



DRIVING MOMENTUM

2021 ANNUAL REPORT
TO THE COMMUNITY



Community. Advocacy. Research. Awareness. Empowerment. Direct Support.

There is momentum in our relentless pursuit of a different future. In 2021, propelled by community needs, the ALS Society of Canada did what we do best – we connected people who can transform the reality of ALS: Researchers, clinicians, policy makers, industry, caregivers, families, and people diagnosed with ALS.

People with ALS don't have time, and our community raised its voice demanding better, faster treatment options. We rode for revolution and walked for awareness. Our staff pivoted and continued to adapt in another pandemic year and built stronger, better systems of support. Researchers remained tirelessly committed to the ALS community to bring forward new discoveries. We were a convenor and a facilitator as we brought together industry and clinicians to identify opportunities for change. We made a deep commitment to empower Canadians affected by ALS to be informed consumers of ALS information and to advocate effectively for change. Our dedicated donors pushed us forward, accelerating this work. Together, we increased our momentum, every one of us agents of change, powered by people who live every day with ALS.

But there is still much more to do.

We continue to innovate and evolve to address the current and future needs of the community as we advance our strategic plan and work toward our shared vision of a future without ALS. The experiences of our community, matched by donor commitment to the cause, make us unstoppable in this pursuit.

Patrick Nelson
Chair, Board of Directors

Tammy Moore
CEO

OUR VISION

**A future
without
ALS.**

OUR MISSION

We work with the ALS community to improve the lives of people affected by ALS through support, advocacy and investment in research for a future without ALS.

The ALS Society of Canada (ALS Canada) is guided in our growth and development with a focus on three strategic impacts:

1. People affected by ALS receive the best possible standard of care.

We see a future where people are diagnosed with ALS earlier than they are today. To get there, we will focus on services and support, system coordination, and tools to measure and improve care.

2. More treatments are available to improve quality of life and extend lifespan.

When we invest in research, nurture relationships between industry, government and community, and facilitate better access to therapies, Canada moves closer to affordable treatments that are available through streamlined processes.

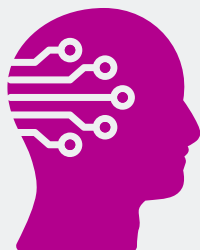
3. People are empowered to make informed decisions about ALS.

People affected by ALS will be better supported through programs, policies, and other initiatives that respond to their unique needs. We will reach this future state with awareness and education, facilitating access to information, and engaging community.

Visit www.als.ca to follow our work in these areas.

ABOUT ALS AND ALS CANADA

ALS Canada is working to change what it means to live with amyotrophic lateral sclerosis, an unrelenting and currently terminal disease.



ALS is a disease of the motor neurons – the living wires that connect our brain and our muscles.

Four out of five people living with ALS will die within **two to five years** of being diagnosed.



WALK
TALK
EAT
MOVE
SWALLOW
BREATHE

Over time, as their motor neurons die, people living with ALS will gradually **lose the ability to walk, talk, eat, move, swallow, and eventually breathe.**

Each year approximately **1,000 Canadians will be diagnosed** and **1,000 will die.**



An estimated **3,000 Canadians are living with ALS.**



We respond to the urgent unmet need for life-changing treatments by **investing in high-quality research** that will fuel scientific discovery and by **engaging industry, supporting increased clinical capacity** and **advocating for equitable, affordable and timely access to proven therapies.**



We empower Canadians affected by ALS to **navigate** the current realities of ALS, be **informed consumers** of ALS information, and **advocate** effectively for change.

OUR DONORS POWER CHANGE

ALS Canada receives no core government funding to support our mission work. Donors drive our momentum. Our work is fuelled by donors and an enthusiastic response to our fundraising events. In 2021, individuals, companies, and foundations stepped forward again to tell us this work remains critical. As an integral part of the ALS community, you help power incredible change.

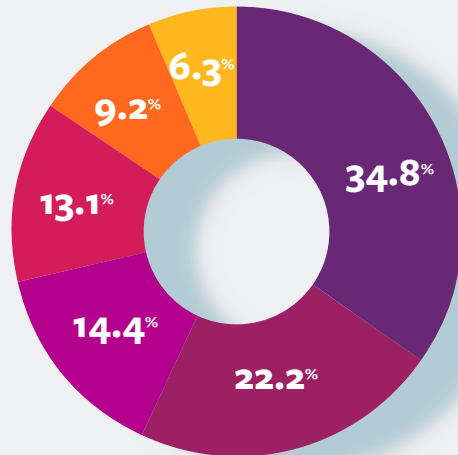
You can make your 2022 donation today on our website by clicking [here](#).

The power of donor investment

Donors were vital to our work in 2021 as we faced another year of fundraising mainly through virtual events. Despite the challenge, donors were unified in their support for our cause, and our services and programs for the ALS community remained secure and strong.

2021 Revenue

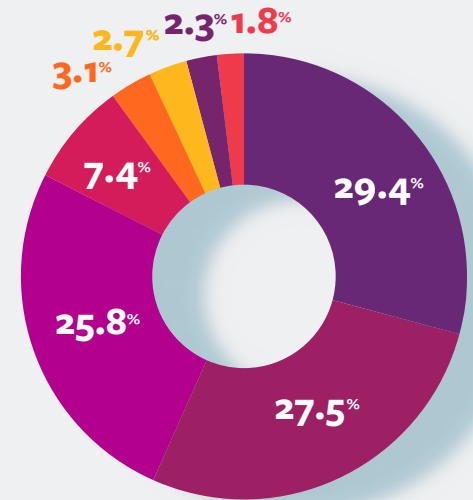
Other Fundraising Donations and Income	\$2,779,021
Ontario Walk to End ALS	\$1,772,107
Direct Mail	\$1,153,095
Tribute and Monthly Giving	\$1,045,418
Fundraising Events	\$737,832
From Provincial Societies*	\$507,006



* Provincial Societies mainly contribute to the ALS Canada Research Program through 40% of net proceeds of Walk to End ALS events, as follows: BC \$181,679, AB \$162,858, MB \$31,571, QC \$109,168, NL \$17,206, PEI \$4,524.

