



Federated
**Health
Charities**

Charity Research Advancements

*These stats can be used in your campaign promotional materials,
communications or speaking points*

ALS Society of Canada

The result of the 2014 Ice Bucket Challenge gave the ALS community a tremendous gift: awareness and unprecedented investment in ALS research. Thanks to the viral fundraising phenomenon that year, along with matched funds from Brain Canada (through the Canada Brain Research Fund with financial support from Health Canada), the investment of \$20 million allowed the ALS Canada Research Program to fund more of the highest-quality ALS research with the most promise to slow down or even stop the disease.

Over the past four years, ALS Canada has invested over \$25 million into ALS research across the country – a responsibility we take seriously, with great care and consideration. We are proud to say that the donations generated from the 2014 Ice Bucket Challenge are nearly fully committed and we want you to know what your donor dollars contributed to.

Decisions around investment of ALS Canada research projects are based on results from a rigorous peer-review process. Independent panels of international scientific experts assess research proposals to identify projects that are grounded in scientific excellence and have the potential to advance the field of ALS research most quickly to develop effective treatments.

Examples of research funded through the ALS Canada Research Program:

- Understanding why eye muscles are often more resistant to ALS, and what we can learn from this that can help to preserve the function of other muscles.
- Determining whether there is a connection between ALS and viral infections.
- Testing a drug called pimozone to determine its ability to slow the progression of ALS.
- Learning about how a particular protein in ALS can be responsible for the spread of the disease within a person.

Thanks to donor generosity, ALS Canada and provincial ALS Societies across Canada are working to find the answers we need to create a future without ALS.

Alzheimer Society of Ontario

New stats or updates to the existing stats:

The Alzheimer Society Research Program (ASRP) has funded \$53 million in grants and awards since its inception in 1989.

The ASRP targets two types of research.

Biomedical: Focusing on the science of the brain and the changes that are associated with dementia and identifying therapeutic targets to reverse, stop or cure the disease.

Quality of Life (QoL): Exploring issues that impact the lives of people with dementia and their caregivers, including risk factors, behavioral and cognitive changes, physical support, caregiving, and health service delivery.

The Alzheimer Society Research Program is a collaborative initiative of the provincial Alzheimer Societies, the Alzheimer Society of Canada, partners, and our valuable donors who support research directed at both eliminating dementia and improving the lives of those affected by it.

Canadian Cancer Society

For over 80 years, the Canadian Cancer Society has brought our country together to fund world class research and to create a world where no one fears cancer. Today, more than 60% of Canadians will survive at least five years after their diagnosis. In the 1940s, survival was only about 25%.

As the largest, national charitable funder of cancer research in Canada, we are leading the way by investing nearly \$40 million in cancer research annually. Including work from a Toronto based research team led by Dr. David Malkin which found that a new cancer surveillance protocol dramatically improved survival for individuals with Li-Fraumeni syndrome, a hereditary disease that significantly increases a person's susceptibility to cancer. This study found that those under surveillance had a 100% survival rate after cancer was detected. For those not under surveillance, the survival rate was 21%.

Thanks to cancer research, we know we are saving lives every single day.

Cystic Fibrosis Canada

In 1989, the gene responsible for cystic fibrosis (CF) was discovered by a team led by Dr. Lap-Chee Tsui at the Hospital for Sick Children in Toronto. At the time, newborn screening for CF did not exist, few treatment options were available, and children with the disease were often misdiagnosed with pneumonia, chronic bronchitis, or whooping cough. Most Canadian children with CF did not live to adulthood.

Today, all Canadian provinces and territories have added cystic fibrosis to their newborn screening programs, allowing children with CF to be diagnosed early, and treatment to start immediately. Thanks to advances in research, these treatment and care programs have come a long way in the past 35 years. Several medications are either available or in development that target the underlying defects in people with CF, rather than only treating symptoms, and research is currently underway to develop personalized treatment for those who live with this complex disease. As a result of all these advancements, half of all Canadians with CF are expected to live into their 50s and beyond. In fact, the current median age of survival for Canadians with CF is 52 years, the highest in the world!

Canadian Liver Foundation

Option 1

35 years ago, a rare genetic liver disease called Wilson disease was leaving Canadian families without hope or answers for their loved ones. Wilson often led to brain complications, liver failure and ultimately, death. In 1993, researchers funded by the Canadian Liver Foundation were able to identify the gene causing Wilson disease, leading to major breakthroughs in the development of treatments. Wilson disease is now a more effectively treated disease, even in advanced stages.

