

EDSS ANNUAL REPORT 2021



2021 STAFF TEAM



ALAN CLAY
EXECUTIVE DIRECTOR



JULIE BOUCHER
MANAGER OF FAMILY SERVICES

LORI PEILL

EXECUTIVE ASSISTANT (RESIGNED APRIL 2021)

IRYNA FEDORIW

OFFICE MANAGER/ADMINISTRATIVE ASSISTANT
(STARTED AUGUST 2021)

ABOUT US

The Edmonton Down Syndrome Society (EDSS) is committed to supporting people with Down syndrome and their families, through programming, information, resources and connecting members with peer-to-peer support.

We respect the rights, abilities, and potential of people with Down syndrome, and we respect and support the role of families and their choices in meeting the needs of people with Down syndrome.

OUR MISSION

Is to benefit people with Down syndrome and their families by providing information and support, facilitating services, and promoting inclusion through public awareness and advocacy, in collaboration with community partners.

OUR VISION

A community that values all people with Down syndrome and supports them in achieving their full potential.

OUR VALUES

- Diversity in our board, staff, volunteers, and membership
- Dignity, respect, and equality for all people
- The inclusion of people with Down syndrome in society
- The excellence and commitment of our board, volunteers and partners in their roles supporting the rights and abilities of people with Down syndrome



Alex touring Government House

2021: A YEAR OF CHANGE

Jennifer Cassidy, Board Chair

"It will be different next year" was a common refrain as we moved through year one of the pandemic and hoped for better days in 2021. If we could just hunker down for a little while longer until the vaccine was available and get vaccinated as we were eligible, that we would put the pandemic behind us much sooner than what turned out to be our reality. So while we still find ourselves and our communities living with the pandemic as part of our daily reality, we also found new ways to adapt. Many of us have experienced waves of change throughout the last two years, and like our lives we find our communities and charities around us changing as well.

Last year, my colleague Jane (former chair of the board of directors) wrote that if she had to describe 2020 at EDSS, it would be about constant change, resilience, and leadership. Here at EDSS, we found that some of our systems did not translate well to the new normal. So we responded by enhancing our technology to contact our families in a more efficient manner. We adapted the programs that we deliver. While year two of this global pandemic has had some trying times in our lives and in our organization, I also believe we have so much to be grateful for.

When people ask me why I am involved with the Edmonton Down Syndrome Society, I simply say that I am grateful for the opportunity to contribute to the work done to support individuals and families living with Down syndrome.

As a charitable organization, our central focus should always be on the services we are able to provide to the community. We know that 2021 was a difficult time with the on-again, off-again service delivery due to changing public health conditions. On behalf of the Board and staff we would like to extend our thanks for your patience and support during these last two years. We know it hasn't always been a smooth journey, but we continue to strive for improvements in our service-delivery models to help families in our broad geographic region, from the Greater Edmonton Area and beyond, from Red Deer to Lloydminster, Grande Prairie, Fort McMurray, and the Northwest Territories.

No charity can survive without its donors and sponsors. Our many donors and sponsors show great commitment to EDSS and on behalf of the individuals and families receiving services funded by their contributions, we are very grateful. There is no shortage of worthwhile charities to support municipally, provincially, or nationally so it is extremely rewarding to see how your donations and sponsorship opportunities have made a significant impact in our local community. We are also grateful for the support we receive from the Government of Alberta and the City of Edmonton.

Passion and commitment to individuals and families served by EDSS is the focus of our professional staff. There is never a shortage of things to do in a not-for-profit organization and the dedication of our staff ensures that our programs and services run smoothly. We know that our staff are proud of the services we offer and share my gratitude to be a part of such an exceptional and accessible charitable organization.

We still have a lot to do to ensure that EDSS is a sustainable charitable organization and relevant to the individuals and families we serve. On behalf of my Board colleagues, thank you for your patience, encouragement, and passion as we work collaboratively in the best interests of the Edmonton Down Syndrome Society.

Jennifer

2021: UNIQUELY EDSS

Alan Clay, Executive Director

"Are we there yet?" While my own son was 30 in 2021, the words uttered on many road trips were echoed throughout the past year as we all waited, sometimes impatiently, for the "back to normal" way of life we enjoyed before the global pandemic of March 2020. Those in-person appointments, social programs, music and dance sessions, Karaoke nights, and play groups.

