

**ALS SLA
ACTION
CANADA**



ALS SUPER FUND
TOGETHER WE END ALS



2024 - 2025

IMPACT REPORT

A Transformative Year: Our Collective Impact

It has been an incredibly transformative year because of you, our community of supporters, members, volunteers, partners, and champions. **SINCE 2023, YOU'VE HELPED RAISE \$1.6M.** Thank you for being alongside us in this journey. Your commitment has been instrumental in advancing advocacy efforts, innovative partnerships, research programs, and patient support in fighting ALS in Canada and around the world.



Thank you to ISA Cybersecurity, Connor McDavid, and OHL Junior league for your golf tournaments in support of ALS.

Over
\$1.8M
RAISED SINCE 2020

Since 2020, you have helped raise over \$1.8M and commit hundreds of thousands of dollars to the most promising research and projects aimed at making a meaningful difference for ALS patients, caregivers, and families in Canada. You've also fueled the extraordinary advocacy efforts of ALS Action Canada driven by dedicated volunteers.

In a time of polarization, you have helped tangibly and meaningfully demonstrate what it means to be on the same team with a steadfast commitment for a common goal: **to end ALS.**

Read on for what you helped make possible. We are grateful for your support - and look forward to keeping you informed of the impact of your contributions to ending ALS.

Thank you to all individual volunteers, donors, partners and supporters:



The Courage to Fight Campaign

Building on the ALS Super Fund launch and partnership with the seven Canadian NHL teams in 2023-2024, the Courage to Fight Campaign in support of the Super Fund launched in December 2024. This was a truly remarkable and joint effort led by former NHL player and ALS advocate Mark Kirton and **ALL 32 NHL TEAMS** to raise awareness and action to end ALS.

\$329,000
RAISED

Virtual Fundraising Concert

Courage to Fight included a free virtual fundraising concert hosted by broadcasting legend Ron MacLean and featuring Jim Cuddy of Blue Rodeo. The event brought together musicians and celebrities to support those affected by ALS, including appearances from NHL Hall of Famers Darryl Sittler and Wayne Gretzky, as well as Jeff Jackson, President of the Edmonton Oilers and others, raising over \$160,000 during and after the online event.



Courage to Fight Super Auction

The second component of the Campaign in February 2025 was the Courage to Fight Super Auction that featured exclusive items donated by celebrities, athletes with proceeds benefiting ALS research and patient care. Raising over \$110,000 (and counting), the auction was about more than just signed jerseys and game experiences — it was about the power of collective action.

Over
\$110,000
RAISED (and counting)

In an incredible show of support, the NHL, together with the Boston Bruins, dedicated two 50/50 draws to support ALS charities through the Super Fund, with over \$41,000 in proceeds going directly to Boston-based organizations. These organizations included the Pete Frates Foundation - the catalyst behind the global Ice Bucket Challenge — and the ALS Therapy Development Institute (ALS TDI), a leader in ALS research.

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Announcing ALS Super Fund Grants



Thanks to your support, the ALS Super Fund has committed hundreds of thousands of dollars across North America to vital research initiatives and effective treatments and access.

Guided by the ALS Super Fund Advisory Council comprised of patients, caregivers, and scientific and medical experts, as well as through directed giving, we are pleased to share the following grants that were qualified through our high priority pillars:



Access to Clinical Trials: To facilitate the initiation and evolution of a Canadian-led clinical trial research consortium, aimed at testing potential therapies and interventions for ALS patients.



Data and Biomedical Research: To improve data and uncover the underlying pathological mechanisms of ALS, and hopefully develop a biomarker one day.



Patient Support and Quality of Care: To improve the care of ALS patients and their families and to raise awareness about ALS within the Canadian community.

GRANTS

Sunnybrook Research Institute:

A two-year funding commitment toward the **The QuARTS ALS Trial**, led by project leader **Dr. Lorne Zinman**. A biomarker-directed neuromodulation trial using quantitative and repetitive transcranial magnetic stimulation in ALS. This study is a multi-stage, adaptive design trial evaluating the safety, tolerability, stimulation dosing, corticospinal hyperexcitability (CSHE) reduction efficacy and changes in biomarkers following high-dose, multi-targeted, accelerated continuous theta burst simulation (cTBS) regimen over the primary motor cortex (M1) bilaterally in patients with ALS.

This study is divided into 2 stages. Stage 1 will evaluate the safety and feasibility of cTBS rTMS treatment over M1 bilaterally using an accelerated, 5 day treatment schedule. Stage 2 will follow the accelerated schedule with the addition of repeated maintenance cTBS treatments for 24 weeks targeting multiple M1 regions.

