

Alzheimer Society

ONTARIO



ANNUAL REPORT 2016/17

Working together to end dementia



Wendy and David Hughes

“You can’t do this on your own, and I’ve realized it’s perfectly okay to ask for help”

Wendy knows these words well. As primary caregiver to her husband David, she understands that it takes a village to care for a person with dementia. For her husband, it began with getting the right diagnosis.

Wendy and David have always kept busy. They loved to garden, read, play golf, and after they both retired, David even drove a school bus for the schools in their neighbourhood.

When David started to become withdrawn and apathetic, Wendy knew something was wrong.

In his mid 70’s, David was diagnosed with Parkinson’s and Alzheimer’s disease. But the symptoms he showed didn’t add up. Wendy noticed his memory loss fluctuated, rather than declined and although his personality had changed significantly, he didn’t fit the

mold of Alzheimer’s. She became an advocate for her husband and sought to learn more about the different types of dementia.

After several years of persistence, the Hughes finally had an answer. David was diagnosed with Lewy body dementia, a form of dementia that interrupts the brain’s messages from being transmitted. A person with Lewy body dementia may experience progressive loss of memory, language, and reasoning. Symptoms can also include stiffness of muscles, shaking, and shuffling movements.

David’s diagnosis came as somewhat of a relief for their family. Now they have access to the right treatments and support. The Alzheimer Society has been an invaluable resource for the Hughes.

THANK YOU FOR STANDING UP AGAINST DEMENTIA

It's remarkable what can be achieved when we join together in the fight against dementia. Your support this past year has been instrumental in helping to change the lives of those impacted by Alzheimer's disease. On behalf of the Alzheimer Society of Ontario's Board of Directors, staff, volunteers and friends – **WE THANK YOU!**

Thanks to your generous support, we have had one of our most successful years full of significant progress and achievement.

We continue to **move research forward** to find a cure and improve the quality of life for men and women living with dementia. Our contributions to the Alzheimer Society Research Program account for their largest source of revenue. Through research grants and awards, we are pleased to help support some of the country's most promising research initiatives. With the growing number of people diagnosed with dementia, we understand that research is the key to unlocking the mysteries of the brain.

Over the last 2 years the Alzheimer Society of Ontario has led the charge to advocate for a fully funded dementia strategy in the 2017 Ontario budget. Through MPP letter writing campaigns, petitions, roundtable discussions and Dementia Strategy Working Groups our efforts (and your support) have led to a greater appreciation of the need for a dementia strategy. The Ontario Government has heard us. The 2017 Ontario Budget will include **\$101 million over three years for the implementation of an Ontario dementia strategy!**

Our **province-wide programs** continue to be a source of knowledge, support and hope for individuals, families, caregivers and professional health workers. Your support makes this possible.

As you read through the following pages, know that the impact that we have had on our province is because of your kind support and commitment to the Alzheimer Society of Ontario.

We have many accomplishments to celebrate this year, but looking ahead there is still much to be done. With 25,000 new cases of dementia diagnosed every year, we must continue to fund research for a cure, advocate for support from the Ontario government and provide programs and support to families and individuals impacted by dementia.

With help from you and other generous donors, we can rise to meet these challenges.

We are incredibly grateful for your support. Thank you!



Chris Dennis
Chief Executive Officer
Alzheimer Society
of Ontario



Pamela Waeland
Chair, Board of Directors
Alzheimer Society
of Ontario

Leading the way to a world without Alzheimer's disease, our researchers are dedicated to better understanding the brain. They are focused on prevention, treatment and improving the lives of men and women with dementia.

There is no cure for Alzheimer's disease, but incredible strides are being made into discovering what causes this disease and how to cure it. Each day, our research teams are one step closer to uncovering important information on how our brain functions. Some of the best and brightest minds in the world are working tirelessly to prevent dementia, find new treatments and drug therapies, uncover solutions for earlier diagnosis and ultimately to find a cure.

The Alzheimer Society Research Program (ASRP) has funded over \$50 million in grants and awards since 1989. We also partner with the Ontario Brain Institute and Ontario Neurodegenerative Disease Network to coordinate research efforts.


