

Building communities, building hope

About us

For 27 years, the Alzheimer Society of Ontario has helped Ontarians with Alzheimer's disease and other dementias live as well as possible. Through our network of 38 Societies across the province, we support Ontarians with dementia by

- Funding provincial and national research to find a cure
- Educating decision-makers about the need for improved health care services and qualified health care workers to support people with dementia
- Increasing awareness of dementia and its impact on the whole family and in our community
- Providing care, information and education in Ontario communities

Learn more or find an Alzheimer Society in your community:

www.alzheimerontario.org



*Thanks to
Karen Del Degan's
generous gift, her mother's
memory lives on.
See back cover.*

Alzheimer Society
ONTARIO

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“2010 has been a tipping point for our organization and for all those who fervently believe in our cause.”

Message from the President and CEO

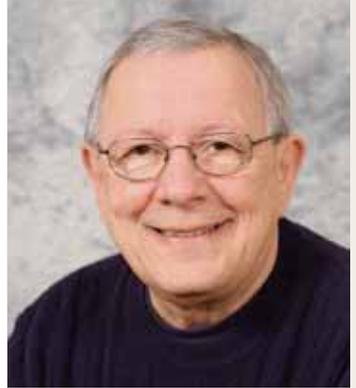
2010 was a watershed. Our *Rising Tide* report and *10 by 20: Ontario action plan for dementia*, an international conference on Alzheimer's disease and a federal election propelled the Alzheimer Society of Ontario (ASO) onto the feature pages of every major national and regional media outlet, into the corridors of Government, onto the agendas of health partners and into the minds of individuals, mobilizing them to action.

Last year we sounded the alarm about the rapidly rising numbers of Ontarians living with Alzheimer's disease and other dementias - a 40 per cent in growth in less than 10 years. That figure doesn't even come close to the number of people who will be plunged into the challenging role of caregiver. Nor does it reflect the increasing health and community costs.

At ASO we are more resolved than ever to be even better at what we do.

We are buoyed, because our distinctive strength has been to galvanize passion and ideas and put our integrated knowledge and diverse voices to work, supporting all Ontarians living with dementia and funding research into prevention and a cure.

From researchers to health care providers, from decision-makers to business leaders, from our dedicated staff in Alzheimer Societies across Ontario to all those we serve, we're building communities of new possibilities, bound by our cooperative spirit and our collective wisdom. Together, we're turning



Bryon Gero, President



Gale Carey, CEO

challenges into opportunities and problems into solutions to create hope for a brighter future for every Ontarian affected by dementia.

2010 has been a tipping point for our organization and for all those who fervently believe in our cause. The dedication and loyalty of our partners, donors, volunteers, staff and Board Members have moved our organization into a promising new era. Not only are we ready for the future, but it's our destiny to build it together. Together, we can make Alzheimer's a priority for each and every Ontarian.

“We need to recognize that people with such brain diseases as dementia ... are part of our lives and our communities, and will continue to be in ever-larger numbers. We don't need to track their movements with electronic gadgets or lock them up. Rather, we need to help them become engaged as citizens, and do so ourselves, with all the rights and responsibilities that entails.”

The Globe and Mail – on wandering and dementia

Year in review

With a renewed strategic vision that harnesses the experience and expertise within and outside our organization, 2010 was a year of continued progress and success for the Alzheimer Society of Ontario.

