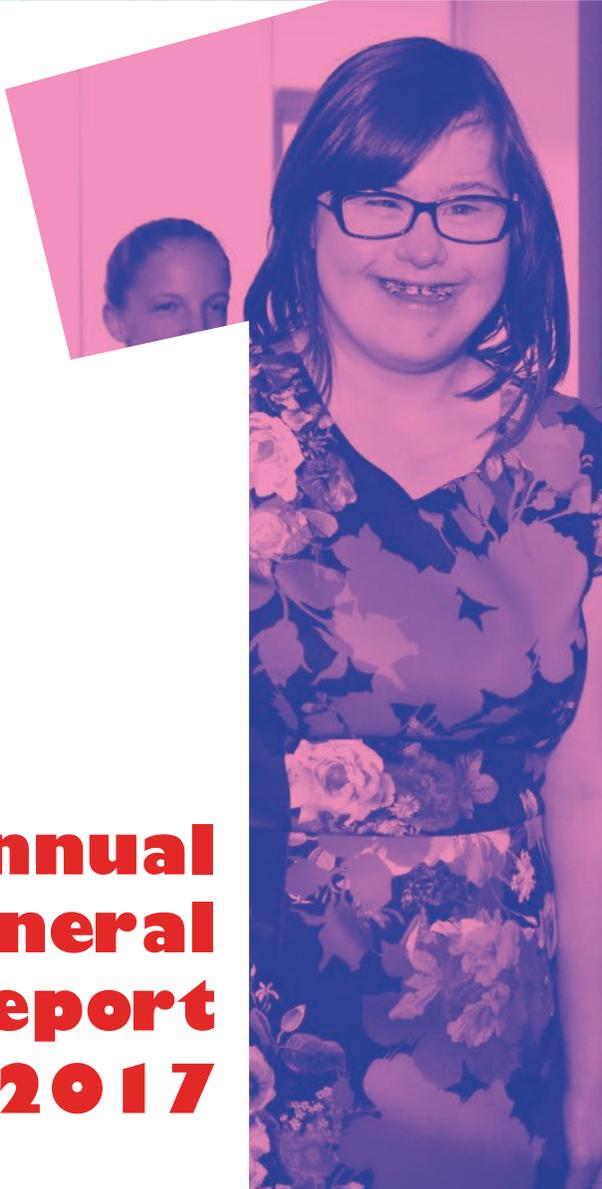
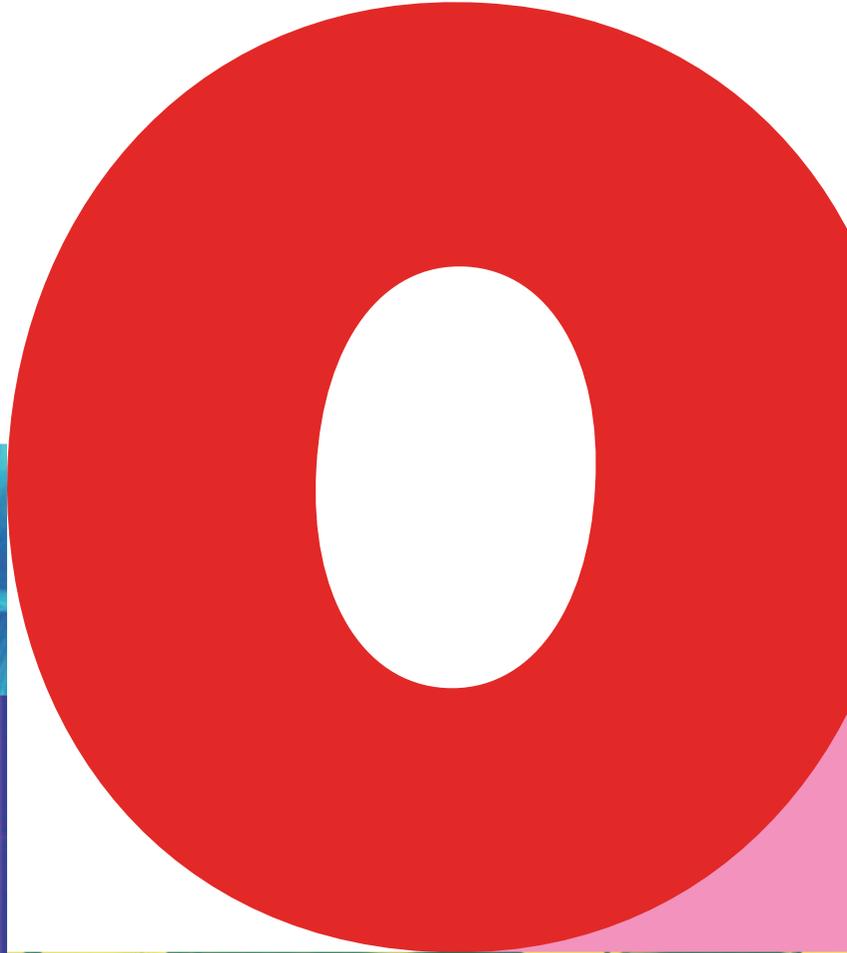




