ANNUAL REPORT 2018/19

AlzheimerSociety



Thank you!

FOR HELPING US TO EXPAND OUR SERVICES AND INSPIRE ACTION.



MARY BERNICE ALLEN MEMORIAL FUND

In the early 1990s, Brent's mother, Bernice, was diagnosed with Alzheimer's disease.

"At the time," Brent explains, "this startling diagnosis was quite overwhelming for our family. It came at a time when less was known about the disease. Back then, dementia wasn't a topic that was openly discussed in families, much less among the general public." He added, "I was compelled and inspired to do something to honour the strong, caring, fun, and charismatic mother she was and the remarkable legacy she left behind."

For the 20th anniversary of his mother's passing, Brent worked with the Alzheimer Society of Ontario to create the Mary Bernice Allen Memorial Fund, which offered a \$50,000 matching gift for donations that support research, programs, and services.

"Our goal for the donation," says Brent, "was to do as much as we can to positively impact the lives of those living with dementia, as well as the network of caregivers who help them through their journey with the disease." Given that so many more people will be diagnosed with Alzheimer's, Brent says, "I believe that without impactful programs and services and cutting-edge research, Ontario will be overwhelmed. I am extremely grateful that the Alzheimer Society continues to work on addressing stigma and changing perceptions of what it is like living with Alzheimer's disease or dementia."

Thanks to the generosity of so many, the matching-gift campaign surpassed its goal of \$100,000. Proceeds from the fund have already supported essential programs like the Alzheimer Society's U-First!® and First Link® programs. More people were connected to available services within their communities or received training to provide the best possible care.

Thanks to your generous support, we've been busy this past year!



Cathy Barrick
Chief Executive Officer
Alzheimer Society
of Ontario

Cathy Barnce



Keith Gibbons Board Chair Alzheimer Society of Ontario

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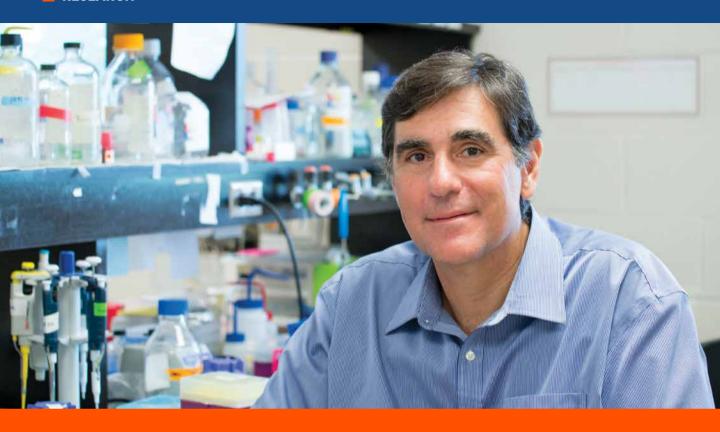
Our top priority has been to increase our capacity and impact in the community, as well as providing more support to our local Alzheimer Society partners. To guide this process over the next three years, we have developed a strategic plan to expand our services, inspire action, increase collaboration, and promote excellence.

A new provincial government created an opportunity to rally our supporters and the people we serve to engage with their representatives at Queen's Park. The focus was clear — ensuring that the necessary supports are in place for those living with dementia and their care partners to remain in the community. We reinforced these appeals by asking the government for ongoing investments in our community-based programs, including our First Link® program and respite services. We have had some great meetings — bringing along people directly affected — and look forward to the government's continued support.

We have built on our success in bringing together our partners across the province to enhance our collective mission and focus. We have had some wonderful discussions with our partners about research, programs, and marketing. We know that is what you, as a supporter, care about.

At the Alzheimer Society we want to be the "Help for today and hope for tomorrow." With your help, we hope, one day, to be part of finding the cure for Alzheimer's disease and other forms of dementia. Until then, our commitment to you is to keep being there for you now so that you and those you care about are supported in the ways that matter to you.