Among our achievements, we:

- Extended First Link® into 80 per cent of Ontario through local Alzheimer Societies thanks to the continued endorsement and funding of Local Health Integrated Networks (LHINs). First Link provides a first point of contact for people with dementia, making it easier and quicker for them to access expert care and resources in their community soon after diagnosis. Its success lies in the coordination of locally available resources.
- Launched the second phase of the Behavioural Support Systems Project (BSS) as the Ministry of Health and Long-Term Care invited submissions from LHINs to adopt the project. It also approved 75 dedicated Behavioural Support nurses. BSS offers guidelines and education to help caregivers at home and in long-term care settings handle difficult behaviours of people with dementia. This is a collaborative initiative with the North Simcoe Muskoka LHIN, the Alzheimer Knowledge Exchange (AKE) and the Ontario Health Quality Council.
- Expanded our community of health partners to strengthen our goal of a province-wide dementia plan with a single unified voice. Presented briefings to the Committee on Retirement Home Act; to the Minister of Finance, and Committee on Economic Affairs in response to the 2011 Ontario Budget; and met with MPPs and opposition critics.
- Developed measurement tools for improved efficiency and governance in our 38 Alzheimer Societies in Ontario (ASiO) thanks to the work of our Organizational Effectiveness Committee (OEC) supported by a \$176,000

Blazing the Alzheimer trail

In the largest international research study of its kind, four new genes linked to Alzheimer's disease were uncovered this year thanks in part to the Tanz Centre for Research in Neurodegenerative Diseases at the University of Toronto. Dr. Peter St George-Hyslop, Tanz Director, led the Canadian portion of



Dr. Peter St George-Hyslop. The Alzheimer Society of Ontario is a co-founder and principal funder of the Tanz Centre. Richard Lautens photo.

the study undertaken by the Disease Genetics Consortium (ADGC), which involved the analysis of genetic data of 54,000 people in Canada, the United States, the United Kingdom and Europe. "Each identified gene adds to the risk of dementia later in life," says Dr. St George-Hyslop. "This information provides great insight into the cause of Alzheimer's disease." "Together, these new genes offer clues about changes that occur in the brain long before symptoms of memory loss appear and could hasten the development of new methods of diagnosing, preventing and treating the disease."

grant from the Ontario Trillium Foundation. OEC's work is integral to creating a more integrated, client-focused and demand-driven organization that will take us into the future.

- Achieved a \$171,360 surplus in operational performance, an increase of 100% over the last fiscal period, redirecting funds to research, programs and services.
- Contributed \$408,000 to the University of Toronto Tanz Centre for Research in Neurodegenerative Diseases, up from \$300,092 last year.
- Led national efforts with a \$1,504,511 contribution to the Alzheimer Society of Canada Research Program, an increase of 28% over the same period last year.
- Established a new Fund Development Committee to increase fundraising capacity across Ontario.

Benefits of quality of life research

While medical research is critical for finding a cure, psychosocial research is equally vital for better practice and quality of care for people living with dementia. Dr. Elaine Wiersma, associate professor with the Faculty of Health and Behavioural Sciences at Lakehead University in Thunder Bay, is one of two Ontario researchers making their mark in this field thanks to ASO funding. Wiersma is studying the experiences of people living with dementia, their family members, and their informal and formal caregivers in rural areas of northwestern Ontario. Little is known about the positive and challenging aspects of living with dementia in such isolated communities. Wiersma is conducting her research in cooperation with the Alzheimer Society of Thunder Bay where she has already interviewed more than 70 residents from two small communities north of Lake Superior. Once the interviews have been analyzed, she expects the findings will help pinpoint gaps in dementia care and recommend ways to close them.

Striking a balance between road safety and protecting the independence of people with dementia is a complex issue, especially as the number of older drivers grows and dementia increases. Dr. Michael Rappaport, clinical scientist at Sunnybrook Health Sciences Centre in Toronto, has assembled a team of dementia experts from various disciplines to determine how best to apply the Highway Transportation Act to individuals with mild dementia. The act requires doctors to report patients to the Ministry of Transportation when they have conditions that could put themselves and others at risk. But clear-cut guidelines for drivers in the beginning stages of the disease are lacking. Dr. Rappaport hopes he and his team will reach consensus that will create guidelines to help physicians in Ontario and across Canada assess the driving competency of patients with mild dementia.

Drs. Elaine Wiersma and Michael Rappaport are grant recipients of the Alzheimer Society of Canada Research Program which provides critical funding for dementia research and care and is supported by ASO, other provincial Societies, partners, and donors.