2021 Expenses

Community Services	\$2,438,964
Fundraising	\$2,284,629
National Research	\$2,138,699
Advocacy	\$613,965
Public Awareness	\$253,175
Governance	\$227,393
Administration	\$188,358
Other Charitable Purpose	\$151,105



The audited financial statements of ALS Canada are available on our [website](#).



RAISING FUNDS IN REAL-TIME

The creativity of ALS Canada donors is abundant as they turn to their own skills and strengths to fundraise and generate support.

Nathan Chan is an example of a donor bringing forward an entirely novel initiative to raise awareness and fundraise. An avid gamer, Nathan has built a large following online through livestreams of his games in Overwatch. His YouTube channel alone has 465,000 subscribers. In 2020, when Nathan and his family couldn't participate in the annual Hike to End ALS due to COVID, he turned to his gaming community to organize his first KarQ Charity livestream event. Over the course of six hours, he and a dozen gamers livestreamed their game, calling for donations in support of ALS from viewers. \$8,600 was raised.



Nathan organized a second fundraiser in 2021, where he shared short videos about ALS, including his own experience as a teen caregiver for his dad, who was diagnosed with ALS in 2007. Viewers stepped up and doubled the previous year by donating \$20,100, bringing Nathan's fundraising total to \$28,700.

"It means a lot for me to give back to ALS Canada," Nathan says, "because they provided a lot of support and resources to my family. I feel I have a duty to be responsible and give back. Now that I have a platform and a large following, I can give back in the way I know best, and maybe another family can benefit like ours did."

As one of his father's caregivers, Nathan was often at home in his teen years. He turned to gaming as an outlet and a comfort, soon finding his place in streaming and gaming communities.

"Donors to ALS Canada are part of a passionate and compassionate ecosystem. It goes beyond the financial gifts that enable us to advance the work. It's also about the emotional support donors show for the ALS community when they show up at our events and community fundraisers, where it's clear we're united in our cause. Our generous donors are behind every aspect of our work."

ELISSA BECKETT

INTERIM VP, FUND DEVELOPMENT,
ALS CANADA

IN PURSUIT OF A DIFFERENT FUTURE

Canadians were eager to get out and support the ALS community in 2021, taking part in our major fundraisers.



WALK TO END ALS When the ALS community sets its eye on the finish line, it gets there. Held virtually in 2021, 349 teams and 1,535 individuals registered to participate in Ontario alone, whenever, wherever they chose. Joining from across Canada, teams walked and rolled through their neighborhoods to honour people we have loved and lost to ALS and to show support for the 3,000 Canadians and their families living with the disease. Together, Canadians surpassed the goal of \$2,050,000 bringing in \$2,185,472, which includes 40 per cent of the net Walk to End ALS proceeds from ALS Societies across Canada. Funds from the Walk to End ALS are directed to the ALS Canada Research Program where they are invested in the best ALS research in Canada and matched dollar-for-dollar by Brain Canada. \$1,772,107 was raised in Ontario with 40 per cent also going to research and 60 per cent directly benefiting community services in the province of Ontario.

Volunteers make these events happen. They coordinate the events, find sponsors, and make sure the public is connected to the cause. You can join the effort by visiting als.ca/get-involved to find out more.

Thank you to all the volunteers who made these events possible. We couldn't do it without your passion and commitment.



ALS CANADA PLANE PULL Like many flights everywhere, we had to ground our exciting in-person event one more year. Instead, teams competed for bragging rights in a three-week virtual challenge showcasing their strength and tenacity. Testing their fundraising and fitness skills, dedicated teams pulled in \$80,175 for community-based support in Ontario, advocacy, and ALS research.



**ALS CANADA
REVOLUTION
RIDE**

REVOLUTION RIDE In September, our inaugural Revolution Ride inspired hard-core and recreational cyclists to gear up for change with a challenging but beautiful 40 km or 90 km ride in Dundas, Ontario. Seventy-five cyclists joined us on a beautiful day, and we rode for revolutionary changes in care and treatment. This volunteer-powered fundraising event raised \$258,856, more than doubling the goal of \$100,000.

OUR WORK IS ABOUT COMMUNITY

Tammy Moore, ALS Canada's CEO, remembers the first Revolution Ride as a perfect example of how the community makes sure no one reaches the finish line alone:

"Revolution Ride took place on a brisk, sunny morning. It was the first time we could come together in person since 2020 and you could feel the energy. Emotions were heightened coming into the event as members of the community were connecting again for the first time in what felt like forever. People had lost family members to ALS during the pandemic, and the restrictions meant some families could not come together to honour their loved ones the way they wanted to.

At the finish line, as we gathered to celebrate our ride, we knew there was a couple still out on the course a long while after everyone had come in. One of the two cyclists was experiencing cramps, but nothing was going to stop them from finishing. Refusing to call off his ride, the participant wanted to support his wife and complete the race with her. The Ride was a symbolic way for her to honour her father who she had lost to ALS during the pandemic. They would not give up.

