

# THE FUTURE IS NOW

2022 ANNUAL REPORT  
TO THE COMMUNITY





# TO THE COMMUNITY



## The Future is Now.

There is simply no time for people living with ALS – the disease moves swiftly, and so must we. That is why we work to support people living with ALS today and lay the foundation for people who will be diagnosed tomorrow. In 2022, the ALS Society of Canada continued to invest in the building blocks that will meet the needs of the ALS community in the years to come.

Change is only made possible by you, our donors, volunteers, partners, and staff, alongside ALS researchers and clinicians, who provide us with momentum to carry forward our work to improve the lives of people affected by ALS. Whether it's through the participation and success of our events; the information, webinars, tools, and community support we provide; the research we invest in; and the calls to action for our advocacy efforts – your contributions and desire to work together to make a meaningful impact for this community are felt.

Together, our work starts in the home and spans provincially, nationally, and beyond borders. Because of your relentless support, we have the unique opportunity to bring an international perspective to our programs and to influence global efforts to realize our common vision of a future without ALS.

As we reflect on the year past and look to 2023, we are excited by the plans we are putting forward, the opportunity to look to the future collectively through the strategic planning process and what we can accomplish together to change the reality of an ALS diagnosis, today and tomorrow.

A handwritten signature in dark ink, appearing to read 'P. Nelson'.

**PATRICK NELSON**  
CHAIR, BOARD OF DIRECTORS

A handwritten signature in dark ink, appearing to read 'Tammy Moore'.

**TAMMY MOORE**  
CEO

# Strategic Impact Plan 2018-2023

**The ALS Society of Canada (ALS Canada)**  
actively works to advance 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**

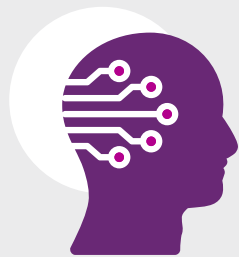
**PEOPLE ARE EMPOWERED  
TO MAKE INFORMED DECISIONS  
ABOUT ALS.**

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.

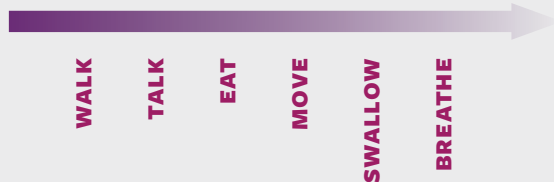
VISIT **WWW.ALS.CA** TO FOLLOW OUR WORK IN THESE AREAS.

# 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 muscles.

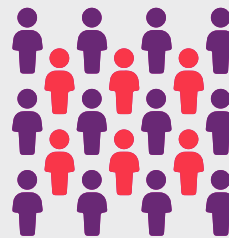


Over time, as their motor neurons die, people living with ALS gradually **lose the ability to walk, talk, eat, move, swallow, and eventually breathe.**

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.



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



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

## THERE IS HOPE.



At ALS Canada, we respond to the urgent unmet need for life-changing treatments by **investing** in high-quality research that will fuel scientific discovery, **engaging** industry, **supporting** increased clinical and research 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 credible information on ALS, and **advocate** effectively for change.



In Ontario, **we directly support** people affected by ALS to ease their journey – through a hybrid model of **in-home and virtual interactions**, facilitated **support groups**, and provision of **mobility equipment and communication devices.**

**TOGETHER** WE ARE WORKING TOWARD A **FUTURE WITHOUT ALS.**

# **SUPPORTING THE COMMUNITY**

**We are here on every level.**



## **INTERNATIONAL**

**Strategic Partnerships**

**Research Investments**

**Advocacy**



## **NATIONAL**

**Research Investments  
& Capacity Building**

**Stakeholder Relations**

**CALS Administration Support**

**Advocacy**

**Knowledge Translation**

**Communications**

**Community Information**

**Community Engagement**

**Fundraising – National**



## **PROVINCIAL – ONTARIO**

**Community Services**

**Equipment**

**Advocacy**

**Fundraising – Ontario**



## OUR MISSION WORK, POWERED BY DONORS

With no government funding to support our mission work, ALS Canada relies on the generous support of our donors. In 2022, individuals, companies, and foundations showed us again and again that they believe we can positively impact the lives of people affected by ALS through support, education and resources, advocacy, and investment in research.

Our donors are the lifeblood of our organization and a vital part of the ALS community. Thank you for your donations, grants, sponsorships, gifts-in-kind, and, most of all, your commitment to working with us toward a future without ALS.

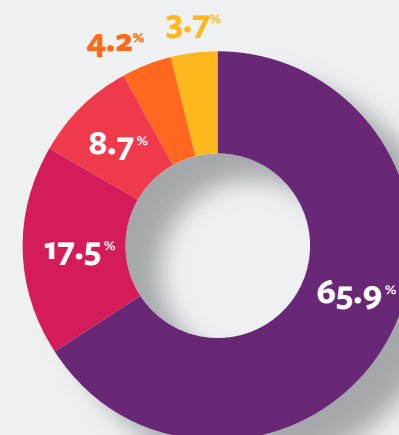
Please make your **2023 donation today** so we can keep the momentum strong.

*“For decades, Canadian ALS research has been an important contributor to the global effort on understanding and treating ALS. Investing in this work, with the generous support of our donors, is critical for us to keep moving the needle closer to more effective ways of helping people live longer and better lives. Our team at ALS Canada ensures that donor dollars are utilized to have the maximum Canadian and internationally collaborative impact as we continually strive forward with urgency.”*

**DR. DAVID TAYLOR**

VICE-PRESIDENT, RESEARCH AND STRATEGIC PARTNERSHIPS, ALS CANADA

	<b>Fundraising Donations and Other Income</b>
	\$6,332,192
	<b>Ontario Walk to End ALS</b>
	\$1,685,770
	<b>Fundraising Events</b>
	\$834,881
	<b>Investment Income</b>
	\$398,941
	<b>From Provincial Societies*</b>
	\$354,948



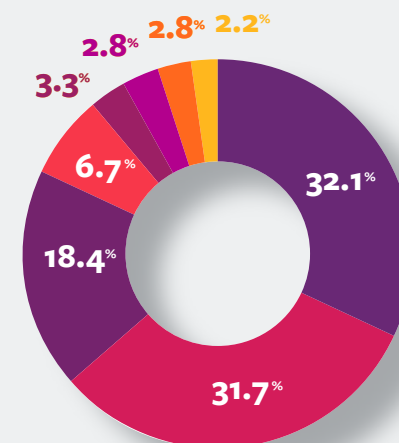
2022 Revenue

\* Participating provincial ALS Societies mainly contribute to the ALS Canada Research Program through 40% of net proceeds of Walk to End ALS events, as follows:

- ALS Society of Manitoba \$38,930
- ALS Society of Quebec \$100,000
- ALS Society of Newfoundland & Labrador \$25,733
- ALS Society of Prince Edward Island \$15,285

The ALS Society of Quebec provided an additional \$175,000 in support of the ALS Canada Research Program, which included \$75,000 on behalf of the Dr. Jean-Pierre Canuel Fund at the ALS Society of Quebec.