2011
**WALK
FOR
MEMORIES**



Walk for Memories, our signature fundraiser in Ontario, set a new record total of over \$2 million, a 12% increase over last year. In fact, 72% of Alzheimer Societies in Ontario reported 2011 as their best Walk ever. This record-breaking revenue supports programs and services provided by local Alzheimer Societies for people living with dementia. Other successes included:

- a 34% increase in online donations for a total of \$822,000
- 2.9 million website visits over a four-month period
- 57 Facebook events to promote the Walk
- 6,300 Walkers
- 1,321 volunteers

Sign up for the 2012 Walk:
www.walkformemories.ca





At the Alzheimer's Disease International Conference (ADI), the Alzheimer Society of Ontario hosted a luncheon in honour of Dr. Amit Dias (fourth from left), a gerontologist from Goa, India and Secretary of the Dementia Institute of Goa to share his novel work in community care for nearly 4 million people living with dementia in his country. The luncheon was generously sponsored by Pfizer (Ontario) Canada Inc. represented by Sean Kelly, (right of Dr. Dias), Director, Public Affairs. Also in attendance, L-R: Byron Gero, Board President and Gale Carey, CEO, Alzheimer Society of Ontario; Donna Cansfield, MPP Etobicoke and the Honourable Sophia Aggelonitis, MPP Hamilton Mountain, Minister Responsible for Seniors. Read about Dr. Dias in *The Globe and Mail*: <http://www.theglobeandmail.com/life/health/dementia/effective-elder-care-starts-at-home-experts-say/article1958956/>

Headlining news

The 26th International Alzheimer's Disease International (ADI) Conference held in Toronto in March capped off a stellar year of heightened public awareness and media attention. The three-day affair, co-hosted by the Alzheimer Society of Canada, united over 1,000 dementia experts, healthcare professionals and people affected by the disease from 63 countries. It also generated more than 100 media placements in every major national and regional media outlet thanks to Alzheimer Society of Ontario's marketing and communications efforts. These efforts also capitalized on the federal election announcement that coincided with ADI, fuelling additional media in support of our call for a national dementia plan. Read the coverage:

<http://www.theglobeandmail.com/life/health/new-health/health-policy/arewe-in-denial-about-the-growing-issue-of-elder-care/article1955902/>

<http://www.theglobeandmail.com/life/health/new-health/conditions/alzheimers/canadas-dementia-dilemma-care-without-a-strategy/article1957422/>

In collaboration with the Alzheimer Society of Canada, ASO was equally instrumental in developing this year's national Alzheimer Awareness campaign in January, ***Alzheimer's disease... it's more than you think***. The campaign informed baby boomers of the early warning signs of Alzheimer's disease and what they can do to lessen their risk. Blending traditional and social media, the campaign achieved a national reach of 50 million plus and secured almost 2,000 media hits in key media outlets across Canada. ASO's efforts accounted for 50% of total media coverage.

As well, we sustained substantive coverage throughout the year, gracing the front pages of *The Globe and Mail* 10 times and including:

A six-part series in the *Globe and Mail*: *Dementia: Confronting the crisis*:
<http://www.theglobeandmail.com/life/health/dementia/>

Three-month exposure on the Toronto Star's healthzone.ca:
<http://www.healthzone.ca/health/mindmood/brainhealth>

A four-part Global National TV series, *Broken Connections*, plus two live web chats:
http://liveblogs.globalnews.ca/Event/Alzheimers_discussion_March_17?
Page=0

Dancing to a different tune

Jenny Hall likens marriage to a dance in which your partner anticipates and responds to your moves – even the mundane ones. But when your partner is a vibrant man barely in his 50s who forgets the choreography because he has Alzheimer's disease, the dance comes to a shocking end.



