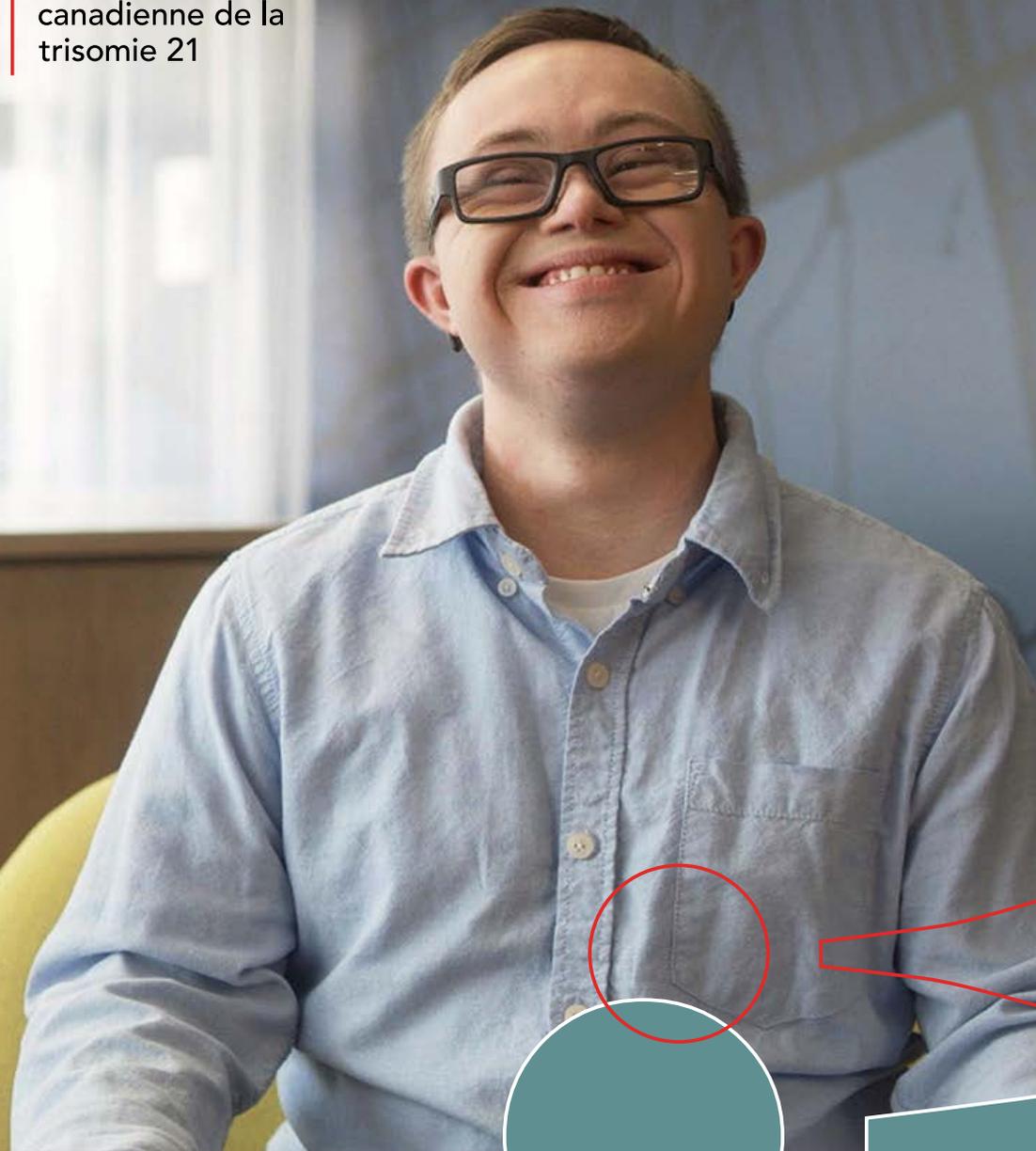




Canadian  
Down Syndrome  
Society

Société  
canadienne de la  
trisomie 21



**2019**

# Annual General Report

# Vision

All people are valued, fully participating citizens.