The community understood and everyone agreed: Nobody gets left behind. When the last riders finally arrived, participants, staff and volunteers lined the street for two blocks, thumping drums and running beside them to the finish line. The support of the ALS community meant so much to the riders and to their entire family. With that final push they knew they could complete the ride. Similar to the support we were able to provide to her father, they knew they could count on the community being there for them – it was truly a day of lifting each other up and inspiring one another."



IMPACT AREA 1 BEST POSSIBLE STANDARD OF CARE

THE FUTURE OF COMMUNITY CARE IS FLEXIBLE

ALS Canada seeks change to ensure people affected by ALS receive the best possible standard of care. In Ontario, we provide one-to-one support for individuals including health system navigation and access to community resources, loaned equipment, and support groups. We work with Ontario health agencies, regional/local organizations and ALS clinics to streamline how care and support are coordinated and we're investing in efforts to measure and improve care in the future. The progression of ALS is different for everyone, and we want a care system that can be flexible and accommodating, no matter what ALS looks like.

REACHING OUR COMMUNITY, IN PERSON AND ONLINE

As we continued to navigate a virtual world, our Community Services team in Ontario designed a hybrid support and services model so **clients and caregivers were supported no matter the restrictions in place**. In 2021, our Community Leads returned to in-person home visits – crucial to clients and caregivers – and continued virtual delivery of ALS Canada support groups. Our community told us they liked these new groups, in some cases finding them easier to attend.

2021 was a year to re-assess and determine how this new model can be sustained. The new hybrid supports leverage the best of both worlds. Its flexibility means we can adapt our supports, moving between online and in-person based on needs. **People affected by ALS can look forward to connecting with others, wherever they are.**

EQUIPMENT, WHEN IT'S NEEDED

It can cost upwards of \$150,000 to \$250,000 to live with ALS, according to Canadian researchers in 2015.* This calculation includes loss of income, modifications to the home, equipment, and additional caregiving support. Equipment shouldn't be an additional expense. In 2021, **2,309 pieces of equipment were provided free of charge** to people living with ALS in Ontario through the ALS Canada Equipment Program at a cost of \$1.4 million. Clients and caregivers were able to access equipment such as wheelchairs, hospital beds, lift chairs, and more.

* Matthew Gladman and Lorne Zimnan published their review of the economic impact of ALS in 2015.

COLLABORATION FOR UNDERSTANDING EARLIER DIAGNOSIS

ALS Canada took the lead in organizing and convening an industry roundtable that explored earlier diagnosis of ALS in Canada. When it comes to an ALS diagnosis, time matters. It can sometimes take years for a diagnosis. It is the hope that an earlier diagnosis can lead to quicker access to healthcare resources and equipment and the ability to pull together the supports needed throughout a person's journey with the disease in a timely way. As a facilitator, we were able to bring together a variety of viewpoints to discuss the topic and what next steps might look like to support a more fulsome strategy. A working group was established and our leadership role on this topic will continue.

SUPPORTING THE COMMUNITY



1,240 people living with ALS in Ontario supported by ALS Canada's Community Leads.



2,309 pieces of equipment provided – free of charge – to people living with ALS in Ontario who are registered with ALS Canada.



192 support groups came together virtually to share their experiences and learn from each other.



1,536 support group attendees, an increase of 58.5%.

"We are extremely thankful to have all of the support and financial help we do for my dad's wheelchair. He wanted to pass on his deep gratitude for all that ALS Canada has done to help him in getting the items he needs."

ANITA
ALS COMMUNITY MEMBER

Joanna Oachis, pictured here with her client Mangal, assists families by sharing the supports that are available to them from ALS Canada and in their communities.

COMMITMENT TO CARE

For most people, their first contact with our organization is through our Community Leads. Joanna Oachis may be a familiar face to clients in Scarborough and York Region. Since 2008, she has been supporting clients, caregivers, and families affected by ALS, sharing information, and pointing them to services and supports in their communities so they can navigate the course of ALS after a diagnosis.

It seemed the universe was directing Joanna to this line of work long before she arrived at it. When she left Romania many years ago, her friend handed her the book *Tuesdays with Morrie*, a book describing the final lessons the author received from a former college professor whose health was in decline due to ALS. An avid reader, Joanna spent the plane ride to Canada reading the book cover to cover.

“I had never heard of ALS before,” she says. “Once we landed in Canada and I got access to the internet, I looked it up and saw the wonderful work ALS Canada was doing. A few years later, I got a job there.”

Her work is rewarding. “Every day I learn something from my clients about resilience, strength, positivity. It inspires me in my day-to-day life. Once, I asked one of my clients how he stayed so positive. He said to me, ‘Misery is a choice and I choose not to be miserable.’ Now, when I am upset or feeling down, I think of that and I say to myself, ‘He’s right. I have a choice.’ This work changes you.”

IN MEMORIAM

ALS Canada acknowledges with deep appreciation the contributions of Alan Medcalf. An active volunteer for much of his adult life, after his diagnosis in 2016 Alan focused his energy on raising awareness about ALS, sitting on the Community Services Advisory Council and lending his voice to various advocacy activities to help policy makers understand the lived reality of ALS. Alan chose to celebrate the journey and “to help create and sustain hope for those living with ALS, and to those around them.” He supported those living with ALS within his own community by facilitating a peer-to-peer ALS support group in the Brockville area. Alan died in February 2022.