We fund two types of research:

- **Biomedical** - focusing on the science of the brain and changes associated with dementia and identifying therapeutic targets to reverse, stop or cure the disease
- **Quality of Life** - exploring issues impacting patients & caregivers

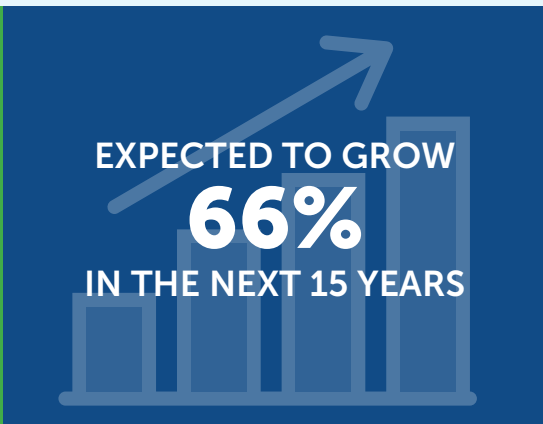
Because of your support and the support of generous people like you, we funded 35 grants and awards in the amount of \$3,303,427 to dedicated researchers across Canada. Thank you for helping us to accelerate promising research initiatives!

"You are absolutely integral to our work. With the support of Alzheimer Society donors like you, I'm optimistic about research. I have great hope that better drug treatments will be available in the future, helping us to stop the disease before it starts."

- Dr. Carmela Tartaglia,
University of Toronto Memory Clinic
Toronto Western Hospital Tanz Centre for Research in Neurodegenerative Diseases