The Royal Institution for the Advancement of Learning at McGill University:

With only 2 ALS disease-modifying therapies approved and few ALS clinical trials run in Canada, this project aims to create Access ALS, **the First National Network for ALS Clinical Trials in Canada** that will increase the number of early phase-ready sites through the expertise developed at the Neuro Clinical Research Unit **under the leadership of Dr. Angela Genge**, internationally recognized for successfully running Phase 1 to 4 ALS clinical trials at the Neuro for the last 20 years. Establishing a centralized, supportive network we believe could make Canada a global leader in early-phase ALS trials, granting access to new treatments from trial to market and empowering Canadian patients in trial participation.

GRANTS

In partnership with ALS BC: PROJECT HOPE at Djavad Mowafahian Centre for Brain Health at the University of British Columbia:

Under the leadership of neurologist and ALS researcher, Dr. Erik Pioro, PROJECT HOPE emerged in 2024 as a pioneering initiative with a bold and visionary agenda for the next 3-5 years.

The mission is to ignite a beacon of hope for everyone touched by ALS – from patients and their families to caregivers, clinicians, specialists, researchers, and beyond. Dr. Pioro is at the forefront of assembling a world-class ALS Clinical Care Team, bringing together specialist staff including occupational therapists, physical therapists, speech therapists, nutritionists, social workers, and nurses.

The ALS Society of Alberta:

Is a non-profit organization dedicated to making each day the best possible day for people living with and affected by ALS and is the **only non-profit organization in Alberta that provides support to those affected by the disease**, and also invests in the most promising research initiatives in Alberta. Funds have been directed to support the Alberta ALS Research Network (AARN).

This collaborative network brings together ALS researchers and clinicians across the province to strengthen local research capacity, foster partnerships, and accelerate discoveries that will ultimately benefit people living with ALS. The funds are helping to lay the foundation for coordinated ALS research in Alberta.

Fueling the highest program and research priority needs through:

- **ALS Therapy Development Institute:** The world's largest drug discovery lab focused solely on ALS based in Massachusetts. As a nonprofit, ALS TDI is only answerable to community stakeholders in finding effective treatments for ALS, and is focused on research to invent and discover treatments to slow, stop, and reverse ALS. The ALS TDI lab executes research encompassing all areas of ALS target and drug discovery research – including preclinical, clinical, and translational – under one roof.
- **ALS Quebec:** To raise awareness, advocate for rights, fund research, and support people affected by ALS with a complete range of services adapted to all stages of the disease.
- **Pete Frates Foundation:** Dedicated to improving the lives of those affected by ALS by providing essential patient care, supporting innovative research for a cure, and educating communities to drive awareness and action.
- **Roger Neilson House:** Based in Ottawa and named after the former NHL hockey coach, this hospice offers a variety of specialized grief support programs for children, youth and adults, as well as end of life and respite care.
- **Vanderbilt University ALS Research Centre:** The ALS laboratory, led by Dr. Veronique Belzil, is dedicated to research, community outreach, and patient support.
- **ALS Action Canada:** The only ALS patient-led organization that raises and amplifies patient voices, and fundraises for and administers the ALS Super Fund.



Advocacy



ALS Action Canada on the Hill

In a powerful demonstration of unity and determination, Parliament Hill played host in September to an extraordinary evening where the worlds of hockey and advocacy converged to fight against ALS. The ALS Advocacy Reception, organized in collaboration with ALS Action Canada, marked a significant milestone in the battle against ALS.

Surrounded by former teammates, dignitaries, and supporters, former NHL player and ALS advocate Mark Kirton was at the center of the evening. Diagnosed with ALS in 2018, Kirton's tireless efforts have mobilized Canada's hockey community and inspired action nationwide.

The event celebrated the ALS Super Fund's milestone of raising \$1 million for ALS research and awareness. Former Maple Leafs captain and Hockey Hall of Famer Darryl Sittler made the announcement and also paid tribute to Kirton's relentless advocacy.



Mark could have felt sorry for himself when he was first diagnosed with ALS. That would have been understandable. Instead, he's trying to help raise funds to find a cure for people who have the same thing.

— Darryl Sittler, Former Maple Leafs Captain and Hockey Hall of Famer

The evening was not only a celebration but also a call to action. Mark Kirton delivered an emotional speech. 'We've been living this nightmare for six years, and I can tell you, it's horrific, it's cruel, it's torturous. The challenges are not daily challenges; they're hourly challenges,' he said. Yet, his determination remains unshaken. 'This is great,' he said of the \$1 million milestone, 'But we can't stop now.'



You are a hero to me.

— Wayne Gretzky, Former Teammate

Wayne Gretzky, who joined the event as a surprise speaker, expressed his admiration for Kirton, recalling their years as teammates and the lasting impact Kirton has had on his life. Gretzky's presence underscored the deep bonds within the hockey community and the collective commitment to supporting ALS advocacy.



Key supporters, **Biogen and Mitsubishi Tanabe Pa**, were recognized for their invaluable contributions to advancing ALS research and care.