ALAN MEDCALF

Community Services
Advisory Council member

IMPACT AREA 2

MORE TREATMENTS,
IMPROVED QUALITY OF LIFE,
EXTENDED LIFESPAN

ACCELERATING TOWARD A FUTURE WITHOUT ALS

CLEARING THE PATH FOR DISCOVERY

The ALS Canada Research Program funds peer-reviewed research grants to support areas of research that are expected to have high impact. It is an investment in a future without ALS. **The Research Program supported 16 research grants in 2021. Donor dollars make this possible.**

Thank you to provincial ALS Societies who collectively provided \$476,347 in funding support to the ALS Canada Research Program.

The 2021 investments are significant. Half a million dollars was granted under the **ALS Canada Trainee Awards** to PhD students and postdoctoral fellows working on projects in research centres and labs across Canada.

ALS research holds more promise than ever. Researchers are working tirelessly to better understand the disease, to find targets, and identify treatments that can alter the course of the disease. ALS Canada is the only source of dedicated ALS research funding across Canada to advance this work.

We also work hard to develop partnerships and facilitate collaboration that leverages our research funding to have even greater impact and help stimulate other opportunities for ALS research investment. Capacity-building is important within the research community as we continue to support Canadian ALS researchers and look for ways to connect the network of ALS researchers across Canada and globally.

\$1.125 million was awarded in **Discovery Grants**, in partnership with Brain Canada,* to nine research initiatives including foundational lab research, clinic-based research, and a clinical trial – all of which demonstrate our continually evolving knowledge in ALS.

Brain Canada's contribution doubled the investment in the Discovery Grants in 2021, and in 2022, we are excited to announce the partnership will be extended further to match all of the grant competitions.

* The Canada Brain Research Fund, is an innovative arrangement between the Government of Canada (through Health Canada) and Brain Canada.

Investments are made to increase clinical capacity and access to clinical trials across Canada.

Dr. Vincent Picher-Martel was awarded \$200,000 for the **ALS Canada Clinical Research Fellowship** to examine a promising new biomarker and therapeutic target.

Dr. Andrea Parks was awarded **The Mitsubishi Tanabe Pharma Canada Fellowship**. Dr. Parks was awarded \$130,000 by ALS Canada in partnership with Mitsubishi Tanabe Pharma Canada, Inc. (MTP-CA). She is measuring psychological distress in ALS patients.

A detailed list of research projects funded in 2021 is available.

INVESTING IN RESEARCH



16 research grants including nine Discovery Grants, five Trainee Awards and two Clinical Research Fellowships.



\$1,955,000 total value of research funding provided in 2021.



319 participants at the 2021 ALS Canada Research Forum.



Convened and facilitated an **industry roundtable to identify areas of collaboration** to address the needs of the ALS community in Canada.

FUELLING THE ENGINE OF RESEARCH

ALS Canada continues to work closely with the network of ALS multi-disciplinary clinics across Canada through the Canadian ALS Research Network (CALS). People and families affected by ALS want equitable and timely access to treatments and clinical research, and we can help facilitate that through **administrative and strategic support of the CALS network.**

Last year we also supported CALS on the development of the first CADTH clinician input submission for an ALS therapy – AMX0035.

ADVANCING TOWARD CHANGE

The ALS research community met once again at the **ALS Canada Research Forum**. Delivered virtually over two days, over **300 participants** gathered to learn and share advancements in science. The event featured presentations on the latest in fundamental, translational, and clinical ALS research taking place across the country.

We were pleased to welcome **13 Community Fellows** to the Research Forum. This pilot program made it possible for people affected by ALS to have insight into the breadth of ALS research underway in Canada and connect with those who are leading it.



ONE BY ONE, A GLOBAL EFFORT TO FIND ANSWERS

Every person's journey with ALS is unique, which makes it very challenging to study. In April 2021, ALS Canada and Brain Canada announced they had joined forces with Alnylam Pharmaceuticals and Regeneron to support CAPTURE ALS, a Canadian research platform that provides the systems and tools necessary to collect, store, and analyze vast amounts of information, creating **the most comprehensive biological picture of people with ALS.**

Led by Dr. Sanjay Kalra and a team of world-renowned scientists, CAPTURE ALS will analyze data and samples from individuals with ALS hoping to identify unique subtypes of the disease. These insights will move us closer to **a future where personalized medicine is possible.**

A \$2.85M Platform Support Grant will fund enrollment of the first 100 people living with ALS (and related diseases) and 25 healthy controls. The Calgary Flames Foundation donated an additional \$240K to CAPTURE ALS in December 2021. This was raised by Flames' Assistant GM Chris Snow, who was diagnosed with ALS in 2019, and his family. This donation supports recruitment of an additional 20 people with ALS to participate in CAPTURE ALS. It is thanks to generous donors like these that the platform will open for recruitment in early 2022.



"Many brains are better than one. When we invest in platforms that convene the research community, we are bringing together experts in the field and enabling science to move a lot quicker."

DR. VIVIANE POUPON
BRAIN CANADA PRESIDENT & CEO



"Through my personal connection to ALS I know that effective new therapies can't come soon enough – which means that high-quality research is essential as the foundation on which therapies are built."

CALI ORSULAK A COMMUNITY MEMBER OF
ALS CANADA'S SCIENTIFIC AND MEDICAL
ADVISORY COUNCIL

INTERNATIONAL RECOGNITION FOR CANADIANS

The International Symposium on MND/ALS is the biggest annual conference dedicated to ALS and motor neuron disease (MND) research and in 2021, two Canadians received prestigious awards.