Canadian
Down Syndrome
Society

Société
canadienne de la
trisomie 21



Annual General Report 2017

2017 Staff

National Executive Director: Kirk Crowther
Office Manager: Lynette Gowie
Resource Coordinator: Carlee Reardon
Database & Fund Development Analyst: Alexandra Prefontaine-Wright
Communications Coordinator: Heather Turnbull
Awareness Leader: Paul Sawka
Office Assistant: Jody Roll
Inclusive Employment Project Coordinator: Kim Bechtel

2017 Board of Directors

Chair: Laura LaChance
Vice-Chair: Ed Casagrande
Treasurer: Caroline Pearce
Secretary: Sonya Billiard
Sean Wiltshire
David Fischl
Jackie Charchuk
Dewlyn Lobo
Ben Tarr
Elaine Willcock
Stewart Moffat

2017 VATTA Members

Chair: Matthew MacNeil
Vice-Chair: Natalie Olson
Nicholas Popowich
Jessie Huggett
Julia Romualdi
Alana Gersky
Jeremy Abramson

2017 Affiliate Council

Down Syndrome Association: National Capital Region
Regroupement pour la Trisomie 21
Down Syndrome Association of Hamilton
Waterloo Regional Down Syndrome Society
Manitoba Down Syndrome Society
Halton Down Syndrome Association
Down Syndrome Society of Toronto
Saskatchewan Down Syndrome Society
Edmonton Down Syndrome Society
Ups & Downs: Calgary Down Syndrome Association
Lower Mainland Down Syndrome Society
Greater Victoria Down Syndrome Society



Looking into 2018



This past year laid the foundation for several new projects in 2018. We are currently developing new resources and continue to raise awareness for people with Down syndrome. A couple of highlights to look forward to include:

Today and Tomorrow: A Guide for Aging People with Down syndrome

A new information resource for the aging community of people with Down syndrome and their families.

Anything But Sorry: because no baby should be welcomed with a “sorry”

Based on the continued success of the 2017 Anything But Sorry campaign we have teamed up with FCB Toronto again to expand on the campaign. We want to change “the sorry” and help all parents welcome their babies the right way.

French Resources: New Parent Package

21 Welcomes, our resource for new parents has been translated into French. In 2018 we will start to provide this free resource in French!

Anything But Sorry

In 2017, CDSS worked with FCB Toronto to develop our second major national awareness campaign, called “Anything But Sorry.” This campaign was released during Canadian Down Syndrome Week and focused on new parents, showing Canada that the only inappropriate way to welcome a baby is with the word “sorry.” The story below is from Dorlean Lieghfars-Rotolo, a parent of one of the self-advocates featured in the “Anything But Sorry” campaign, sharing her story and why they decided to be involved with the campaign.



Self-advocate Jessica Rotolo in the “Anything But Sorry” video

“My husband Joe and I live in Toronto and have been married for 22 years. We have been blessed with two beautiful daughters. Jessica is 19 years old and attends Heydon Park Secondary School. Bobbi is 18 years old and attends the University of Waterloo in Ontario, Canada, studying Health Sciences. We are so proud of them and their many accomplishments.