Today, 1 in 4 Canadians may be affected by liver disease. The Canadian Liver Foundation continues to pledge millions of dollars annually to Canadian researchers who are investigating methods that prevent, diagnose, treat, and cure all forms of liver diseases affecting everyone from children to adults. Still, as the only non-government organization funding all forms of liver disease research in Canada, 80% of qualified research grant applications we receive annually remain unfunded. It's hard for this not to beg the question, "what if one of those unfunded grants held the key to a treatment or cure?"

Option 2

35 years ago, liver transplants were in their infancy and a rare occurrence. In 1993, the first living liver transplant between a mother and son was conducted in Canada. Now, this is a much more common procedure saving the lives of thousands of Canadian children with biliary atresia, the leading cause of liver failure in infants and children. Biliary atresia occurs when the bile ducts are either damaged or disfigured, resulting in bile build-up in the liver and leading to cirrhosis and liver failure. However, not all children are fortunate enough to receive liver transplants due to the difficulty in finding a compatible donor. Without the reestablishment of bile flow, children with biliary atresia will not live past the age of two.

There is still so much left unknown in biliary atresia and most other liver diseases. That is why the Canadian Liver Foundation continues to fund research into the

prevention, diagnosis, treatment, and cures of all liver diseases including those that affect children. Research is the only hope children have to live a life full of happy memories with their families and friends. Unfortunately, 80% qualified research grant applications we receive annually remain unfunded. It's hard for this not to beg the question, "what if one of those unfunded grants held the key to a treatment or cure?"

Spinal Cord Injury Ontario

After sustaining spinal cord injuries in the Second World War, our founders looked to rebuild their lives in Ontario, but found little medical and social support. Undaunted, they worked with community leaders to build Canada's first spinal cord injury rehabilitation center and introduced greater mobility and independence for people with SCI in this province. In fact, they brought the first folding wheelchair to Canada and spearheaded the development of the first mass-produced electric wheelchair, creating a revolution in mobility.

Over the past 35 years of the Federated Health campaigns, many of our achievements have come about through the tireless advocacy work of our clients, volunteers and donors including:

- With our partners we built the very first Accessibility Legislation in Canada - AODA.
- We collaborated to create the Ontario Neurotrauma Foundation to ensure health and reduction of secondary complications in neurotrauma is a priority in Ontario.
- We built a network of Employment Supports across Ontario- to advocate for opportunities for full gainful employment for people with disabilities.
- We co-founded the Ontario SCI Alliance and continue to co-manage its operations. We resolve systemic barriers that impact the quality of life of

people with spinal cord injuries and implement good research into practice faster.

- We work with all municipalities to advocate for accessible transportation services. Most recently, we collaborated with Uber to develop UBER WAV - which is known as the most efficient accessible transportation services in the world.
- In addition, we have supported a Postdoctoral Fellowship on spinal cord research for over 15 years.

Crohn's & Colitis Canada

- GEM Project - The Crohn's and Colitis Canada Genetic, Environmental, Microbial (GEM) Project is a global research study that looks to uncover possible triggers of Crohn's disease.
 - Launched in 2008, the GEM Project has reached its goal of 5,000 participants and that over 70 participants had developed Crohn's. It is also the world's largest clinical study investigating the causes of Crohn's disease.
- PACE Network - The Promoting Access and Care through Centres of Excellence (PACE) network brings together leading inflammatory bowel disease (IBD) centres to advance best practices for medical professionals and elevate the standard of care for patients in Canada with IBD.

Heart & Stroke

Women's hearts are victims of a system that is ill-equipped to diagnose, treat and support them. Close to 25,000 women die each year from heart disease. A research study revealed that early heart attack signs were missed in 78% of women. This began in research where, for decades, specific therapies were tested in controlled studies on primarily middle-aged white male subjects. In fact, two-thirds of heart disease clinical research focuses on men. However, this one-size-fits-all assumption is incorrect as women's hearts are different. Not only are women's hearts smaller, they are also affected by hormones, pregnancy, and menopause. Heart disease may also develop differently in women. In other words, sex and gender blinders have caused too many women's lives to be cut short.