Thank you again for your support. We couldn't do any of this without you. You make a difference and, on behalf of those living with dementia, we are deeply grateful.



Researching Better Treatments and a Better Future

The Alzheimer Society Research Program (ASRP) is a collaborative initiative among the provincial Alzheimer Societies, the Alzheimer Society of Canada, our partners, and generous donors like you.

ASRP funds two types of research:

- Biomedical, to understand the science of the brain and changes associated with Alzheimer's disease and other forms of dementia, as well as to discover therapies to reverse, stop, or cure these disorders.
- Quality of Life, to identify issues impacting people living with dementia and their care partners, including risk factors, behavioural and cognitive changes, physical support, caregiving, and health service delivery.

This past year, your support helped:

- Identify potential new drugs to treat Alzheimer's disease.
- Distinguish different forms of dementia by applying neuroimaging techniques.
- Study how diet and other lifestyle choices may delay the onset or progression of dementia.
- Develop technology to enhance quality of life, care, and safety.
- Improve care delivery in the community and in long-term-care settings.

Neda Rashidi-Ranjbar

University of Toronto, Toronto, ON



PROJECT: Neural mechanisms of transcranial Direct Current Stimulation Plus Cognitive Remediation in the prevention of cognitive decline, Alzheimer's, and dementia

\$66,000 - Biomedical, Dr. and Mrs. Albert Spatz doctoral award

"This project focuses on the potential preventative treatments for elderly at risk of Alzheimer's disease and other dementias. If we can better understand how the treatment might work and predict who will respond to such treatment, our study could impact clinical care through dementia prevention."

Pamela Durepos

McMaster University, Hamilton, ON



PROJECT: Caring ahead: development and evaluation of a auestionnaire to measure preparedness for end-oflife in dementia

\$66,000 - Quality of Life, doctoral award

"Many family care partners and people with dementia feel unprepared and unsupported at the end of life because dementia is unpredictable and palliative care is not optimal. Care partners who feel unprepared struggle with decision-making for their loved one, and suffer from intense grief and problems with health or functioning after death. Bu understanding and then assessing how prepared care partners feel, health care professionals can improve palliative care and advance end-of-life care and planning."

Vania Prado University of Western Ontario, London, ON



PROJECT: Modulation of brain inflammation in Alzheimer's dementia using microglial chemogenetics

\$150.000 - Biomedical. grant

"My study will test a novel therapeutic approach to activate a special class of neurotransmitter receptors specifically on brain immune cells. If successful, in the future it could be adapted to be used in humans to treat dementia."

Rikke Hahn Kofoed University of Toronto, Toronto, ON



PROJECT: A combined therapy targeting amyloid and TrkA using MRI-guided focused ultrasound gene and drug delivery in a mouse model of Alzheimer's disease

\$83,000 - Biomedical, post-doctoral award

"I will target two of the key processes behind the development of Alzheimer's disease, namely protein accumulation and loss of neuronal connections. Previous therapies focusing solely on one have failed in the clinic. so I'm proposing this combination therapy as a new treatment strategy. My hope is to lay the groundwork for a new therapeutic strategy, which could ultimately lead to the development of future disease-modifying treatments for Alzheimer's."

Lauren Bechard University of Waterloo, Waterloo, ON



PROJECT: Enhancing the use of physical activity for the prevention and management of dementia: from population-level to person-centred

\$66,000 - Quality of Life, doctoral award

"I'm currently researching health promotion through physical activity for persons living with dementia. The problem I'm trying to solve is how we can create more inclusive spaces and opportunities for persons living with dementia to participate in physical activity. The tools and knowledge I'm developing will help community exercise providers understand the unique needs and abilities of persons living with dementia for exercise participation."