As parents of a daughter with Down syndrome, Joe and I heard “we are so sorry” so

many times when Jessica was born, starting with the midwives, nurses, and doctors. Family and friends were also very sad for us. Unfortunately, people fear the unknown, and, in their ignorance, they say “sorry”.

For us, we just had a beautiful baby and we felt blessed to raise her. We were good!!! I was totally fine until two days after Jessica was born. We took Jessica back to the hospital to see a doctor for her check-up. He started to use Jessica as a “training specimen” to show a fellow doctor all the traits of Down syndrome. When we left his office I totally lost it. Maybe everyone was right; I should be sad and sorry that our baby was born with Down syndrome.

The next day a relative gave me a poem by Irma Bombeck. After I read it, once again I knew there was a special plan for our family. We dug our heels in to help Jessica become the best person she could be.

She is one amazing young woman. We cannot imagine our lives without her or her sister Bobbi. Jessica being born with Down syndrome is her “normal.” As parents the last thing we are is SORRY that either of our daughters was born.

When we were approached by CDSS to have Jessica audition for the PSA, we immediately replied “yes.” We feel it is important for people to understand that SORRY is truly the wrong word to say when any child is born with Down syndrome. The response from our family and friends has been so positive – everyone loves the strong message it has sent to the world.

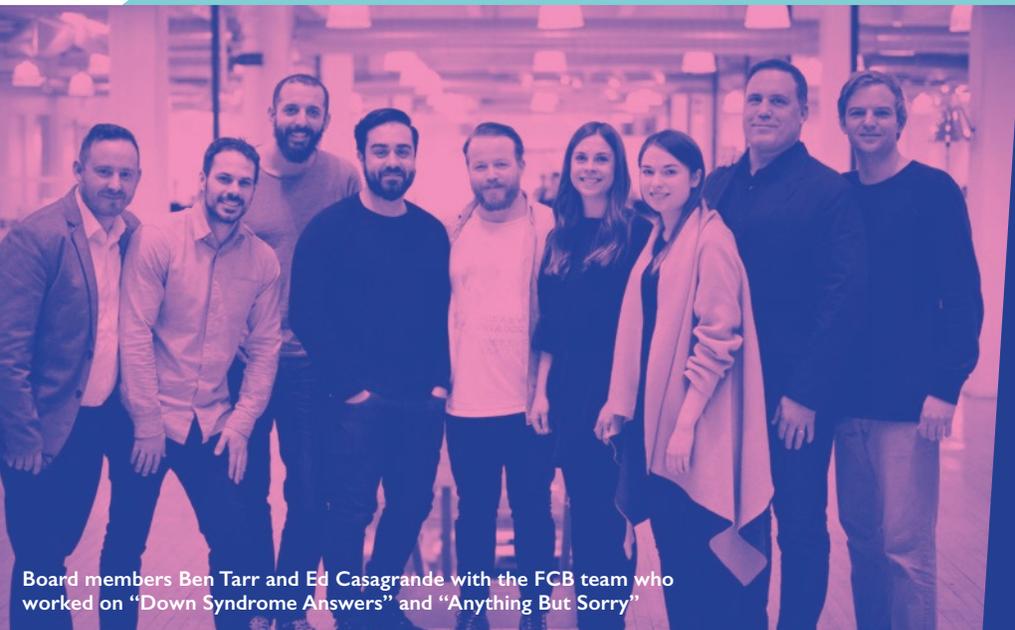
Being part of this campaign was such a positive confidence boost to Jessica. She wants the world to know that she is NOT SORRY THAT SHE WAS BORN, she loves life, and she lives life to the fullest.”



We are extremely grateful to our agency partner FCB Toronto for the incredible contribution they have made to CDSS over the past 18 months. Not only have we seen increased awareness and engagement across Canada and internationally! The ‘Down Syndrome Answers’ campaign went on to be one of the most awarded campaigns in the world, sweeping the most prestigious awards shows including Cannes, D&AD, The One Show, The Webbies, The Clios & the Andys to name a few. In 2017 CDSS was ranked the number two brand in Canada out performing the likes of global brands such as IKEA & McDonalds. “Down Syndrome Answers” has been recognized internationally as an educational resource.

Watch the videos for both FCB campaigns (Anything But Sorry and Down Syndrome Answers) at youtube.com/cdndownsyndrome

Thank you FCB Toronto for all of your continued support!



