



In This Together

A Proposal for Financial Support as Partners of the Government to Sustain the Health System in responding to COVID-19

Health Charities Coalition of Canada's Financial Support
Proposal

January 2021

Support to Maintain Services for People Living with Diseases is Urgent.

HCCC and its members urgently need the federal government to partner with us to ensure that people living with diseases and their caregivers continue receiving the necessary support they need right now.

The current COVID-19 pandemic has impacted people living with disease and their caregivers in a significant way. This challenge is particularly acute as our health care system has been operating at reduced capacity, and people living with diseases have had surgeries cancelled or delayed. Governments themselves, as well as caregivers, are relying on health charities for advice on how to support patients during COVID-19 and we have had to rise to the challenge. On the other hand, health charities still need to deliver on their core mandates to provide critical support services and conduct life saving research for Canadians while faced with up to 50% reduction in revenue as a result of COVID-19. The substantial decrease in revenue has greatly affected health charities' ability to provide critical services and fund life-changing research programs. Without support, research projects have the potential to lose key personnel and capacity and experience considerable setback.

This is why health charities are seeking financial support from government. We need to protect the supports that those living with disease and their caregivers need and prevent further losses in vital health research. By working together, we can help improve the health outcomes of Canadians and we want to leave no one behind.

We are calling on the Government of Canada to establish a \$131 million funding program for health charities over two years to support Canadians living with diseases.

About Us

Founded in 2000, the Health Charities Coalition of Canada (HCCC) is a member-based organization comprised of national health charities and patient groups who represent the voice of patients at all levels of the health care continuum. Our mission is to strengthen the voice of Canadians, patients, and caregivers by promoting enhanced health policy and increased investment in health research.

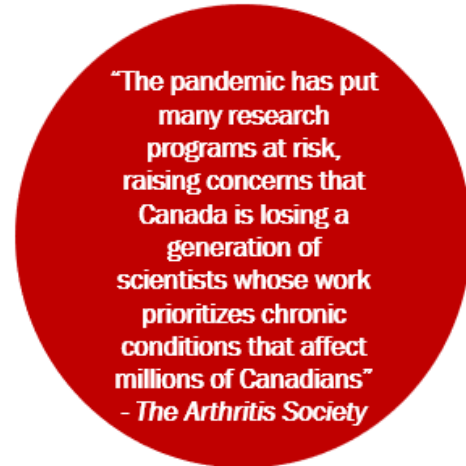
Our coalition is made of 25 health charities who help patients living with a wide variety of complex diseases and conditions. We represent a \$650 million industry- supporting 2,500 employees and 2.9 million patients across the country.



Research Initiatives at Risk

Health charities play a critical day to day role for Canadians. Health charities support people living with diseases with information that has been backed by research and clinical studies.

Our charities' broad array of patient support services and programs range from providing education resources to ensuring patients and caregivers receive the care and supplies they need directly in the home. Some examples of key programs and initiatives at risk include:



- Investments of up to \$155 million made annually by HCCC members into health research in Canada. This supports over 1,300 primary investigators and over 2,500 trainees, co-investigators, chairs, and professorships, all contributing to the breadth and depth of Canada's scientific capacity each year. Without health charities' investments in early-stage research and targeted research areas, we will not be able to advance new knowledge across many areas of health our members are currently funding.
- Important and complementary role played by HCCC members to other funders; partnering with the Canadian Institutes of Health Research, filling essential funding gaps, and offering stable funding, and promoting patient-centred research and direct connections to patient communities.
- Pathways for researchers to pursue funding for investigator-led research that promotes the exploration of new concepts, process and technologies that may lead to cures or improvements in treatment or care for patients.
- Translation of knowledge gained through research to affect better public policy and better health outcomes for Canadians.

Impact of COVID-19 on Health Charities

COVID-19 has greatly impacted people living with diseases. The pandemic's influence has created significant demand for health charities' support programs and the need for health research. Some areas of our work that have been impacted by COVID-19 include:

- **Revenues:** In order to support the vital programs/services and health research that our patients rely on, we need to have sufficient resources. Much of this revenue comes through donors. However, due to COVID-19, donations have been significantly reduced, and our charities cannot hold the usual fundraising events that they require. Many of our in-person volunteer-driven programs have also been put on hold.