Rachel Lackie University of Western Ontario, London, ON



PROJECT: Regulation of amvloid toxicity in Alzheimer's disease by the co-chaperone stressinducible phosphoprotein 1

\$66,000 - Biomedical, Dr. and Mrs. Albert Spatz doctoral award

"I study a particular protein, STI1, that is a key component of the cell's quality control system that can protect brain cells and stop corrupt protein clumping. Our work will reveal whether STI1 may increase brain-cell resilience to toxic protein aggregates, which are hallmarks of Alzheimer's disease."

Visit alzheimer.ca/en/on/research to read more about our researchers.

Providing supports and care as early as possible - before a crisis.

First Link® is Ontario's only single access point for education, supports, and services for people living with dementia and their care partners.

In fiscal years 2017/18 and 2018/19, the Government of Ontario increased First Link® funding to enhance and expand programming, underscoring the critical role of local Alzheimer Societies. First Link® Care Navigators are now in place at every Society across Ontario. They provide direct client services that include individualized assessments, care planning, ongoing proactive follow up, and communication between providers and across sectors along the continuum of care.

The government's investments plus ongoing First Link® programming have increased capacity to serve the growing number of people living with dementia and their care partners. In 2018/19 alone, local Societies served almost 86,000 clients and received 28,000 new First Link® referrals. Across the Societies, more than 340,000 phone or in-person visits were accommodated to provide support.

Thank you for all of your help and information. You have been a real lifeline!"

- Care partner, daughter

To learn more, visit firstlinkontario.ca.





Staying Safe with First Responders



We expanded access to our Finding Your Way® program to further reduce the risks associated with going missing for people living with dementia.

This past year, we launched an online First Responder Information Centre. It provides first responders in Ontario with information about preparing for and quickly responding to missing-person events associated with dementia.

Learning content was developed collaboratively by a group comprised of the Alzheimer Society of Ontario, police officers, and University of Alberta PhD candidate Noelannah Neubauer, whose research in occupational therapy helped guide the development of the Centre.

The First Responder Information Centre provides resources that include:

- · Tips on communicating with a person living with dementia.
- Search programs first responders can use to help find missing people with dementia more quickly.
- · Helping people living with dementia and their families create safety plans and prepare for missing-person incidents.



First responders can access in-person training offered through the Finding Your Way program and delivered by local Alzheimer's Societies. Last year, there was a 24 per cent increase in the number of training sessions hosted throughout the province. That means more people who can help someone living with dementia if they appear to be missing.

To learn more, visit **findingyourwayontario.ca**.



Giving Mind and Body a Boost

Minds in Motion

We all need to stay active as we age. The Canadian Society for Exercise Physiology recommends at least 150 minutes of moderate to vigorous intensity exercise every week for adults aged 18 to 64. Minds in Motion® helps people reach this goal in a dementia-friendly setting where they stay active to improve their endurance, mobility, and balance. They also receive take-home exercises to help them keep moving throughout the week. The program also creates opportunities for all-important social interactions, which reduce isolation, create opportunities to make new friends, and expand support networks.

More than 20 local Alzheimer Societies partner with community service providers in their region to run Minds in Motion®. Each program consists of a weekly two-hour session and runs for eight weeks. Activity modifications are included to ensure accessibility.

This beloved program is now entering its fifth year and remains in high demand across Ontario, with many participants signing up for multiple programs. This past year, 3,800 people participated at more than 40 different community venues — a 90 per cent increase over last year.

"We have made some wonderful new friends. We go to hunch together each week, and we've having so much fun."

To learn more, visit **mindsinmotion.ca**.



Shifting the Culture of Care



Together with our health care providers, we are improving the way that health care is delivered to people living with dementia and their families through U-First!®. This education and training program helps front-line staff to develop a common knowledge base, language, and approach by:

- Understanding the person living with dementia and associated changes in behaviour.
- Working as a team to develop individualized support strategies.