	<b>Community Services</b>
	\$2,874,165
	<b>Fundraising</b>
	\$2,844,618
	<b>National Research*</b>
	\$1,649,054
	<b>Advocacy</b>
	\$602,681
	<b>Public Awareness</b>
	\$290,928
	<b>Governance</b>
	\$255,285
	<b>Other Charitable Purpose</b>
	\$247,409
	<b>Administration</b>
	\$197,869



2022 Expenses

\* In partnership with Brain Canada, \$2,113,900 was awarded in research grants in 2022 for a total research investment of \$2,706,004.

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





## The power of community tattooed on our hearts

**Jane Cubitt, fearless advocate, wife, mother, sister, friend, and so much more, will be remembered for her uplifting spirit and courage by the ALS community. Jane and her husband David learned she had ALS in 2020 after a slur in her speech and a series of tests revealed she had bulbar onset ALS.**

Jane and David dedicated themselves to raising awareness and fundraising to support leading-edge research and ALS Canada programs and services serving people affected by the disease. In addition to joining the annual ALS Canada Walk to End ALS and participating in our #WhileIStillCan Year-End Campaign, Jane

took to the skies and landed a tandem skydive as part of a fun and daring fundraising event in Wasaga Beach, Ontario.

Jane's shining spirit inspired people to rise to the challenge. "While I still can," she said, "I will bring my passion for engaging people in my world... so that one day it will all be worth it." In a gesture of solidarity, she invited family, friends, and neighbours to choose a meaningful tattoo that she matched on her own arm. Those symbols remain a living testament to her faith in the power of community to change the future of ALS and empower people living with ALS today. Jane died in February 2023 but will continue to fly fearlessly in our memories.



*"The money we have been able to raise through the Hickory Dickory Decks Charity Golf Classic in support of people living with ALS and their families gives me hope for the future and in the inevitable eradication of this disease. ALS has touched the lives of so many, and I am no different. When my best friend succumbed to ALS in his thirties, I found a way to honour his life by making ALS Canada a recipient of funds raised at the HDD tournament each year. It is important that we continue to support the community as a thank-you for all the community has done for us."*

**TOM JACQUES**

CEO AND PRESIDENT, HICKORY DICKORY DECKS AND COMMUNITY FUNDRAISER

## 2022 EVENTS

**One team, one goal = #aFutureWithoutALS.** The ALS community supported Canadians living with ALS throughout 2022 with an enthusiastic return to in-person fundraising events.

For every event, there was a dedicated group of volunteers generously giving their time and effort to help coordinate the logistics, find sponsors, connect the public to the cause, and raise much-needed funds! To each of you, thank you – we couldn't do the work that we do without your support.

**Be a part of the change!**

Visit [als.ca/get-involved/](https://als.ca/get-involved/) to find out more.



### Walk to End ALS

After two years of virtual-only events, 2022 brought with it the opportunity for our community to come together again in-person. **More than 2,500 individuals and 368 teams** united for the ALS Canada Walk to End ALS in Ontario alone, taking part in **23 events across the province.**

*Walk to  
End ALS*

**A total of \$2,040,718** was raised by ALS Canada and participating provincial Societies across the country. Forty per cent of the Walk to End ALS proceeds 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. Sixty per cent of proceeds benefit community services in the participating provinces where the funds are raised. **In Ontario, \$1,685,770 was raised**, with 40 per cent going to research and 60 per cent directly benefitting community services in Ontario.



## 2022 EVENTS



### Revolution Ride

In September, the ALS Canada Revolution Ride brought together **80 participants making up 20 teams**. The cyclists took part in either a 40km or 90km ride through beautiful Dundas, Ontario.



The day was particularly meaningful to Guelph resident and avid cyclist Darrell Kane, whose father passed away from ALS on September 24, 1992. Thirty years and one day later, Darrell participated in the Revolution Ride in memory of his father and for himself. Following his own ALS diagnosis in July 2022, Darrell has found new strength to raise awareness for the cause.

“When my father passed away, it was too painful for me to be part of the ALS community,” says Darrell. “Now that I have been diagnosed with ALS, and for as long as I have the quality of life and mobility, I want to do what I can to support the cause. Families caring for a loved one with ALS need support services, which the ALS Society of Canada can provide with the help of our fundraising efforts.” Because of those efforts – fueled by the volunteer-powered Ride committee – the challenging and inspiring event **raised a total of \$213,410**.



### Pull to End ALS

2022 saw a reimagined ALS Canada Pull to End ALS. In October, **11 dedicated teams of 80 total participants** gathered at CityView in Toronto for the ultimate challenge in strength and determination. The teams raced to pull a 42,000-lb transport truck for 100 metres in a fun and powerful competition. **\$157,111 was raised** for community-based support in Ontario, advocacy, and ALS research.



## STRATEGIC IMPACT 1

# People affected by ALS receive the best possible standard of care

### Helping all Canadians living with ALS

People living with ALS are at the centre of everything we do. We aspire to ensure that people affected by ALS receive the best possible standard of care in Ontario, across Canada, and around the world.

We strive to improve the clinical care and support for people living with ALS by providing direct services with one-to-one system navigation, support groups, and equipment for people in Ontario; creating resources, educational materials, and informational webinars for Canadians affected by ALS; acting as a catalyst for clinical advancements such as the clinical fellowships to build clinical trial capacity; and using the Canadian Best Practice Recommendations for the Management of ALS across Canada.

#### By 2023:

**A Patient Bill of Rights is helping to address gaps in service within Ontario and federally.**

#### By 2028:

**People are diagnosed with ALS earlier than they are today.**

### Providing services in the community



**1,289 people living with ALS** in Ontario are supported by **ALS Canada's Community Leads**.



**More than 500 people** from across Canada **attended our Community Services webinars** on mobility, financial resources, caregiver supports, and more.

More than **2,800 pieces of equipment** provided to people living with ALS in Ontario registered with ALS Canada.



**140 support groups** came together virtually, allowing people to share their experiences and learn from each other.



*"I can't thank ALS Canada enough for being there to teach, guide, and help people who are faced with an ALS diagnosis. I'm so grateful for the difference you've made in my mom's life. I can't imagine people living with ALS not having access to these items – all made possible with the help of donors."* KATHY, WHOSE MOTHER LIVES WITH ALS

## STRATEGIC IMPACT 1

### Connecting our community

Leveraging the learnings from the pandemic, the Community Services team in Ontario developed a **hybrid service delivery model**, returning to in-person home visits augmented with virtual interactions with clients and caregivers. This enabled us **to meet each person where they were** in terms of the type of connection that worked best for them. New systems were adopted by the team to **improve client intake and experience** and to allow us to capture data to **support the future needs of our community**. See Krishna's story on page 11 for more on adapting to the needs of our community.

### Diversity in support group offerings

ALS Canada supported an increased number of people living with ALS. This included **hosting nearly 150 virtual support groups**. In 2022, the Community Services team broadened their offering to include specialized support groups for bereaved community members. This allowed more opportunities for people who had lost a loved one to ALS, including caregivers, family members, and friends, to **share their unique experiences and connect with others**.

