



ALS DOESN'T STOP
NEITHER WILL WE

LEADERSHIP MESSAGE



A RALLY CRY
FOR OUR
COMMUNITY

“ALS doesn’t stop. Neither will we.”

These words, confidently stated by Board member and ALS researcher Dr. Christine Vande Velde as the pandemic forced people everywhere to figure out a new way forward, were made in reference to her team’s work in the lab. But they were quickly adopted as a rally cry by ALS Canada and ALS organizations around the globe.

And you, the ALS community, responded. Across Ontario, people living with ALS invited our Regional Managers into their homes virtually and attended online support groups and webinars to stay connected and informed as new details emerged. Across Canada, we convened calls with researchers and clinicians so they could learn from one another while responding nimbly to the crisis so that ALS research and care could continue. Donors gave generously to our COVID-19 relief fund and readily embraced virtual fundraising events to ensure we had the resources to continue our work.

Our results in 2020 speak to the power of community to make things happen across all of our areas of focus that will improve what it means to live with ALS: A better quality of life. Access to difference-making therapies. Quality information for decision-making.

As we look to a post-pandemic world, we have an opportunity to help others understand the parallels between COVID-19 and ALS: the urgency and the hope, the possibilities when effort and funds are focused on a common goal. A future without ALS remains our vision. Thank you for so relentlessly supporting it.



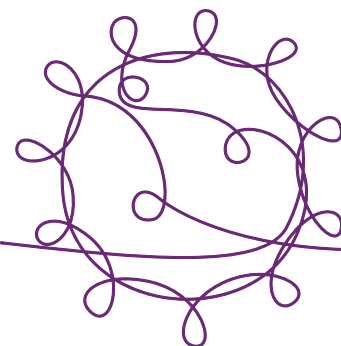
Josette Melanson
Josette Melanson
Chair,
Board of Directors



Tammy Moore
Tammy Moore
CEO

SUPPORTING THE ALS COMMUNITY DURING AN UNPRECEDENTED TIME

In the pandemic’s early days, we worked to quickly understand how families with ALS were being affected. We shifted our support services to a virtual model and connected with every family we support so they had information and knew they were not alone.



Thanks to the generosity of donors, critical support and services for the ALS community continued at a time of urgent need.

Within the first three weeks of the pandemic:

Regional Managers reached out to each Ontario family (nearly 1,000 in total) to understand challenges and needs, help problem solve, and reduce social isolation. Families reported a good, very good or excellent experience with our programs and services¹:

- 91%** Regional Manager support
- 94%** Support Groups
- 91%** Equipment Loan Program

We worked to ensure people were able to live safely in their homes and to reduce strain on caregivers, coordinating with vendor partners to offer our equipment loan program across the province despite funding shortfalls and physical distancing requirements.

We convened clinicians from across Ontario and Canada for regular information-sharing meetings to minimize gaps in care.

As issues were anticipated or identified, we worked to advocate to the Ontario healthcare system to minimize disruption to essential programs.

- A LHIN extended its equipment loan program beyond the mandated 30-day period to minimize duplication and number of external providers in the home.
- We helped care providers to understand that feeding tube insertions were essential and not elective surgery.

We brought the research community together virtually and worked with them to minimize the impact of the pandemic on their projects, so that the process and urgency of scientific discovery wasn’t disrupted.

¹ALS Canada client survey, May 2020

WHO WE HELP

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

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.

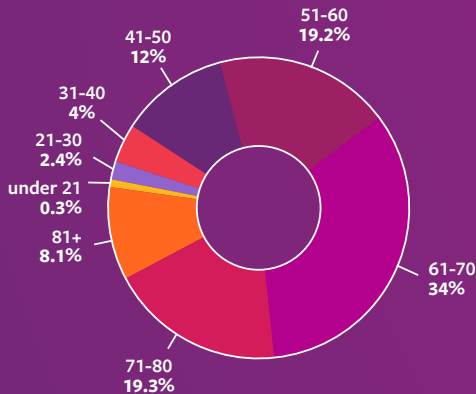
4 out of 5 people living with ALS will die within two to five years of their diagnosis.



There is no definitive understanding of what causes the disease, and **THERE IS NO CURE.** But there are more potential treatments in the pipeline than ever before.

We support more than **1,000 families across Ontario**. We help them to navigate complex care needs and provide information and practical assistance to ease the disease’s heavy burden.

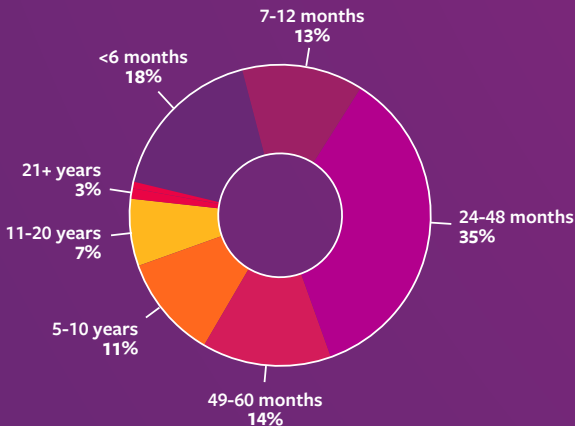
More than half the people we support are over the age of 50, but some are much younger.



