



The Honourable Ginette Petitpas Taylor, P.C., M.P.
Minister of Health
House of Commons
Ottawa, ON K1A 0A6

Re: Dedicated ALS Research Funding

Dear Minister Petitpas Taylor,

I am writing to you today on behalf of the nearly 3,000 Canadians living with ALS today and the 1,000 Canadians who will be diagnosed each year in the future, all of who continue to face the realities of this challenging and terminal disease – realities that led Carol Skinner and Eddy Lefrançois, two Canadians affected by ALS, to start a letter-writing campaign. The campaign asked Members of Parliament to hold themselves accountable following their unanimous approval of Motion M-105, which called on the government to play a leadership role in supporting ALS research and national efforts to find a cure.

Over the course of four months, more than 2,300 Canadians joined Carol and Eddy in their initiative. But even that short time proved to be too long for someone living with ALS: Eddy Lefrançois died in January 2019 before he could see the results of his initiative.

The reality is that ALS continues to be a devastating disease and the impact on families – emotionally, financially, and psychologically – is tremendous. Despite advancements in research the causes of ALS are unknown, and 80 per cent of people with ALS die within two to five years of being diagnosed.

Since the unanimous approval of M-105 in April 2017, there has been little action from the federal government to act on the repeated calls from the ALS community to invest in dedicated, sustained funding for ALS research. Instead, we have seen multiple responses from Health Canada, as well as numerous MPs, that reiterate past support for ALS research.

Enclosed we have outlined the information provided to the ALS community by government about federal investment in ALS research to date, along with an analysis based on our own fact-checking, to illustrate the ongoing need for sustainable and direct ALS research investment as was requested in ALS Canada's 2019 pre-budget submission (also attached). We hope you will consider this information as you determine health funding for the future.

Without government investment there will continue to be no cure for ALS and few treatment options that have a significant impact on the disease. The federal government has an opportunity to provide critical funding to support impactful and evidence-based research directly focused on developing effective treatments that will have a meaningful impact for those living with ALS.

Sincere regards,

Tammy Moore
CEO

Enclosures

**ALS Society of Canada Analysis of Government Response Regarding Research Funding for ALS
February 2019**

In response to repeated calls from the ALS community to invest in dedicated, sustained funding for ALS research, the federal government has reiterated its past support for ALS research. This document summarizes the statements made by government, with additional context provided by ALS Canada to illustrate the ongoing need for sustainable and direct ALS research investment as was requested in ALS Canada’s 2019 pre-budget submission.

GOVERNMENT STATEMENT	ADDITIONAL CONTEXT
<p><i>“The Government of Canada, through the Canadian Institutes of Health Research (CIHR), is supporting ALS research. Between 2012-13 and 2016-17, the CIHR invested close to \$20 million in research related to ALS. Much of this research is focused on understanding the underlying mechanisms of ALS and investigating potential treatments.”</i></p>	<p>Based on our calculations of the CIHR funding database, from 2012 to 2017 CIHR invested just under \$16 million in research related to ALS. Included in this amount is funding for research projects examining many related diseases, such as Parkinson’s, and other neurodegenerative disorders. Of this almost \$16 million, CIHR invested just over \$10 million in research directly related to ALS, an amount that other disease areas often receive in one year or even one grant. Additionally, when comparing this amount to the total CIHR funding profile from 2012 to 2017, less than two-tenths of one per cent (0.19 per cent) was invested in grants directly related to ALS research.</p> <p>For a fatal disease like ALS, less than 1 per cent of overall federal health funding is not enough – nor does it demonstrate Canada is playing a “leadership role in supporting ALS research, and to support national efforts to find a cure for ALS at the earliest opportunity.”</p>
<p><i>“The Canada Brain Research Fund, administered by the Brain Canada Foundation, has a system of matching funds under which federal funding provided by Health Canada is matched with equivalent funding from private donors and charities involved in brain research.</i></p> <p><i>Since 2014, the money raised for ALS by the ice bucket challenge has been doubled by the Canada Brain Research Fund to provide discovery grants in order to promote research into the causes and treatment of ALS.”</i></p>	<p>Following the Ice Bucket Challenge in 2014, Brain Canada provided \$10 million in matched funds for ALS research through the Canada Brain Research Fund. Combined with contributions from ALS Societies across Canada, this brought the total funding portfolio for ALS research to \$20 million. Brain Canada also contributed matched funds of \$150,000 in 2017 to support Canada’s investment in Project MinE. The partnership with Brain Canada enabled a significantly higher level of ALS research funding than was previously possible and based on the achievements of the last five years, indicating that the Canadian ALS research community has the capacity for research with a higher price tag that is limited only because of available funds.</p> <p>Brain Canada’s commitment of matched funds now complete and the ALS Canada Research Program will return to its historic funding levels with \$1.5 million to \$2 million in</p>