### Equipment support and system navigation

An ALS diagnosis can cost families hundreds of thousands of dollars. In 2015, Canadian researchers estimated that **living with ALS could cost upwards of \$150,000 to \$250,000**.<sup>\*</sup> This includes loss of income, modifications to the home, equipment, and additional caregiving support. To support people living with ALS in Ontario, **more than 2,800 pieces of equipment were provided**, free of charge, through the ALS Canada Equipment Program at the cost of \$1.6 million, providing people living with ALS independence, safety, and an **increase in quality of life**. This program is a model for expeditiously meeting the urgent needs and unique timeframes of a person with ALS and it is also cost-effective, as the equipment is recycled and reused to allow multiple people to benefit from a single piece of equipment.

In Ontario, we provide **health system navigation and access to community resources**. We work with Ontario health agencies, regional/local organizations, and ALS clinics to streamline how care and support are coordinated, and we are investing in efforts to measure and improve care in the future.

<sup>\*</sup> Matthew Gladman and Lorne Zinman published their review of the economic impact of ALS in 2015.

### Moving the needle on earlier diagnosis

ALS is a rapidly progressing, fatal disease where timeliness is essential in all aspects, making **the time to diagnosis a critical part of the journey with the disease**. This issue was identified in the previous strategic plan, with a goal to **reduce the time to diagnosis**. In 2021, we reported on organizing and convening a group of industry leaders and clinical experts, including a subset of members of the Canadian ALS Research Network (CALS), to explore earlier diagnosis of ALS in Canada. In 2022, this group took time to work on **ReferALS**, a program designed to expedite a referral of a suspected ALS case to a specialty CALS Clinic. See the full story on ReferALS on page 17.



*Clients, their caregivers, and loved ones come out to Walk to End ALS events in support of community services, advocacy, and investment in research.*



## STRATEGIC IMPACT 1



### **A return to home visits opens the door for a better standard of care**

When Krishna Sagoo started her new job as an ALS Canada Community Lead during the COVID-19 pandemic, her contact with the ALS community was entirely virtual. She was thrilled with the return to regular in-person visits last year. “When we go into the home, we can better assess the progression of the disease and really understand what the challenges and barriers are in the home environment – for the person living with ALS and the caregiver,” she explains. Joint visits with community care teams and other healthcare professionals are also highly valued because they create opportunities for collaboration that lead to better-individualized care. For example, a joint visit with an occupational therapist conducting a safety assessment may help identify an equipment need that ALS Canada’s Equipment Program can meet.

Many of Krishna’s clients have welcomed the return to home visits to help alleviate feelings of isolation. However, virtual meetings continue to offer people choices and enable support groups that might otherwise preclude people living with ALS or their caregivers who face challenges getting to an in-person meeting. Ultimately, the hybrid model offers flexibility so ALS Canada’s Community Leads can offer more tailored support.

Whether meeting in person or virtually, Krishna’s goal is always to gain deeper insight and understanding. “Listening is the most important part of this job,” she says. “I ask questions like, ‘How can I help you?’ and ‘How do you want to move forward with this?’ I may have supported 500 people with ALS, but every person’s situation is unique. So, what I want to know is how to support that person in that particular moment.”

*Krishna Sagoo, pictured here with her client Anne-Marie Marcil, is always looking to gain better insight, and understanding of her clients needs.*

## STRATEGIC IMPACT 2

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

### Investing in research today to make a difference tomorrow

The ALS Canada Research Program fosters collaboration, builds capacity, and is changing the landscape of ALS. Our investments in ALS research ensure that Canadian research has a global impact today and tomorrow.

Researchers are relentless in their drive to better understand the disease, identify treatments, and slow the progression. The ALS Canada Research Program is the only national dedicated source of funding for ALS research across Canada to fuel this work. This Program, coupled with our advocacy efforts, allows ALS Canada to push for more treatments to be available and accessible to improve quality of life and extend lifespan.

**By 2023:**  
**Affordable ALS treatments are available in Canada through a streamlined process.**

**By 2028:**  
**ALS is seen as a chronic illness and is no longer a “bankruptcy disease.”**

### Research investment



**Four grant competitions, 14 research grants**, including nine Discovery Grants, four Trainee Awards and one Career Transition Award.



**\$2,113,900 total value of research funding** provided in 2022.



**270 participants** at the 2022 ALS Canada Research Forum.

*“Our unique partnership with ALS Canada has the potential to lead to better diagnosis and treatment for people living with ALS, and it’s something that we are very proud of.”*

**DR. VIVIANE POUPON,**  
PRESIDENT AND CEO OF BRAIN CANADA

## STRATEGIC IMPACT 2

### Supporting the change-makers of ALS research

Through the ALS Canada Research Program, we fund peer-reviewed research grants, foster collaboration and build capacity within Canada's ALS research and clinical community, and invest in new areas of research positioned to have a high impact. In 2022, the Research Program supported 14 research grants.

Projects the ALS Canada Research Program funds are supported by the generosity of participating provincial ALS Societies, ALS Canada donors, and community-based fundraising efforts.

**\$1.4 million was awarded** to nine projects as part of the **ALS Canada – Brain Canada Discovery Grant Program**. As part of the Program, Dr. Alex Parker,

Université de Montréal, was awarded \$300,000 with support from the Dr. Jean-Pierre Canuel Fund – SLA Québec for his project that will explore whether targeting a specific region of the motor neuron, called the axon, represents a promising treatment strategy for ALS.

The **ALS Canada – Brain Canada Career Transition Award** enables talented early-career lab researchers to become permanent ALS research contributors and leaders. Dr. Philip McGoldrick at the Tanz Centre for Research in Neurodegenerative Diseases, University of Toronto, **was awarded \$250,000** for his project, *A new way to look at the most common genetic form of ALS*.

The **ALS Canada – Brain Canada Trainee Award Program** invests in the brightest young minds in ALS research, bringing new ideas to the field and maintaining Canadian ALS research excellence into the future. In 2022, **\$390,000 was invested** in projects that will build on existing knowledge of the biological processes that lead to the onset and progression of ALS and explore new therapeutic targets and a possible treatment strategy for ALS. The 2022 Postdoctoral Fellowship, awarded to Dr. Hussein Ghazale, a postdoctoral fellow in Dr. Carol Schuurmans's lab at Sunnybrook Research Institute, was supported by Fondation Vincent Bourque.



*"Opportunities like the ALS Canada Research Program are vital to support researchers early in their careers, to pursue new avenues of research, and advance our understanding of ALS. I am incredibly honoured to receive this support from ALS Canada and their generous donors. This support will allow me to investigate a fundamental mechanism that may contribute to ALS, which hasn't been studied before and enhance my opportunities to become an independent researcher to continue cutting-edge ALS research. I am sincerely grateful for this amazing support, which wouldn't be possible without the kind donations made to ALS Canada to support research."*

**DR. PHILIP MCGOLDRICK,**  
2022 CAREER TRANSITION AWARD RECIPIENT



## STRATEGIC IMPACT 2

### Bringing the Canadian research community together

We were proud to bring together the research and clinical community at the **2022 ALS Canada Research Forum**. With more than **270 participants**, the Forum was delivered virtually over two days. Participants included researchers and clinicians from across Canada and touched on topics such as ALS clinical trials, biomarkers, and moving promising basic research closer to clinics.