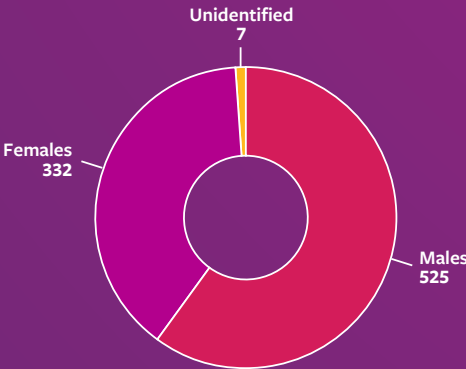
Youngest client supported in 2020 **13 years old**

Oldest client supported in 2020 **93 years old**

Most people we support have been living with ALS for two to four years.



Gender Breakdown in Ontario



Beyond our support role in Ontario, **we work to change the status quo for the 3,000+ Canadians living with ALS** by funding research and leading advocacy efforts that will transform the reality of an ALS diagnosis.

1,000 Canadians are diagnosed with ALS every year.



1,000 Canadians die of ALS every year.

HOW WE HELP

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.

Strategic plan 2018-2023
Grounded in strategic impacts that describe how the lives of people affected by ALS will be different in the future, our strategic plan identifies focus areas for ALS Canada and the outcomes we are working toward.
It is understood no one organization can or will create this future state; it will take the global ALS community working together to achieve the outcomes.

“My focus is not on the three letters A-L-S, but on four letters: HOPE. In addition to my appreciation for the practical support ALS Canada provides, to me it’s equally important to focus on new treatments, research, and hopefully a cure one day. This inspires me to fundraise and I am filled with gratitude for all others who do, too.”

Steven Gallagher
Living with ALS since 2019



STRATEGIC IMPACT

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

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

3 People are empowered to make informed decisions about ALS

2028 OUTCOME GOALS

People are diagnosed with ALS earlier than they are today

Affordable ALS treatments are available in Canada through a streamlined process.

People affected by ALS are better supported through programs, policies and other initiatives that respond to their unique needs.

ALS CANADA FOCUS AREAS

- Services and support
- System coordination
- Tools to measure and improve care

- Research investment
- Research capacity-building
- Access to therapies

- Awareness and education
- Access to information
- Community engagement

IMPROVING THE STANDARD OF CARE

Services and support

What ALS Canada donors do:

Provide people with a practical and emotional safety net in the form of our

11 Regional Managers in communities throughout Ontario who provide navigation support.

1,156 people living with ALS and their families supported in 2020.

1.7 days from people registering with ALS Canada to being contacted by one of our Regional Managers. (target = 10 days)

16,251 telephone, text message and email engagements.

715 in-home or virtual visits.

1,218 people including people living with ALS and their personal caregivers attended virtual support groups.

Sustain people’s dignity, independence and safety through mobility and communication equipment from our Equipment Loan Program.

\$180,252 appraised value of equipment donated to ALS Canada.

2,200 pieces of equipment loaned to Ontario families.

9.1 days average turnaround from request to delivery. (target = 10 days)

System coordination

What ALS Canada donors do:

Support education and advocacy initiatives to optimize care

Nearly 100 occupational therapists attended education sessions about our equipment loan program and best practices to support people living with ALS.

Ongoing touchpoints with health care providers to advocate for access to care, make expert referrals, and improve support.

“Donor support enabled us to bring the ALS Best Practice Recommendations to life. These guidelines for clinical care are an important step in improving the lives of people living with ALS in Canada by helping ALS clinics across the country to meet a common national standard and offer the best possible care to their patients.”

Dr. Christen Shoesmith

Neurologist and Motor Neuron Disease Clinic Director, London Health Sciences Centre
Chair, ALS Best Practice Recommendations Working Group

Tools to measure and improve care

What ALS Canada donors do:

Drive consistent care across the country
For the first time, there are clinical guidelines that establish the standard of care for any Canadian diagnosed with ALS’.

130+ recommendations published, including access to multidisciplinary care.

13 areas of focus from communicating the diagnosis, to symptom management, to treatments.

13 clinicians from across Canada involved.



“When my mom was diagnosed with ALS, we had no clue what to expect. ALS Canada was with us from the beginning, providing guidance, education and support. The only way I could show my gratitude was to offer my time to raise awareness and funds so that this program can be offered to other families dealing with the same things my family went through.”

Ritu Sethi
ALS Canada Volunteer

The change we are working to achieve by the end of 2021:

- People supported by ALS Canada are having a better experience
- Ontarians living with ALS have access to multi-disciplinary care

GETTING TO MORE TREATMENTS

Research investment

What ALS Canada donors do:

Contribute to global efforts for effective and personalized ALS therapies

3 funding partners for CAPTURE ALS. The most ambitious initiative in Canadian ALS research history, CAPTURE ALS will enable researchers to study why people experience ALS symptoms and progression so differently. This essential knowledge will help identify treatment targets and develop Canadian infrastructure to attract companies developing therapies.