Like many other charities across this country, we experienced the effects of a second year of on-again, off-again disruptions because of provincial mandates and public safety measures. We tried new things, scrapped some things, re-imagined things, and wished for things.

While the word 'pivot' became the pandemic buzzword, for better or for worse, I prefer to say that we tried to do some things differently given the circumstances we faced, and the rules around what could and couldn't happen regarding social gatherings and our participation in fundraising activities and third-party events. The not-for-profit sector in Canada was tested again in 2021 like never before and for EDSS, it was an emotional time for our families, volunteers, and professional staff. We missed being together. We missed our families and volunteers and look forward to our family centre once again being a hub of learning, laughter, and inspiration.

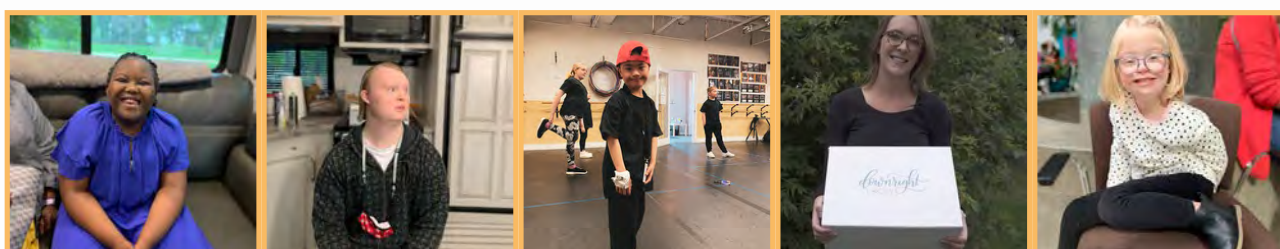
We were amazed at the generosity of our current donors, sponsors, and foundations. In the future, we will do a better job recognizing you all through an enhanced website and marketing materials, including in our annual report. To our federal, provincial, and municipal governments, thank you! The funds to assist with wages, rent, and personal-protective equipment (PPE) made it possible for us to reimagine and continue delivering our core services.

The Board of Directors faced some incredible challenges, and we are grateful to them, under the leadership of Board Chair Jennifer Cassidy, as they continued to govern and support the new pandemic initiatives. Their support and encouragement during this past year in my leadership and that of the EDSS team was truly appreciated and I thank you.

To Julie Boucher, our Manager of Family Services, thank you for embracing the 'new normal' and continuing to support our families while working from home and in the office. Your dedication was truly amazing, and I am so thankful.

On the following pages of this annual report, we will share some incredible photos that tell the stories of our families as well as the events that helped give hope to the future. Thank you all for building endless potential.

Alan



Pictured left to right: Keturah, Josh, Cameron, Adele (Visiting Parents' Team) and Charlotte on set for Uniquely Me TV

2021 BOARD OF DIRECTORS

JANE JESS

CHAIR (RESIGNED APRIL 2021)

JENNIFER CASSIDY

VICE CHAIR (CHAIR EFFECTIVE MAY 2021)

ELIA DAMIS

SECRETARY (STEERING COMMITTEE REP -
RESIGNED MARCH 2021)

BRENT JOHNSTON

TREASURER (RESIGNED DECEMBER 2021)

ERIKA BAROOTES

DIRECTOR

MIKE KOSTUIK

DIRECTOR (VICE CHAIR EFFECTIVE MAY
2021)

PATRICIA PASEMKO

DIRECTOR (RESIGNED DECEMBER 2021)

LAIBA RIZWAN

DIRECTOR

MABEL TU

DIRECTOR (STEERING COMMITTEE REP -
RESIGNED APRIL 2021)

SHANE POSPOSIL

DIRECTOR (STEERING COMMITTEE REP -
APPOINTED MARCH; RESIGNED APRIL 2021)



Alana enjoys reading in the Joey Moss Literacy Centre for Excellence



Meher gives the sign for 'Cameras Rolling'



Jordan Grace stars in Uniquely Me TV



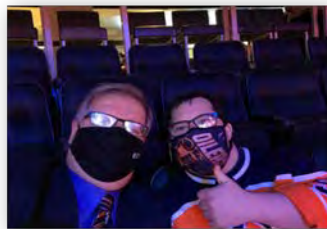
Leilana has fun on set in downtown Edmonton