Ensuring that people living with ALS are at the centre of everything we do, we were pleased to welcome **12 Community Fellows** to the Research Forum. This 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 leading it.

### Advances in approved treatment options

In 2022, **two therapies were approved** for the treatment of ALS in Canada, demonstrating advancement in the number of therapies coming to market for people living with ALS.

- ALBRIOZA (AMX0035) approved with conditions in June 2022
- The oral formulation Radicava (edaravone) approved in November 2022

### Part of the national discussion

Participating in roundtable discussions on **Health Canada's National Strategy for Drugs for Rare Diseases** helped ensure that the **experiences and perspectives of Canadians living with ALS** were considered at each stage of the government consultation process.

### A global contributor

ALS Canada is a **leader on the global stage** and a significant contributor to the **international effort for a world without ALS**. ALS Canada collaborated on ALS/MND initiatives in the U.S., United Kingdom, Netherlands, Italy, Australia, Iceland, and also worked with the International Alliance of ALS/MND Societies to drive forward global ALS research, care, and awareness.



*"The ALS Canada Research Forum is an essential component of the ALS Canada Research Program. It provides an outstanding educational opportunity for fundamental researchers, clinicians, trainees, clinic teams (including allied health professionals) to learn about ALS research across Canada and is a unique networking event. I view it as the glue that holds the Canadian ALS Research/Clinical community together."*

**DR. CHRISTINE VANDE VELDE**  
CENTRE DE RECHERCHE DU CHUM,  
UNIVERSITÉ DE MONTREAL

## STRATEGIC IMPACT 2

### First volunteer recruit for CAPTURE ALS draws on hope for the future



In early 2022, Garry Zelasek was the first volunteer to sign up for an extensive new research initiative to collect, store, and analyze vast amounts of information about ALS. “I just said ‘Yes’ as soon as they asked me,” said Garry. As someone living with the disease, he is in the unique position of being able to help researchers learn more about the complexity and variability of ALS that can’t be adequately explained by studying cells and animals in the laboratory.

Michelle is Garry’s high school sweetheart and wife of 32 years. After all that time getting to know him, she is not surprised that Garry is motivated by the desire to help advance ALS research despite the likelihood that it will be too late to change the course of his own disease. “Since being diagnosed,” she explains, “he swore that every trial that would come out he was going to join it because he said, ‘If I can’t find a cure for myself, hopefully, I can find a cure for someone else.’”

**CAPTURE ALS (Comprehensive Analysis Platform to Understand, Remedy, and Eliminate)** is a Canadian platform that unites people living with ALS, physicians, and researchers in academia and industry to study ALS in hopes of gaining a better understanding of why ALS presents and progresses differently for everyone, making it a very challenging disease to decode. Researchers are hoping with more detailed information, they will have the tools to develop more personalized and effective treatment regimens. By openly sharing the results with the international ALS community, Canada will also play a significant role in the global effort to understand and treat ALS.



### Father fuels researcher's passion to find answers



**PhD student Charlotte Manser is the recipient of a \$75,000 ALS Canada – Brain Canada 2022 Doctoral Award to investigate how ALS-linked genes contribute to the loss of normal stress granule formation.**

She is part of a research team committed to solving unanswered questions that might inform the development of more effective, personalized treatments aimed at slowing or stopping the progression of ALS. She is also a member of the broader ALS community of people affected by the disease.

Charlotte says her connection drives her passion for succeeding. After her father passed away from ALS in 2013, she transferred out of forensics into a neuroscience undergraduate program and immediately realized she was on the right path. Along the way, fellow graduate students have shared personal stories that have also influenced their desire to alter the course of ALS. “I feel a lot of people here, like me, are trying to channel some of that grief into something productive,” she explains. “If I can help even one person not go through what my family did, it’s all worth it.”

The future looks promising in the eyes of this young researcher. “We are closer to answers than ever before,” she says.



### ReferALS: A new initiative addresses long wait times for diagnosis

**ReferALS is a new resource developed by ALS Canada and a working group of clinicians and industry experts that seek to reduce the time to receive an ALS diagnosis, hastening critical access to multidisciplinary care, approved treatments, and clinical trials, which may slow disease progression and improve quality of life.**

### DON'T DELAY, REFER ALS.

COULD THIS BE ALS? A TOOL FOR PHYSICIANS

**REFER BEFORE YOU'RE SURE**

**You DO NOT need confirmation of an ALS diagnosis to refer.** Clinicians at CALS Clinics prefer that referrals are sent while exam results are pending and before a diagnosis.

**Patients with a DELAYED referral may:**

- Circulate through the healthcare system undergoing numerous tests and specialist referrals leading to misdiagnoses
- Receive later than recommended multi-disciplinary support
- Not qualify for important standard of care treatments, emerging therapies and/or clinical trials due to disease progression (Note: some treatments require initiation before 18 and 24 months of symptom onset)

**DIAGNOSTIC DELAY:**

**up to 2 years**

This may be most of an ALS patient's remaining life.

**SIGNS/SYMPTOMS & CLINICAL FEATURES**

Amyotrophic lateral sclerosis (ALS) is a heterogeneous disease that can be difficult to diagnose. It is critical to identify both the **onset AND progression** of these symptoms

**HEAD AND NECK (BULBAR)**

- Emotional lability
- Slurred speech
- Difficulty swallowing
- Excess saliva

**RESPIRATORY**

- Shortness of breath with exertion or activities of daily living
- Orthopnea

**UPPER BODY**

**Progressive weakness resulting in asymmetric decline in motor function:**

- Impaired handwriting
- Difficulty lifting, reaching, carrying
- Difficulty with everyday tasks (e.g., preparing food, steering the car, using keys, opening jars or bottles, removing change from pockets, etc.)
- Trouble with dressing/hygiene (e.g., doing buttons, cutting fingernails, etc.)

**LOWER BODY**

**Progressive asymmetric weakness resulting in a decline in gross motor function:**

- Frequent tripping
- Difficulty on stairs, getting out of a chair, standing on toes, etc.
- Foot drags when walking; cannot walk as long/far

**REFER IMMEDIATELY**

- ☐ **Asymmetry + Progression** (progression of the motor syndrome within a region or to other regions)
- ☐ **Progressive Speech and/or Swallowing Difficulties**
- ☐ **Pseudobulbar Affect**

**CONSIDER A REFERRAL**

- ☐ Cognitive complaints/symptoms in presence of mobility impairment/weakness
- ☐ Upper/lower motor neuron signs
- ☐ Failure to thrive in elderly patient
- ☐ Patient suspects ALS

**NOTE THESE COMMON ALS MISDIAGNOSES**

- Carpal Tunnel/Sciatica/Ulnar Neuropathy** are UNLIKELY if patient exhibits hand weakness/foot drop with no pain or sensory loss
- MSA, Parkinson's, Alzheimer's** may have SIMILAR symptoms

The ALS Society of Canada has worked closely with the CALS Network and funding partners to present this critical referral information to you. For more information visit [www.alscanada.ca/refer-als](https://www.alscanada.ca/refer-als) or contact [info@alscanada.ca](mailto:info@alscanada.ca)

In Canada, it can take up to two years for someone to be diagnosed with ALS. Therefore, the need to accelerate referrals to neurologists specializing in ALS has been high on the list of issues identified by the ALS community. In 2022, in response to this call, ALS Canada convened and facilitated a working group of industry experts and members of the Canadian ALS Research Network (CALS) to find a solution.

