervention Programs

Resource Section

Early intervention programs are available for children from birth through to about five years old. Through these programs, early childhood specialists provide families with supports and ideas for activities that will be beneficial to their child’s development. It is important to start early intervention programs as soon as possible, especially for children with Down syndrome.

Common early intervention programs for children with Down syndrome are physical therapy (PT), speech-language pathology (SLP), and occupational therapy (OT). During early interventions, professionals will observe your child’s gross and fine motor abilities, language skills, social development, and self-help skills, and will then develop focused activities specific to your child. This will allow for your child’s individual skills to be developed and strengthened.

Your child could be introduced to many specialists and therapists during their first few years. If you feel that something is being missed, don’t be afraid to talk to other professionals or other parents to make sure your child is receiving all the support they need. They may be able to suggest additional therapies or programs that could benefit your child. It is important that you advocate on behalf of your child, as you know your child best.

Depending on which province you live in, assistance for services can differ. Contact your local Down syndrome organization and provincial/federal offices about the services available in your area.

Babies with Down syndrome are expected to meet all milestones, however, they are often met at a slightly slower rate. Below is a chart that suggests when milestones will be met. Many children benefit from early intervention to help them reach their milestones.

milestone	Range for Children with Down Syndrome	Typical Range
Sits Alone	6 – 36 months	5 – 9 months
Crawls	8 – 22 months	6 – 12 months
Stands	1 – 3.25 years	8 – 17 months
Walks Alone	1 – 4 years	9 – 18 months
First Word	1 – 4 years	1 – 2 years
Two-Word Phrases	2 –7.5 years	15 – 32 months
Responsive Smile	1 – 5 months	1 – 3 months
Finger Feeds	10 – 24 months	7 – 15 months
Drinks from Cup Unassisted	12 – 32 months	9 – 18 months
Uses spoon	13 – 39 months	12 – 20 months
Bowel control	2 – 7 years	16 – 42 months
Dresses Self Unassisted	3.5 – 8.5 years	3.25 – 5 years

National Down Syndrome Society
www.ndss.org/resources/early-intervention





Embrace Your Child's Potential

And Support Them as Best You Can

By Dan McEwen

We didn't know for sure that Leona would be born with Down syndrome. We were given increased odds and offered more testing, but we were not concerned. I guess we were expecting to be told in the delivery room the moment she was born, but instead we waited for what seemed like forever for the test results. One way or another the results didn't matter, but maybe we would have been more prepared had we known in advance? Who knows. We were new parents and were sure to be winging it no matter what; a diagnosis of Down syndrome would not make things worse or better, just different.

Leona and her younger sister Andy have brought so much joy to our lives. Leona arrived about 21 months before her sister so we had lots of time to learn her character and settle in. Certainly, we had to approach milestones at our own pace with Leona. We were always finding new ways to incorporate various therapies into play to make them seem fun and not 'work'. Leona's determination is admirable, and it is incredibly rewarding when she masters a new task.

When Andy arrived, Leona was right there, ready to help. She wasn't quite walking yet, but it was clear that she was a caretaker. Bottles, stuffies, three soothers, more stuffies, a blanket, Andy did not go without.

Over the years we have watched our children grow and thrive in their own ways. We see Andy 'just do' things that took her sister months to learn. We've watched Leona teach Andy tricks and skills that her parents could not. There are no limits set, just a desire to embrace their potential and support our children as best we can.



"We were now parents and were sure to be winging it no matter what; a diagnosis of Down syndrome would not make things worse or better, just different."

– Dan McEwen

Dear Lucky Ones

(You May Not Feel Lucky Yet)

By Tara McCallan

If you are reading this letter, you somehow, someway, are on a similar path that I've walked. A path that, maybe, probably, wasn't one you wanted to go down. A path that looks terrifying, uninviting, and not at all what you expected.

If you are reading this letter, you have a baby with Down syndrome.

When I found out I was having a little girl, I let my dreams build up, my expectations soar, and my mind ponder all that she would be. Then a few days after she was born, a doctor looked at me with the saddest eyes possible, eyes that will forever haunt me, and said, "I'm sorry to be the one to tell you this, but your daughter shows many signs of Down syndrome."