- **1.3 billion media impressions**
- **50,000 social media shares**
- **140,000 views of the videos**
- **Extensive PR including CBC, Today’s Parent, National Post**

Board members Ben Tarr and Ed Casagrande with the FCB team who worked on “Down Syndrome Answers” and “Anything But Sorry”

CDSS International

2017 was another year of growth and opportunity for the Canadian Down Syndrome Society (CDSS) and contained several memorable moments on the world stage.

One of the biggest highlights took place on World Down Syndrome Day, March 21, 2017. CDSS was invited to speak at the United Nations in New York City about the importance of self-advocacy and people with Down syndrome sharing their collective voices. Self-advocate and VATTA Chair Matthew MacNeil and National Executive Director Kirk Crowther spoke to delegates from around the world. The UN was the perfect platform to share our experiences. Canada is a leader in supporting people with Down syndrome have the opportunity to create a future that is based on their needs and desires.

The 2017 UN conference theme was #MyVoiceMyCommunity, which allowed CDSS to showcase all of the great work self-advocates are doing across Canada. We had the opportunity to speak about the importance of including people with Down syndrome in conversations to allow their voices to be heard and to influence government policy and actions. "Everyone should be proud of who they are. I'd like to show more people that they should treat us just the same as everyone else," said Matthew MacNeil. CDSS also spoke with delegates from around the world and shared valuable information, resources and advocacy stories.

CDSS had the opportunity to meet with the Permanent Representative of Canada to the United Nations to discuss how CDSS is on the forefront of helping communities be more inclusive in Canada.

We talked about our VATTA committee, which is made up of self-advocates from across Canada, and how they have changed the landscape for future generations. "VATTA was created in 2005 with the belief that having adults with Down syndrome play a major role in the Canadian Down Syndrome Society would be beneficial to all Canadians with Down syndrome," said Kirk Crowther. "Twelve years later, VATTA having the opportunity to present at the UN is just further proof that people with Down syndrome have the tremendous power to shape their own futures and make all communities more inclusive."

CDSS is continuously working to promote the inclusion of all people with Down syndrome. Speaking at the United Nations allowed us to reach a large and powerful audience while strengthening our international influence. There are 45,000 Canadians with Down syndrome contributing to their communities in their own individual ways – each one making an impact.



VATTA Chair Matthew MacNeil and CDSS National Executive Director Kirk Crowther at the United Nations in New York



From left to right: Advocate of the Year winner Eric Vriend, Inspiration Award Winners Teresa Pinkoski and Laura Stremble accepting their awards at the Canadian Down Syndrome Conference in Banff, Alberta

CDSS Awards

Advocate of The Year: Eric Vriend

The Advocate of the Year is awarded to a self-advocate who is a community leader. The recipient is a person who gives to the community, through work or volunteering, and contributes meaningful change to people's perceptions of disability and Down syndrome. This person shows their community how to "See the Ability."

Inspiration Award: Teresa Pinkoski and Laura Stremble

The CDSS Inspiration Award is awarded to two people with Down syndrome each year. These are the unsung heroes of the Down syndrome community. This award is best suited for people who feel as though they're not typically represented in the community, but have a story worth celebrating. The two recipients are people who demonstrate the range that "See the Ability" encompasses.

Jane Cameron Award: Wendy Hladik

In memory of Jane Cameron (1949 – 2000), a talented artist with Down syndrome, and in recognition of her contributions to the arts, in 2001 the Jane Cameron Archives Committee (JCAC) and the Canadian Down Syndrome Society (CDSS) established an annual award for a person with Down syndrome who displays expertise in an area of the visual arts.



"I Like It" by Wendy Hladik, 2017

Looking back & looking ahead:

building our inclusive future

In 2017, CDSS received a grant from community foundations across the country which allowed us to develop and present on inclusion in Calgary, Winnipeg, and Prince Edward Island to grade four through nine students. The presentation is called Looking Back and Ahead: Building Our Inclusive Future. Each of the presentations were hosted by either a CDSS employee or board member and VATTA member. CDSS Resource Coordinator Carlee Reardon and current VATTA member Natalie Olson presented in Calgary, Carlee Reardon and VATTA Alumni Ruth Joseph presented in Winnipeg, and VATTA Alumni Janet Charchuk and current Board Member Jackie Charchuk presented in PEI.