# Mission

To empower Canadians with Down syndrome and their families. The CDSS raises awareness and provides information on Down syndrome through the prenatal, early childhood, school years, adulthood and retirement stages of life.

*See The Ability!*

## Our Values

### The CDSS believes that...

#### People First Approach

Individuals with Down syndrome are people first and foremost.

#### Inclusion

Inclusion is an attitude and means more than individuals with Down syndrome simply being present in a family, classroom, community or job. It means that individuals with Down syndrome are recognized as full citizens in a society where diversity is welcomed, and relationships are built. Inclusion is the practice of welcoming, valuing, empowering and supporting people of all abilities.

#### Self-Advocacy

The voices of Canadians with Down syndrome inform the direction of the Society.

#### Equity

Equity is about fairness and goes beyond treating everyone equally to understanding people's different strengths, needs and circumstances.

#### Plain Language

Communication must occur within a manner suitable to the needs of individuals with Down syndrome.

#### Partnership

The Society must work to build upon the diversity of individual, community and group strengths to provide advocacy, support and information.

#### Accountability

The CDSS is accountable to our members and to Canadians with Down syndrome and their families.



# Strategic Plan

During 2019, CDSS engaged in strategic planning sessions to determine our priorities, objectives and to set the pace for the next three years.

*CDSS is transforming to better serve the Canadian Down syndrome community.*

## Our Strategic Priorities

1. To broaden the understanding of Down syndrome in Canada
2. To build strong relationships with key stakeholders in Canada
3. To diversify our fund development
4. To develop a workplace support resource for job seekers and employers in Canada

# 1. Broadening the Understanding of Down Syndrome in Canada

In 2019, to complete the life stage resources for people with Down syndrome and the people who care for them, CDSS added new prenatal and aging publications.

## Information about Down Syndrome for Expectant Parents

Women choose to undergo prenatal screening and diagnostic testing for many reasons. This resource helps expectant parents prepare for the birth of their child; to learn more about Down syndrome and what it is like to raise a child with Down syndrome; to learn about resources and supports available and advice on working with their health care team to access the best care.

## Today & Tomorrow: A Guide to Aging with Down Syndrome

This resource was designed to help people with Down syndrome and the people who care for them to learn about the aging process and to plan and prepare for the future.

## French Resources

In efforts to provide resources in both official languages, all of CDSS' life stage resources are now available in both French and English including the new prenatal resource "Information sur la trisomie 21 pour les futurs parents" [Information about Down Syndrome for Expectant Parents] and "Aujourd'hui et demain un guide sur le vieillissement avec trisomie 21" [Today and Tomorrow: a Guide to Aging with Down Syndrome].



*All released in 2019!*

# Project Understood

## 2019 Awareness Campaign

The future is voice-first, but currently not for everyone...



Planning for our national awareness campaign began in June, when CDSS alongside our partner agency for a fourth year in a row, FCB Toronto, worked with the VATTA team to gather a list of 'accessibility' topics they struggle with regularly. What consistently rose to the top of that list was voice technology, giving us our 2019 theme and two challenges to solve: To make voice technology more accessible for people with

Down syndrome, and to shift perceptions about people with Down syndrome when it comes to independence and communication.

A third partner was needed from the technology world. A partnership was formed with Google's AI (artificial intelligence) Euphonia team, a group "...focused on improving how systems recognize impaired speech...". Because people with Down syndrome

To improve Google's voice technology, the Down syndrome community became Google's teachers.

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have atypical speech, on average Google's voice assistant misunderstood one in every three words they speak.

