



Written Submission to the Legislative Assembly of Ontario Standing Committee on Finance and Economic Affairs

August 28, 2020

Submitted By:

ALS Society of Canada
393 University Avenue, Suite 1701
Toronto, ON M5G 1E6
416-497-2267
www.als.ca
advocacy@als.ca

Summary of Recommendations:

The following is a summary of recommendations for the Government of Ontario to consider as the Standing Committee on Finance and Economic Affairs undertakes its study of the recommendations relating to the Economic and Fiscal Update Act, 2020 and the impacts of the COVID-19 crisis on certain sectors of the economy:

Recommendation 1: As Ontario recovers from the COVID-19 pandemic, mandate a standard approach that LHINs and Ontario Health Teams must provide people living with ALS access to essential medical equipment for the length of time the person needs it.

Recommendation 2: Create a stabilization fund for the non-profit sector so that charitable organizations, like the ALS Society of Canada, can continue to provide the critical support services that are helping people living with ALS and their caregivers across the province.

Recommendation 3: Double the provincial portion of the Charitable Donation Tax Credit through to the end of 2021 and make the credit refundable so that charitable contributions are treated the same as a contribution to a political party in Ontario, and commit to matching donations from all Ontarians to provincial charities or national charities with provincial offices.

Introduction:

The ALS Society of Canada (ALS Canada) appreciates the emergency actions the Government of Ontario took in response to the COVID-19 pandemic. While programs and supports announced thus far have helped to mitigate the effects of the outbreak and its impact on Ontarians, we are concerned that a charity like ours – that supports a vulnerable population throughout Ontario by filling critical gaps within the formal healthcare system – may not be addressed in the proposed fiscal response programs announced to date.

The ongoing COVID-19 pandemic continues to create an unprecedented challenge for our province, our health care system as well as organizations like ours that are actively providing essential support, services and information to Ontarians. Efforts to bend the curve and address impacts from the volatile economy have resulted in essential health charities facing a significant funding shortfall in donation revenues. This has put many charities' ability to continue operations as usual and serve some of the province's most vulnerable communities at risk. If the current situation continues, and without increased financial assistance from the government, many vulnerable Ontarians could be left without the essential services and programs they rely on – resulting in a dire and tragic situation where people are unable to access the care they need. Without such, vulnerable Ontarians will have no choice but to turn to hospitals or long-term care homes, putting more strain on our system at a time when we need to ensure capacity is there for those with the most critical need.

In this time of crisis, the services of health charities are even more vital, the demands greater, and donor support to carry out day-to-day operations even more challenged. As governments of all levels begin to support the economy and path to recovery from COVID-19, it is critically important that the Government of Ontario continue to help the province's many health charities and the people who depend on their programs, services and care.

ALS Canada is eager to be a partner in Ontario's COVID-19 recovery and to work with government toward this goal. We encourage the government to consider the recommendations in this submission so that ALS Canada and many other health charities can continue to provide critical services to vulnerable Ontarians during this pandemic and beyond.

The Impact of COVID-19 on Ontario's ALS Community:

Amyotrophic lateral sclerosis (ALS), is a progressive neurodegenerative disease resulting in progressive paralysis and eventually the loss of the ability to move, to speak and to breathe. Any given year, approximately 1,000 Ontarians are living with ALS, but the number of people affected is even more significant when you consider the profound emotional, financial and psychological impact of the disease on family members, caregivers, and friends. There is no cure and most people with ALS will die within five years of diagnosis.

Due to the complex and progressive nature of ALS, people living with the disease have substantial home and community care needs. At a minimum, this care can include personal support, occupational therapy, respiratory services and nursing services. Additionally, as a person's ALS progresses, mobility and communications equipment is critical to helping them maintain independence and ability – all while helping them live safely within their homes and out of the hospital or long-term care.

The COVID-19 outbreak has significantly impacted health services throughout Ontario and complicated the lives of people living with ALS even further. For example, during the pandemic, we have seen an increase in virtual care. While this has enabled people living with ALS to remain connected to many of their health care practitioners, certain assessments can't be completed in this manner and people with ALS are losing access to vital in-person care. For example, an occupational therapist must be able to conduct an in-person visit to properly assess safety and access issues in a person's home.

In the face of the COVID-19 pandemic, the day to day stressors of dealing with disease progression, the financial impacts, inability to access qualified paid caregivers, and the outreach from our community to help advocate for their needs are all on the rise. The pandemic has increased the overall pressure and level of uncertainty on the lives of Ontarians living with ALS, heightened the risk of losing access to essential care and equipment, and increased isolation and mental health challenges.

The Impact of COVID-19 on the ALS Society of Canada:

The COVID-19 pandemic has created a reality where health charities like ALS Canada are reporting a devastating reduction in revenues paired with an often-overwhelming increase in demand for services. ALS Canada is anticipating a decrease in our revenues of 40 to 60 per cent in 2020 due to the inability to host in-person events and onsite activities with our corporate partners, which are such a critical aspect of our fundraising initiatives. For example, in April 2020 ALS Canada experienced a 46 per cent reduction in revenues.

It is not expected that a full recovery to pre-COVID revenue levels will occur for several years. As a 100% donor-funded charity, the pandemic is threatening the way we provide support to Ontarians living with ALS. Yet, the support services we're providing during the COVID-19 crisis are critical to helping people with ALS and their caregivers remain safely in their homes and out of the hospital and long-term care homes, reducing the strain on the health care system during this time of crisis. Moreover, because we fill a significant gap in the health care system during "normal" times, we fear that these economic and

fundraising impacts will soon begin to affect people living with ALS more negatively and result in people living with ALS having even more of their needs go unmet. Given this situation and the impact of COVID-19 on ALS Canada and Ontario's ALS community, we urge the Government of Ontario to build on the initial programs announced at the beginning of the pandemic by implementing the following recommendations.