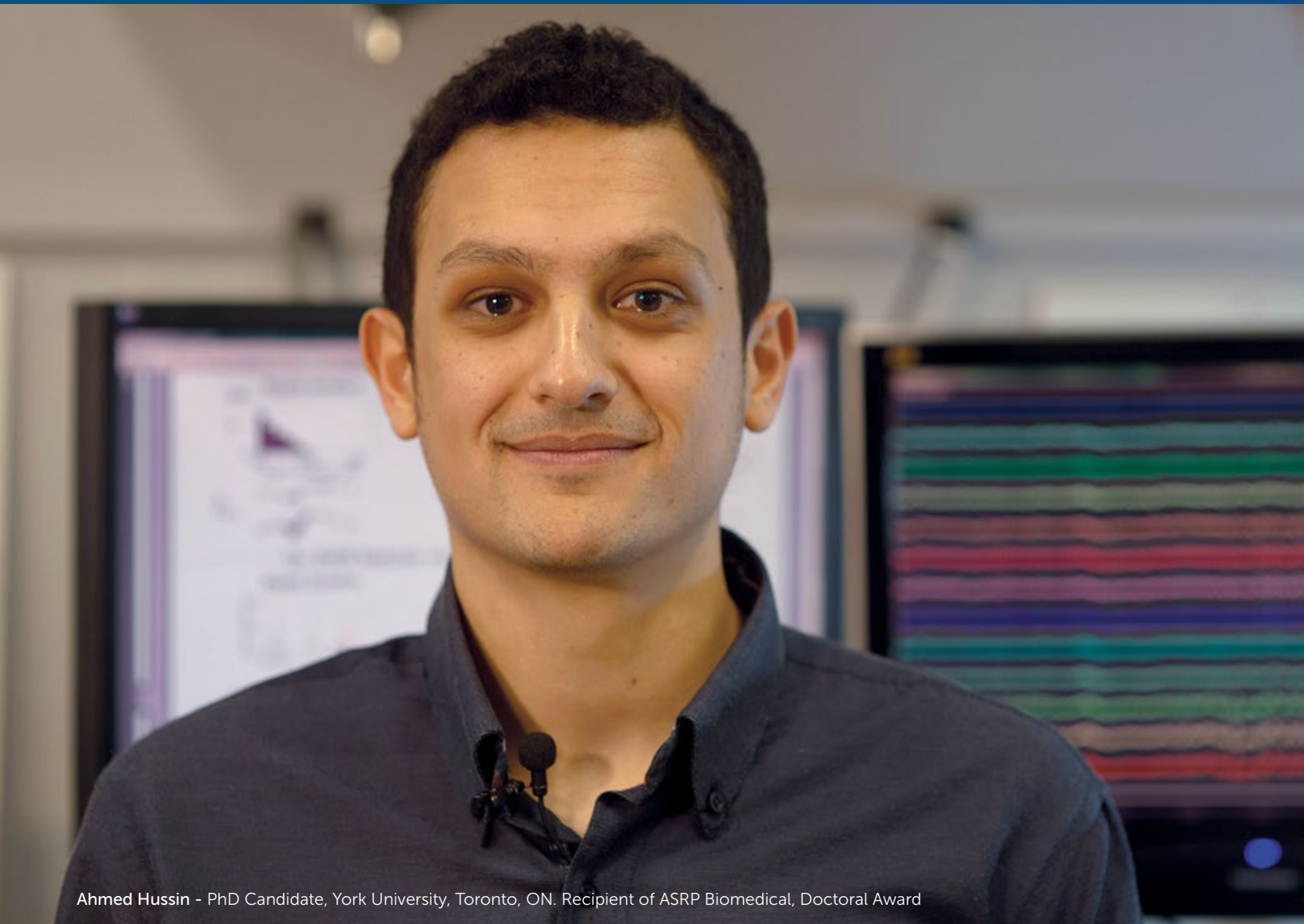
564,000
CANADIANS LIVING
WITH DEMENTIA



EXPECTED TO GROW
66%
IN THE NEXT 15 YEARS



25,000
NEW CASES OF DEMENTIA
WILL BE DIAGNOSED
THIS YEAR



Ahmed Hussin - PhD Candidate, York University, Toronto, ON. Recipient of ASRP Biomedical, Doctoral Award

“Your generosity makes a real difference.”

“ Thanks to generous people like you, I am working to improve the memory-deficits associated with Alzheimer’s disease. My aim is to improve the quality of living for people with these disorders.

In our lab, we are studying treatments that have been commonly used to help people with Parkinson’s disease and applying them to treatment for memory deficiencies associated with Alzheimer’s disease. We are using a specialized technique called Deep Brain Stimulation (or DBS) which delivers electric pulses to selected areas of the brain.

We hope to find the precise pattern of pulses based on frequency, intervals, and duration, which could help memory and improve the function of the brain’s memory circuit.

If successful, the research could prove vital in developing effective DBS therapy for men and women with Alzheimer’s disease.

It is thanks to your support of the Alzheimer Society of Ontario that I am able to conduct this research that could one day help thousands of men and women with dementia”.

To learn more about the researchers you support, please see www.alzheimer.ca/Research



Pamela Waeland, Chris Dennis, Phyllis Fehr, Frank Palmer, and Karen Harrington

Leading the way to a dementia strategy for Ontario

Working closely with the provincial government and other stakeholders, over the past two years, the Alzheimer Society has engaged thousands of men and women in Ontario to provide input and demonstrate their support for a fully-funded strategy.

Since 2016, our Action for Dementia Campaign has helped to build public profile and awareness. Over 4,000 people added their names to support the development of Ontario's dementia strategy and 80% of responses to the Ministry's survey were as a result of our campaign. We also played a key role in ensuring that the voices of people with dementia and their families were heard at public consultation Town Halls, in addition to co-hosting local discussions in 6 other communities.

At the beginning of 2017, our campaign resulted in 6,872 letters to MPP's in Ontario and in person meetings with MPPs across the province. In April 2017, we were pleased to see that our efforts and your support are making an impact!

Together, we helped lead the way to the Government of Ontario's commitment to invest \$101 million over 3 years towards the implementation of a provincial dementia strategy! This is a major win for the over 214,000 Ontarians and their families who have been impacted by dementia!

A fully-funded and comprehensive dementia strategy will help ensure people living with dementia, their care partners and families have access to the resources and services they need.

Thank you to all of our Champions, partners and allies who are out there every day improving the lives of Ontarians living with dementia and their families. Without your support, a fully-funded dementia strategy in Ontario may not have been realized.

We look forward to continuing our work to help guide and deliver the implementation of the Ontario Dementia Strategy.

"My government colleagues and I are committed to ensuring that everyone living with dementia in Ontario, their families and their care partners have the right supports, funding and tools in place to make informed decisions about their care, and that they can continue to be treated with the dignity and respect that they deserve. I look forward to further opportunities for collaboration with you and the Alzheimer Society of Ontario."

– Kathleen Wynne, Premier

“I didn’t really know where to go for help. That’s when I reached out to the Alzheimer Society for support”



Kim with her father and brother

The first signs of Kim’s father’s dementia were easy to brush off. “My father started to become overwhelmed, depressed and argumentative – very unusual for him. Other times, he would be boyish and silly. He just wasn’t himself,” explains Kim.