	<p>research grants awarded each year. As a result, this national donor-funded research program is now the positioning of trying to support the entire ALS research community on the same amount of funding it could previously provide in one grant.</p> <p>Without sustainable federal funding for ALS research, there is significant risk of losing the opportunities and momentum achieved through the previous \$20 million commitment. Considering that Canadian families living with ALS are often already burdened by the financial costs of the disease, the pool of funding that grassroots efforts can generate is usually very small, especially given there is no survivor community. Donor dollars alone will not support the scientific breakthroughs needed to see a future without ALS.</p>
<p><i>“Health Canada also approved a new drug recently to treat patients with ALS through the priority review process. Health Canada continues to work with the Canadian ALS network and the manufacturer of this drug to facilitate access and ensure this drug is made available to all Canadians ALS patients as soon as possible.”</i></p>	<p>Health Canada’s recent approval of edaravone is an important and hopeful milestone for the ALS community and provides people living with ALS the option of a second treatment for the first time in nearly twenty years. As momentous as this moment was, it underscores how vital a sustained investment in ALS research is for the community.</p> <p>It took almost 20 years for a second ALS therapy to come to market, in which time approximately 20,000 Canadians died. And in the 180 days it took Health Canada to complete its priority review period, approximately 500 Canadians died of ALS.</p> <p>Health Canada’s approval of edaravone was only a first step. Other considerations, like the price of the drug and whether provincial drug plans will cover it, have not yet been determined. In the meantime, only 210 Canadians living with ALS are able to access the therapy through the MTPC Edaravone Canadian Supply Programme.</p> <p>While we hope to see a positive reimbursement recommendation, how many more Canadians will die while we continue to wait for a CADTH decision? And after that, how many will die awaiting availability through publicly-funded drug programs? With no defined timeframe for a decision and little transparency in the process, Canadians living with ALS have no sense of how long they might have to wait or if they will even be alive long enough to have affordable access to the drug with public reimbursement.</p>
<p><i>“Since 2013, the CIHR has participated in the launch of six joint funding opportunities with our international</i></p>	<p>The work E-Rare and IRDiRC are doing is important and a worthwhile investment, however, given ALS is one of many diseases being examined the direct funding impact to</p>

E-Rare partners to support research on rare diseases, thereby increasing Canada's capacity to prevent, diagnose and more effectively treat these diseases. Canada's participation in these international collaborations will enable the Canadian rare disease community to leverage international expertise to address rare diseases, including ALS."

the ALS community is limited. ALS is difficult to diagnose because no single test or procedure can firmly identify the disease. Many common diagnostic tools used to rule out other diseases that share similar initial symptoms are unable to confirm a diagnosis of ALS. As such, the IRDiRC diagnostic tool would likely have little impact on the overall ALS community and may be unable to confirm a diagnosis of ALS despite being able to work for other diseases.

Unlike many other rare diseases, promising new treatments and therapies have the potential to push ALS out of the rare disease category. Given this, the impact of IRDiRC is not as significant as direct funding for ALS research would be.