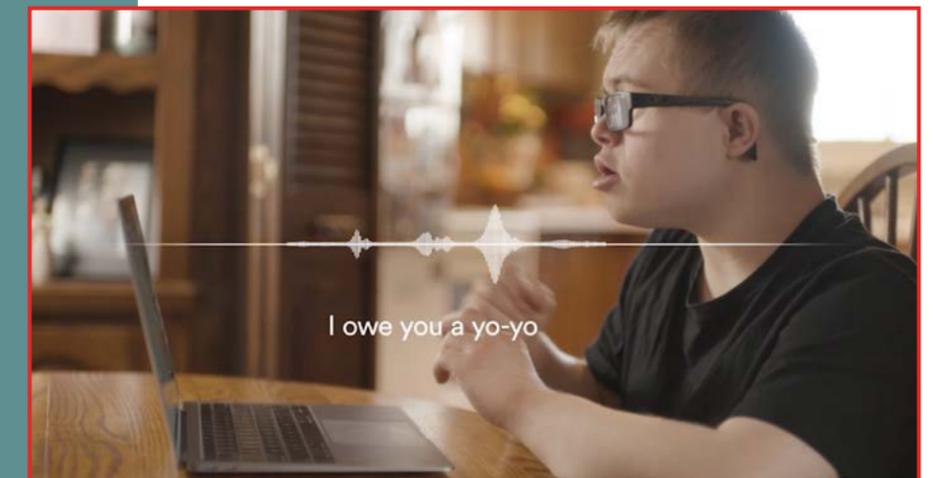
"Project Understood" was released during Canadian Down Syndrome Week in November. Two videos shed light on the inaccessibility of voice technology and served as a recruitment tool, mobilizing the community to donate their voice to train Google. Young adults with Down syndrome encouraged the rest of the community to become 'Google's teachers', by registering and recording simple sets of phrases which would improve Google's algorithm. This Phase One recruitment drive was very successful, and the initial project research goal of 500 registered participants was reached.



"For people with Down syndrome, access to voice technology is more than just a convenience—using it can lead to life-changing independence.

By recruiting members of the Down syndrome community from our CDSS network, the 2019 campaign empowered them to play an active role in improving this technology, which in turn, will impact many people."

— Ed Casagrande  
BOARD CHAIR FOR CDSS



## Project Understood by the Numbers

- **775 million** media impressions worldwide.
- **Over 826,000** individuals and groups were reached via Facebook. Over 82,000 of those reached engaged with the post, with just \$1,000 spent on online media.
- **Nearly 1 million** test phrases had been recorded by the end of 2019.
- By the end of 2019, there were **500** Project Understood participants.
- CDSS shared Project Understood with over **405** Down syndrome organizations across the globe.

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## I'm teaching Google. You can too.

The Canadian Down Syndrome Society is partnering with Google to help make voice technology work better for people who need it the most. By sharing voice samples, adults from the Down syndrome community are teaching Google's technology to better understand them. But we need more voices.

If you have Down syndrome or know someone who does, visit [ProjectUnderstood.ca](http://ProjectUnderstood.ca) to donate your voice.

PROJECT UNDERSTOOD



## The Future

Voice technology is reshaping the digital world, and we plan continued work to ensure that people with Down syndrome are not left behind as this technology rapidly advances. Long-term, the project's goal is to create a data recognition model that can be scaled to other voice platforms, in the hopes that the entire 'voice revolution' is accessible to those with Down syndrome. Early beta testing in December of 2019 showed promising results. In 2020 the project has continued, with a presentation to the United Nations in March of 2020, further recruitment, and ongoing data studies.

For current project status and numbers please visit:

[www.ProjectUnderstood.ca](http://www.ProjectUnderstood.ca)

To create, launch and manage this global campaign and research project, many groups came together to make this all possible. Special appreciation goes out to:

- Matthew MacNeil, VATTA Chair
- CDSS's VATTA Team
- Shannon Stephaniuk, Glossy Inc.
- Google AI
- CDSS Board of Directors
- Participants from around the globe who have recorded their phrases with Google

Special thanks to FCB Toronto for their support!