Tom knew something was wrong the year he turned 51. He was forgetting words, struggling to identify things in conversation. A construction supervisor with a reputation for being conscientious, he began misplacing his tools.

He and Jenny consulted a doctor who put it down to stress. They wanted to believe him so the couple left it at that.

A year later, they were back at the doctor's. Tom was now sure something was seriously wrong. He was forgetting his way back to a job site after bathroom breaks and couldn't fill out time sheets.

At 53, the diagnosis was confirmed. "He wasn't allowed to drive home from the hospital. He quit work that day. His licence was taken away. Bam. Just like that," says Jenny. Jenny, her daughter and son sought help from their local Alzheimer Society where support groups and planning sessions helped them to understand what was going on. "Knowing what to expect made such a difference. I remember they put on a three-day workshop. They had a financial planner and a lawyer. And a woman was explaining that we take for granted putting butter on bread, but for someone with Alzheimer's there are steps - taking the butter out, putting the butter on the knife, taking the bread out of the package. When you can't do that, how incredibly hard is that? That opened my eyes."

By the time Tom turned 59, he went to live in a long-term care home and while Jenny visits him every day, she's now learning a different dance and wants others to know it's possible.

"I don't want people to think they are alone. I know how lonely you get and how incredibly withdrawn you become," she says. "Actually that's my biggest fight right now – reinventing a new norm. I know this sounds crazy, but I've been out to lunch by myself and I've gone to a movie by myself. I haven't been to dinner yet by myself but I'm going to try it one day."

Alzheimer Society of Ontario Board of Directors 2010 - 11

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Alzheimer Society of Ontario

Summarized statement of financial position

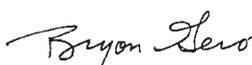
(Year ended March 31, 2011)

	2011	2010
ASSETS		
Current assets	2,921,448	1,749,467
Capital assets	189,519	250,526
Long term investments	1,905,729	1,770,073
	\$ 5,016,696	\$ 3,770,066
LIABILITIES AND NET ASSETS		
Liabilities	2,122,763	630,301
Net assets	2,893,933	3,139,765
	\$ 5,016,696	\$ 3,770,066

Statement of operations, year ended March 31, 2011

	2011	2010
REVENUE		
Net fund development revenue	5,398,996	4,977,650
Investment income	142,277	258,538
Grants - government	493,200	343,756
Other	47,504	40,247
	\$ 6,081,977	\$ 5,620,191
EXPENDITURES		
Alzheimer Society of Canada operating cost assessment	1,544,082	1,331,832
Public policy and program initiatives	805,208	808,151
Marketing and communications	289,336	322,196
Finance and operations	258,064	379,149
Governance	327,231	349,944
Grant expenses	493,200	331,906
	\$ 3,717,121	\$ 3,523,178
Operating surplus	2,364,856	2,097,013
Member Chapter contributions to research	186,880	300,173
Research expense	(1,495,511)	(1,454,076)
Net surplus	1,056,225	943,110
Revenue sharing - Member Chapters	(884,865)	(882,898)
Excess of revenue over expenses	171,360	60,212
Research Contribution from Campaign Fund	(417,192)	
	(245,832)	60,212

On behalf of the Board:



Bryon Gero
President



Bob Jamison
Treasurer

Juggling family and Alzheimer's disease

When Kathryn Harrison gave birth to her first child, she looked forward to sharing the joy of a new baby with her mom, Bonnie. While they both delighted in the little girl, it was soon clear there would be no traditional grandmother-granddaughter relationship.



The year after Tristin was born, Bonnie, who was just 61, began showing signs of dementia. Two years later, when Kathryn's second child, Rory, turned one, Bonnie was well into her illness.

"She started developing obsessions, one of which was colouring," recalls Kathryn. "She completed dozens and dozens of books, with every single page coloured to perfection."

When Kathryn brought her children to visit their Nana, they would sit at the kitchen table and while Nana coloured in her books, they coloured in theirs. Kathryn remembers watching them together, marvelling at her kids' complete acceptance of their grandmother's behaviour.