ALS Canada's Vice President of Research **Dr. David Taylor** was awarded with the **2021 Humanitarian Award** from the International Alliance of ALS/MND Associations, recognizing him for a contribution of international significance for people affected by ALS or MND. "Modern leadership requires a combination of strong ethics, effective cross-cultural communication, and a focus on others," the Alliance wrote. "Dr. Taylor embodies all these traits and more."



Dr. Silvia Pozzi, who received the La Fondation Vincent Bourque-ALS Canada Career Transition Award in 2020, continues to garner attention, this time receiving the prestigious **Paulo Gontijo Award**, an international award given to top young researchers dedicated to finding the cause and cure of ALS. The award recognises young researchers below 40 who have dedicated their scientific work to investigate the causes and treatment of MNDs.



THE TIME IS NOW AN URGENT CALL TO ACTION

The current drug approval and reimbursement processes in Canada do not reflect the urgent realities of an ALS diagnosis.

During the significant time it takes for a new therapy to move from regulatory approval through to the reimbursement decisions that result in patient access, thousands of Canadians with ALS will die waiting for much-needed treatments.

Every minute of every day is critical for people living with ALS who are awaiting access to treatment. And, there is a need for government to play a role in reducing the time it takes for new therapies to be made available to Canadians living with ALS. So, in 2021, our community stood up and called for changes to the status quo.

Building on the grassroots movements of Canadians, ALS Canada – **in consultation with the Canadian ALS community** – undertook the development of a position paper called ***The Time is Now***. The paper offers two concrete solutions to getting Health Canada approved therapies to Canadians living with ALS in a timeframe that more accurately reflects the urgent needs of the community.

The position paper was supported by an e-advocacy campaign that called on Canadians to tell their elected officials it is unacceptable to make Canadians with ALS wait years to access new treatments after they've been approved by Health Canada. **Nearly 8,000 people sent letters to their elected officials**, the Federal Minister of Health and their Provincial Ministers of Health. Joined by a number of community advocates, **the position paper's recommendations were also formally brought forward to governments** at provincial and federal levels. The position paper sets a foundation for future advocacy actions related to access to therapies.

The Time is Now for immediate and long-term drug access solutions that will meet the urgent needs of people living with ALS – now and in the future. **Expedited and, ideally, immediate access to approved ALS therapies is urgently needed.**

***The Time is Now* campaign became the centrepiece of 2021** for ALS Canada advocacy efforts, informed and supported by people and families affected by ALS.

ALS Canada will continue to respond to the concerns voiced by the community and amplify the voices calling for changes to improve the lives of people living with ALS and their families.

Susheela Balasingam was determined to help other people living with ALS in any way she possibly could. Featured on the cover of The Time Is Now position paper, she was also the spokesperson for ALS Canada in a 2021 direct mail fundraising campaign. Susheela died in November 2021 leaving a legacy of strength and determination.

IMPACT AREA 3

EMPOWERED, INFORMED DECISION-MAKING

AN EMPOWERED & INFORMED COMMUNITY

The ALS community must have access to factual information that can inform personal decision-making and the community must be empowered to advocate for change.

Members of the ALS community tell us that understanding the direction and implications of research is important to them. In 2021, the Canadian ALS Research Forum included more than a dozen Community Fellows who took part in the virtual conference, observing the scientific presentations, and contributing their experience to the discussions. The inaugural Canadian ALS Learning Institute followed, helping community members to understand clinical research and learn from the research community (see page 14 for more).

VOICE OF EXPERIENCE

We connect people living with ALS and their caregivers to opportunities to raise their voices and share their experiences, and we advocate for those opportunities when they are not available.

To inform decision-making in the drug approval and reimbursement process, ALS Canada prepared and submitted a patient input submission to the Canadian Agency for Drugs and Technologies and Health (CADTH), for the therapy AMX0035. We invited the ALS community to share their experiences and views during this vital process by completing a survey to inform the submission. An impressive **629 Canadians** affected by ALS participated in the survey and the one-on-one interviews. **This enthusiastic response – and the information shared by respondents – were key**

to making sure our final submission reflected the diversity of experiences

among people and families living with ALS. In addition, the first clinician submission to CADTH provided an important perspective from ALS clinicians into the nuance of the disease and the impact of this therapy.

ADVOCACY, ALL YEAR

ALS Canada is dedicated to advocacy year-round. We use our strength as a hub for the ALS community to call for change wherever there is unmet need. In Spring 2021, we heard from the ALS community that **people living with ALS and their caregivers needed priority access** to second doses of the COVID-19 vaccine, along with other high-risk populations. On June 4, as part of a coalition of health charities in Ontario, ALS Canada asked that vulnerable Ontarians and their caregivers be prioritized.

A HOME RUN FOR PUBLIC AWARENESS

In 1939, Lou Gehrig announced to 62,000 fans at Yankee Stadium that he had to retire as the star player for the New York Yankees after a diagnosis of ALS, which soon became known as Lou Gehrig's disease. In early 2021 following grassroots efforts by the ALS community including Taya Jones and Mark Kirton that resulted in support from all Major League Baseball teams, MLB announced that it will recognize **Lou Gehrig Day** every year on **June 2**. With the power of the MLB behind this awareness day, North Americans will learn more about the challenges of ALS and the efforts to "strike out" this disease.

The annual Lou Gehrig Day will be the "first inning" to the month we know as ALS Awareness Month in Canada.

ACTION MAKES CHANGE



30 meetings with government (5 provincial, 25 federal).