Inspiring Endless Potential

2021 YEAR IN REVIEW

ZOOMING ACROSS ALBERTA & BEYOND

Family Services Manager Julie Boucher and Behaviour Therapist Sasha Robinson did an online orientation with all contracted therapists around technology and business processes as our virtual appointments started filling up. EDSS also introduced direct billing to insurance companies which meant families can now use employer benefits to pay for therapies. *Nichole and John Clayholt and Family of Delia featured in The Drumheller Mail newspaper*



EDMONTON OILERS COMMUNITY FOUNDATION 50/50 IN MEMORY OF JOEY MOSS

In partnership with the Edmonton Oilers Community Foundation, Special Olympics Edmonton, and the Winnifred Stewart Association, a 50/50 was held on February 15, with a total jackpot of **\$2,393,630**. Executive Director Alan Clay appeared on CTV Morning Live that day with Co-Host Ziyah Karmali and former Oilers great Craig Simpson to talk about Joey's legacy.

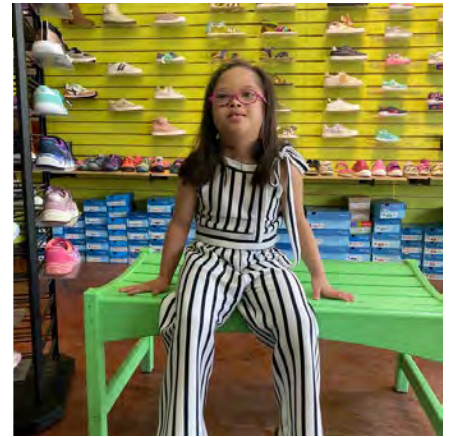
Pictured top to bottom: Wade at Rogers Place; "O Canada" by Joey Moss; Alan and David at Oilers game for 50/50 night



Pictured left to right: CTV Morning Live host Ziyah Karmali and former Oilers great Craig Simpson talk with Alan about Joey Moss

WORLD DOWN SYNDROME DAY

Lots of Rockin' Socks and special events to celebrate, thanks to members Kaylyn Juchli and Sonja Malaniuk who organized an activity book for families and a Zoom scavenger hunt that was televised during CTV's nightly newscast with Sonja and 11-year-old daughter Ana; High-Level Bridge lit up in blue and yellow thanks to the City of Edmonton; Western Hockey League players in the Alberta Division wore mismatched socks during games on March 21 in support of EDSS; support from public figures posting photos and challenging colleagues, including Premier Jason Kenney donning mismatched socks in his office; declaration by Alberta Health Minister of World Down Syndrome Day.



Pictured from top left to right: Premier Jason Kenney celebrates World Down Syndrome Day; Scott trains Mike in weightlifting; Doug strolls around Government House; Princess Angelyn enjoys shoe shopping; Madison outside Floc for dress rehearsal; EDSS Family Centre; Rylie and her dad Richard at Summerside Beach Club; Shelby and his son Grayson at a neighbourhood park



EDMONTON DOWN SYNDROME CLINIC

With Nurse Gayle leaving the Edmonton Down Syndrome Clinic for another position at Alberta Health Services, EDSS families had a chance to meet via Zoom Nurse Melissa, the new coordinator at the Stollery Children's Hospital Down syndrome Clinic.



Isabella ready to go on air with Uniquely Me TV

NORTHERN OUTREACH

Funded through Jordan's Principle, EDSS worked with various agencies to support a family in Nunavut. Jordan's Principle is a child-first and needs-based principle used in Canada to ensure that First Nations children living on, and off reserve have equitable access to all government funded public services. *Pictured: The official flag of the Northwest Territories*



Pictured: Janette Appelt joins in our Musical Theatre Class

ANNUAL PLANNED GIVING PROGRAM

Thanks to Janette Appelt and family, EDSS was fortunate to establish the Denis P. Constantin Performing Arts Memorial Scholarship in memory of her brother Denis. This annual gift will see the awarding of six musical theatre scholarships.



Adam, participates in EDSS outdoor fitness classes



Wade welcomes guests at Festival Place



Shannon returns to the set of Uniquely Me TV

MUSICAL THEATRE - SHOWTIME!