Wham-Bam-Slam-Slap! Right across the face—that's honestly what it felt like, as I was utterly stunned. Everything I ever hoped for my daughter, for my little family, for our life together, seemed to crumble in that moment. It was as if in his words, that doctor took the entire happiness out of our new baby.

I've never wept like I did in that hospital bed. I've never cried for something I wished wasn't true so hard—I've never begged fate to undo what couldn't be undone. I was literally shattered in devastation.

The following few days were a whirlwind of medical appointments to rule out other complications associated with Down syndrome. I couldn't tell you one thing the doctors said during that time. My mind was in such a weird space, almost as if I was in the room but not truly believing that this was even happening, that this was our life, that this was our daughter. But a fierce, protective love was growing inside of me even though I didn't know it. In one appointment with a genetics specialist and a counsellor, my mind drifted as they talked about the makeup of chromosomes, FISH test, and a wide variety of spectrums, until the doctor said, "For your next baby, we can do testing and prevent this." Right there, a few days after our daughter Pip was born, the tone of how people, doctors, and others would value her life was set. In a way, that kind of made me love her more.

Because, you see, that doctor doesn't know what I now know. A diagnosis can't predict the extraordinary love you will have for your child. A genetic specialist can't understand the fierce value you place on your baby's life. A friend might not realize that your baby is an individual made up of so much more than a diagnosis. And a stranger can't possibly know the outrageously beautiful insight you get to experience by seeing life through the eyes of someone with Down syndrome.

“

A diagnosis can't predict the extraordinary love you will have for your child.

- Tara McCallan

”



An extra chromosome doesn't mean the end of what you imagined. It almost means a life more beautiful than what you ever could envision. But it may take time to get there; this path of ours is meant to be different. And know it is okay to take time to grieve what you envisioned in a child—because from that you will grow.

And my hope for you, friend, is that from this grief you will then blossom. You will find your own way, glimpses of hope, moments to celebrate, tears to shed, anger to let go of on this journey.

For my husband, the meetings with the doctors, the New Parent booklet from the Canadian Down Syndrome Society, and reading as much information about Down syndrome as he could, helped. For me, it did not. I wanted what doctors, organizations, and articles couldn't tell me. I wanted a look inside other parents' lives, perspectives on how it all has changed them, and what to expect. The more I looked, minus what Google or Wikipedia said about Down syndrome, the more I discovered what a unique and special diagnosis this really is.

For me, one of the hardest things after finding out Pip had Down syndrome was telling people. I didn't know how to do it, how to react to strangers, what to say, what not to say. So I started by sitting down one night a few weeks after Pip was born and through tears, wrote out some pretty raw and emotional thoughts on her diagnosis—and from there my non-profit Happy Soul Project started. But it's one thing to share your thoughts behind a computer and another to be out in the world. A moment that really changed things for me was when Pip had her first surgery at five weeks old. I had only written about Down syndrome on Happy Soul Project. So on this fated day I was down in the hospital gift shop and an older lady behind the counter asked why I was there. I explained Pip's surgery and added, "And she has Down syndrome." It was as if by finally saying it out loud, I had accepted it.

The lady dropped everything, came around the counter, grabbed my shoulders, looked intently in my eyes and said "You are so lucky," for which of course, I thought maybe she had misunderstood me. Here I was scared to say it out loud, unsure of how to tell people, almost embarrassed because of it, and she was telling me I was lucky. She went on to explain through genuine tears that she had a brother with Down syndrome and it was the absolute best thing in her life. It made her who she was and kept her entire family together. He was the joy the world needed and that I was so lucky to have that. Fearing an "I'm sorry"-type comment, only to be given the exact opposite, changed how I viewed a Down syndrome diagnosis and how I will respond to any new parent moving forward. In that moment I realized she was so absolutely right. I had been looking at it all wrong. I thought I needed to learn to accept my

"So now it's my mission to prove to the world that we really are the lucky ones."

- Tara McCallan



daughter for her differences, when really I needed to learn how to celebrate and be blessed by them. Changing my perspective has changed my life and, I'm sure, the life Pip is going to have.

