



Keeping families strong.

2017 ANNUAL REPORT

Canadian Angelman Syndrome Society
210105 Priddis Valley Road W.
Priddis, AB T0L 1W4
Phone: 403-931-2415
angelmancanada.org



UPDATED MANDATE TO “FAMILIES SUPPORTING FAMILIES”

Following the 2016 International CASS Conference in Edmonton Alberta, we (the Canadian Angelman Syndrome Society-- CASS) recognized that the Angelman syndrome community in Canada was looking for something new, something that provided direct and tangible support for their family's needs, something that was technologically modern, that facilitated making local connections, that supported hands on help for communication for AS individuals. Further CASS was asked to place greater emphasis on engaging the AS community and being more strategic in its funding decisions for events that benefit our community.

To this end, we have rebranded the Canadian Angelman Syndrome Society to be a modern and 'connected' way for “Keeping Families Strong”. Through our new website, our presence on Social Media, a new conference format, the AS Ambassador Program, support for AS clinics as well as continuing to support research, education, and community building we are better placed to serve the Angelman syndrome community in Canada.

IMPROVED SOCIETY GOVERNANCE, STRENGTHENED LEADERSHIP, FISCAL MANAGEMENT AND ADMINISTRATION

CASS has changed its' Societal Governance significantly over the last two years. We have created a more nimble and responsive decision-making structure at the board level and enhanced our liability foundations. We also saw and acted on the need to become more modern with our fiscal management and administration. As a board it was important that we demonstrated our support for each other by distributing work more evenly. We also strategically now utilize the services of external professionals to leverage their expertise and efficiency in supporting our administrative functions. In this way CASS could focus more effort on its core activities thereby freeing the board of directors to focus on building community, fundraising, and providing relevant programs in direct support of the AS community.

WEB AND IT UPGRADE

Our Web and IT infrastructure were in desperate need of a reboot, and we did just that. Our old site no longer served the community's needs for connection, for social integration, for efficient links and for mobile compatibility. Our new site showcases our new brand as well as playing host to our Red Gala fundraiser. The AS community and its supporters can now register for the conference and can purchase gala tickets online. We have a process where directors and society members can share information through our own email and document management sub systems. We will soon be adding capability for



WEB AND IT UPGRADE cont'd...“live” events, direct access to the new regionally supported AS Ambassador program, and the ability to sell merchandise to help with fundraising and to provide a venue for anyone interested in supporting individuals and families dealing with AS.

ENHANCED SOCIAL MEDIA PRESENCE

2017 has meant that we pay more attention to our community’s use of Social Media by posting regularly on Twitter and Facebook. We have also implemented a more responsive process for answering questions from the AS community in a timely manner. These platforms are the forums most used by individuals looking for information on Angelman syndrome. It is our goal that this type of support is backed by the community’s experience in a way that reflects Canada’s diversity and unique perspective when dealing with Angelman syndrome. To this end we are striving to always be available, inclusive and easy to find.

FUNDRAISING WALK/RUN WENT ‘NATIONAL’

“Walk for Angels” has been an amazing success for two years in row. The first year (2016) saw over 200 participants and raised over \$20,000 in funds going directly to CASS. In 2017 the Walk for Angels went “National” with over 500 participants taking part in 3 walk locations in Edmonton, AB, Winnipeg, MB and Elkford BC. This allowed us to have record setting one-day fundraising thru the Walk for Angels. Plans are well underway for 2018!

REVAMPED BUSINESS MODEL EXPANDING SERVICES TO COMMUNICATION CAMPS, ANGELMAN SYNDROME CLINICS, AS AMBASSADOR PROGRAM, CONFERENCE GALA EVENT

Our main areas of focus at CASS this past year have been in developing and implementing a revamped business plan to expand and regularize support and services including: Communication Camps, AS Clinics, the AS Ambassador Program and the all new CASS Red Gala Charity Event.

SUPPORTED AN INTERNATIONAL RESEARCH STUDY

In 2017, along with ASF, CASS continued its financial sponsorship of the Angelman behaviors project. Families struggling with difficult to manage behaviours in AS can find information and practical guidance through this website: http://www.angelmanbehaviors.org/user_mod.php This multi-year, international effort was led by Canada’s own Dr. Jane Summers.





TREVOR JANZEN

What are your ties to the Angelman community?

My youngest son, Ben, was diagnosed with Angelman syndrome in spring of 2004 at age 2-1/2. We were fortunate to attend our first Angelman syndrome conference just 2 months later. Our ties to Canadian AS families and the professionals who support us has grown since then.

How long have you been involved with CASS?

I have been a part of the CASS leadership team since 2007 and a member of the Board of Directors since 2010. I have held roles of Community Relations Committee Member, Director and current President.



BRADLEY SCHIELE

What are your ties to the Angelman community?

My daughter Ali was diagnosed at 18 months with Angelman syndrome (deletion).

How long have you been involved with CASS?

My wife Tracy and I attended our first CASS conference in Ottawa of 2014. In 2015, I became a Community Relations member for CASS and in 2017, the Vice President/Director



JOHN CARSCALLEN

What are your ties to the Angelman community?

My wife, Janet, and I have a daughter, Karen , who is 28 years old.

How long have you been involved with CASS?

We have been involved with CASS since 1993 and with the AS community since 1991, a month after Karen's diagnosis.



KENT FLEMING

What are your ties to the Angelman community?

I have a son who was diagnosed at 2 years old with Angelman syndrome. UPD is his diagnosis.

How long have you been involved with CASS?

We started attending conferences about 10 years ago after the diagnosis of our son.



KARA HANCHAR

What are your ties to the Angelman community?

We have a daughter who was diagnosed with Angelman Syndrome (UPD) at 23 months.

How long have you been involved with CASS?

We went to our first CASS conference in Ottawa of 2014. I knew from that conference that I wanted to be a part of CASS and support CASS with fundraising and to help raise awareness to Angelman syndrome. I organized the first Walk for Angels in Edmonton in May of 2016. I then became a Community Relations Director for CASS in July 2016.



TERRY SINGLETON

What are your ties to the Angelman community?

Our son Daniel was the first person in Alberta to be diagnosed with Angelman syndrome.

How long have you been involved with CASS?

I have been involved with CASS since 1996 after my wife Linda attended her first conference in Calgary. Before joining the CASS board, I had been involved in Kiwanis for 15 years previously, and my club had sponsored and worked with Developmental Disability causes.