FCB TORONTO

# 3.21 Magazine

## New National Publication

The Canadian Down Syndrome Society and the Down Syndrome Resource Foundation (DSRF) teamed up in 2019 to bring the expertise of Canada's leading Down syndrome professionals and advocates to families across the nation with a new and completely free national magazine. The magazine is digital and is produced four times a year. Written for and about the Down syndrome community in Canada – it includes stories about advocacy, advice from professionals, the latest news, and important dates about upcoming events and activities.

Feedback from the first issue, which focused upon employment, was wonderful. The magazine has very quickly become a valuable resource and source of inspiration for people with Down syndrome and all who love and support them. We can't wait to work on more issues



with our great partner DSRF and some very talented contributors.

If you are not yet subscribed, please visit our website under Education & Resources and click on Publications. In this section you can also access and download previous issues.

"I look forward to seeing what the next issue holds!"

"LOVE IT! Wonderful first edition!"

"Great information and inspiration!"



Down Syndrome Resource Foundation  
Together. Hand in Hand.

## World Down Syndrome Day

On March 21, 2019 we heard speeches about growing awareness and support, received generous donations, and shared inspiring social media messages. Our goal is that this inspiration carries into advocacy work all year. Working together brings community awareness to the next level – we believe in the power of partnerships.

CDSS mailed out awareness packages containing information that would be shared with more than **4300 children across Canada**, providing a structured program to celebrate and educate peers.



Self-advocates gave school presentations

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Landmarks lit up across Canada, and images were shared on social media



Communities wore #lotsofsocks and many celebrated by taking a break and having a dance party

## 2. Building Strong Relationships with Key Stakeholders in Canada

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### Summit 2019

The CDSS 'Crossroads' Summit Event - our first ever national forum, took place in Toronto in February 2019. Participants included representatives from the CDSS Affiliate Council, twelve of the largest regional Down syndrome groups across the country, other Down syndrome groups, sister organizations representing those with disabilities, education and fund development experts, VATTA members and CDSS Board Members and staff.

### Five Initiatives

Based on the outcomes of the 2019 Summit, five major initiatives were identified and became a major focus for our Operational Plan:

- Review our commitment to common values
- Enhance the voice of adults with Down syndrome
- Enhance CDSS communication strategies
- Create a national information hub to inform the Down syndrome community
- Build a collaboration process among Down syndrome groups and partner organizations



## 2019 CDSS Conference

The 32nd Annual Canadian Down Syndrome Conference was held in Victoria, British Columbia and was co-hosted with the Greater Victoria Down Syndrome Society. A pre-conference Educator Day was hosted by the Down Syndrome Resource Foundation.

The 2019 Canadian Down Syndrome Conference brought delegates from across Canada, including children and youth for organized programs, and 100 professional educators. The weekend was filled with dynamic and informative speakers, networking opportunities and social engagement. The latest information was shared with delegates about education, aging, health care, research, and advocacy. The conference created an opportunity for people with Down syndrome and their families to come together for information sharing, connecting and learning.

Speakers included: Dr. Dennis McGuire, Dr. Lina Patel, Dr. Kishore Vellody, Lori Pollett, Shelley Moore, CDSS VATTA committee, Tamara Taggart and many others.



No conference could be successful without the many people working hard behind the scenes. A special thank you goes out to:

- Greater Victoria Down Syndrome Society under the leadership of Paul Crowley
- More than 50 volunteers who gave their precious gift of time and energy
- Down Syndrome Resource Foundation
- Special Olympics British Columbia