This year alone, nearly 900 health care providers took part in 81 in-person U-First!® workshops. We also worked to make an even bigger impact by training more facilitators to offer U-First!® in Ontario and beyond. Twenty-two new facilitators were trained in Ontario, and workshops were rolled out to our colleagues in Saskatchewan and Nova Scotia.

This is the perfect method! I will be using U-First! and I'm excited to share this with my co-workers and start seeing better results."

- personal support worker

Based on what I have learned in U-First!, I will make multiple changes in my work. It is very helpful, and I am looking forward to implementing it in our care here."

- registered nurse

U-First! is a tool for the caregiver, as well as the client. It assists in systematic documentation and resolution in the care of a patient with dementia. It aids in personal reflection and development of the caregiver."

- registered practical nurse

To learn more, visit **u-first.ca**.

DEMENTIA-FRIENDLY COMMUNTIES™



Building a Dementia-Friendly Ontario™

We are helping to build dementia-friendly places across Ontario where people are understood, respected, and supported to stay active. Alzheimer Societies are mobilizing the support of the entire community, including people living with dementia, care partners, businesses, and service providers.

With this support, we have:

- Delivered dementia-friendly training to 13,500 individuals.
- Partnered with age-friendly communities, which help seniors live safely and remain active, to develop common principles and guidelines.
- Partnered with libraries to create dementiafriendly spaces with services that include dementia-friendly reading lists. They also provide accommodations for Society staff and volunteers to train community members.

To support these important efforts, the Alzheimer Society of Ontario is undertaking research, creating training and evaluation tools, identifying new partners,

sharing knowledge and resources with Alzheimer Societies across Canada and our international partners, and assisting with fund development.

Join thousands of Ontarians supporting the Dementia-Friendly Ontario movement. Contact your local Alzheimer Society to see what opportunities are available, including:

- Signing up for a dementia-friendly training session near you.
- Having your co-workers trained to support a dementia-friendly workplace.
- · Becoming a volunteer.



To learn more, visit dementiafriendlyontario.ca.

Advocating for Better Care

Last year's provincial election brought about Ontario's first change of government in 15 years. It also led to the election of 73 rookie Members of Provincial Parliament

— more than half of all MPPs at Queen's Park

This wave of new faces presents exciting new opportunities, as well as some challenges for the Alzheimer Society of Ontario. While many MPPs were already familiar with the work of the Alzheimer Society in their constituencies, they welcomed the opportunity to learn more about our work in their community.

Since the June 2018 election, we have met with over two-thirds of Ontario's MPPs — including more than half of all Cabinet Ministers. We conveyed to them the experiences and impactful stories that community advocates shared with us, helping to forge stronger relationships between the Alzheimer Societies and their local elected officials.

Maintaining these lines of communication is helping the Alzheimer Society navigate the changing landscape of health care in this province. The government has moved quickly to transform Ontario's health care system, introducing legislation that will change health care delivery in the province. Changes include creating a province-wide agency called Ontario Health, which will incorporate 20 provincial agencies, including all 14 Local Health Integration Networks.

The Alzheimer Society of Ontario was among nearly 2,000 individuals and organizations who asked to give testimony prior to the act's passage and one of only 30 invited to do so. We took this opportunity to make your priorities heard and advocate for a stronger emphasis on community support services.

Aside from establishing Ontario Health, the new law allows for the creation of integrated care delivery



From Left: Caregiver Jane Kennedy; CHATS board chair lan Hilley; CHATS CEO Christina Bisanz; Honourable MPP Christine Elliot; AS York board chair Zahid Salmon; and AS York CEO Loren Freid

systems — more commonly known as Ontario Health Teams (OHTs). Composed of health service providers, OHTs will be responsible for delivering health care in defined geographic areas. Eventually, every health care provider in Ontario, including local Alzheimer Societies, will be part of an OHT.

As we learn more about how OHTs will develop, the Alzheimer Society will continue to share information with local Societies, helping them navigate this transformation. We are committed to keeping our community advocates — including board members and volunteers — informed as details of ongoing health system changes continue to emerge.