Kim’s father went to his family physician who prescribed some medication, but they didn’t completely understand what was going on. It wasn’t until 9 months later that his symptoms seemed to be getting worse. Their physician mentioned Creutzfeldt-Jakob disease (CJD) and things became clearer. CJD is a form of dementia that comes on fast and can have devastating effects.

Kim became an advocate for her father and began researching as much as she could. “I didn’t really know where to go for help. That’s when I reached out to the Alzheimer Society for support. I started going to the First Link Learning Series. Then, I started getting individual counselling. They helped me understand the disease, how to mitigate various behaviours, and they also gave me practical advice such as how to go about getting the Power of Attorney papers sorted out.”

“By the time the diagnosis of CJD came through from a neurologist, my father’s condition had progressed and we knew he would need palliative care.”

Kim recalls how confusing it was to try to find the support her family required. “Trying to navigate long-term care is very difficult. As someone who was already witnessing the advanced impact of the disease on my father, I found that very frustrating.”

Kim’s father passed away a couple months after his diagnosis. As Kim reflects on the biggest challenges faced by her and her family, the answer has to do with a person-centered approach to care, and consensus-building health teams.

“My hope is that the Ontario Dementia Strategy will give appropriate funding to agencies like the Alzheimer Society, toward palliative care and other support-driven organizations. We have to keep these services in place, and enhance the services for our community.”

THE ANNUAL COST TO CANADIANS TO CARE FOR THOSE LIVING WITH DEMENTIA IS **\$10.4 BILLION**

BY 2031, THIS FIGURE IS EXPECTED TO INCREASE TO **\$16.6 BILLION**

COSTS FOR PEOPLE WITH DEMENTIA ARE ESTIMATED TO BE

5 1/2

TIMES GREATER THAN FOR THOSE WHO DO NOT.



Minds in Motion[®] Living well and keeping active

Minds in Motion is a therapeutic recreation program offering physical activity, mental stimulation and social interaction for people with dementia and their care partners in a supportive environment. Combining gentle and easy to follow physical activities with fun social activities that focus on building personal skills, the program meets for 2 hours/week for 8 weeks.

Thanks to the support of our donors along with the Ontario Trillium Foundation, the program has continued to expand and is now offered in 35 communities. With over 2,000 active participants, it has nearly double its reach in the last year!

Your Impact:

- Participants' endurance improved by 20% and strength by 15%.
- Participants reported decreased social isolation and an increase in informal networks of support.
- 79% of participants continue with physical and social programs after participating
- Close to 100 volunteers and students have been trained and are active in program delivery
- 90% of staff, volunteers and students identified an increase in their dementia knowledge

"Among older adults with Alzheimer's disease, regular physical activity can improve performance of daily living, depression, mobility and balance"

- Ontario Brain Institute

First Link[®]

Your first step to living well with dementia

A diagnosis of dementia can be a difficult and confusing time for families. First Link makes it easier for people to understand what it means and how to navigate the healthcare system. This innovative program connects people with dementia and their families to information, support services and education as early as possible after diagnosis.

Over the past five years, the number of clients directly referred to First Link has increased from 9,500 to 13,800 individuals.

Through the First Link Learning Series, people living with dementia and their care partners have the opportunity to share their experiences with others that understand and learn strategies for managing their diagnosis.

Thanks to your kind support, over the past year, more than 3,000 Ontarians participated in this educational program through local Alzheimer Societies across the province.

"When my wife was initially diagnosed we made contact with the Alzheimer Society through First Link...and I can't imagine being down this road without them."

– First Link care partner

Taking Control of Our Lives

Empowering people living with dementia

Taking Control of Our Lives is an eight-week, self-management program for people with dementia, developed in partnership with the Centre for Education and Research in Aging and Health at Lakehead University.

The program gives people with dementia the chance to learn from and share with each other as they

explore new ideas, question assumptions about their own abilities and build skills for living well with a diagnosis of dementia.

In thanks to our generous community of donors, this past year we expanded our province-wide education program to 17 local Alzheimer Societies.

"I feel better now that I can start and do things that I couldn't do before because I was being pressed down. Whereas now I'm getting stubborn and saying 'I'm going to do it!'"