The presentation was designed to spark ideas and conversations with today's youth. The presentations focused on understanding inclusion and how it continues to grow in classrooms and communities across Canada. The presentations walked students through some of the history of inclusion for people with disabilities, giving a small glimpse into how different things used to be and how far we have come today. The presentations finished with a conversation about how we can continue to develop inclusive classrooms and communities to make sure that everyone has the opportunity to fully participate in their community.

During these presentations, students from across Canada watched videos and heard stories first-hand from self-advocates. Students were able to interact and learn more by asking questions and making suggestions for the future.





Giving Tuesday



Jody Roll with her original artwork created for Giving Tuesday

Thank you for making this year's Giving Tuesday campaign (November 28, 2017) an overwhelming success – we exceeded our goal. This year's campaign was our third time participating in Giving Tuesday. Each year the events have grown, and 2017 was no exception. Giving Tuesday is a global day of giving that follows American Thanksgiving. Organizations across Canada and around the world participate in this one-day event. CDSS chose to raise funds to support all new babies born with Down syndrome through our New Parent Package, 21 Welcomes.

Each year about 500 babies with Down syndrome are born in Canada. It is important to CDSS that all babies with Down syndrome receive a warm welcome and that families feel supported and part of the Down syndrome community. Our New Parent Package, 21 Welcomes, features 21 stories from families about their loved one with Down syndrome. This resource is provided to families free of charge and was distributed across Canada and around the world in 2017.

Thanks to your generous donations we reached our goal of being able to send a copy of 21 Welcomes to each of the 500 families who will welcome a baby with Down syndrome into their family in 2018. This is our way of welcoming and congratulating them.

This year's campaign featured Jody Roll, an artist with Down syndrome. She has been involved heavily in the art world for several years; she has even created a number of original pieces that have been featured on CDSS cards. We were lucky enough to involve Jody this year by having her create an original art piece and participate in two Facebook Live events.

“Art means everything to me! It’s a way for me to express how I feel inside,” said Jody Roll. “This piece represents me as ‘Flowers of Many Colours’.”

Since we exceeded our goal of \$11,500 we are able to include a print of Jody's art in each New Parent Package that is sent in 2018. How did we celebrate? We randomly selected someone from our membership to receive Jody's original piece.

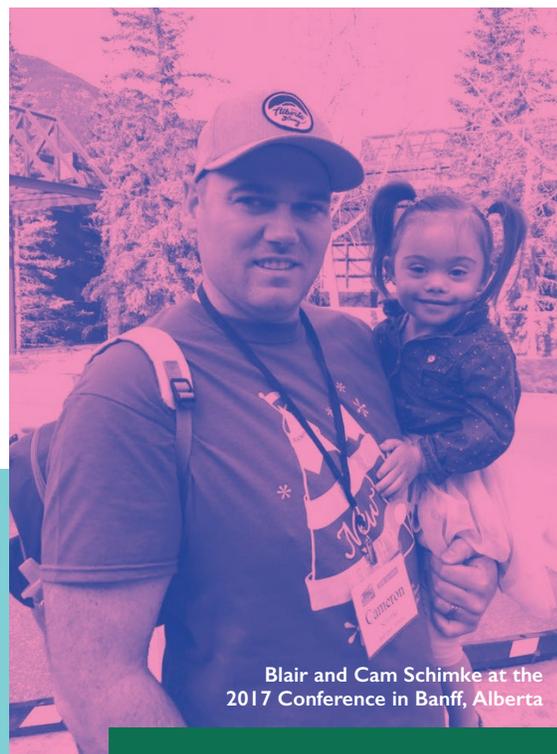
Banff Conference

The 30th annual Canadian Down Syndrome Conference was held in Banff, Alberta. Over 450 people came to learn from experts and to build relationships within the Down syndrome community. Below is a story from Cam and Caitlin Schimke from Red Deer, Alberta, about why our annual Canadian Down Syndrome Conference has become a family tradition.