Taking cues from the kids

In fact, Tristin and Rory helped in unexpected ways as Kathryn struggled to raise young children, support her Dad as he cared for her Mom at home and run her own business making decor items for children's rooms.

"Your rules of what's right and acceptable get pushed to the limit," she says. "But the kids did not care if my Mom was walking around with barely any clothes or making strange statements. I had to let it go," she says.

Don't be a hero

In the fall of 2006, however, Kathryn became overwhelmed. Her Dad had just had a minor stroke and it was clear her Mom would need a lot more care.

She sought out a psychologist to augment her caregiver support group at the Alzheimer Society of Toronto. She also shut down her decor business.

"It was really hard for me to stop," says Kathryn. "I was slow in recognizing the impact of the caregiving demands. If I could do it again, I would have started therapy sooner and stopped the business sooner."

If there is one piece of advice she could offer others in her situation, it would be to get help and get it early. "Don't be a hero," she says.

In loving memory of Bonnie who passed away in November 2010.

Your local Alzheimer Society can help, from counselling to education and more. Locate one nearest you: www.alzheimerontario.org

We are the Alzheimer Society of Ontario

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Is it Alzheimer's?

How many of us have overlooked Mom's forgetfulness as part of aging or made excuses for Dad's repetition and money mistakes, before we learned it was Alzheimer's? Early diagnosis helps people plan for healthcare, and financial and legal issues with the patience and insight that comes with knowledge and understanding of the disease. That's why it's in your best interest to be familiar with Alzheimer's warning signs. Family background, lifestyle and age are risk factors, but it's also important to watch for these common signs:

- Repeating questions multiple times
- Forgetting recent events, conversations, appointments and faces
- Becoming disoriented in familiar places
- Having problems following simple instructions, operating appliances or even driving
- Confusing dates or having difficulty counting change or calculating numbers
- Showing signs of behavioural changes, such as apathy, sleep problems, agitation and paranoia

Don't ignore these signs. Discuss them with your doctor sooner rather than later.

For other tips and practical advice: www.alzheimerontario.org

Our generous donors

Gifts of \$1,000 or greater between April 1, 2010 and March 31, 2011.

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Building a Circle of Hope

Seven years ago, Karen Del Degan was at her wit's end when her 78-year-old mother Dorothy was finally diagnosed with Alzheimer's disease. The telltale signs were always there but it never crossed Karen's mind that it was Alzheimer's.

"I thought I was losing it, until we got the diagnosis," she says. "Then someone gave me the number of the Alzheimer Society and it saved my life."

Karen started attending support groups at her local Society in Peel where she met other caregivers like herself. She learned about the disease and how to cope with the ups and downs. Most important, she learned she was not alone. "It meant the world to me," she says. "You can't underestimate the value of having an expert right there for you. Being able to ask questions can help you learn what applies to your situation so you have peace of mind that you can actually do something. In a strange way, the last year of my mother's life was one of the best years we had together."

After her mother's death, Karen approached the Society determined to give back to the organization that was there for her at a low point in her life. She decided to make the Society the sole beneficiary of her estate and made sure it would go towards research to improve the lives of people living with Alzheimer's and to find a cure.

"It's simple," says Karen. "The Society has been very good to me. This is my way of showing my gratitude and honoring my mother's memory."

"I want to make a difference in peoples' lives," she emphasizes. But her message is more far-reaching than that. "I also want the staff to know they had a measurable impact on my life. I want other donors to know that the Society helps create turning points in their lives and helps make our community a more caring place. Everyone wins in the end."

Karen recently joined the Society's Circle of Hope. Thanks to the generosity of donors like herself, the Alzheimer Society can invest in pioneering and innovative research in Ontario and across Canada and continue to provide programs and services that benefit people with dementia and their families.

For information about the Circle of Hope:
www.alzheimerontario.org

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