Recommendations:

Recommendation 1: *As Ontario recovers from the COVID-19 pandemic, mandate a standard approach that LHINs and Ontario Health Teams must provide people living with ALS access to essential medical equipment for the length of time the person needs it.*

Currently, there is no government-funded mechanism that enables people with ALS to access mobility equipment for more than 30 days consecutively. While some Local Health Integration Networks (LHINs) provide some equipment, it is for acute short-term use only and there is considerable variation in practice across the province.

For Ontarians living with ALS to access equipment for the length of time they need it, which is often longer than 30 days, they must rely on the support of ALS Canada, a charitable organization that is funded entirely by donors, to fill the gap. We do this by providing much-needed equipment free of charge to people living with ALS and financial assistance to people in need for the additional costs of power wheelchairs and communication devices not covered by government programs.

Normally, our equipment loan pool is comprised of both newly purchased equipment and gently used items that have been generously donated. However, due to COVID-19, we were no longer able to accept equipment donations, which is a lifeline for our inventory. To make sure no person living with ALS goes without the essential equipment they need, we have begun incurring the cost of purchasing new pieces of equipment to accommodate each request. To put it into context, in 2019, 206 people donated on average 2-3 pieces of equipment at a total value of over \$360,000 to our equipment loan pool. Without this contribution, we needed to purchase a similar amount of new equipment of comparable value. With this new cost and the economic impact of COVID-19 on our revenues, our ability to provide Ontarians living with ALS with essential equipment is at risk.

For several years, ALS Canada has been calling on the Government of Ontario to allow people living with ALS to use the equipment given to them by the LHINs for the complete length of time needed. During the heart of the pandemic, we proactively sought solutions by working with the Mississauga Halton LHIN to develop a pilot project that allows Ontarians living with ALS to continue using a piece of LHIN-loaned equipment beyond the 30-day limit to reduce the risk of exposure caused by having multiple vendors in the home to unnecessarily pick-up and deliver equipment.

While a step in the right direction, there are many lessons learned from this pilot project that will enable us to create a better, more efficient program that can be scaled across the province to ensure people living with ALS get timely, long-term access to the equipment they need. This pilot project made clear that the Ministry of Health must modernize Ontario's equipment program to allow people living with ALS to use the equipment for as long as they need it. Implementing a standard approach that mandates all LHINs and OHTs to provide access to loaned equipment to people living with ALS for the total length of time needed – instead of piece-meal extensions at the individual LHIN level – would simplify the

process for people and families affected by ALS. Not only that, but it would also remove inefficient and unnecessarily expensive duplication of work that occurs between the LHINs, occupational therapists and ALS Canada and ensure consistent access to vital equipment.

As well, if adequately executed, a long-term equipment loan program will also help contain the spread of the virus by reducing the number of people entering the homes of people living with ALS, while also enhancing their level of independence and reducing the stress, anxiety, and pressure put on families caring for a person living with the disease that has been intensified during the pandemic.

Recommendation 2: *Create a stabilization fund for the non-profit sector so that charitable organizations, like the ALS Society of Canada, can continue to provide the critical support services that are helping people living with ALS and their caregivers across the province.*

Unfortunately, many health charities – particularly with a provincial-wide reach – do not qualify for recent initiatives like those announced by the Government on April 21, 2020 ([“Ontario Providing Additional Relief to the Province's Most Vulnerable”](#)). These kinds of funding structures fail to provide significant financial assistance to help health charities continue the services, support, and care they deliver to Ontario’s most vulnerable communities.

In alignment with the Ontario Nonprofit Network, we are calling on the Government of Ontario to create a stabilization fund for the non-profit sector. A stabilization fund would be a simple measure that allows charitable organizations across the province to maintain consistent levels of health care supports and services to Ontarians. Similarly, in an unprecedented time with significantly lower revenue streams, it would provide charities with a sustainable level of funding that would allow them to maintain a more constant level of operations and support to Ontario families.

For ALS Canada this means we can continue to provide many of the essential supports like the ALS Canada Equipment Program as well as other services such as virtual support groups and health care system navigation.

Recommendation 3: *Double the provincial portion of the Charitable Donation Tax Credit through to the end of 2021 and make the credit refundable so that charitable contributions are treated the same as a contribution to a political party in Ontario, and commit to matching donations from all Ontarians to provincial charities or national charities with provincial offices.*

Taking measures to double the provincial portion of the Charitable Donation Tax Credit, making the tax credit refundable, and matching donations will encourage more Ontarians to continue or start donating to their favourite charities. This is extremely important for health charities who heavily rely on the generosity of Ontario donors.

As a 100% donor-funded charity that receives no government funding, this step would have a very significant positive impact on ALS Canada. Donations and fundraisers are paramount to our overall revenue and consequently all of the support, services, and equipment that we provide to Ontarians living with ALS. Because our fundraising events have all been compromised, any additional financial incentives that can support our fundraising efforts would be incredibly beneficial and help off-set our fundraising revenue shortfalls.

Conclusion:

We applaud the Government of Ontario's response to the COVID-19 pandemic thus far, However, more can and must be done to support Ontario's most vulnerable communities. In order to do this, health charities must be included in the path to recovery. We urge the Government of Ontario to consider the recommendations included in this submission and implement them as soon as possible. The recommendations help not only the struggling health charity sector, but also the vulnerable people that receive their essential services, care, and support.

This pandemic is a once-in-a-lifetime phenomenon that warrants once-in-a-lifetime policy change. Despite the devastating impacts of COVID-19, this recovery is an opportunity to create change for the better, so every Ontarian gets the care they need when they need it. We ask the Government to join us in working together to make this a reality.