Fill important knowledge gaps in our understanding of ALS

8 discovery grants awarded to pursue innovative new areas of ALS research including genetics, biomarkers, pathways for future therapies and quality of life.

23 peer-reviewed research papers published. Evidence that research funded by ALS Canada is contributing new knowledge to the field.

Capacity-building

What ALS Canada donors do:

Sustain research learning in a virtual world

170+ webinar attendees. When the 2020 ALS Canada Research Forum was cancelled due to the pandemic, we brought Canada’s ALS research community together virtually to share knowledge via a webinar series. Topics included ALS clinical trials, animal models, and moving promising foundational research closer to clinics.



Thank you to Biogen Canada for your sponsorship of this program.

100+ Canadian researchers attended the virtual ALS/MND International Symposium as an opportunity to learn and collaborate on a global stage.

949 webinar attendees viewed a live or archived session on ALS clinical trials.

Ensure a strong pipeline of ALS researchers

1 Career Transition Award given enabling a talented early-career researcher to become a permanent ALS research contributor and leader.

Access to therapies

What ALS Canada donors do:

Strengthen Canada’s infrastructure for ALS clinical trials

2 clinical fellowships awarded to provide early-career clinical researchers with specialized training in clinic-based research, increasing capacity for ALS clinical trials.

22 meetings convening Canada’s ALS clinic leaders to continue strengthening the country’s network of ALS clinics and improve patient and clinic participation in clinical trials.

Enable advocacy for ALS treatment access

Two extensions granted for the personal importation of edaravone following advocacy to Health Canada.

8 provinces agreed to reimburse Radicava through public drug plans, following a letter-writing campaign that saw 3,600 Canadians advocate to their provincial governments.

1,600+ Canadians voiced their concerns to the federal health minister about proposed reforms to how newly patented drugs are priced in Canada. By the end of 2020, the introduction of these reforms had been delayed two times.



“Pattern recognition is essential to success on any battlefield and the fight against ALS is no different. CAPTURE ALS aims to fill a glaring deficiency in our fight against this disease by way of data collection and analysis to identify the patterns.”

Deane Gorsline
Engineer officer in the Canadian military, living with ALS since 2018

The change we are working to achieve by the end of 2021:

- The impact of high-quality ALS research investments is accelerated
- Canada is seen as an attractive country for ALS clinical trials and drug commercialization

RESEARCH FUNDED IN 2021

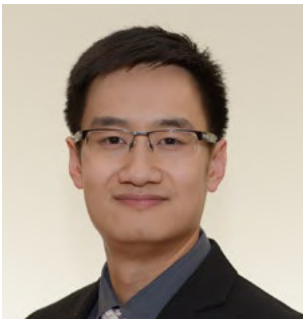


ALS Canada Clinical Research Fellowship

Dr. Colin Luk, University of Alberta | \$188,000

Mitsubishi Tanabe Pharma Canada Fellowship

Dr. Gordon Jewett, University of Calgary | \$200,000



“After my fellowship, I am hoping to secure a university position where I can continue my research and clinical practice, helping to strengthen the capacity for future ALS clinical trials in Canada. Adding research to my clinical training is not an obvious path and is truly the road less traveled. This award has been fundamental in providing me the opportunity to travel this path and to turn my passion into reality.”

Dr. Collin Luk
University of Alberta

La Fondation Vincent Bourque – ALS Canada Career Transition Award

Can identification of new biological targets represent promising new antibody treatment strategies for ALS?

Dr. Silvia Pozzi, Université Laval CERVO Brain Research Centre | \$250,000



ALS Canada-Brain Canada Discovery Grants*



How do mutations in CHCHD10 cause ALS?

Dr. Gary Armstrong and Dr. Eric Shoubridge, The Neuro (Montreal Neurological Institute-Hospital) at McGill University | \$125,000

How does loss of normal function of DNAJC7 lead to ALS?

Dr. Martin Duennwald, Western University and Dr. Sali Farhan, The Neuro (Montreal Neurological Institute-Hospital) at McGill University | \$125,000

Enhancing a clinical trial of enoxacin in ALS through addition of biomarker analysis and better monitoring of safety.

Dr. Angela Genge, The Neuro (Montreal Neurological Institute-Hospital) at McGill University and Dr. Eran Hornstein, Weizmann Institute of Science | \$125,000

*Awarded in partnership with Brain Canada, with matched funds contributed, through the Canada Brain Research Fund, an innovative partnership between the Government of Canada (through Health Canada) and Brain Canada.

Funding research can be a complex process – there is more research to pursue than dollars available, and the investments made today will take years to yield results. Awarding research grants on an annual basis means that there is a steady pipeline of work underway, and engaging panels of scientific experts in reviewing and evaluating research proposals means there is rigour in assessing the quality and meaningful impact of the research we fund.

Thank you to our donors – including provincial ALS Societies that direct 40% of net proceeds from Walk to End ALS events – for your role in supporting **Canada’s only dedicated source of ALS research funding at a time when health research funding was extremely challenged due to the COVID-19 pandemic.**

Can an interdisciplinary approach to mindfulness improve the quality of life for people with ALS and their primary caregivers?