My daughter is 10 now and I can honestly say, no one has impacted my life like her. Watching her navigate through each hard-earned milestone; hearing her say "Momma!" for the first time after years of longing for her to speak; seeing her make friends and be included at school; and being in awe of the advocate she is becoming herself...has changed me.

The lessons she has taught me, simply by just being herself, how she looks at life, and how she treats, and sees other people is incalculable.

So, now it's my mission to prove to the world that we really are the lucky ones. That is what now fuels Happy Soul Project: to show others that the unnecessary, negative stigma behind a Down syndrome diagnosis needs to change.

I wish there was a way I could go back and save all those tears I shed when I found out Pip had Down syndrome. But I also think that grieving the loss of what I had envisioned for our future gave me the room for expecting the unexpected. Pip is not what I thought I wanted in a daughter until I realized I never knew I needed this kind of love.

So with that, take this letter as if I'm shaking your shoulders like that lady did to me. Actually, I'm wrapping my arms tightly around you, I'm holding you tight as you cry, scream, and work through your grief, begin to see the beauty in the path you've been chosen to walk and letting you go to smile at you and welcome you to the club, my friend.

We're the lucky ones...

Love,

Tara (Pip's Momma), Happy Soul Project

I Will Always Love You

By Krista Rowland-Collins

We found out about Adele's diagnosis early on in our pregnancy. It was a difficult time for us with emotions running on high. Our minds raced. Our doubts and fears took over. Our hopes of having a perfect child shattered right before our eyes. We thought that the perfect child would be one without Down syndrome. How could we raise a child with additional needs? Are we strong enough? Would we be good parents? Our thoughts were so clouded by statistics. It was overwhelming and our hearts ached. We were facing the unknown. Emotions had taken over logic, we needed to grieve.

Three weeks later, at our eighteen-week ultrasound, we saw this perfect little miracle, flailing her arms and legs and bouncing all around. She wasn't a baby with Down syndrome anymore. She was just our baby. We fell madly in love with this little being whom we had not even met.

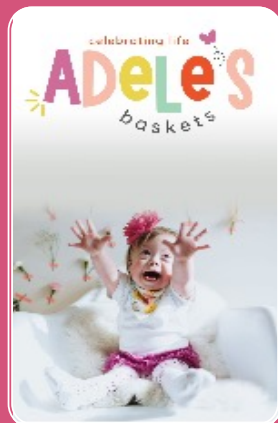
Today, we have a beautiful daughter. We see this little being, a human life that is capable of so much. There are no limits for Adele; there are only hopes and dreams, resilience, love, and encouragement from the world around her.

When I look into Adele's eyes, I see strength, courage, and beauty. I see right into her soul. I see a beautiful angel who has impacted many lives in such a short period of time. I see that she has changed so many views and perspectives, and she has done this not only in our town, but all across the world. Adele has taught me about diversity. She has taught me about patience, about slowing down, and enjoying the little moments throughout the day.

Adele, I will always look after you. I will always advocate for you. I will always hug you when you need a hug, although, it is your hugs that bring the most comfort. I will always show others that you came into this world for a reason. You were given to us for a reason. You are a miracle my sweet Adele.

“There are no limits for Adele; there are only hopes and dreams, resilience, love, and encouragement from the world around her.”

- Krista Rowland-Collins



Welcome Baskets

Every baby should be welcomed into the world with excitement and love. The Rowland-Collins family started Adele's Baskets in 2014 with the mission of providing families with comfort, reassurance, and most importantly, congratulations!

The baskets are filled with beautiful gifts and resources. There are free Welcome Basket programs across Canada, look for one near you!

Nothing Down About It

Self-Advocates

What will life be like for your child with Down syndrome when they grow up? Learn more from our community members with Down syndrome across the country, also known as self-advocates!



"I'm 29 years old and I work at my job at VDG Salumi 3 times a week. I'm dating Paul Sawka for 4 years now and I watch football, I love to cook, I also go stargazing, and I love to write and read. My goal is to get married and have kids and to move out. I also love to travel."