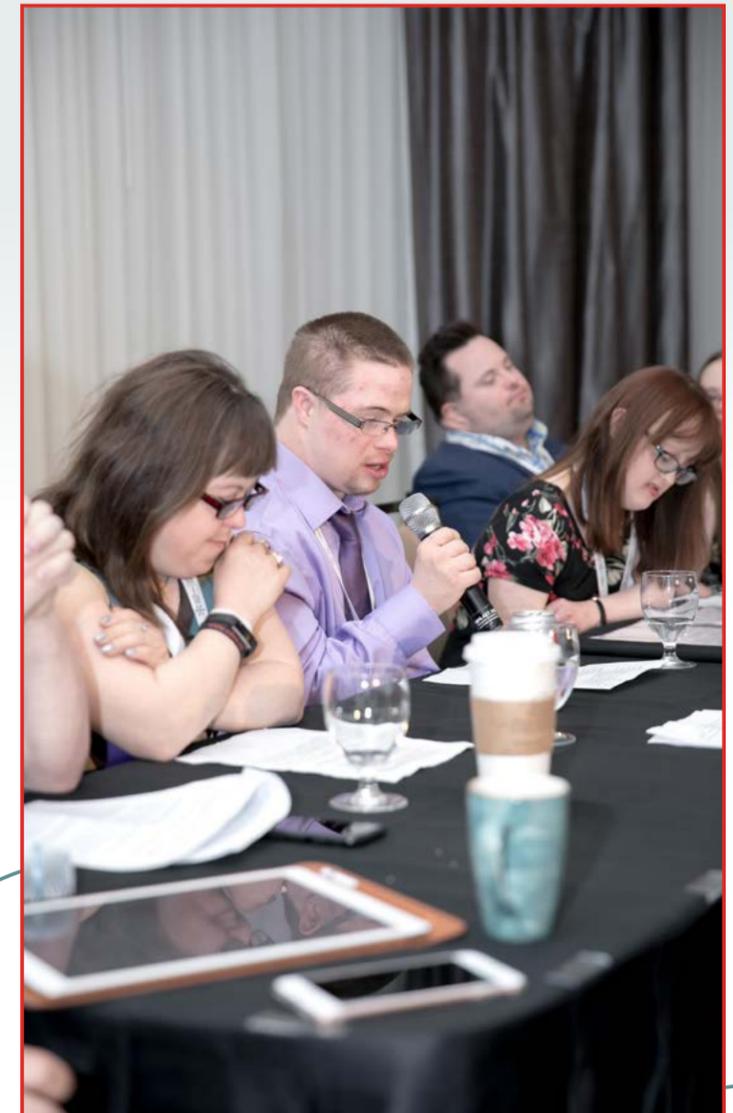
## National Disability Summit Ottawa May 9 & 10, 2019

The Summit, named “Building an Inclusive Canada” provided an opportunity for CDSS and approximately 200 others from across Canada to exchange best practices, learn from the experiences of others, create and build on partnerships, highlight Canada’s achievements and reaffirm the Government’s commitment to achieving the full inclusion of persons with disabilities. The Government of Canada shares the ideas and key finding from the Summit in the “What We Learned Report,” click [here](#) for more information:

### VATTA, Voices At The Table For Advocacy

#### CDSS' Self-Advocate Committee Members

At the Victoria Conference VATTA had great discussions with CDSS about the future of VATTA and what VATTA can do to help local communities. We discussed the use of technology and how to improve accessibility and how we can continue to spread awareness about Down syndrome.





*"It was so much fun to reconnect and listen to amazing speakers. VATTA members had opportunities to introduce the speakers to their sessions and it was a good experience for us at the conference. We had a great time working with Tamara Taggart in our VATTA panel discussion and the topics we discussed were about independence and our advice to other self-advocates and this discussion was so special to VATTA because we did it on Mother's Day."*

*- Matthew MacNeil*  
**VATTA CHAIRPERSON**

During 2019 many of our VATTA committee members were part of these following projects to build awareness about Down syndrome:

- Inclusive employment stories
- 'Crossroads' Summit Event
- Promoting Bully Day and World Down Syndrome Day
- Raising awareness around voter participation during elections
- Some members were part of CBC's new show "You Can't Ask That"
- Participation in CDSS and Google's Project Understood
- Contributions to 3.21 Magazine, CDSS Blogs and Special Olympics stories

*"VATTA has not only inspired me to give self-advocates the support they need, but also the freedom to make decisions for themselves."*

- 2019 CONFERENCE ATTENDEE

# 3. Diversifying Fund Development

CDSS does not receive any government funding. Your generous donations fuel everything we do. Whether you made a donation over the phone, participated

in a Go21 event in your community or became a monthly donor--- your contributions have made big difference for the community.