Dr. Angela Genge, The Neuro (Montreal Neurological Institute-Hospital) at McGill University; Dr. Francesco Pagnini, Università Cattolica del Sacro Cuore; Lana Kim McGeary, Antonietta Vitale, Kendra Berry, Maura Fisher, Kalyna Franko, and Dr. Rami Massie, The Neuro (Montreal Neurological Institute-Hospital) at McGill University | \$121,950

Can a novel metabolic pathway serve as both a biomarker of disease progression and a pathway to treatment?

Dr. Jasna Kriz, CERVO Brain Research Centre at Université Laval; Dr. Nicolas Dupré, CHU de Québec-Université Laval; Dr. Angela Genge, The Neuro (Montreal Neurological Institute-Hospital) at McGill University | \$125,000

Is a novel neuroinflammatory pathway critical to motor neuron degeneration in SOD1?

Dr. Honglin Luo and Dr. Neil Cashman, University of British Columbia | \$125,000

Through what mechanism does a probiotic cause therapeutic effect in ALS animal models?

Dr. Alex Parker, CRCHUM, Université de Montréal and Dr. Matthieu Ruiz, Université de Montréal | \$125,000

Is it possible to use a drug to reduce the size of ALS-associated C9ORF72 repeat expansions and does that have potential to alter the disease?

Dr. Christopher Pearson, The Hospital for Sick Children (SickKids) and Dr. Ekaterina Rogaeva, University of Toronto | \$125,000



ALS CANADA RESEARCH PROGRAM

Thank you to provincial ALS Societies who collectively provided \$366,454 in funding support to the ALS Canada Research Program

BETTER INFORMATION, BETTER DECISIONS

Awareness and education

What ALS Canada donors do:

Help more people understand the realities of ALS

61 meetings with the federal and Ontario governments to lobby MPs and MPPs (49 meetings and 12 meetings respectively) on the urgent needs of people living with ALS as well as the impact of COVID-19 on health charities that serve vulnerable populations.

8 industry partners attended our first-ever roundtable with pharmaceutical companies to discuss how we can work together to help decision-makers understand the urgency and needs of the ALS community.

25+ people affected by ALS shared their personal experiences on our blog and social media, helping others to understand the challenges and complexities of living with the disease.

Create awareness of the ALS cause

424 branded items ordered through our first-ever online shop, enabling people to share their support of the cause and raise awareness at the same time.

2 Ontario landmarks lit in purple for ALS Awareness Month in June: the CN Tower and Niagara Falls.

298,785 visitors to als.ca. Against a target of 300,000; average visit of 2 minutes 26 seconds.

Access to information

What ALS Canada donors do:

Provide families affected by ALS with credible information

1,000+ attendees at our series of eight webinars offered in response to the challenges of the pandemic. Topics included how to stay safe at home and maintain social distancing, navigating end of life during the pandemic, wellness and relaxation, and easing fears. The series was so well-received that it is continuing in 2021.

671 downloads of the newly-produced ALS Guide – making it the most-downloaded resource on our website!



Community engagement

What ALS Canada donors do:

Create opportunities for people affected by ALS to make a difference

2 new leadership volunteers with a personal connection to ALS joined our Board of Directors.

35 ALS community members trained on advocacy issues through webinars about drug reimbursement and a one-day advocacy training session, providing foundational knowledge for a community-led e-petition urging the federal government to run a pilot project hastening the timelines for access to approved ALS therapies.

“The training and opportunities provided by ALS Canada have provided foundational knowledge for patient-led advocacy that is making a difference in the fight for timely access to ALS treatments.”

Norman MacIsaac
ALS Ambassador



“While it can be hard to do, I boldly share the realities of living with ALS so others understand the effects of this devastating disease. This awareness combined with my advocacy for new treatment options will help to create a brighter future for others.”

Mike Cels
Living with ALS since 2017

The change we are working to achieve by the end of 2021:

- Healthcare providers, government representatives and other decision-makers are better informed about ALS

HOW YOU STEPPED UP

We are humbled by the many ways our donors and volunteers supported us and the ALS cause in 2020. No matter how physically distant we may have been in 2020, we were united in our efforts to end ALS. Thank you for your support and generosity.

Thank You!

\$6,714,785 donated to ALS Canada in 2020

The in-person events and community-based fundraisers that normally provide such vital support were not possible for the vast majority of 2020. Instead, fundraising events transitioned to virtual and the community showed up to support them along with non-event donors including major donors, corporations, and individuals who make one-time and monthly gifts through direct mail, via phone and online. This generosity sustained and stabilized the organization.

We are grateful for every dollar and recognize individuals and organizations giving \$1,000+ at www.als.ca/donors and on pages 16 and 17 of this report.

\$1,282,525 raised* in Ontario through our first-ever virtual Walk to End ALS event. Held on global ALS Awareness Day, June 21 and hosted by emcee extraordinaire Justin Landry, it enabled thousands of people across Ontario to do the Walk in their own way and come together at virtual start and finish line.

**before expenses*



9,391 hours generously donated by volunteers sharing their time and talents, including local Walk to End ALS committees, and the inaugural committee for the new Revolution Ride cycle event in 2021.