Together, the working group designed the **ReferALS Early Referral Tool**, an initiative aimed at helping non-ALS general or community

neurologists recognize and understand the signs and symptoms of ALS and how to refer suspected ALS cases to a specialty CALS clinic. A clear and concise downloadable document, the resource answers questions physicians and their patients may have about why and how to refer someone who may be living with ALS.

Additional engagement strategies are being developed as part of a comprehensive plan to provide specialized care sooner to people who do not have the time to wait.

### STRATEGIC IMPACT 3

## People are empowered to make informed decisions about ALS

### Building a community of ALS champions

Access to timely, relevant, and credible information is integral to the ALS community to help understand their reality and inform their decision-making.

We empower Canadians affected by ALS to navigate the current realities of ALS and be informed consumers of ALS information while also being able to advocate effectively for change.

#### By 2023:

**People affected by ALS have better access to high-quality, comprehensive, and up-to-date information.**

#### By 2028:

**People and families living with ALS are better supported through programs, policies, and other initiatives that respond to their unique needs.**

### Change starts with community



**21 community members from across Canada graduated** from the second annual ALS Canada Canadian ALS Learning Institute (CALI). They will **continue to champion the needs of people affected by ALS** as ALS Canada Community Ambassadors, growing the list of Ambassadors across the country to almost 50.



Over **45 government officials engaged** through **30 meetings** at the federal and provincial levels to discuss the urgent issue of access to therapies.



Volunteers and ALS Canada Community Ambassadors **participated in 21 HealthPartners speaking opportunities**, raising awareness of the reality of ALS with public sector employees.



More than **50 different community members and staff** shared their stories through media interviews, blog posts, social media, and email campaigns.

## STRATEGIC IMPACT 3

**Our voices are stronger together**  
**We continue to advocate**  
**for change every day, and**  
**the voices and experiences of**  
**people living with ALS must be**  
**heard. Empowering members**  
**of our community to meet**  
**with government officials and**  
**share their personal experiences**  
**living with ALS helps decision-**  
**makers better understand the**  
**urgent needs of Canadians**  
**affected by ALS.**

With concentrated efforts during our first virtual advocacy week in Ontario, nearly **30 community members came together** to have their voices heard by Members of Provincial Parliament and bureaucrats. Participants included people living with ALS, caregivers, family members, volunteers, and staff.

During the year, we also look to government leaders to provide support and awareness through their communication efforts. We were pleased to have Federal Minister of Health Jean-Yves Duclos share a ministerial statement and video in recognition of ALS Awareness Month. Three additional Members of Federal Parliament shared statements in the House of Commons in support of Canadians living with ALS, and throughout the month, Ontario-based MPs voiced their support of people affected by ALS through videos published on ALS Canada's social media pages.

### **While I still can**

June's ALS Awareness Month provided an opportunity for the community to act as **catalysts for change** in the ALS clinical trial landscape. We asked Canadians to raise their hands in support of **continuing to establish Canada as a primary destination for ALS clinical trials**, and they delivered. Through our awareness campaign, **we reached nearly 300,000 people across Canada** to help strengthen our efforts toward building a future without ALS.

### **MLB support for Lou Gehrig Day**

Having returned to in-person games at the Rogers Centre, Major League Baseball and the Toronto Blue Jays were able to host their first home game since officially **recognizing Lou Gehrig Day on June 2**. The Jays Care Foundation supported ALS Canada by inviting our community to join them for the home

game, including having Peter Wood, diagnosed with ALS in 2015, and his son Zachary, throw out the first pitch. It was a special moment that allowed **members of our community to connect** over a day of baseball while also building vital awareness for the disease.



*Peter Wood with son Zachary, pictured here with Blue Jays mascot Ace and Pitcher Julian Merryweather, at the Rogers Centre on Lou Gehrig Day.*



## STRATEGIC IMPACT 3



### CALI informs and inspires hope for continuing a sister's fight against ALS



While caring for her sister, Carla, who passed away in 2021, Paula Rodriguez felt “utterly devastated” that existing therapies to help slow the progression of ALS symptoms were inaccessible due to the rapid onset of Carla’s disease. Compelled to learn more about the ALS research landscape and what could be done to help advance access to new treatments, Paula became one of the first graduates of the ALS Canada **Canadian ALS Learning Institute (CALI)**, a new program that educates people affected by ALS about the Canadian ALS research ecosystem, the drug access processes, and how to advocate for change in a system weighted down by long review periods and inequitable access.

“Attending the CALI gave me hope. It made me realize that the researchers were as relentless as the disease,” says Paula. She felt privileged to have access to leading researchers who spoke in layperson’s terms about promising new treatments. She was impressed to learn how much is happening behind the scenes working with relatively small budgets. Paula was also encouraged to learn there is consensus within the scientific community about being close to finding answers with adequate funding to maintain the momentum.

One of Paula’s favourite sayings is: “You need to be aware to care.” She is working hard to get the attention of decision-makers with the power to affect positive change. One of the practical takeaways from the course is an “Advocacy in a Box Toolkit” that provides templates for writing letters to elected representatives and pointers on how to organize meetings and conduct outreach. In her new role as an ALS Canada Community Ambassador, she has never felt more motivated to carry out her promise to “channel Carla’s strength and courage to continue the fight against ALS once she was gone.”

2022 saw the second cohort of CALI graduates come through the program, helping us continue to build a community of champions.

# CATALYSTS FOR CHANGE

**2023 will be an exciting time for ALS Canada! The stage is set for planning our next Strategic Plan. As we convene together and engage members of the ALS community across Canada to look to the future, we continue to invest today to plan for tomorrow.**

**Our work seeks to empower and engage the community to take an active role in advocating for themselves. Government investment in innovative ALS research is of the utmost importance as we continue to address the urgent need for timely and equitable access to therapies and system changes for better access to healthcare system resources.**

We continue to make strides in Inclusivity, Diversity, Equity, and Accessibility (IDEA) as an organization and for the community. From the programs we offer to our volunteer engagement to the accessibility of our resources, we look to identify opportunities and demonstrate leadership to address systemic issues.

Our commitment to our community is unwavering. Each of us plays an essential role in working toward our shared vision of a future without ALS, and we will not stop in this relentless pursuit. Whether you are a donor, volunteer, or partner, your contribution to this work is vital, and we are delighted to have you join the community. With your generous support of time and dollars, we are making progress. We are making a change.