The curtain finally lifted for a full performance and awards celebration for Centre Stage Musical Theatre on Sunday, June 6th, 2021. Performances by Newsies, Guys & Dolls, Spotlights, Dream Girls, The Producers, and Jersey Boys.



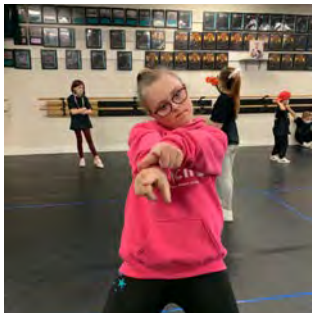
Pictured left to right: Leilana and Shannon giving the cue for "QUIET ON THE SET"

Pictured: Musical Theatre teacher Meghan leads solo performances by Charlie (Gaston from Beauty and the Beast) and Hanna (Let it Go from the Disney movie Frozen)



FILM NEGATIVE

Jane leads the dance troupe

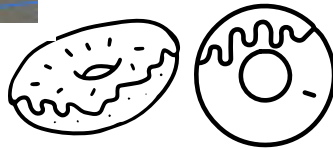


FILM NEGATIVE

TOTES FOR EDSS - INSPIRATIONAL LOVING CARE PACKAGE

Thanks to member Toni Rocca and business partner Farrah, totes were filled with games, activities and self-care items and given out to every individual over the age of 18, along with a small plant that individuals could take care of and watch grow over the summer.

KREMY FUNDRAISER



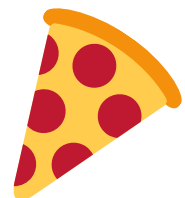
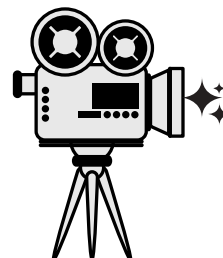
Thanks to members Adele, Aimee, Alexia and Kristen of the Visiting Parents' Team (VPT), approximately \$3,000 was raised through a Krispy Kreme Doughnuts fundraising event with proceeds going to re-stock the gift boxes presented to all new parents at the Edmonton Down Syndrome Pediatric Clinic



Charlie says "Scene 3, Take 2"

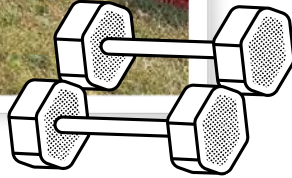
SUMMER FUN

Five camps were held for more than 45 individuals in every age category featuring social skills and musical theatre. Thanks to Angie, our therapists Heidi, Candace, Sasha, and musical theatre teacher Meghan. Sasha and parent volunteers also put on a Club 21 pizza and movie night.





Left to right: Adam gives the 'thumbs up' to fitness trainer Cody



OUTDOOR FITNESS

Free fitness classes for families at Hawrelak Park every Monday by two certified trainers with degrees in kinesiology. Classes were via Zoom on Fridays. It's a fun way for our families to meet up and enjoy some fitness routines. The program will resume again outdoors, weather permitting. All are welcome.

NEW FACEBOOK PAGE

Families of Edmonton Down Syndrome Society Facebook went live, as staff and families resumed sharing news and events as well as other topics of interest. Members can join by going to this link:

<https://www.facebook.com/groups/328883685481614>



BACK TO THE COURT

After a cancelled 2020 season, the EDSS Basketball League resumed weekly play at Allendale Elementary-Junior High School. Thanks to Pam and Brad Smith for their volunteer commitment to running our basketball league. About 20 athletes enjoy shooting hoops in fun and friendly competition.

STRIKERS & SPARES

The EDSS Bowling League resumed Saturday play and an estimated 30 bowlers were back at Bonnie Doon Bowling Lanes. Thanks to Sue Kuzio and Jody Dossier for their continued dedication to running this fun program.



Carly takes to the court to shoot hoops with community basketball players



Bonnie Doon Bowling Lanes



Bonnie Doon Bowling Lanes



LIBERTY CLASSIC CHARITY GOLF TOURNAMENT

Thank you Nate Baldry and Russell Keddie who presented EDSS with a cheque for \$30,000 from the annual Liberty Classic Charity Golf Tournament held August 23, 2021 at the Quarry Golf Club. There were 145 golfers who braved the elements!