\$99,898 raised at the virtual ALS Canada Plane Pull to End ALS.

\$1,392,265 in corporate and other major gift support given by corporations, individuals, foundations and others who continued to support us through COVID-19, whether by reallocating event sponsorships or finding innovative ways to support virtual events.

\$391,780 raised through community-based fundraising events. Community event organizers embraced change, adapted their events, and showed their creative side in how to fundraise from a distance, like this **Paint a Paddle auction (Part 2)** that raised \$21,305 in 2020.



1,112 monthly donors who provided \$248,455 in reliable funding support for our programs.

\$219,130 from workplace giving campaigns with federal government employees contributing through HealthPartners and provincial (Ontario) employees giving through Federated Health Charities. These amounts are reported within the “other fundraising donations and income” section of our revenue.

\$25,000 raised at the Shorcan Charity Day. We are proud and grateful to have been a beneficiary of this annual initiative since 2016.

5,076 tribute gifts given in honour or memory of a loved one, totalling \$607,263.

“After losing her only child Heather to ALS in 1999, Anna felt it was important to continue to fundraise for and support the ALS Society of Canada. She was honoured to leave this legacy gift in memory of her daughter with the hope that one day ALS would be a disease of the past.”



Ann Louise Iwanski (family friend) on behalf of the Estate of Bertha Anna Belinda Stuart who contributed a legacy gift in memory of her daughter Heather April Stuart.

YOUR DONATIONS AT WORK

Support and Services: To respond to the needs of people living with ALS in Ontario, we spent \$1,122K providing direct service to people and families living with ALS and additional \$1,301K to support the equipment program including \$280K in purchased items and \$101K in rented items.

National Research: In 2020, ALS Canada awarded \$2,184K, including the \$1,000K CAPTURE ALS grant which we partnered with Brain Canada on, in new grants. We accounted for the full financial commitment of these grants in the year as is our accepted accounting practice even though most grants will be paid out over multiple years. An additional \$532K was used to support the ALS Canada Research Program and the broader ALS research community in Canada.

Fundraising: Our revenue and the expenses associated with generating it are analyzed regularly to ensure our cost of fundraising is controlled. In 2020, our cost of fundraising was 29% which includes fund development support costs to generate donations as well as other costs such as credit card processing fees, direct mail and production costs; cost of fundraising (COFR) for 2020 is well within the Canada Revenue Agency’s guidelines for a health charity.

Advocacy: Through our advocacy investment this year of \$423K, ALS Canada was able to host a federal advocacy day and training, as well as engage the community in multiple e-advocacy campaigns.

Public Awareness: Investments made in 2020 amounted to \$352K allowing ALS Canada to increase awareness of the organization through digital marketing and advertising, and to make improvements to our visual identity to better reflect the tenacity of our community and raise the profile of ALS Canada and the ALS community and cause.

Other Charitable Purpose: We invested additional funds in volunteer development and other national programs, including coalition approaches on issues shared by others in the health and charitable sectors, in the amount of \$180K.

Governance: The Board of Directors met once only in-person in February 2020 due to COVID-19 and 11 additional times through video- and teleconference, in addition to other calls as required. Similarly our advisory councils met virtually throughout 2020. While out-of-pocket expenses for travel and accommodation are reimbursed for in-person meetings, no compensation is given for the generous giving of their time.

Making donor dollars go further

At a time when health research investment in Canada was significantly challenged, ALS Canada’s donors stepped up in an impressive way. Because of you, the \$2.184 million in donor dollars directed to grants and CAPTURE ALS was leveraged with our partner Brain Canada,* resulting in more than double the research investment.

* With the financial support of Health Canada, through the Canada Brain Research Fund, an innovative partnership between the Government of Canada (through Health Canada) and Brain Canada

Grants:	\$1.18 million	donor-funded
	+	
	\$498,475	matched by Brain Canada
	+	(Discovery grants)
CAPTURE ALS:	\$1 million	donor-funded
	+	
	\$1.43 million	grant awarded by Brain Canada
	+	
	\$250,000	matched by Alnylam Pharmaceuticals
	+	
	\$250,000	matched by REGENERON Science Medicine
	\$4.61 million	