The evening also set the stage for the Courage to Fight campaign, including a virtual auction event at Real Sports restaurant and online fundraiser and concert.

The ALS Advocacy Reception underscored the power of collaboration between advocates, policymakers, and the hockey family.

ADVOCACY LETTER

Building on the Hill event, ALSAC delivered a statement in direct response to the Federal Government's 2023 announcement of a \$1.5 billion National Strategy for Drugs for Rare Diseases, delivered to provincial and federal leaders. We acknowledged that while the announcement was promising, the needs of the ALS community remain largely unmet by its current implementation.

YOU can download and customize the letter, and share with your networks and representatives of provincial and federal government to compel action on ALS.

We stressed three issues:

- **Time is a critical factor for ALS patients.** After Health Canada approval of a drug, waiting periods for drug coverage —up to 18 months or more—are unacceptably long and diminish the potential benefits of these treatments.
- **Challenges in care access.** ALS patients face significant barriers to affordable and adequate home and institutional care, with access varying widely across provinces.
- **Diagnostic delays.** Delays in diagnosis and access to treatment significantly hinder ALS patients' ability to benefit from available interventions.

CANADA DRUG AGENCY

In January the Advocacy Committee provided recommendations to and met with the CDA on improving drug reimbursement review procedures. In March, the Committee submitted a statement for Patient Input on Tofersen, with the final recommendation of:

ALS Action Canada urges the Canadian Drug Agency to recommend its reimbursement under provincial drug benefit plans, to all patients without any restrictions other than confirmation of a SOD1 mutation.

We recommended two solutions:

1. Invest in Expanded Access Programs
2. Establish a Panel of Rare Disease Experts to Advise Canadian Drug Agency

And provided these calls to action:

- **Increased funding and support for ALS research.** By prioritizing ALS research, we can work towards the discovery of diagnostic tools, biomarkers and new treatments, ultimately aiming for a cure.
- **Improved access to marketed drugs and expedited approval processes.** Reforming drug approval processes specifically for ALS treatments would make life-extending drugs accessible to more patients, faster.
- **Standardized care access.** Consistent and equitable care across Canada is essential. We need standardized access to ALS-specific home care and institutional support.

Our work and engagement with the new federal government continues in partnership with other ALS and allied organizations.



Join us!

Are you a person living with ALS or a caregiver to someone living with ALS? You can consider joining us as a formal Member of ALS Action Canada, or joining our Patient Support Group as a participant. Reach out to Executive Director, Leigh Naturkach, at leigh@alsactioncanada.org for more information.



Receiving a diagnosis of ALS is a visceral experience, you feel gutted. You are fully aware of the progression, what lies in wait and its impact on yourself and your loved ones.

As a newly retired grandparent, I didn't know how I would confront the challenges that lie ahead. Sadly, many individuals receive this news at a significantly younger age than I did. It was over a year before the fog started to lift a little, though my body was in decline. When I connected with ALS Action Canada, I discovered a community of individuals who genuinely comprehend the challenges, questions, and complexities associated with the disease.

This community has, and continues to be, a pivotal source of understanding regarding therapies, research, clinical trials, advocacy, funding, equitable access to healthcare and equipment.

— Colleen Hudson

People

We were pleased to welcome three new board members over the 2024-2025 year, including:



Jeff Jackson,
President and CEO
of the Edmonton Oilers



Cali Orsulak, former cALS



Louis Del Re, pALS

In December 2024, we thanked and wished former Executive Director Jida El Hajjar all the best in her new endeavours as she moved onto a new role. Jida led the organization through a transformative year of firsts and new initiatives, and we are grateful for her contributions.



In March 2025, we were thrilled to confirm **Dr. Erik Pioro** as the newest member of the ALS Super Fund Advisory Council. Based at the Djavaid Mowafaghian Centre for Brain Health at the University of BC, Dr. Pioro is a Professor of Neurology at the UBC Department of Medicine and also holds the ALS Society of BC Professorship in ALS Research.

We welcomed new **Executive Director, Leigh Naturkach**, to the team in March 2025. Leigh is honoured to bring her nonprofit leadership and health equity skills to ALS Action Canada.





Advocacy Committee:

Matthew Brown
Dr. Andrew Darke
Louis Del Re
Leigh Naturkach
Cali Orsulak
Rick Zwiep

Board of Directors:

Darryl Borsato
Roger Charles, **Treasurer**
Louis Del Re
Jeff Jackson
Mark Kirton
Crystal Krandel, **Secretary**
Adrienne Molinski
Kevin Moorhead, **Vice Chair**
Erin Morantz
Cali Orsulak
Paul Thandi
Don Wright, **Chair**
Rick Zwiep

Fundraising Committee:

Gino Del Re
Louis Del Re
Wade Hall
Mark Kirton
Kevin Moorhead
Erin Morantz
Leigh Naturkach



www.alsactioncanada.org
www.alssuperfund.ca