“Just after Blair celebrated her first birthday, we attended our first conference in Edmonton in May of 2015. We had mixed emotions of uncertainty, excitement, and a fear of the unknown. That weekend we found our roots within the Down syndrome community. We connected with young families, built new relationships, and left with a new family tradition.

The next year our family (with a new little brother in tow) flew to Montreal. This conference was exciting because Blair was becoming her own little person, interacting and sharing her personality with everyone. This is when we realized these conferences were as much for Blair as they were for us. We came home with so much practical knowledge and strategies to work on with Blair and a dose of information to share with friends and family.

Last year’s conference in Banff was by far our favourite. We felt comfortable and at ease as parents, and went to sessions that we felt were a good fit for Blair. We had conversations with familiar faces from past conferences, and there was a positive energy that you feel when you’re at a family reunion.



Blair and Cam Schimke at the 2017 Conference in Banff, Alberta



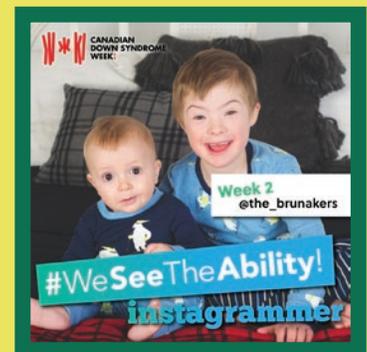
Sean McElwee from A&E’s “Born This Way” during the Keynote address at the 2017 Canadian Down Syndrome Conference

Last year, the welcome reception was a camping theme. Our whole family came and it became one of our most memorable experiences so far. Elena from the series “Born this Way” was on the dance floor and Blair strolled right up there and started dancing too. We cannot express as parents how this made us feel. The two gravitated towards each other, with Elena showing her nurturing side to a little girl, and Blair thriving from special attention with an adult. This was a glimpse into the future for us – independence, acceptance, and a love for dance no matter the age. These conferences can bring out some powerful emotions, and for us it is knowing that the Down syndrome community is our tribe. They are our allies and strength on this beautifully chaotic journey.

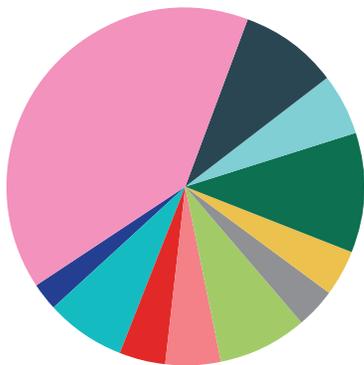
We have built a strong connection with CDSS, and value the support it brings to families, including ours. The conferences hosted by CDSS are like extending an olive branch for all families across Canada to come together to learn and unite. No one understands your journey like someone who is on the same path. These conferences allow us as parents to let our guard down and expose the vulnerability that comes with parenting our little ones. For us that means swapping therapy stories, sharing preschool insecurities, and laughing about how determined four year olds can be. It also gives us a chance to have conversations with adults who have Down syndrome about everyday things like hockey stats and sports. This glimpse into the future takes away some of our worries and fears for Blair.”

Canadian Down Syndrome Week

CDSS held its second annual Canadian Down Syndrome Week (CDSW) from November 1 to 7 in 2017, celebrating the abilities of Canadians with Down syndrome. This year's CDSW was a great success and was celebrated Canada-wide with the help of our Instagrammers. Leading up to CDSW five people from the Down syndrome community did week-long Instagram takeovers with the CDSS account. They showcased their ability and celebrated CDSW.



CDSS 2017 at a Glance:



Info Requests:

40% – General

9% – Events

5.5% – Resources

11% Fundraising

4% – Education

3.8% – Medical

8% – New Parents

5% – Immigration

4.2% – Advocacy

7.1% – Media & Communications

2.4% – Employment

 **GO21**

6 events:

1. Down Syndrome Association of Hamilton
2. Edmonton Down Syndrome Society
3. Saskatchewan Down Syndrome Society
4. Halton Down Syndrome Association
5. Down Syndrome Association National Capital Region
6. Down Syndrome (Caring Parents) Niagara

Total money raised:

\$191,392.21

Once again Yogen Früz locations across Canada sold Kayla's Flavour to raise funds for CDSS! Thank you for your continued support and **thank you Kayla for another great flavor!**

yogen früz



We're in the top



CDSS is in the top 21% of stores on Shopify that launched the same week as us!