- **Service delivery:** When demand for education and support services increased as a result of the pandemic, health charities responded by offering digital education, webinars, and pivoting their services to a digital format. Despite financial difficulties, health charities have been responding to patients' calls for resources and remained extremely active during the pandemic. As an example, Osteoporosis Canada ran online programs to support joint mobility in homes to help people manage their disease. Heart & Stroke also developed new digital tools to provide CPR training to medical professionals to accommodate urgent training needs while respecting the need for physical distancing. Furthermore, since March 2020, the Canadian Cancer Society has reported a 93% increase in the number of clients contacting information specialists through their website's online chat feature.

- **Research:** Without the same revenue levels from donors in prior years, research projects will lose key personnel and capacity and experience an erosion of expertise. These are examples of how our research program have been affected:
 - The Canadian Cancer Society has decreased its research budget by almost 50%.
 - ALS Society of Canada has decreased its investment in ALS research Discovery Grants by 50%.
 - Heart & Stroke has reduced its research awards from three years to one year, and the current competition is running without committed funds. Declines in charitable revenues have resulted in a 35% cut to annual lifesaving research investments (approximately \$11M).
 - Diabetes Canada's research budget has decreased by \$1.5M.
 - Canadian Lung Association has cancelled three research awards, other multi-year rewards, and reduced fellowships and scholarships for physicians and allied health professionals by 66%.
 - Parkinson Canada is unable to fund two key research streams, Pilot Project Grants and New Investigator Awards, totaling \$600,000.

- Canadian Liver Foundation estimates that they will not be able to support over \$1M in research funding in the coming year.
- The MS Society faced a 60% (nearly \$33M drop) in its revenue for 2020 and will be unable to fund key research programs totaling over \$9M.

These setbacks will have lasting impacts on health research in Canada, affecting hundreds of researchers, undermining millions of dollars in investments already made, and contributing to poorer health outcomes for Canadians.

Health Charities as Partners During and Post COVID-19

Health charities are an integral part of the social fabric of Canada, providing support, information and hope to Canadians in times of need. Our member organizations have a long history of being trusted partners of the government and we have adapted to the operational and service challenges due to COVID-19. Some examples of COVID-19 specific work that our charities have done are listed below:

- Asthma Canada experienced a 174% increase in Helpline inquiries from April 2019 to April 2020. 30% of those inquiries were COVID-19 specific.
- Health charities have conducted webinars and disseminated resources to our patients and caregivers on how to manage through COVID-19, linking them to various government resources. One example is the [Alzheimer Society of Canada's resource page](#).
- [Canadian Cancer Society](#) has funded clinical trials to test treatment for mitigating COVID-19 infections in people with diseases such as cancer and [Multiple Sclerosis Society of Canada](#) has worked with global partners to develop registries and data with respect to COVID-19 and those with multiple sclerosis.
- Our charities have also provided vital information to patient groups regarding vaccine hesitancy and information that people living with specific diseases need in order to have confidence in taking the COVID-19 vaccine.

The federal government can leverage the help of our organizations to meet immunization goals and provide communications about vaccines, particularly at a time when the health system is overburdened.

In the same vein, 1 in 3 Canadians suffer from a chronic disease and COVID-19 has greatly impacted Canadians' access to care, including the cancellation of hundreds of thousands of surgeries. According to the Canadian Institute for Health Information (CIHI) there has been a 17-21% decline in life-saving and urgent surgeries (procedures in this category include pacemaker insertions, bypass surgeries and cancer surgeries) and from March to June

2020, overall surgery numbers fell to 47% compared with 2019, representing about 335,000 fewer surgeries.¹

The impact of cancelled surgeries mean that patients are utilizing health charities to provide access to critical information and resources. We must maintain investments in supports for people living with disease and their caregivers and do so while preserving investments in health research. We are proud that Health Canada references research that members of HCCC produce and believe that it is equally important that the gains already made in health care research are protected so that scientific knowledge and discoveries can continue to benefit all Canadians.

Existing government relief programs have been unable to fully meet health charities' needs.

While HCCC is appreciative of the Canada Emergency Wage Subsidy, the program has not been able to fully meet our charities' needs. Many health charities were also unable to leverage the use of support programs such as the Emergency Community Support Fund, Canada Emergency Commercial Rent Assistance, and funding announced for small-medium-sized businesses and researchers due to ineligibility.