Heart & Stroke is on a mission to make positive changes in women's heart and brain health. Along with our powerful campaign #TimeToSeeRed, we have worked hard in the past 2 years to encourage and invest in research for and about women in Canada to ensure women are equitably represented. Since Heart & Stroke's Women's Heart and Brain Research Initiative launched in 2016, we have funded 15 researchers from 11 institutions in 5 provinces and secured over \$3.5M of partner funding to fund gender equitable research. We also require that women be equitably represented in research so that we can understand how women's hearts and brains are different. This will significantly reduce the number of women who are under-diagnosed, under-treated and under-supported. Help us close the research gap. Donate today to help us double the dollars we invest in research for women.

[Hemophilia Ontario](#)

Experimental methods are currently being investigated as possible breakthroughs for curing bleeding disorders.

Researchers are working on a method to insert better functioning factor VIII or factor IX genes into the cells of people with hemophilia so their blood will clot more effectively. It is hoped that gene therapy will lead to patients having fewer bleeding episodes. Gene therapy might eventually help people with hemophilia begin producing their own clotting factor, alleviating the need for, or reducing the number of weekly infusions. With this advance, there exists the potential for someone born with severe hemophilia to eventually have significantly milder symptoms.

Some gene therapy research trials have been performed in humans with mixed results. The future for gene therapy in hemophilia is continuing albeit at a moderate pace. There are many projects continuing in animal models. Improved long-term expression of the new genes will require the development of better vectors (the means of delivering the new genes into the cells).

Several new technologies are also being implemented to advance hemophilia treatment. These new technologies, once used to destroy viruses in blood, have been successful in virtually eliminating the risk of contracting HIV or hepatitis C from clotting factor today. Pharmaceutical companies are continuing to investigate genetically manufactured product alternatives derived from little to no human blood products. New products have consistently been developed that have an even higher purity than previously available.

The Kidney Foundation of Canada

In the 1960s, people with kidney failure had little hope of survival. Dialysis was considered an extraordinary treatment and restricted to very few. Transplantation was still experimental. The amazing advancements in kidney research, supported by individuals like you who participate in the Federated Health Charities Campaign, have created a new reality for those living with kidney disease. A kidney transplant is the best treatment option with success rates of over 82% after five years. Dialysis treatments have vastly improved and patients can exercise greater choice in finding a treatment that best suits their lifestyle whether it be in hospital, in a community setting or at home.

Thank you for helping to make a difference, and for improving the quality of life for thousands of Ontarians living with kidney disease.

Lung Health Foundation

While we were originally founded to provide care for tuberculous patients, over the years we've evolved to meet the changing needs of Ontarians, expanding our focus to asthma, chronic obstructive pulmonary disease, lung cancer and other forms of lung disease.

We help Canadians breathe by:

PROMOTING HEALTHY BREATHING

We promote healthy breathing by fighting for policies that protect our air and educate Canadians about what they can do to promote their own lung health.

SUPPORTING THOSE WITH LUNG DISEASE

We support and advocate for those living with conditions that affect the lungs and the ability to breathe, and fight to challenge the stigma and ignorance that can be associated with lung disease.

FINDING FUTURE SOLUTIONS

Through education and research, we work to turn knowledge into action and find cures to diseases that will deliver a future of better breathing for all.

We have invested \$30 million in the past 20 years in lung health research to help the 1 in 5 Canadians living with lung disease.

Ontario Federation for Cerebral Palsy

Cerebral Palsy describes a neurological condition affecting body movement and muscle co-ordination. Cerebral Palsy is considered a non-progressive but not unchanging condition of movement and posture. It is not a disease or illness, but rather a broad term that describes a group of brain disturbances that impair the ability to control some muscles, especially those affecting movement and posture.

In the past, there was widespread misunderstanding and exclusion of people with cerebral palsy and other disabilities. The OFCP recognized that the public needed to be informed and educated around inclusion, integration, participation, independence, and the rights of people with disabilities. The OFCP was particularly concerned with ensuring that people who have cerebral palsy were given the opportunities and support needed to live a meaningful life.

For the past seventy years, it has been the mandate of the OFCP to engage in the long-term work of creating permanent fundamental changes that will empower people with cerebral palsy. Through an ongoing campaign of workshops, articles, lectures, videos, conferences, fairs, pamphlets, fundraising activities, and advocacy, the OFCP works to raise awareness and understanding about cerebral palsy.

For over 70 years, the OFCP has been committed to supporting the most advanced and highest quality of Cerebral Palsy research relevant to the cure, cause, prevention, improved treatment, and ways to improve the quality of life for people with cerebral palsy.