## Go21

In 2019, the Canadian Down Syndrome Society worked to improve the Go21 program platform to make it easier and more streamlined for communities to host their own Go21 event. 95% of dollars fundraised in the community, stays in the community, the remaining 5% goes towards national awareness projects with the Canadian Down Syndrome Society.

### 2019 Go21 Participants:

- Project 321 Peel Down Syndrome Association
- Gage's Swim with Bright Socks in Rocky Mountain House, Alberta
- Edmonton Down Syndrome Society
- Greater Victoria Down Syndrome Society
- Down Syndrome Guelph
- Down Syndrome Niagara
- The Down Syndrome Association-National Capital Region
- Down Syndrome Association of Hamilton
- Waterloo Regional Down Syndrome Society



**These community events raised \$137,765**

### Join our movement:

- Host an event that helps build community
- Raise awareness about Down syndrome
- Fundraise for your community, and people across Canada

**FOR MORE INFO ON HOSTING A GO21 EVENT, PLEASE EMAIL: GO21@CDSS.CA**

# 4. Developing a Workplace Support Resource for Job Seekers and Employers in Canada

## Inclusive Employment Success Stories

In collaboration with the Down Syndrome Resource Foundation, CDSS gathered and shared "employment success stories" in a social media campaign.



"I value my job because it is my dream job. I have a reason every day to wake up and go to work and contribute to my country's economy. This makes me proud."

- DEWLYN LOBO



"I value everything about my job. I value my job because my employer values ME."

- NICK POPOWICH

## Other Employment Initiatives

- Shared resources on hiring a person with disabilities
- Shared resources on employer webinars
- Shared Down Syndrome International's (DSi) resource "What Employment Means to Me"

# CDSS Office Volunteer Appreciation

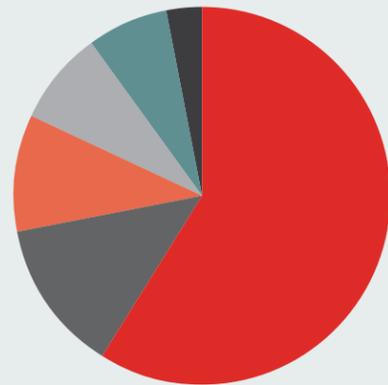
Thank you volunteers!!

We celebrated our very special local Calgary volunteers who come and help our organization with their irreplaceable time and energy all year long, many of them have been coming to help CDSS for a number of years.

Our volunteers assembled 1200 information packages and helped process over 5000 tax receipts to be mailed to our generous donors.



**Information Requests**



- 35% Resources, Education & Links**
- 25% Donations & Recepting**
- 18% Marketing & Events**
- 15% Administration**
- 2% Immigration**
- 5% Support for Individuals Overseas**

**2019 New Social Followers**

**f +1657**

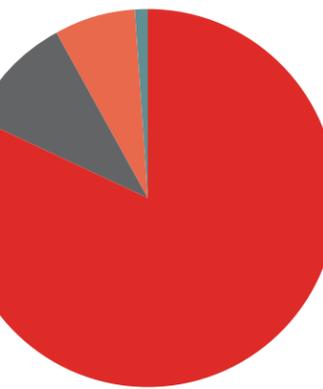
**🐦 +302**

**📷 +833**

**2019 CDSS.ca Top Stats**

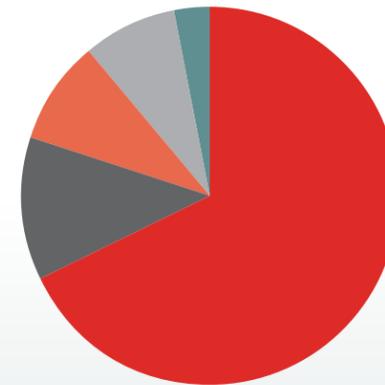
2019 Total Page Views:  
**571,173** (435,175 in 2018)