We have been dealing with the financial challenges in our own individual ways to try and prevent layoffs through salary reductions (with executive leadership teams taking a greater reduction), furloughed days, vacancies, and unpaid leave of absences. Despite these efforts, there have been a significant number of permanent layoffs - upwards of 50% of the workforce in larger charities and more significant reductions in smaller charities. It is essential that our sector continues supporting the development of treatments and therapies for those living with disease. Charities are unable to do this vital work with rapidly decreasing revenues.

¹ <https://www.cihi.ca/en/covid-19-resources/impact-of-covid-19-on-canadas-health-care-systems/covid-19s-effect-on-hospital>

We are in this together and are asking for the government's financial support.

We know that there is more support needed to help health charities continue to provide critical services for vulnerable patients throughout this pandemic, and as we emerge from it.

This is why we are calling on the Government of Canada to establish a \$131 million funding program for health charities over two years to support Canadians living with diseases.

HCCC would manage two funding streams to support health research and patient support services.

Canadian health charities would be eligible based on:

- Initiatives focused on supporting people living with diseases, with a particular focus of people managing their disease throughout the COVID-19 pandemic; and
- Existing research initiatives that have been impacted as a result of COVID-19 dynamics.



\$28 million to support patient support initiatives.



\$103 million in funding to support research initiatives that are at risk.

This funding would support the health charities that are part of HCCC who provided financial information to establish their fiscal need in FY2020 and FY2021 for health research and supports for people living with diseases. Amounts allocated for each funding stream were determined by a HCCC member survey that sought to understand the gaps in fiscal year 2020 and the anticipated budgets gaps for fiscal year 2021.

HCCC is asking to establish a master services agreement with the federal government to execute this funding program. HCCC has already identified a charity (an HCCC member) that has the credentials and capabilities to support this work. Furthermore, individual charity's audited financial statements would be proposed to validate government funds and rectify any discrepancies to prevent 'double dipping' of public funds.

Research Budgets

2019 Budget	FY2020 Pre-COVID Planned	FY2020 Actual*	FY2020 Shortfall	FY2021 At-Risk Budget Planned	FY2021 GAP (2021 budget difference to 2019 budget)	OUR ASK: (FY 2020 Shortfall + 2021 Gap)
\$111,119,514	\$119,698,649	\$64,688,336	\$56,226,828	\$64,559,039	\$46,560,475	\$102,787,303

*FY 2020 year end is the survey's end date as of October 15, 2020

Patient Support Budgets

2019 Budget	FY2020 Pre-COVID Planned	FY2020 Actual	FY2020 Shortfall	FY2021 Planned	FY2021 Shortfall (2021 budget difference to 2019 budget)	OUR ASK: (FY2020 Shortfall + FY2021 Gap)
\$47,942,478	\$53,106,471	\$37,430,865	\$15,570,606	\$35,119,951	\$12,822,527	\$28,393,133

In May 2020, the importance of funding from health charities to Canada's research community was highlighted by 1,013 signatories in a [letter](#) that was sent to the Prime Minister asking for the government's support of health charities in this difficult time.

Canadians place a high level of trust in Canada's national health charities. They look to us for information, reassurance, assistance, and leadership as they navigate their way through the health and social system. There is no question that health charities need financial support of the Government of Canada immediately and timing is of the utmost importance.

Our Members

HCCC is comprised of a broad coalition of Canadian health charities including:

- ALS Society of Canada
- Alzheimer Society of Canada
- The Arthritis Society
- Asthma Canada
- Canadian Cancer Society
- Canadian Hospice Palliative Care Association
- Canadian Liver Foundation
- Canadian Orthopaedic Foundation
- Crohn's and Colitis Canada
- Cystic Fibrosis Canada
- Diabetes Canada
- Fighting Blindness Canada
- Heart and Stroke Foundation
- Hope Air
- Huntington Society of Canada
- Kidney Cancer Canada
- The Kidney Foundation of Canada
- The Lung Association
- MitoCanada
- Multiple Sclerosis Society of Canada
- Muscular Dystrophy Canada
- Osteoporosis Canada
- Ovarian Cancer Canada
- Pancreatic Cancer Canada
- Parkinson Canada

For further information regarding this proposal please contact:

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