Kelsey, Age 29
Calgary, Alberta

"I compete and play bocce ball and curling and golf as well. I also watch hockey and all sports. I live on my own in my own house with my friend. I am always working on my goals. I have met so many of them. I would love to make new goals as well, but at this time I am working on being the best employee I can be at my work. Life is great for me and I am sure your child will do well, too."



Matthew, Age 33
Tillsonburg, Ontario



"I work at Melly's cafe 4 days a week. I go to yoga class, fitness class, and Hindu heritage class. I have a small business making lip balms - summer is very busy. I love watching Netflix, my favourite show is Supergirl. I want to be a teacher like my mom and help children learn to read. I want to continue to be an entrepreneur and travel to a lot of different countries and meet new people."

Anasuya, Age 17
Markham, Ontario

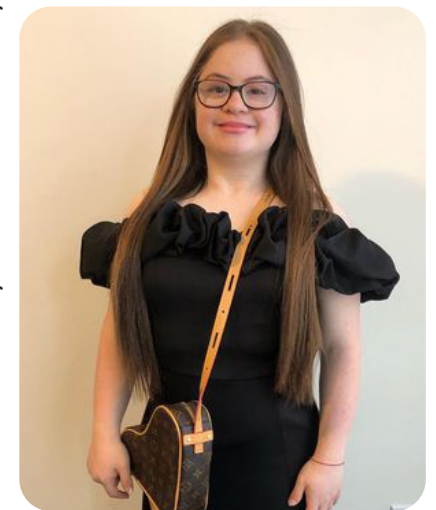


"Some of my favourite things to do are reading, working out, art therapy class, singing in music class, and camping. I also love modelling, being on stage, and walking the runway in fashion shows. My goals are to keep working at school and as a model to help me land jobs with big brands. I plan on getting my drivers licence one day. I also want to fall in love and get married to a handsome, nice guy when I'm older. For now, my focus is on getting strong and healthy."

Annika, Age 15
White Rock, British Columbia

"I enjoy going to school and learning. I have lots of friends there. I love to dance, sing, and do gymnastics. I've been in lots of fashion shows which I also enjoy. I've just finished a program in Cosmetology as well. In my spare time, I also enjoy volunteering at Kayla's Children's Centre, a school for kids with special needs. In the future I will be attending College so I can have a good career, do some acting and modelling, and of course I want to get married. I am Lily and I love my family and I love my life."

Lily, Age 16
Thornhill, Ontario



"During the week, I volunteer 2 days a week at a pre-k program. I go to an equine program where I ride horses, work on a farm, and do social activities. I do advocacy work as I am Canada's rep for Down Syndrome International. I am also an athlete leader with Special Olympics and a motivational speaker, so sometimes have work to do on talks and meetings. My big goal was to live on my own and I am doing that now. My next goal is to be an assistant coach with Special Olympics."

Janet, Age 40
Alberton, Prince Edward Island

Promising Futures

Resource Section

Although you may be overwhelmed with all of this information, the future is very bright for people with Down syndrome. Now more than ever, there are great supports and programs that allow people with Down syndrome to flourish. People with Down syndrome are living longer, happier, more fulfilled lives. This can be attributed to early interventions, the development of accessible resources, and the inclusion of people with Down syndrome at school, in the workplace, and in the community. Many people with Down syndrome attend post-secondary school, get jobs, and are choosing to get married.

Raising a child with Down syndrome will be much like raising any child. There will be ups and downs, challenges, successes, smiles, laughter, and tears.

If you have questions or need support, you can contact our team by calling 1-800-883-5608 or emailing info@CDSS.ca. You can also visit the Resource Hub on the CDSS website for information about each stage of your journey, including Education, Adolescence, and Employment: www.CDSS.ca/Resources/



Who's Teaching Who?

By Scott Anderson

It's September, and once again it's time for that nervous first day back to school. But as you scan the long lineup of awkward children waiting anxiously outside the front door, you'll notice something different about one of these junior high students. It's not just that he happens to be the shortest person in line. No, it's our 12-year-old son Maxwell, and with the biggest, toothiest, most genuine grin you'll ever see, Max confidently struts into the building like he owns the place.