2019 New Users:  
**317,590** (232,042 in 2018)



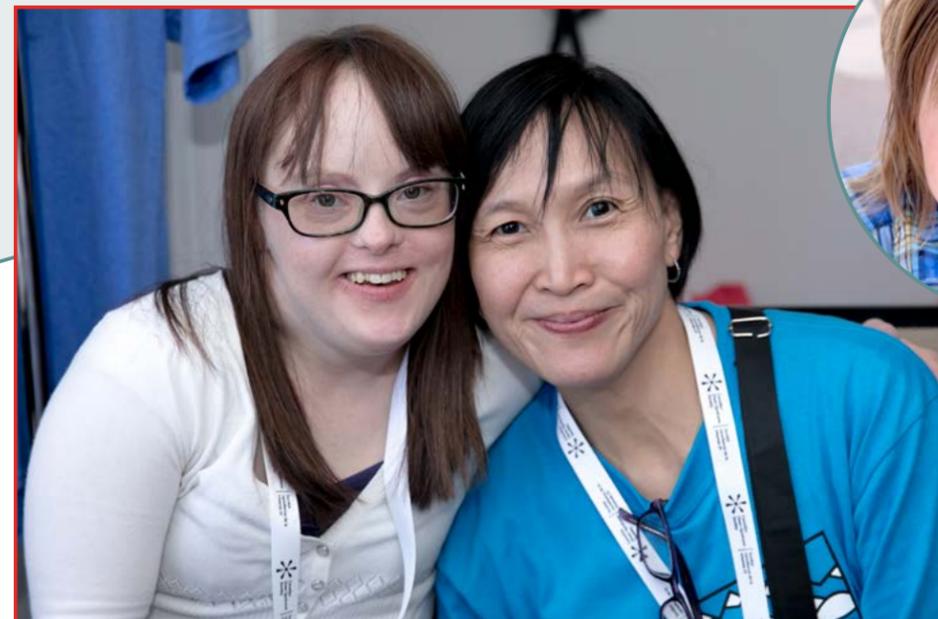
**Where money came from in 2019**

- 82% Donations (\$1,394,000)**
- 10% Special Events**
- 7% Conference Revenue**
- 1% Memberships & Product Sales**



**What the money supported in 2019**

- 68% Public Education**
- 12% Administration**
- 9% Resource Development**
- 8% National Down Syndrome Conference**
- 3% Awareness Events & Promotional Material**



### 2019 Board of Directors

Ed Casagrande, *Chair*  
 Paul Crowley, *Vice Chair*  
 Yelman Siddiqi, *Treasurer*  
 Jackie Charchuk, *Secretary*  
 Dave Fischl  
 Laura LaChance (retired)  
 Dewlyn Lobo  
 Christine McConnell  
 Stewart Moffat (retired)  
 Ben Tarr  
 Sean Wiltshire  
 Elaine Willcock (retired)

### CDSS Staff

Interim Executive Director: Laura LaChance  
 Marketing & Communications Manager: Kristen Halpen  
 Resource Coordinator: Liza Kiegler  
 Bookkeeper & Facility Coordinator: Marion Lauzon  
 Database Coordinator: Debbie Monaghan  
 Administrative Support: Jody Roll  
 Awareness Leader: Paul Sawka

### 2019 VATTA Self-Advocate Committee Members

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

# Looking ahead

During the second year of our Strategic Plan 2019-2021 we will be developing new resources and continue to raise awareness for people with Down syndrome.

## Plans for 2020

- CDSS single-day presentations and workshops
- Continuation of our quarterly 3.21 Magazine
- Down Syndrome Awareness and Educational Resources
- Employment Support Resource
- Online Resource Library
- Reaching out to provincial and federal governments on behalf of people with Down syndrome
- Regional Adult Outreach Resource
- Webinar development
- Website user experience enhancement

## Affiliate Organizations