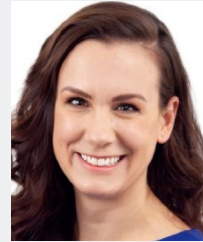
# ALS CANADA LEADERSHIP

## Governance

ALS Canada's 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 various disciplines, a genuine passion for the cause, and a strong desire to make a difference.



Patrick Nelson,  
*Chair*



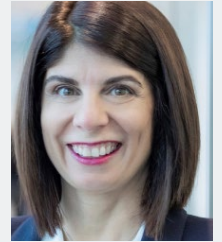
Alyssa Barry



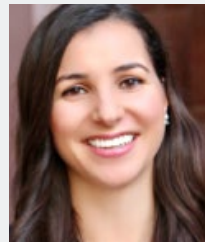
Ken Chan



Richard Ellis



Lisa Flaifel



Elizabeth Gandolfi



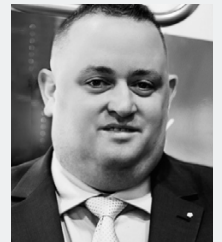
Laura Gay



Dr. Angela Genge



Dr. Leslie Green



Jude Groves



Dr. Wendy Johnston



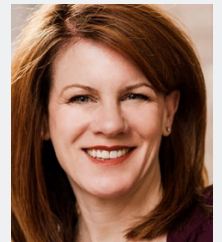
Kris Noakes



Dr. Michael Spivock



Dr. Christine  
Vande Velde



Tammy Moore,  
*ex-officio*



# ALS CANADA LEADERSHIP

## 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. Martin Duennwald  
Dr. Wendy Johnston  
Dr. Hanns Lochmüller  
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. Richard Robitaille  
Dr. Kerri Schellenberg  
Dr. Chantelle Sephton  
Dr. Christen Shoesmith, *ex-officio*  
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  
Lisa Sullivan  
Dr. Anu Tandon  
Denise Martins  
Lisa Zanyk  
Paula Rodriguez  
Steve Parker  
Laura Henstock

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*  
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, *ex-officio*  
Kris Noakes  
Lauren Poplak (staff), *ex-officio*  
Dr. Karin Schnarr

# THANK YOU | TO OUR 2022 DONORS

Our work is only possible because of the generosity and dedication of our donors and fundraisers. ALS Canada relies on the support of thousands of individuals, corporate donors, and foundations through events, monthly donations, annual gifts, and planned gifts.

We appreciate the generous support of donors and participating provincial Societies through their dedication to the Walk to End ALS and other investments for research: A huge thank you to 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 2022. Many of our supporters have been personally impacted by ALS and have donated in honour of loved ones. We make every effort to ensure the accuracy of this list. If you have questions or corrections, please contact us at [donations@als.ca](mailto:donations@als.ca).

## Individuals

Alex Riggins	Bill and Brenda Vella, in honour of Peter Tinsley	Cory Bentley, in honour of Steve Daly
Alice Sisler, in honour of Nancy Wright	Bo McCloskey, in honour of Patricia McCloskey	Craig Bushell, in honour of Neil Londry
Allan and Kim McGlade	Bob Brethour, in honour of Charlotte Brethour	Daniel Pugiotto, in honour of Steve Daly
Allan and Sigrid Steedman, in honour of Nadine Steedman	Brenda Gelowitz, in memory of Audrey Head	Daphne Corbett, in honour of Donald Corbett
Andree Demers, in honour of Anne- Marie Marcil	Brian K Jones, in honour of Sandra F Jones	Dave Rudell, in honour of BA Bottrill
Anonymous (33)	Brianna Marshall	David McKay, in memory of Linda McKay
Anonymous, in honour of Dr. David A Israel	Cameron and Karen McLean	Deanna and Mike Fantini, in honour of Daniel D'Aloisio
Anonymous, in honour of Eric Anderson	Cameron and Nancy Wood, in honour of all those working to find a cure for this relentless disease	Deb & Ray Hansen, in honour of Chuck Hansen
Anonymous, in honour of Gail Sharpe	Cameron McGlade, in honour of Allan McGlade	Debbie McNamee
Anonymous, in honour of Mark Ianniello	Carl Spiess, in honour of Allan McGlade	Deirdre O'Connor, in honour of husband Floyd Chrysler
Anonymous, in honour of Patricia Bergen	Carmen Cels, in honour of Mike Cels	Dennis Zinger, in honour of Brenda Power
Anonymous, in honour of Ron Bower	Carol Burke, in honour of late husband John Burke	Diana and Lou Provenzano
Anonymous, in honour of Scott Wallace and Dr. Robert Brian	Carola Englert, in honour of father Heinz Bergmann	Dirk Miedema, in honour of The Miedema Family
Ashley Fenwick, in honour of grandmother Jo Anne McCaig	Carolynn Whiteley, in honour of Alan Whiteley	Donald and Elaine Triggs, in honour of Cheryl Orr and Jaime Partida Grey
Barbara Hopkins, in honour of Bob and Doug Hopkins	Catherine Bélanger, in honour of Mauril Bélanger	Donna Rutherford
Barbara Wicks, in honour of James (Jim) Wicks	Catherine Cummings, in honour of Bette Gibson	Doris Smith, in honour of Donald Smith
Beth Robertson, in honour of Tim Robertson	Catherine Martell, in honour of Joseph Alexander Martell	Doug Hassard, in honour of Lori Hassard
Betty Keating in honour of Maxine Joy Lanktree	Cathy and Garth Steele, in honour of Phillip Serez, Robert Sargent, and Garth Steele	Dr. Benjamin Ritsma, in honour of ALS Patients and their families
Betty Lee & family, in honour of Dr. K. P. Lee	Cathy Williamson, in honour of Del Wright	Dr. Ken Hotson
Beverly Crandell and Christopher Worth, in honour of Ann Crandell	Chris Ford	Dr. R. Amaratunga, in honour of Dr. L.M. Amaratunga
Bill and Betty Lou Fox, in memory of Ron Reimer, a wonderful man	Claire Berthiaume, in honour of Jacques Berthiaume and Theresa Gagnon	Dr. Timothy Gilchrist, in loving memory of Lisa Gilchrist
		Dr. Vicky Banks, in honour of Ricky Griffith
		E. Ann Herring