*Pictured: The Baldry Family
Liberty Classic Charity Golf Tournament*



*Left to right: Dennis Johnson, Mark Johnson, and Alan
at the 9th Annual Weiss-Johnson Golf Classic*



Liberty Golfers attempt to dunk Alan



Thumbs up with this foursome at the Liberty Classic



WEISS-JOHNSON GOLF CLASSIC

Thanks to Mark Johnson and Dennis Johnson and the Weiss-Johnson Team, the 9th Annual Weiss-Johnson Golf Classic raised \$16,182.53 in support of our Society in September 2021 at the Ranch Golf & Country Club.



*Nate Baldry (left), and Russel Keddie (right)
present EDSS with \$30,000 cheque*

INNOVATIVE MEETINGS AT EDSS

As schools across Alberta and beyond experienced virtual learning, EDSS joined the classroom by having our Manager of Family Services Julie presenting to schools on the topic of *Effective Education Practices for Students with Down syndrome*. Guest lectures and presentations were held with educators in various public and Catholic schools and to MacEwan University students in the Department of Human Services and Early Learning.



UNIQUELY ME TV - THE POWER OF X IN XXI

The 10th anniversary of Uniquely Me told the stories of EDSS families in Edmonton, rural Alberta and beyond. This 30-minute program aired on CTV Alberta six times in October during Down Syndrome Awareness Month. Due to public health restrictions, unfortunately, our watch party scheduled for 21-10-21 (October 21, 2021) had to be cancelled. Thanks to EDSS Advocate Alana Gersky, we held a UMTV Family Party to end the summer. The reimagining of this fundraiser has proven to be a successful awareness campaign for the programs and services we provide our families. With the reopening of public appearances and social events, we need to build on the success of UMTV as our signature fundraising event in support of operations at EDSS



From top left to bottom right:
Thanks to Edmonton Police Service for your community support of EDSS;
Thank you to Ledcor for supporting Uniquely Me; Thank you CTV for broadcasting our stories; Mark at Head Shoulders Knees & Toes; The Power of X in XXI; Popular UMTV personality Daniel; Jen and daughter Mya; Shannon and Leilana stylin' in Edmonton; Hockey Hero Jackson

To celebrate their 125th anniversary year, The Wawanesa Mutual Insurance Company announced a \$200,000 community-giving initiative that involved employees across the country selecting organizations to receive donations of \$12,500 each. After a competition by the more than 4,000 Wawanesa employees, EDSS was selected as one of the winners of \$12,500. Thanks to EDSS member Ruth Ball, an employee of Wawanesa, for working with us on this incredible award submission. It was an honour to be one of 11 charity-of-choice recipients in Canada as selected by Wawanesa employees.



Ruth Ball and son Darren

HOLIDAY PARTY



2021 ended with a Christmas Party at the Delta Edmonton South. It was wonderful to see so many families enjoying the holiday festivities. Thanks also to Mr. and Mrs. Claus.



Natalie and Steve with their son Callum visiting with Santa Claus on stage with EDSS Board Chair Jennifer Cassidy, and Vice-Chair Mike Kostuik. Seated in front are Charlotte (left) and Lucy



EDSS' own Santa and Mrs. Claus on the Christmas Party Train at the Delta Edmonton South Hotel



Jolly Old St. Nicholas



THANK YOU MEMBERS

"The Edmonton Down Syndrome Society (EDSS) holds a special place in my heart as they have been a resource and support for my family since my son Darren was born in April of 2000. The EDSS was welcoming to Darren, his brothers, grandparents, aunts, my husband, and myself. I am grateful to EDSS for your services and supports to persons, families, and caregivers for individuals born with Down syndrome and for your resilience during COVID to continue those supports."

Ruth Ball

Commercial Property Underwriter

The Wawanesa Mutual Insurance Company

"I've met some of my greatest friends through EDSS. We have one thing in common, and that's the extra chromosome, but there's so many other things we have in common with these families too which is ultimately what keeps us together."

Adele Olsen

Volunteer, EDSS Visiting Parents' Team

"It's been remarkable. We look forward to spending many, many years to come on the ice. And we get to be those hockey moms that maybe we didn't think we'd get to be."

Lisa Bussièrès

Hockey Mom

HEROS Hockey



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Charitable Registration # BN – 899799753 RR0001

Our Audited Financial Statements can be found on our website at www.edss.ca