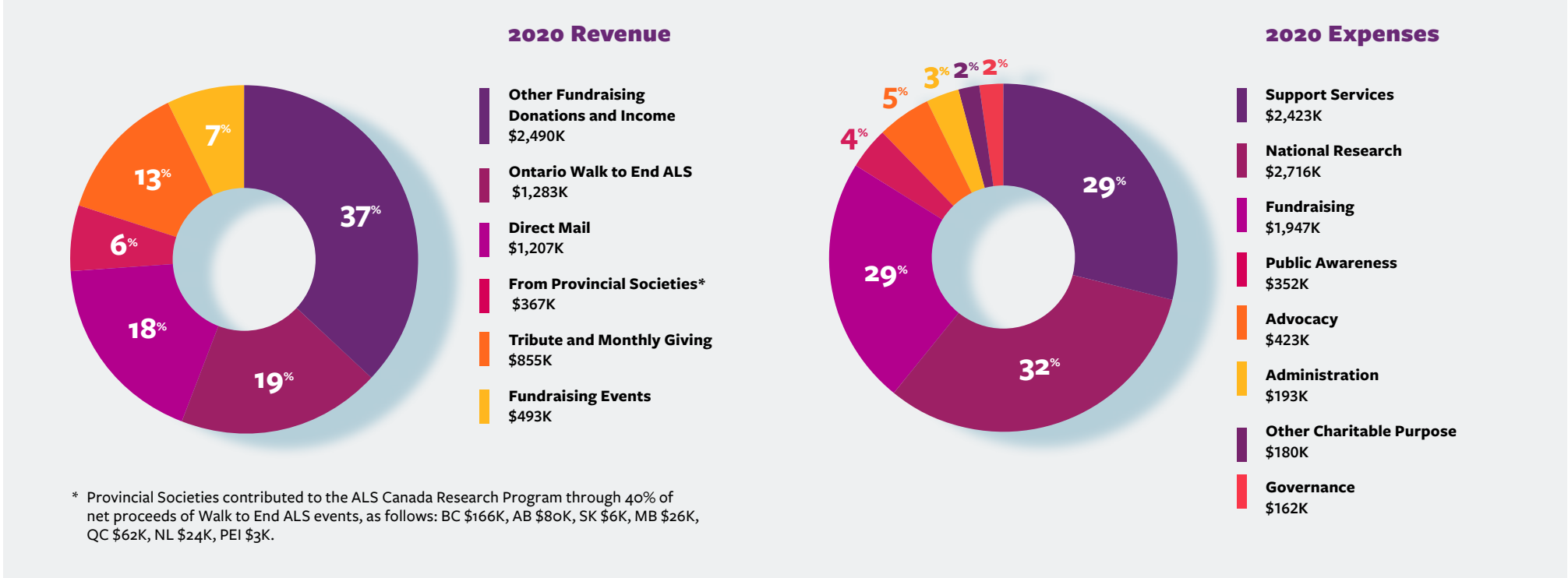
“After mobility equipment became a necessity, ALS Canada always had the next thing we needed through their equipment program – or as I called it, ‘the cupboard.’ By my estimate, we accessed about \$45,000 worth of wheelchairs, cushions, lifts, mattresses... the list goes on. I’m grateful to ALS Canada donors that this program is available and will be pushing to make sure it carries on through my own fundraising and advocacy.”

Sandra Vivarais
Personal caregiver to her husband Mark, who died in 2021

FINANCIAL SUMMARY

Our leadership carefully monitors the organization’s fundraising revenue and expense to ensure the organization’s needs and goals can be met in a fiscally responsible way that maximizes the use of donor dollars. Our audited financials are available on our website.

- ALS Canada adheres to generally accepted accounting standards for not-for-profit organizations that comply with the Canada Revenue Agency’s requirements. Since 2014 we have used the deferral method of recognizing revenue, which allows us to recognize externally restricted revenue in the period where the future investments in research and client services occur. At December 31, 2020, we had **\$1,808K** in deferred revenue remaining which are held in income-generating secure investments.
- ALS Canada invests all funds under the guidelines of an established investment policy approved by the Board of Directors. At December 31, 2020, ALS Canada held **\$4,140K** in cash and **\$11,588K**, including the **\$1,300K** Tim Noël endowment fund, in short term pooled investment funds.
- The global pandemic has had a significant impact on businesses and organizations through the restrictions put in place by federal, provincial and municipal governments. ALS Canada saw reductions in budgeted / expected revenue and needed to defer some projects to the following year, however, through the additional support provided by the federal government, were able to retain all necessary resources to ensure that community support or the research program was not affected.



FINANCIAL SUMMARY

STATEMENT OF FINANCIAL POSITION

For the year ended
December 31, 2020

In \$	General Fund	Research Fund	Tim E. Noël Endowment Fund	2020	2019
Assets					
Current assets					
Cash	\$ 4,139,508	–	–	\$ 4,139,508	\$ 5,910,962
Short-term investments	\$ 2,011,368	\$ 8,276,404	\$ 1,300,000	\$ 11,587,772	\$ 9,410,096
Accounts receivable	310,819			310,819	379,471
Prepaid expenses and other assets	86,129	–	–	86,129	144,771
	\$ 6,547,824	\$ 8,276,404	\$ 1,300,000	\$ 16,124,228	\$ 15,845,300
Long-term investments	–	–	–	–	1,140,753
Capital assets	41,423	–	–	41,423	56,081
Intangible assets	8,239	–	–	8,239	35,960
	\$ 6,597,486	\$ 8,276,404	\$ 1,300,000	\$ 16,173,890	\$ 17,078,094
Liabilities					
Current liabilities					
Accounts payable and accrued liabilities	\$ 435,212	\$ 39,231	–	\$ 474,443	\$ 545,985
Current portion of deferred revenue	687,633	512,600	–	1,200,233	903,374
Current portion of research grants payable	–	3,948,787	–	3,948,787	3,989,242
	\$ 1,122,845	\$ 4,500,618	–	\$ 5,623,463	\$ 5,438,601
Long-term deferred revenue	\$ 354,449	\$ 253,764	–	\$ 608,213	\$ 959,320
Long-term research grants payable	–	657,884	–	657,884	1,635,145
	\$ 1,477,294	\$ 5,412,266	–	\$ 6,889,560	\$ 8,033,066
Commitments					
Net assets	\$ 5,120,192	\$ 2,864,138	\$ 1,300,000	\$ 9,284,330	\$ 9,045,028
	\$ 6,597,486	\$ 8,276,404	\$ 1,300,000	\$ 16,173,890	\$ 17,078,094