Elena Daly, in support of Kevin Daly	Heather Deans, in honour of Mary Ann Forte	John M. Smyth, in honour of Gerard Judge	Love your Edmonton friends, in honour of Steve Daly	Norah McAuliffe, in honour of Kerry Stratton	Sandra Upjohn, in honour of Wendy Fitzgerald Spratt
Elizabeth Mitchell and Stephen Lloyd, in honour of Mary Mitchell	Heather D. Durham PhD, in honour of ALS Canada Team	John MacGowan	Lydia Jean Stratton, in honour of son Kerry Stratton	Osmak Family, in honour of Jeanne Osmak, dear wife and loving mother & nana	Shane and Nancy Livingstone, in honour of Gene Staniforth
Estelle Rannie, in honour of Mike Rannie	Helder Ribeiro, in honour of Carla Puglia-Ribeiro	Judith Cathcart, in honour of husband Ralph Cathcart	M Kimura, in honour of Francois Bregha	Pat Bouchard, in honour of Bob Bouchard	Sharon Marks, in honour of late husband Ron Marks
Euan Carlisle, in honour of Jane Carlisle	Hélène and Bernard Marcil	Judy Lusk, in honour of Gary Lusk	Marcia Sweet, in honour of Patrick W. Colgan	Pat Leith Castonguay (PALS caregiver), in honour of Guy Castonguay	Sharon Neville, in honour of Marjory Mowatt Naylor
Ex de Havilland colleagues of Jim Lister	Henderson Family, in honour of David R. Henderson	Kanna Sivakumar, in honour of father Kanapathipillai Sivakumar	Margaret Southern	Patricia Fortier, in honour of Paul Durand	Sophia Wu, in honour of Paul Wu
Family of Mary of Elisabeth Goodings	Jacqueline Lemery, in honour of Marcel Lemery	Karen and Aharon Kagedan, in memory of Ian Kagedan	Margaret Whelan, in honour of father William Whelan, brother James Whelan, and sister Shelia Whelan	Patrick and Nancy McNally, in honour of Ian Johnson	Steve Lachance, in honour of Denise Lachance
Fiona Alexander Black, in honour of mother Elizabeth Catherine Alexander	James Hinton, in honour of Carol Ann Hinton	Karen and Bill Barnett	Marie Maltais, in honour of Yves Blanchard	Patrick Dunnill	Stewart Scott, in honour of Andy Yemen
Florence and Graham Wiseman, in honour of son Franklin Stefan Halderson and his father Franklin Robert Halderson	James Pearson, in honour of Sheila Whelan	Kari Christiansen, in honour of Stephanie Christiansen	Mark and Alisha Hurley, in honour of Steve Daly	Patrick Nelson, in honour of Laura Coughlin	Susan Peacock, in honour of Jeff Peacock
Gail Gordon Oliver, in honour of Steven Gallagher	Jamie Harnish, in honour of Jennifer Liu's mother	Karin Schnarr, in honour of Fern Schnarr	Mary Hodgins, in honour of husband Dale Hodgins	Paul Bush and Sue Martin in honour of Joe McGuire	T. Sugar, in honour of Joanne Nelson
Gale Robertson, in honour of Lana Robertson	Jane Waterson, in honour of Francois Bregha	Kathleen Caughey, in honour of George Panchuk	Mary Pretswell, in honour of Bill Pretswell	Peter and Lorraine Moore, in honour of Scott Matzka	Tammy Moore
Garry Perrin, in honour of Mary Isabel Perrin	Janet Jucu, in honour of George Jucu	Kathleen Vanhelvert in honour of Steve Gallagher	Marilyn Kanee and Shelia Block, in memory of Karen Luks	The Pierino Peloso Family, in honour of Pierino Peloso and Matilde Peloso Alimonti	Tayler and Katie Henderson, in honour of Stephen Henderson
Gerry Doedens, in honour of Kevin Murray	Jean M. Taylor, in honour of Simon L. Taylor	Kenneth and Sheila McArthur	Mehboob Damji	Phil Schmitt and Sheena MacDonald, in honour of Carol Schmitt	Ted, in honour of Jim and Harry
Gerry Wyant, in honour of Sylvia Wyant	Jenelle Johnstone, in honour of Jennifer Spencer	Kenneth Pau, in honour of Alice Li-Ying Pau	Merrilyn Driscoll, in honour of Maureen Butler	R McCullough, in honour of Tom McCullough	Terry Murphy, in honour of Jim Wright
Gilles Berger and Valérie Marcil in honour of Anne-Marie Marcil	Jens and Qui-Nhi, in honour of Karim Sediri	Kevin Andrew Palin, in memory of beloved wife Camille Kanhai	Michael & Renae Tims	Ray McNeil, in honour of Joan McNeil	Tom Carbone
Ginelle Baur and Jason Klassen, in honour of Frieda Baur	Jim Warden, in honour of Jane Warden	Kim Arrowsmith Mohr and Miles Mohr, in honour of Del Wright	Michael Mitchell, in honour of Mary Mitchell	Richard Ellis, in honour of Cathy Payne	Tom Stanley, in honour of Ross Stanley
Glenn Mongillo, in honour of Joseph Mongillo	Joan and Don Wood, in honour of son Peter Wood	Kim McGlade, in honour of husband Allan McGlade	Michael Taylor	Richard T. Stilwell, in honour of Mary Elizabeth Stilwell	Ursula Wedmann, in honour of Helma Wedmann
Gordon Cowie, in honour of Roberta Cowie	Joan Murray, in honour of Kevin Murray	Kristin Collins (Move 4 ALS), in honour of Eleanor Philips	Michelle Lennox, in honour of Kevin M Daly	Robbie Clement, in honour of Francis Clement	Vernon Solomon, in honour of Don Lighthall
Greg and Judi Wallace, in honour of Michelle McKenzie	Joe and Judy Ferguson, in honour of Dale Hodgins	Laura Gay	Mikayla Colozza, in honour of Michele Colozza	Roman Tykajlo, in honour of Dr. Linda Panaro	Vivian McGuire
Hart and Amanda, in honour of Ruby Crew	Joseph Alexander Martell, in honour of Catherine Mary Martell	Lesley Anderson, in honour of Ian Anderson	Mike Cels, living with ALS	Ron and Anne Foerster, in honour of Brigitte Foerster	William Anderson, in honour of Annette Macdougall
	Joseph Preiditsch, in honour of Marlene Preiditsch (ALS) and Erwin Preiditsch (Caregiver)	Lolo Lam, in honour of Albert Lam	Mitsuyoshi Ito, in honour of Dick Ito	Roy Hewson	William J S Boyle
	John C. Darling, in honour of Ruth A. Darling	Lori Sasso, in honour of Norina Sasso	Mrs. Margaret Van Egmond, in honour of brother Peter Marcus		Wink's Warriors, in honour of Mary Lynn Zardkanlou (Wink)
		Louise Harris, in honour of Arthur Hosios	Nancy and Murray Wiegand, in honour of Diane Wagner		Wisebrod Family, in memory of Dov Wisebrod
					Zinta Erdmanis, in honour of husband Edmund Arthur Erdmanis



## Companies

1079588 ON LTD.  
 2022 Annual Hickory  
 Dickory Decks Charity  
 Golf Tournament  
 Amylyx Pharmaceuticals  
 Biogen Canada  
 Canada Steel Service Centre,  
 in honour of Ron Bower  
 Canso Investment Counsel Ltd.  
 Cardinal & Son Wholesale  
 Meats, in honour of  
 Raymond Champagne  
 Cates Ford Soll & Epp LLP,  
 in honour of Brig. Gen.  
 Christopher Kevin Ford (retd)  
 CN Employees' and Pensioners  
 Community Fund  
 Craveth Nursing Home Limited  
 CSN Collision Centres, in honour  
 of Christopher C. Chattington  
 Cytokinetics Inc.