- Taking Control of Our Lives participant





For people with dementia, every step counts

Due to changes in the brain, usual surroundings may no longer be familiar for people with dementia. In fact, 60 percent of people with dementia-related memory problems will become lost at some point.

Your support has helped our Finding Your Way program reach as many Ontarians as possible.

In the past year Finding Your Way has grown to include a free online course with four educational modules. We have also introduced a web portal for people with dementia and their families with information on locating technology products.

Awareness and outreach strategies reached new heights, nearly tripling the number of visitors to the Finding Your Way website for information in 12

languages and doubling the number of seminars delivered in communities across the province.

Thanks to you and program funding from the Province of Ontario, this resource helps people learn about:

- What to do when a person with dementia goes missing
- How to communicate with a person with dementia who might be lost or confused
- Balancing the risks of living with dementia while maintaining a healthy lifestyle

Funding provided in part by



Helping care providers to understand the “whole person”

Our U-First! program is a leader in Ontario for dementia education and training for healthcare professionals. It is designed for people working in community care, acute care, and long-term care to ensure that people with dementia receive sensitive, specialized attention that is suited to their needs at every stage of the disease.

Thousands of professional care providers in Ontario have attended U-First! workshops and report that the training has given them greater awareness of

the causes of behaviour in people with dementia, an improved ability to handle situations that arise, better teamwork with other staff and reduced stress.

Thanks to your support this year, 25% more healthcare professionals attended U-First! training. To extend the program’s reach even further, we invested in the development of a new 3-week online U-First! course that will provide even more access to the U-First! Certification.



The Liao Family

“Alzheimer’s disease may have taken away my father’s memory, but it has not taken away my father”

“ I once heard Alzheimer’s disease being referred to as ‘the memory thief’. And a thief it certainly is – its target was my father, Louis.

My father was the person everyone wanted to be around. In the years before he met Alzheimer’s disease, he was simply magnetic. With five kids, a daughter and son-in-law, and 2 grandkids, in our family there is never a dull moment. He loved to spend time with our family, cooking (and eating), but my father’s biggest passion was music. The harmonica is his instrument of choice.

Things changed for our family four years ago, when at the age of 60, my father developed Alzheimer’s

disease. His memories slowly started to fade away and his personality soon followed. His charming and charismatic self has become quiet and reserved.

Our local Alzheimer Society was there to help us through my father’s diagnosis. They provided us countless educational resources and we continue to have the support of a social worker.

Alzheimer’s disease may have taken away my father’s memory, but it has not taken away my father. My family is hopeful that one day a cure for Alzheimer’s disease will be discovered. I hope you share in this belief.”

- Sara Liao
Caregiver and Volunteer



Caron with her son, Jaelon and mother, Marlene

“I share my story with you because I want to see a world without Alzheimer’s disease and other dementias”

“ My Mom, Marlene, is a registered nurse so I knew my newborn son, Jaelon, would be in good hands. Or so I thought when my mother decided to fly in from Trinidad to help me with the baby. It only took me a few days to realize something was very wrong. Mom kept forgetting things and couldn’t even follow simple directions to mix baby formula.

This was 15 years ago when I’d never heard of Alzheimer’s disease. I took Mom to the doctor who gave her a basic memory exam. I saw her struggle with simple questions. He checked his chart and simply stated: “You have Alzheimer’s.” Then he looked at me and said: “Things are going to change.”

I walked out of the doctor’s office numb, not understanding what was happening. There I was, 30 years old, with a newborn son and a mother who has Alzheimer’s. When I Googled the disease and saw no cure, I started to panic. Meanwhile, Mom was weeping. She kept asking over and over: “Who has this Alzheimer’s disease?” “Who has this Alzheimer’s disease?”

As hard as this is, I share my story with you because I want to see a world without Alzheimer’s disease and other dementias. I know how challenging it can be to care for someone with the disease. My father passed away 14 months after Mom was diagnosed. I’ve been her sole caregiver ever since, while balancing a job and raising my son. But I do it out of love.

Life with Mom has been a rollercoaster. You never know what each day will bring. If you or someone you love has dementia, I don’t have to tell you how unpredictable it is. Or how heart-wrenching it is to watch them slowly lose their identity and forget every memory they once cherished.

My Mom is now in the late stages of the disease. She’s forgotten how to walk and how to chew, so even eating is difficult. This disease has taken so much from my family. I am determined to make a difference so others don’t have to go through this painful journey.