STATEMENT OF OPERATIONS

For the year ended
December 31, 2020

In \$	General Fund	Research Fund	Tim E. Noël Endowment Fund	2020	2019
Revenue					
Fundraising and donations	\$ 4,251,293	\$ 1,256,622	–	\$ 5,507,915	\$ 9,450,068
Direct mail campaign	1,147,215	59,655	–	1,206,870	1,131,696
Interest and investment income	582,337	–	31,067	613,404	370,072
	\$ 5,980,845	\$ 1,316,277	\$ 31,067	\$ 7,328,189	\$ 10,951,836
Expenses					
Research grants	–	\$ 2,184,345	–	\$ 2,184,345	\$ 1,575,250
Other research support	–	532,077	–	532,077	672,241
National programs	121,854	–	–	121,854	125,348
Ontario client support services	2,423,022	–	–	2,423,022	2,847,129
Public awareness	351,481	–	–	351,481	593,257
Advocacy	422,844	–	–	422,844	386,373
Volunteer development	57,973	–	–	57,973	63,717
	\$ 3,377,174	\$ 2,716,422	–	6,093,596	6,263,315
Other expenses					
Fundraising	\$ 1,947,145	–	–	\$ 1,947,145	\$ 2,217,788
Administrative	141,112	52,192	–	193,304	252,699
Governance	80,885	80,884	–	161,769	180,502
	\$ 2,169,142	\$ 133,076	–	\$ 2,302,218	\$ 2,650,989
	\$ 5,546,316	\$ 2,849,498	–	\$ 8,395,814	\$ 8,914,304
Excess (deficiency) of revenue over expenses before other items					
	\$ 434,529	\$ (1,533,221)	\$ 31,067	\$ (1,067,625)	\$ 2,037,532
Other Items					
Government subsidies	\$ 843,047	–	–	\$ 843,047	–
Unrealized gain (loss) on investments	483,504	–	(19,624)	463,880	386,397
	\$ 1,326,551	–	\$ (19,624)	\$ 1,306,927	\$ 386,397
Excess (deficiency) of revenue over expenses					
	\$ 1,761,080	\$ (1,533,221)	\$ 11,443	\$ 239,302	\$ 2,423,929

STATEMENT OF CHANGES IN NET ASSETS

For the year ended
December 31, 2020

In \$	General Fund	Research Fund	Tim E. Noël Endowment Fund	Total
Balance, December 31, 2018				
Excess (deficiency) of revenue over expenses	2,798,586	(413,657)	39,000	2,423,929
Interfund transfers	–	39,000	(39,000)	–
Balance, December 31, 2019				
Excess (deficiency) of revenue over expenses	1,761,080	(1,533,221)	11,443	239,302
Interfund transfers	–	11,443	(11,443)	–
Balance, December 31, 2020				
	\$ 5,120,192	\$ 2,864,138	\$ 1,300,000	\$ 9,284,330

PARTNERSHIPS AND ALLIANCES

TOGETHER WE CAN ACHIEVE MORE

ALS Canada is proud to partner with organizations and associations in Ontario, across Canada and around the world to improve the lives of people living with ALS.

Internationally

As a member of the **International Alliance of ALS/MND Associations** we collaborate with other ALS organizations on borderless opportunities for global change.

- Our CEO Tammy Moore serves on the Alliance's Board.
- Our VP Research Dr. David Taylor serves as Chair of its Scientific Advisory Council.
- ALS Canada ambassador and advocate Carol Skinner served on the pALS and cALS Advisory Council.
- Our virtual Walk to End ALS event and patient journey map were presented at the Alliance's annual meeting as best practices.

Nationally

Working with **provincial ALS Societies** we lead federal advocacy and fund ALS research through the ALS Canada Research Program, to which provincial Societies generously contribute 40% of net proceeds from local Walk to End ALS events.

ALS Society of Alberta
ALS Society of British Columbia
ALS Society of Manitoba
ALS Society of Newfoundland and Labrador
ALS Society of Prince Edward Island
ALS Society of Quebec
ALS Society of Saskatchewan

We work with and provide administrative support to the **Canadian ALS Research Network (CALS)**, the neurologists who lead Canada's 19 multidisciplinary ALS clinics.

As a member of the **Health Charities Coalition of Canada (HCCC)** we advocate with other health charities on shared priorities. Our CEO Tammy Moore served as HCCC Chair in 2020.

Our membership in **Research Canada** provides a platform to champion Canada's global leadership in health research and advocate for its support.

We are a member charity of **HealthPartners**, which offers federal workers the opportunity to support the ALS cause through workplace giving.