We remain committed to amplifying the voices of Ontarians impacted by dementia, as well as advocating for a health care system that is better equipped to address the unique needs of people living with dementia, their care partners, and families.

Since the June 2018 election, we have met with over two-thirds of Ontario's MPPs — including more than half of all Cabinet Ministers.

To learn more, visit alzheimer.ca/en/on/advocacy.

Helping You to Raise Support

We want to make it easy for our supporters to raise funds on our behalf, so we're pleased to announce we have a brand-new do-it-yourself event platform called Anything for Alzheimer's.

Anyone wishing to hold their own fundraiser can now do so. Use your creative ideas, passions, and talents to hold an event in support of people living with dementia.

Kyle Black, our first Anything for Alzheimer's fundraiser, lost his mother to Alzheimer's four years ago. He wanted to help others going through this difficult journey. Using his 40th birthday as an opportunity to honour his mother's memory, he raised a remarkable \$4,000 to support Alzheimer's research.

Register your plans on our website and you will receive a customized web page with a unique link to share and promote your fundraising event. Donors can complete their donations online and will automatically receive a tax receipt.





Savhanna and Connor hosted a lemonade stand in honour of the Alzheimer Society.



Kyle Black and his mother Jane.

"One of the things I loved most about fundraising in honour of my mom was bringing memories of her back to life. It was incredible to hear the stories that people were sharing about how she touched their lives. The generosity of our friends and families, as well as people we didn't even know, was astonishing." – Kyle Black

Anyone wishing to hold their own fundraiser can now do so. Use your creative ideas, passions, and talents to hold an event in support of people living with dementia

To learn more, visit alzgiving.ca/anything.



Saving the World from Dementia

Help stem the rising tide of dementia and other brainrelated diseases. Become a Super Hero by doing your Will and including a charitable gift to the Alzheimer Society of Ontario. In addition to protecting the world from the evils of dementia, you will save taxes on your hard-earned assets (and who doesn't want to save taxes?).

Anyone can be a superhero. Why not you? By joining our Super Hero Legacy Giving Program, you can help invest in a future where dementia is defeated.

Did vou know:

- More than 70 per cent of Canadians do not have Powers of Attorney for Care and Property.
- More than 50 per cent of Canadians do not have a Will.
- Only about 15 per cent of Wills include a charitable gift in their estate plans — despite this being an excellent way to save taxes.

I can think of no other disease that has such a profound effect on loss of function, loss of independence, and the need for care.

I can think of no other disease so deeply dreaded by anyone who wants to age gracefully and with dignity.

I can think of no other disease that places such a heavy burden on families, communities, and societies.

I can think of no other disease where innovation, including breakthrough discoveries to develop a cure, is so badly needed."

Margaret Chan, Director General, World
 Health Organization, speaking at the First WHO
 Ministerial Conference on Global Action Against
 Dementia in 2015

Ask for our free Super Hero Will Planner and Guide today. To learn more, visit alzsuperhero.ca.



Members of the Alzheimer Society of Ontario's Board of Directors, elected from across Ontario, generously guide and support our efforts with their time, talent and passion. We thank you for your leadership!

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We are incredibly grateful to the Individuals, Corporations and Organizations that have supported the Alzheimer Society of Ontario. For a full list of donors who have made contributions over \$1,000 this past year, please visit: annualreport2019.alzheimerontario.ca



OUR MISSION

The mission of the Alzheimer Society is to alleviate the personal and social consequences of Alzheimer's disease and other dementias and to promote research.



OUR VISION

A world without Alzheimer's disease and other dementias.

REVENUE



EXPENSES



Complete audited financial statements are available at alzheimer.ca/en/on/About-us/Annual-Report.

You can do something about dementia.

DONATE TODAY

www.alzheimerontario.ca

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