50 elected officials engaged.



10 community advocates in government meetings.

Affordable access to Radicava available to all eligible Canadians. **More than 3,600 Canadians** helped make this possible.



First Health Canada Patient Input Listening Session focused on the ALS community.

Open letter from all-party ALS Caucus to Federal Health Minister calling to reduce **Health Canada approval time for new ALS drugs**.



THE CANADIAN ALS LEARNING INSTITUTE, FUELLING EMPOWERMENT

“Participating in the Canadian ALS Learning Institute was an awesome experience. It was the first time I had the opportunity to meet and speak to other people living with ALS. It was encouraging to hear researchers present their work with such passion. Knowing that many people care about finding better treatments and a cure for ALS gave me hope. My overall experience was one of empowerment. People living with ALS can become foot soldiers making a change.”

CLAUDETTE STURK
NOVA SCOTIA

With many promising ALS therapies currently in clinical trials, there is increasing interest from people and families living with ALS to learn more about the research landscape and how new therapies become available to Canadians.

That’s why ALS Canada launched our inaugural **Canadian ALS Learning Institute**, an online, small-group learning experience to understand the Canadian ALS landscape, clinical research and therapy development, and how new therapies become approved and accessible to Canadians.

The program included participants from all parts of the country, representing urban and rural areas, with personal experience of ALS or as a caregiver. Topics ranged from How to Read a Research Paper to Statistics to Understanding the Fundamental Science of ALS, to name a few. Guests included some of Canada’s most prominent ALS researchers and clinicians.

Sandra Lytle, newly diagnosed with ALS, arrived at the Learning Institute wanting to learn more about it. “I was somewhat still shell shocked on my diagnosis and was looking for any information that would help me understand ALS. You know what they say about knowledge – it has power.”

By the end of the program Sandra felt more knowledgeable about ALS and life cycle of therapy development. “I better understand the complexities and costs of identifying and developing therapies. It takes years.” Even more valuable to her was being connected to other learners who are living with ALS. “I walked away knowing I am not alone in what I feel. Whether you are an ALS patient, caregiver, or friend, we all must come to terms with the diagnosis.”

Graduates of the 2021 Institute have eagerly taken on new roles as ALS Canada Community Ambassadors who are ready to transfer their new knowledge into advocacy for the entire ALS community. Sandra soon put her new skills to use, participating in ALS Canada’s first Virtual Advocacy Week in March 2022.

“It’s very emotional when I talk about my story,” Sandra says. “Even so, I plan to do it again and hold a face-to-face meeting with my MPP.”

Small in numbers but mighty in outcomes, the success of the program is undeniable, and ALS Canada has committed to running it again in 2022.

We thank the working group from across Canada who contributed so much to the development of this exciting, new initiative.

ADVANCING OUR CAUSE

The momentum of 2021 is propelling us into 2022 and beyond with immense power. We continue our work, accelerating toward a future where people living with ALS have access to timely treatments, they are supported in their needs, and empowered with knowledge and tools to advocate for change and a future without ALS.

New family and caregiver services, like bereavement support groups and resources for children and youth, will be introduced in 2022. ALS Canada will continue our commitment to seek opportunities to share the journey and experiences of the ALS community, and to amplify its voice. The Canadian ALS Learning Institute will continue in 2022, and our work on *The Time is Now* will be pushed forward for improved access to therapies.

The future we envision may be on the horizon still, but we advance toward it unyieldingly. Donors, volunteers, and strong partners will remain vital to this work, and we invite you to join this community. Your generous investment of time and dollars will make us unstoppable.

LEADERSHIP & GUIDANCE

Governance

ALS Canada's competency-based Board of Directors provides strategic direction and oversight to ensure donor dollars are maximized to serve the organization's areas of charitable purpose. These leadership volunteers contribute expertise across a range of disciplines, a genuine passion for the cause, and their strong desire to make a difference.



Patrick Nelson,
Chair



Alyssa Barry



Norma Beauchamp



Catherine Bélanger



Ken Chan



Richard Ellis



Lisa Flaifel



Elizabeth Gandolfi



Laura Gay



Dr. Angela Genge



Dr. Wendy Johnston



Josette Melanson,
Past Chair



Jim Mitrakos



Dr. Michael Spivock



Dr. Christine
Vande Velde



Tammy Moore,
ex-officio

Advisory Councils & Committees

The **Scientific and Medical Advisory Council** provides guidance to ensure research activities contribute to the strategic priorities of ALS Canada and are carried out with integrity. This broad group includes researchers and clinicians across disciplines, as well as community members actively living with and affected by ALS.

Dr. Christine Vande Velde, *Co-Chair*
Dr. David Taylor (staff), *Co-Chair, ex-officio*
Dr. Turgay Akay
Dr. Vanina Dal Bello-Haas
Colleen Doyle (staff), *ex-officio*
Dr. François Gros-Louis
Dr. Wendy Johnston
Dr. Hanns Lochmüller
Dr. Geneviève Matte
Tammy Moore (staff), *ex-officio*
Patrick Nelson, *Chair, ALS Canada Board, ex-officio*
Cali Orsulak, *ALS Community Representative*
Dr. Robin Parks
Dr. Gerald Pfeffer
Dr. Janice Robertson
Dr. Kerri Schellenberg
Paula Trefiak, *ALS Community Representative*

Grounded in personal and professional experience with ALS, the **Community Services Advisory Council** guides our community services programming to optimize how we support Ontarians affected by ALS.