- Caron Leid, Advocate and Caregiver to mother Marlene since 2000

“With broad awareness and a collective commitment to the idea that more can be done in health, communities and research, we can positively change the lives of individuals, families and communities impacted by dementia.”

Lauren Rettinger | Public Policy and Stakeholder Relations Coordinator



WHERE THERE'S A WILL, THERE'S A ... SUPER HERO

“A simple act of kindness can make a tremendous impact on a person’s life.” - Anonymous

Standing together in the fight against dementia starts with you – our dedicated supporters. We are incredibly grateful to those individuals who have included us in their estate plans. You are our Super Hero!

Not only have you taken the steps to protect what is important to you, but you are helping to ensure that world-class research, education and support programs for those affected by Alzheimer’s disease continue to be available to those who need it most.

What makes a Super Hero? It is someone who shows courage, puts the needs of others before themselves, and wants to make the world a better place. In our opinion, completing your Will and Powers of Attorney makes you a Super Hero. You are taking care of your family, protecting your assets, saving taxes and joining us in the fight for good – all at the same time.

This past year, we were pleased to accept 82 estate gifts as well as a gift of life insurance policy.

Did you know that more than 50% of Canadians do not have a Will? Over 70% of us do not have Powers

of Attorney for Personal Care or Property? These are alarming statistics. We hope to educate people on the benefits of completing their estate plans and share the urgency it requires. When mental capacity diminishes with dementia, it may be too late to create these important legal documents.

We can't defeat dementia alone. We need the help of Super Heroes – just like you. By including a gift to the Alzheimer Society of Ontario in your Will you can help create a future where dementia is defeated and Super Heroes rule the day.

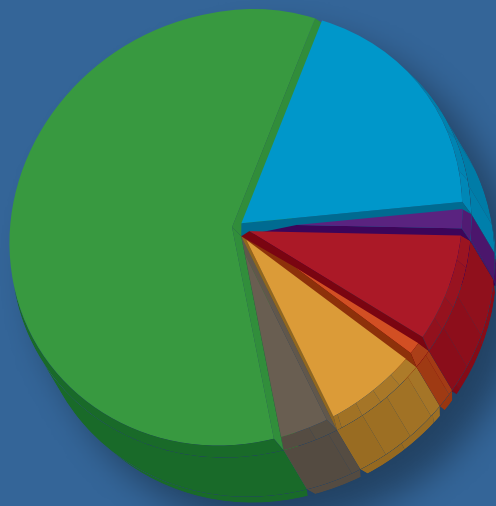
A big thank you to all those who requested information, got into action and completed their estate plans.

Being a Super Hero is easy. And we are here to help! To request your complimentary Estate Planner and Guide, please go to www.alzsuperhero.ca or contact Kristy Cutten at 416-847-8915.

FINANCIAL HIGHLIGHTS

We are pleased to present the Alzheimer Society of Ontario's Statement of Financial Activities for the 2016/2017 fiscal year. Our financial position and fundraising activities support our ability to fund vital programs for individuals with dementia and their care partners, influence public policy, and advance innovative research for a cure for Alzheimer's disease and other types of dementia.

REVENUE



Individual giving	\$5,803,040
Bequests	\$1,829,817
Corporate giving	\$187,615
Government health programs	\$803,555
Partner Alzheimer Societies	\$158,779
Literature and seminars	\$662,088
Investment and other income	\$375,220

TOTAL REVENUE

\$9,820,114

EXPENSES



Programs and Services	\$1,440,678
Research	\$1,872,227
Partner Alzheimer Societies	\$2,829,962
Government health programs	\$803,555
Fundraising and Marketing	\$1,109,621
Administration	\$1,841,122

TOTAL EXPENSES

\$9,897,165

[Click here](#) for our complete audited financial statements.



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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Chris Dennis, CEO,
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* Term started June 2017

† Term started May 2017

‡ Term ended March 2017

§ Term ended January 2017

|| Term ended May 2017

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.

We are incredibly grateful to the Individuals, Corporations and Organizations that have supported the Alzheimer Society of Ontario. Below are donors who have made contributions over \$1,000 this past year.

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You can do something about dementia.

DONATE TODAY

www.alzheimerontario.ca



Alzheimer Society of Ontario

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Toll-free: 1-800-879-4226

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