If you ask either Max or his sister Libby what it means to be an Anderson they'll likely respond with something to the effect of, "We are kind, encouraging, and we look for lonely people." These are some of the qualities we are hoping to ingrain into our young children's hearts. Yet without intending to, Max is teaching me so much more:

How to not always be in such a big hurry.

How to be more patient, forgiving, and understanding.

How to love unconditionally.

How important it is to hug.

How to appreciate the awe in the everyday ordinary little things.

Case in point: recently, Max tested positive for Covid and we were a little concerned how it might affect him. Later that same day we cooked and ate outside on our back deck, and as Max dove into his grilled cheese sandwich he exclaimed, "this is the best day of my life!"

It's a statement you'll frequently hear from Max and he means it every single time. And there are so many days where I'm left wondering... who's teaching who?

"I'm learning all the time, and I'm so blessed to have such an amazing little teacher to take my hand and guide me along the way."

- Scott Anderson



The Power of "Yet"

By Jaime Kulik

When I was growing up, I imagined how my life would be in my future. I would go to school, get a job, get married, and have kids. That is how it is supposed to be, right? Easy. I saw all of these milestones happen with other individuals, every single day. I was sure if I set my mind to it, it would happen. That was the way I worked. I've always been very determined to reach an end goal. Earning an B.A. in elementary education? Check. Getting a job teaching middle school science? Check. Finding a man who supported me and who asked for my hand in marriage? Check. For years we enjoyed traveling, bowling, and talking about our future. All around us, we saw our friends were having children and, while we wanted to have a child as well, it wasn't in the cards for us...yet. We were asked, daily, when we were going to have children. It was a good question. When was it our time?

PCOS

As years passed, my husband and I became determined to start a family of our own. It wasn't until we considered going the IVF (in vitro fertilization) route that I was officially diagnosed with PCOS (polycystic ovary syndrome). It was a strange realization to hear the doctor give me the diagnosis as, deep down, I felt like I had it all along. When I heard those words, I couldn't help but wonder how our path would have changed, had I known this information earlier. Regardless, PCOS meant that we couldn't have a child...yet. We still had options. We would be going on a different journey than we originally anticipated, but we would navigate it together.

IVF

What did we have to lose by trying IVF? Nothing. We tried all of the different options available to us, and nothing had worked, yet. The science enthusiast in me was fascinated by the entire IVF process. Ultimately, we were able to experience things that most couples don't get to experience who don't go through IVF. The journey of IVF could be an entire article in itself, but I will fast forward to one of the best days of our lives - July 4, 2017. Independence Day. This was the transfer day. The day we could potentially become parents! The doctor completing the transfer was amazing. He answered all of our questions, talked us through the process, and told us to "Enjoy the best firework show you will ever see." It was true. It was a show we would never forget. Our little firework is beautiful, bright, and can always be heard.

Pregnancy

My pregnancy was amazing. I had never felt better in my life. I had suffered from migraines my entire life, and for the first time, without any medications, I was migraine free! It was such a fantastic feeling, knowing that we were soon going to be parents. With each passing day, I became more and more excited to meet our baby. We had scheduled our 20-week scan to find out if we were having a boy or a girl. We were both planners. We wanted to get the baby's room together and have clothes ready to go before the baby was born. We sat in our 20-week ultrasound eager to get the news, but something felt off. It seemed like something was wrong. There were very long stretches, during the ultrasound, that nobody was talking to us. What could it be? Did I do something wrong? Why won't they speak to us? They finally told us that they could not get good enough pictures of the heart and that we needed to see a specialist. We left the ultrasound with lots of questions and fears. But, the ultrasound technician did tell my mom the sex of the baby. That night, we went out to dinner and opened a special package that my mother had wrapped for us. It was a blue shirt that said, "Little Man." We read it together and were all smiles. Tears of joy were abundant. Our night was spent talking about room colors and decor. We shared our list of names that we both had come up with. It was such a special night that I know neither of us will forget. But there were still those lingering questions that we didn't have answers for....yet.