D'Orazio Infrastructure Group,  
 in honour of Tim Robertson  
 Federated Health Charities  
 FWA Consulting Inc.  
 HealthPartners  
 Ionis Pharmaceuticals Inc.  
 Lamb O'Brien Professionals  
 Corporation  
 Lambton Kingsway Junior  
 Middle School, in honour of  
 Steve Daly  
 Merivale Loyal Orange Lodge  
 in honour of Rev. David  
 Lajeunesse  
 Miller Saperia and Company  
 Mitsubishi Tanabe Pharma  
 Modern Beauty  
 Modu-Loc Fence Rentals LP  
 Molded Precision Components  
 Nicholson and Cates Limited,  
 in honour of Bill Simpson  
 Nieuport Aviation Infrastructure  
 Partners GP

Oxford Mobility  
 QuadReal, in honour of  
 Donna Daye  
 RAM Consulting  
 Salon Eleven Hair Co., in honour  
 of Joe Humenick  
 Secura Financial Group  
 SHOEBOX Ltd., in honour of  
 Kelly Torrance  
 Shorcan Brokers Limited  
 Superior Machining Limited,  
 in honour of Piergiorgio  
 Boaretto  
 The Clara Quinn Cup for ALS  
 Tom Mustapic Memorial Golf  
 Tournament  
 Twin Streams (Boere and Bower  
 Families), in honour of Ronald  
 Bower  
 United Way East Ontario

## Foundations

The Andree Rheaume and  
 Robert Fitzhenry Family  
 Foundation  
 The Bruce H. Mitchell  
 Foundation  
 Charities Aid Foundation  
 Crist Family Foundation  
 The De Boer Foundation  
 Lenny's House in honour of  
 Richard Wall  
 Michael R. Williams Foundation  
 Nelson Arthur Hyland  
 Foundation  
 North Bay and Area Community  
 Foundation  
 The Pottruff Family Foundation,  
 in honour of Barry Sproule  
 Salden Foundation  
 The Silverberg Fund at the  
 Jewish Foundation of  
 Manitoba  
 Srivastava Family Giving Fund

## Estates

Estate of Helen Marie Lewis  
 Estate of James G. Leyser, in  
 honour of Ruth and Kate  
 Estate of Karen Elizabeth Wilson  
 Ruddick  
 Estate of Margaret German  
 Estate of Susan Jennings, in  
 honour of James Barry Worth

# 2022 ALS CANADA RESEARCH AWARDS

The ALS Canada Research Program is the only national program investing solely in ALS research across the country. Research is the pathway to creating a future without ALS. 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 participating ALS Societies across Canada, who donate 40 per cent of the proceeds from the Walk to End ALS and 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.

All competitions in 2022 were awarded in partnership with Brain Canada through the Canada Brain Research Fund\*.



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

## 2022 ALS CANADA-BRAIN CANADA TRAINEE AWARDS

### 2022 Doctoral Awards

**Does this newly discovered tag on TDP-43 have an important role in ALS?**

*Lucia Meng Qi Liao, University of Waterloo, \$75,000*

**How do ALS-linked genes contribute to the loss of normal stress granule formation?**

*Charlotte Manser, University of Ottawa, \$75,000*

**How does tRNA function contribute to ALS disease processes?**

*Donovan McDonald, Western University, \$75,000*

### 2022 Postdoctoral Fellowship

**Could neuronal reprogramming serve as a potential treatment strategy for ALS?**

*Dr. Hussein Ghazale, Sunnybrook Research Institute, \$165,000*



FONDATION  
VINCENT BOURQUE

*Funding for the 2022 Postdoctoral Fellowship was made possible by Fondation Vincent Bourque, who generously contributed \$82,500 to ALS Canada, which was matched by Brain Canada through the Canada Brain Research Fund (CBRF).*

## 2022 ALS CANADA-BRAIN CANADA DISCOVERY GRANTS

**Can this routine and inexpensive procedure have a neuroprotective effect in ALS?**

*Dr. Carlos Rodrigo Camara-Lemarroy, University of Calgary, in collaboration with Dr. Minh Dang Nguyen, University of Calgary, and Dr. Deepak Kaushik, Memorial University of Newfoundland, \$125,000*

**Could this new mouse model help to understand the potential role of retroviruses in ALS and lead to new treatments?**

*Dr. Renée Douville, University of Winnipeg, in collaboration with Dr. Jody Haigh, University of Manitoba, and Dr. Domenico Di Curzio, St. Boniface Hospital Albrechtsen Research Centre, \$125,000*

# 2022 ALS CANADA RESEARCH AWARDS

## **Could this new 3D cell culture model help researchers better predict disease progression in ALS?**

*Dr. Thomas M. Durcan, The Neuro (Montreal Neurological Institute-Hospital), McGill University, in collaboration with Dr. Yasser Iturria-Medina, McGill University, \$125,000*

## **Could protecting the axon represent a promising treatment strategy for ALS?**

*In partnership with Dr. Jean-Pierre Canuel Fund – SLA Québec and Brain Canada, Dr. Alex Parker, Centre de recherche du CHUM, Université de Montreal, in collaboration with Dr. Gary Armstrong, McGill University, \$300,000*



## **Could the study of neuromuscular junction proteins aid in the development of essential biomarkers?**

*Dr. Richard Robitaille, Université de Montréal, in collaboration with Dr. Danielle Arbour and Dr. Roberta Piovesana, Université de Montréal, and Dr. Robert Bowser, Barrow Neurological Institute, \$300,000*

## **Could improving the mechanisms of toxic protein disposal in motor neurons become a future treatment strategy?**

*Dr. Gary S. Shaw, Western University, in collaboration with Dr. Martin Duennwald, Western University, and Dr. Elizabeth Meiering, University of Waterloo, \$125,000*

## **Can computational methods aid in the design of key antibodies for the diagnosis and treatment of ALS?**

*Dr. Maria Stepanova, in collaboration with Dr. Holger Wille, University of Alberta, \$125,000*

## **What role does its sister protein play when restoring G3BP1 levels as a potential ALS treatment strategy?**

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

## **Will this new way of looking at certain protective proteins better explain their role in ALS?**

*Dr. Maria Vera Ugalde, in collaboration with Dr. Heather D. Durham, McGill University, \$125,000*

## **2022 ALS CANADA CAREER TRANSITION AWARD**

### **A new way to look at the most common genetic form of ALS**

*Dr. Philip McGoldrick, Tanz Centre for Research in Neurodegenerative Diseases, University of Toronto, \$250,000*



## ALS Society of Canada

393 University Avenue, Suite 1701  
Toronto, ON M5G 1E6  
T 416-497-2267 F 416-497-8545  
Toll-free 1-800-267-4257  
[www.als.ca](http://www.als.ca)



@ALSCanada

## Pictured on front cover:

Peter Wood and the ALS Canada Walk to End ALS  
Team Wood's Iron Horses

© Amyotrophic Lateral Sclerosis Society of Canada  
Charitable Registration Number 10670-8977-RR0002

## 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  
Trustmark is a mark of Imagine  
Canada used under license by the  
ALS Society of Canada.