Lisa Flaifel, *Co-Chair*
Kim Barry (staff), *Co-Chair*
Margot Algie
Ron Black
Sheldon Crystal
Heidi Kinnon
Stephanie Mazzei
Alan Medcalf
Patrick Nelson, *Chair, ALS Canada Board, ex-officio*
Vincent Quinn
Christen Shoesmith
Lisa Sullivan
Sherry Szucsko Bedard
Dr. Anu Tandon

Reflecting the increased effort in federal and provincial (Ontario) advocacy, the **Advocacy Committee**, established in 2020, provides professional and personal insight to help advance our advocacy priorities.

Richard Ellis, *Co-Chair*
Lisa Marchitto (staff)
Catherine Bélanger
Carmen Cels
Mike Cels
Ryan Clarke, *ex-officio*
Lisa Flaifel
Dr. Angela Genge, MD, FRCP(C)
Sherry MacLauchlan
Stephanie Mazzei
Tammy Moore (staff), *ex-officio*
Patrick Nelson
Lauren Poplak (staff), *ex-officio*
Dr. Karin Schnarr

THANK YOU | TO OUR 2021 DONORS

The generosity and commitment of thousands of donors and fundraisers make our work possible. We rely on the support of individuals through events, monthly donations, annual gifts, and planned gifts. We are also grateful for the generous corporate donors and foundations who provide us vital financial support.

We are appreciative of the generous support of donors and the provincial societies, through their dedication to the Walk to End ALS and other investments for research: ALS Society of BC, ALS Society of Alberta, ALS Society of Manitoba, ALS Society of Quebec, ALS Society of Newfoundland & Labrador, and ALS Society of PEI.

The following list of donors reflects individuals, foundations, and companies who donated \$1,000 or more to ALS Canada in 2021. Many of our supporters have been personally impacted by ALS and have made donations in honour of loved ones.

We make every effort to ensure the accuracy of this list. If you have a question or a correction, please contact us at donations@als.ca.

Individuals

Anonymous (26)
Anonymous, in honour of Paul Durand
Anonymous, in honour of Angella LeBlanc
Anonymous, in honour of Paul McMann
Katherine Alyea, in honour of David Anthony Burger and Mike Whitaker
Dr. R. Amaratunga, in honour of Dr. L.M. Amaratunga
Brian Awrey, in honour of Wib Awrey
Q.C. Baldock, in honour of Deane Gorsline
Andrea Baxendale, in honour of father Dennis Baxendale
Bekendam Family, in honour of Anne Bekendam
Catherine Bélanger, in honour of Mauril Bélanger
Claire Berthiaume, in honour of Jacques Berthiaume and Theresa Gagnon
Monica Bertolo and the Sallows Family, in honour of sister Lisa Gilchrist
Fiona Alexander Black, in honour of mother Elizabeth Catherine Alexander
François Bregha

Bob Brethour, in honour of Charlotte Brethour
Carol Burke, in honour of late husband John Burke
Robert Burgess, in honour of daughter Gale Burgess
Robert Burnside, in honour of Irene Burnside
Love your Edmonton friends, in honour of Steve Daly
Judith Cathcart, in honour of husband Ralph Cathcart
Kathleen Caughey, in honour of George Panchuk
Scott and Colleen, in honour of Faye Lee
Mike Cels
Eric Chan and Flora Chan, in honour of sister Wendy Chan
Paul J Charbonneau, in honour of Dale Hodgins
Julia Charles, in honour of Deane Gorsline
Robbie Clement, in honour of Francis Clement
Lisa Connolly, in honour of Diane Luke
Maxine and Richard Cook, in honour of Lloyd May
Beverly Crandell and Christopher Worth, in honour of Ann Crandell

George W. Cummings, in honour of wife Lorna Cummings
Steve Daly
John C. Darling, in honour of Ruth A. Darling
Michelle Drewery, in honour of Randy Drewery
Merrilyn Driscoll, in honour of Maureen Butler
Richard Ellis, in honour of Cathy Payne
Judy Ferguson, in honour of Dale Hodgins
Jean-Pierre Fréchette, in honour of Anne-Marie Marcil
Kathy Frost, in honour of Maria Frost
Jocelyne Gall, in honour of Bill Gall
Maxie Bluestein
Laura Gay
Julia Gorman, in honour of ShirleyAnne Gorman
Avery Grant, in honour of Rodney Helfrich
George G. Gratton, in honour of wife Diane E. Gratton
Les Green
Colleagues and friends of Jim Lester
Charles Guertin
Ted, in honour of Jim and Harry

Francine Harris, in honour of Sheldon Harris	John MacGowan	Estelle Rannie, in honour of Mike Rannie	Sandra Vivarais, in honour of husband Mark Vivarais	FWA Consulting Inc.	Foundations
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Helene Lavigne and Scott Stevenson, in honour of Steve Daly	Patrick Nelson, in honour of Laura Coughlin	T. Sugar, in honour of Joanne Nelson	Amylyx Pharmaceuticals	ALS Charity Stream	The De Boer Foundation
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Judy Lusk, in honour of Gary Lusk	Michael Petrachenko, in honour of Monique Coutu	Margaret Van Egmond, in honour of brother Peter Marcus	Brown Mills Klinck Prezioso LLP	Scotia Wealth Management	Estate of Susan Jennings, in honour of James Barry Worth
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2021 ALS CANADA RESEARCH AWARDS

Research is the pathway to creating a future without ALS. As one of the only charitable organizations that invests in ALS research across Canada, we fund high-quality science that offers the most promise to slow down ALS or even stop it.