Down Syndrome

After our ultrasound, we met with a fetal cardiologist. It was determined, after many ultrasounds, that our unborn child had three holes in his heart. I asked if this was a marker for Down syndrome because I remember reading about 50% of people who have Down syndrome have some kind of heart condition. They suggested we have genetic testing done using a cell-free DNA test. I remember the day we were told that our unborn child had a very high chance of having Trisomy 21, also known as Down syndrome. Every emotion came crashing down on me. I had a legitimate fear that I wouldn't be able to be the best mother that I could be. What did I know about Down syndrome? Nothing, and it was terrifying that I'd soon have to raise a child with a diagnosis that I knew very little about. It took a few months, and a lot of conversations with my husband and doctors to open my eyes and realize not to focus on the diagnosis. This was a child. This was our child, and he wasn't even born yet. This was something we had wanted so badly and for so long. We became determined to put our fears aside, focus on our little guy, and welcome him into the world with as much love as humanly possible. Fast forward to March of 2018. Our son was born and guess what, he was perfect!

Heart Surgery

The first three months of our son's life went by so fast. The anticipation of our June date for heart surgery was nerve-wracking. We had many doctor visits to monitor his three holes in his tiny little heart. We were prepared to get them fixed; once his body was ready. We spent those first months of his life loving him to pieces and helping him gain weight. His heart was not whole yet. But we had an excellent team that was confident in their ability to operate successfully. When it came time to put him in the hands of those who would make his heart whole again, we waited for hours for the doctors to walk through the door. When they did, they stated that the surgery went smoothly, the surgeon did a fantastic job, and that our little man was waiting for us in recovery. June 18 will always hold a special place in our hearts.

Early Intervention and Milestones

Learning about all the different milestones a child needs to hit and at what age they should meet these milestones is eye-opening, exciting, and terrifying all at once. I've always focused on what our son could do, rather than getting hung up on what he couldn't do. Again, enter the power of yet. He wasn't rolling over yet. He wasn't crawling yet. He wasn't walking yet. He wasn't talking yet. Guess what? All of these things happened on his terms, when he was ready. I've never witnessed anything more inspiring than seeing his willingness, eagerness, and determination to learn new skills. He continues to move mountains each and every day of his life, and he makes us better parents. Early intervention is what you make of it. It could be the most daunting task or an incredibly inspirational time in your life. Our son's therapists came into our home and gave us the education we needed to help our son hit his milestones. I made sure we used this time to focus on his successes.

Pandemic

I have accomplished some great things in my life, including winning a high school bowling state championship, earning my master's degree while working a full-time job, marrying the love of my life, and having a beautiful baby boy. Becoming a mom was the most empowering title I've ever had. The day my son was born was the day I realized that every move and decision I made would impact this child for the rest of his life. I want my son to look back at all the memories we created during this time and realize that he was the reason we did what we did. I want him to see the smile on our faces in those pictures and understand that we took this moment in time, to embrace family and create a lifetime full of memories.

I want him to see that life isn't always easy, but you can choose how to respond to what is happening. In many daily interactions, I am reminded often that our child does have special needs. However, I never think of myself as a special needs parent. Am I wrong in this line of thinking? He is my son, and I would do anything to make his life the best it can be, with or without the label of special needs. I think every parent handles things in their unique way. For me, there are no labels, no barriers, and certainly no stopping my son from doing what he wants to in his life. He's overcome so much adversity in his short little life. I feel comfort in knowing that we've continued to support, challenge, and encourage him to develop into a fine young man through all the uncertainty.

The Best is Yet to Come

When I was asked to write an article about myself, I found it hard to write about my story. Why me? What makes my life inspiring or even remotely interesting to others? I haven't created a business, nor have I created a name for myself or designed something that anyone would want to purchase. I hope that in reading my story, someone can relate to my experiences, find hope, and realize that they can make a difference in the lives of others. It may not happen right away, but that's the power of "yet". Every day you have choices to make. Don't get lost in small details, don't let anyone derail your hopes and dreams, and continue to find the best in all situations. "Yet"...it will happen.