Provincially

We share the perspectives of the ALS community by serving on the patient and community advisory committee of the **Ontario Neurodegenerative Disease Research Initiative**.

As a member of the **Quality Hospice Palliative Care Coalition of Ontario** we help to improve how the province delivers an integrated system of hospice palliative care.

Our membership in the **Canadian Assistive Devices Association** gives us a coordinated voice with others who understand the importance of assistive devices to maintain quality of life.

As a selected charity of the **Federated Health Charities**, members of the Ontario Public Service across Ontario can support ALS Canada through workplace giving campaigns.

In memory: Carol Skinner

Diagnosed with ALS in 2013, Carol soon after became an ALS advocate and an ambassador for ALS Canada. She attended the first meeting of the all-party ALS Caucus on Parliament Hill in November 2016 and many other government meetings thereafter. With determination and passion, she helped others to understand the harsh realities faced by people living with ALS and the need for government to do better, working with others in the community to spearhead a letter-writing campaign calling on the federal government to provide dedicated ALS Research funding. Carol, with her smile and laugh that made others feel good, was a source of positivity and strength for many. Her contributions extended into the global arena where she shared her experience and perspective of the International Alliance of ALS/MND Associations' pALS and cALS Advisory Council.

We are so grateful for Carol's many meaningful contributions and the difference she has made.



A STRONG TEAM

Leading by example

During a year that tested us all in new and previously unimaginable ways, we were proud to be recognized as one of **Canada’s Most Admired Corporate Cultures** by **Waterstone Human Capital**. This national program identifies organizations with a best-in-class culture that fosters high performance.

Our virtual Walk to End ALS was among the top 30 peer-to-peer fundraising events in Canada in 2020, as recognized by **Peer-to-Peer Fundraising Canada**.



Advisory Councils and 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.

- Dr. Christine Vande Velde, *Co-Chair*
- Dr. David Taylor (Staff), *Co-Chair*
- Colleen Doyle (ex-officio, Staff)
- Dr. Aaron Izenberg (ex-officio)
- Dr. François Gros-Louis
- Dr. Wendy Johnston (ex-officio)
- Dr. Hanns Lochmüller
- Josette Melanson (ex-officio)
- Tammy Moore (ex-officio, Staff)
- Dr. Janice Robertson
- Dr. Robin Parks
- Dr. Kerri Schellenberg

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

- Patrick Nelson, *Co-Chair*
- Lisa Droppo (Staff), *Co-Chair*
- Margot Algie
- Ron Black
- Sheldon Crystal
- Tasneem Dharas
- Heidi Kinnon
- Stephanie Mazzei
- Alan Medcalf
- Josette Melanson (ex-officio)
- Tammy Moore (ex-officio, Staff)
- Vincent Quinn
- Sarah Reedman (Staff)
- Dr. Christen Shoesmith
- Lisa Sullivan
- Sherry Szucsko-Bedard
- Dr. Anu Tandon

Reflecting the increased effort in federal and provincial (Ontario) advocacy, the **Advocacy Committee** held its inaugural meeting in 2020, providing professional and personal insight to help advance our advocacy priorities.

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

“Our work is meaningful, but challenging. The strength of our culture supports our team in our mission, as everyday, our staff demonstrates our values of accountability, collaboration, compassion, integrity, resilience and respect. These values have been put to the test during the COVID-19 pandemic and have enabled us to navigate this challenging year as a strong team, united by our focus on creating a future without ALS.” **Tammy Moore, CEO**

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 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.



Josette Melanson,
Chair



Patrick Nelson,
Vice Chair



Norma Beauchamp



Catherine Bélanger



Carol Cottrill



Richard Ellis



Lisa Flaifel



Laura Gay



Dr. Wendy Johnston



Jim Mitrakos



Vincent Quinn



Daniel Rivero



Dr. Michael Spivock



Dr. Christine
Vande Velde



Tammy Moore,
ex-officio

FUNDRAISING

THANK YOU
TO OUR 2020
DONORS

The generosity and commitment of thousands of donors and fundraisers make our work possible. We rely heavily 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 grant us vital financial support.

The following list of donors reflects individuals or companies who donated \$1,000 or more to ALS Canada in 2020. 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.

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“ALS is a cause close to our hearts and each year we honour our colleague who is living with this devastating disease. Through our annual Shorcan Charity Day in 2020, we were proud to once again support the efforts of ALS Canada with a donation of \$25,000.”

John McArthur
Managing Director Head of Rates Trading Canada, Bank of America

ALS Society of Canada

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Toll-free 1-800-267-4257

www.als.ca



@ALSCanada

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

Founded in 1977, ALS Canada works 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.

We are a registered charity that receives no core government funding – all of our services and research are funded through the generosity of our donors. Through the ALS Canada Research Program, we fund peer-reviewed research grants, foster collaboration and build capacity within Canada's ALS research community and participate in new areas of research where we are well-positioned to have an impact. Within Ontario, ALS Canada has a role similar to that of the provincial ALS societies providing services and support to help meet the needs of people living with ALS. Through advocacy federally and provincially within Ontario, ALS Canada gives voice to the collective experience of people living with ALS to help drive program and system changes for the ALS community.



The Standards Program
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