The research we fund is only possible because of the generosity of donors and our partnership with ALS Societies across Canada, who donate 40 per cent of the proceeds from the Walk to End ALS as well as additional support throughout the year from other fundraising and donor initiatives.

The research studies we invest in are selected through a rigorous peer-review process. Proposals are evaluated and ranked based on scientific merit and their potential to advance ALS research. We are proud to put our name behind these researchers.

2021 ALS CANADA CLINICAL RESEARCH FELLOWSHIP

Could a promising new biomarker also be a target for future ALS therapies?

Dr. Vincent Picher-Martel, Massachusetts General Hospital | \$200,000



THE MITSUBISHI TANABE PHARMA CANADA FELLOWSHIP

Could a screening tool help to identify early psychological distress in ALS and guide appropriate management?

Dr. Andrea Parks, Sunnybrook Health Sciences Centre | \$130,000



ALS CANADA-BRAIN CANADA DISCOVERY GRANTS

Awarded in partnership with Brain Canada through the Canada Brain Research Fund

Can image-guided focused ultrasound technology aid in the delivery of promising new ALS therapies?

Dr. Agessandro Abrahao, Sunnybrook Health Sciences Centre, with Dr. Lorne Zinman, Dr. Nir Lipsman, Sunnybrook Health Sciences Centre, Dr. Kullervo Hynynen, Dr. Simon Graham, Dr. Jamie Near, Sunnybrook Research Institute, Dr. Sanjay Kalra, Dr. Kelvin Jones, University of Alberta, Dr. Isabelle Aubert, and Dr. Sonam Dubey, Sunnybrook Research Institute | \$125,000

Can a cutting-edge imaging technique identify a link between a signalling pathway in the brain and ALS?

Dr. Freimut Juengling, in collaboration with Dr. Sanjay Kalra and Dr. Ralf Schirrmacher, University of Alberta | \$125,000

Can novel biomarkers help researchers to evaluate the effectiveness of promising new ALS therapies?

Dr. Gerhard Multhaup, McGill University, in collaboration with Dr. Angela Genge, The Neuro (Montreal Neurological Institute-Hospital) at McGill University | \$125,000

Does hypermetabolism contribute to ALS disease processes?

Dr. Jeehye Park, in collaboration with Dr. Hoon-Ki Sung, The Hospital for Sick Children | \$125,000

How could the loss of the normal function of C9ORF72 contribute to ALS?

Dr. Janice Robertson, Tanz Centre for Research in Neurodegenerative Diseases, University of Toronto, in collaboration with Dr. Liang Zhang, University Health Network | \$125,000

Can small tags on TDP-43 influence its abnormal behaviour in ALS?

Dr. Maxime Rousseaux, University of Ottawa, in collaboration with Dr. Martin Duennwald, Western University | \$125,000

Does a newly discovered protein play an important role in ALS?

Dr. Christine Vande Velde, Centre de recherche du CHUM at Université de Montréal, in collaboration with Dr. Marlene Oeffinger, Institut de recherches cliniques de Montréal (IRCM) | \$125,000

Can undiscovered protein interactions influence FUS dysfunction in ALS?

Dr. Ji-Young Youn, SickKids Research Institute, in collaboration with Dr. Hyun Kate Lee, University of Toronto | \$125,000

Could a new biomarker in the eye help to advance ALS research and care?

Dr. Yeni Yucel, in collaboration with Dr. Neeru Gupta, Unity Health Toronto | \$125,000



2021 ALS CANADA TRAINEE AWARDS

2021 DOCTORAL AWARDS

Could a new 3D model of the neuromuscular junction help advance drug screening in ALS?

Maria José Castellanos Montiel, The Neuro (Montreal Neurological Institute-Hospital), McGill University | \$75,000

Does a protein in the cerebrospinal fluid play a role in the progression of sporadic ALS?

Amélie Poulin-Brière, Centre de recherche CERVO, Université Laval | \$75,000

How might reduced levels of C9ORF72 contribute to ALS disease processes?

Belay Gebregergis, TANZ CRND and LMP, University of Toronto | \$75,000

2021 POSTDOCTORAL FELLOWSHIP AWARDS

Can artificial intelligence detect bulbar ALS in Canadian French speakers?

Dr. Liziane Bouvier, Sunnybrook Research Institute | \$110,000

Does TDP-43 mislocalization contribute to impaired stress granule formation in ALS?

Dr. Hana Fakim, Centre de recherche du CHUM, Université de Montréal | \$165,000

ALS Society of Canada

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Pictured on front cover:

Mangal Balbachan
Susheela Balasingam
Dr. Silvia Pozzi
Revolution Ride participant

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About the ALS Society of Canada

The ALS Society of Canada is working to change what it means to live with amyotrophic lateral sclerosis, an unrelenting and currently terminal disease.

Grounded in and informed by the Canadian ALS community, we respond to the urgent unmet need for life-changing treatments by investing in high-quality research that will fuel scientific discovery and by engaging industry, supporting increased clinical capacity and advocating for equitable, affordable, and timely access to proven therapies.

Responding to the tremendous need for current and credible ALS knowledge, awareness, and education, we empower Canadians affected by ALS to navigate the current realities of ALS, be informed consumers of ALS information, and advocate effectively for change. In Ontario, we provide direct community services to help people navigate ALS.

Founded in 1977, we are a registered charity that receives no core government funding – our work is powered by generous donors who share our vision of a future without ALS.

The Standards Program
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