Thank you for downloading our digital resources!



2017 social media climb:



1,591 new followers!



518 new followers!



504 new followers!



Views: 170,000!

100

World Down Syndrome Day packages were sent out &

100

were downloaded!

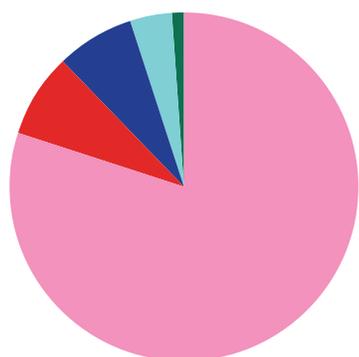
Monthly donors: 320

Money raised: \$36,640.00

Financial Charts

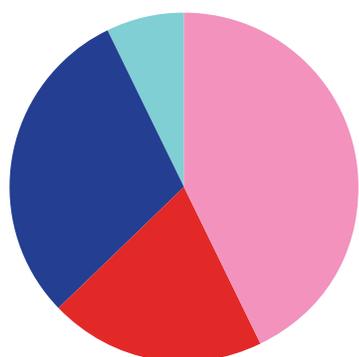
Here is a snapshot of the Canadian Down Syndrome Society's financial position.

Where the money came from in 2017:



- 80% Donations
- 8% Conference Revenue
- 7% Special Events
- 4% Government Grants
- 1% Membership & Product Sales

Where the money went in 2017:



- 43% Promote awareness in areas of rights, health, social participation, education and employment
- 20% Enable people with Down syndrome and their families to advocate on their own behalf
- 30% Change perception about the skills, abilities, dreams, and goals of people with Down syndrome
- 7% Canadian Down Syndrome Conference

* Note: CDSS's 2016 and 2017 Financial Statements are available on the Canada Revenue Agency website (www.cra-arc.gc.ca)

Thank you to our donors:

Thank you to our donors! Thanks to you and your continued generosity and support we were able to provide new parents with the free New Parents package, host the 30th Annual Canadian Down Syndrome Conference, and continue to raise awareness for Canadians with Down syndrome.



COMMUNITY FOUNDATIONS OF CANADA
FONDATIONS COMMUNAUTAIRES DU CANADA
all for community. ensemble pour tous.



cutting through complexity™

The Whyte Family

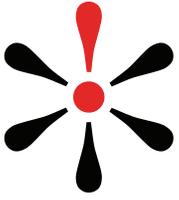
Heather Kaine

Rod & Stephanie Roll

Club 21

1. Edmonton Community Foundation
2. Brampton Plant
3. Tom Koch
4. Sandpiper Contracting LLP
5. Tech To U
6. The Calgary Foundation
7. Executive Millwork
8. Fairfield Watson & Lewis
9. Investors Group Financial Services
10. Brian Sacchieri
11. James N Allan Family Foundation
12. Gracin Black
13. ATCO Electric
14. Community Foundations of Canada
15. Child Development Dayhomes
16. Linda Henry
17. Barbara Wysocka
18. Tom Briggs
19. Pogo Logistics
20. Mary Normandeau
21. Community Foundation of Prince Edward Island

and many more ...



Canadian
Down Syndrome
Society

Société
canadienne de la
trisomie 21

The Canadian Down Syndrome Society (CDSS) is a vital resource linking individuals, parents and professionals through advocacy, education and providing information. Since 1987, CDSS has been proud to be the voice of Canadians with Down syndrome and their families. **#SeeTheAbility**

Our Vision

All people are valued, fully participating citizens.

Our Mission

To empower Canadians with Down syndrome and their families.

We raise awareness and provide information on Down syndrome through the prenatal, early childhood, school years, adulthood, and retirement stages of life.



Suite 103 – 2003 14 Street NW
Calgary, AB, Canada, T2M 3N4

Toll-free telephone in Canada: 1-800-883-5608
Local/International telephone: +01 403 270 8500

See The Ability **cdss.ca**

CDSS is a Registered Charitable Organization
(Canada Customs and Revenue Agency Business Number: 11883 0751 RR 0001).