Next Steps

Resource Section

Taking care of you and your baby is the most important thing in the first few months. Give yourself time to adjust and enjoy the pleasures of having a newborn. Most importantly, just like any baby, your baby with Down syndrome needs love. As you adjust to your newborn, there are resources that may help you on your journey. Some of these include local groups, internet communities, and books.

LOCAL GROUPS

When you are ready, connecting with a local Down syndrome group near you can be a great starting place after welcoming your new baby. Many towns, cities, and provinces have organizations and support groups to connect local families. A list of local groups can be found on our website: www.CDSS.ca/About/

ONLINE

Many new parents find it helpful to connect with parents who have been in their shoes. If you are not quite ready to be a part of your local group, many parents are now connecting online.

The Down syndrome community has so many wonderful parents who are willing to share their stories that can help to inspire and uplift other parents and help you feel like you are not alone. Often Google can be an overwhelming starting point when learning about Down syndrome. Visit the CDSS New Parents and Early Years Information Hub at www.CDSS.ca/Resources/New-Parents/

“I asked my mom how I changed her life. She said that I have introduced her to an inclusive and diverse community. My mom said that I have taught her joy. And also that she now has met lots of great people who she would have never met if it wasn’t for me.”

- Jessie Huggett

FAQ

Are there government programs or services to help my family? When should I apply for them?

Yes, each province and territory has ways to provide support to families with a child with a disability. You can find helpful resources on our website under the Federal and Provincial Supports Information Hub:

www.CDSS.ca/Resources/Disability-Supports/

What will life be like growing up with Down syndrome?

People with Down syndrome have shown they can excel in areas never thought possible. There are more supports and resources available to people with Down syndrome now. Children with Down syndrome are learning together in inclusive classrooms with their peers, some adults with Down syndrome go to university, find employment, and live independently or with support in their communities.

Your child with Down syndrome will face some challenges in his or her life, just like other children, but with the proper supports and resources, your child will be able to live a full and meaningful life.

I’m still pregnant. Should I do anything different to prepare for my baby’s birth?

Like any expectant mom, you should try to get the rest you need. Allow yourself some time to learn about Down syndrome. Help your family and friends learn about Down syndrome. Any feelings you have are okay. Allow yourself and other people close to you time to experience loss and grief but also to celebrate the expected arrival of your baby. You can start to look into early intervention programs in your area and provincial government services. You can also connect with a local Down syndrome group close to you.

I do not have a Down syndrome clinic in my area or my doctor has little experience, what should I do?

Many medical professionals are willing to learn more about Down syndrome and how to better help their patients. Sharing current, accurate information about Down syndrome with your medical team is a good place to start. Refer to our website for more information and health care guidelines.

For more commonly asked questions, please visit the Down Syndrome Answers page on our website:

www.CDSS.ca/Awareness/Down-Syndrome-Answers/



Canadian Down Syndrome Society (CDSS) is a national non-profit organization focused upon human rights, health, social participation, inclusive education, and employment for those with Down syndrome. CDSS supports self-advocates, parents, and families through all stages of life.

Our Vision:

All people are valued, fully participating citizens.

Our Mission:

CDSS is the national source of expertise promoting the abilities and contributions of people with Down syndrome. We provide reliable information and connections to people with Down syndrome and those who support them, while positively shaping the social and policy contexts in which they live.

CDSS Provides:

- A Resource Hub supporting all aspects of living with Down syndrome.
- Major life-stage resources available in digital format in English and in French.
- 3.21 Magazine, Canada's Down syndrome magazine. It includes first-person stories, advice from professionals, and advocacy news.
- Advocacy efforts with Federal, Provincial, and Territorial Governments on issues affecting the lives of Canadians with Down syndrome.
- Access to a network of Down syndrome groups in Canada.
- Person-centered supports and connections to resources, services, and information for the Down syndrome community through all life stages.
- Ongoing learning opportunities through information webinars and events facilitated by community subject matter experts.
- Regular updates about important advocacy news, services, studies, and programs for the Down syndrome community.

Canadian Down Syndrome Society is a Registered Charitable Organization, Charitable Registration: 11883 0751 RR 0001.

CDSS.ca