We know Ontario's population is aging and that the number of seniors with dementia and other complex health needs is going to increase. Patients deserve to be managed with sensitive care.

AlzheimerSociety

We're currently diagnosing only 50 per cent of people with dementia; of these, we're treating half. My doctor told me that it was a fatal disease and there was no cure, but I decided to get on with my life.

parent can't do it themselves. Don't minimize their symptoms.

You've got to take on the role of advocate because your partner or

> The Alzheimer Society is the shoulder to lean on. If you don't have that early diagnosis, you don't have that support, you don't have that understanding.

The conversation is changing...

Annual Report 2011-2012

Join the conversation – you can make a difference

Vision

A world without Alzheimer's disease and other dementias

Mission

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

Connect with us on



Alzheimer Society

20 Eglinton Avenue West, Suite 1600 Toronto, Ontario M4R 1K8 Tel: (416) 967-5900 Toll free: 1-800-879-4226 Fax: (416) 967-3826 E-mail: staff@alzheimeront.org Web: www.alzheimer.ca/on "Research is our enduring commitment to Ontarians living with dementia and their families and shared by our researchers and members of the community through giving. We hope you'll consider contributing to our goal of a world without dementia."

Bryon Gero, President

• Make a secure deductible donation online or mail your cheque made payable to the Alzheimer Society of Ontario.

www.alzheimer.ca/on

- Register for a Walk for Memories, our provincial fundraising event supporting programs and research. Ask your friends and family to join.
 www.walkformemories.ca
- Organize your own fundraiser by signing up to our Memory Makers for Alzheimer's website:

www.memorymakersforalzheimers.ca

- Become a Dementia Champion. Help educate opinion leaders and elected officials about dementia issues and priorities:
- www.championsfordementia.ca
- Write a blog. Make your opinion count and inspire others.
 http://alzheimersocietyblog.ca
- Post your story on Facebook. Help spread the word about dementia.
- Volunteer your time and talents to programs and services run by your local Alzheimer Society.
- Remember us in your will and estate planning – and give hope.



Bryon Gero, President



Gale Carey, CEO

Message from the President and CEO

The conversation is changing

2011 has been an exciting and productive year at the Alzheimer Society of Ontario (ASO); it has also brought our cause to the cusp of historic change.

Through education, advocacy and research we have made significant advances in understanding dementia. Through public discussion, we have propelled the disease to new heights of awareness.

More than ever, dementia has been the topic of many conversations – in the media, in the halls of government, in corporate board rooms, in health care and at the kitchen table.

These conversations have echoed our call for improved care, more effective treatments and prevention, and ultimately a cure. They have also guided and inspired us at the Alzheimer Society to fashion a new strategic plan: **Strengthening communities: Achieving excellence, 2011-2014.**

We believe our plan brings our organization to a pivotal point in our history to lead change, to transform our conversations into actions, and to deliver real benefits for Ontarians living with dementia and their families.

We also know that a combination of hope, hard work and imagination is required to keep these conversations moving forward. But our tenacity comes from our vision for a future free of dementia, the knowledge that the pace of research is accelerating and that our collective strength and mutual commitment are driving progress.

And if timing were not reason enough, we need only remind ourselves of our mission of fostering a better quality of life and brighter future for Ontarians affected by Alzheimer's disease and other dementias.

To our donors, advocates, corporate sponsors, volunteers, Board Members and staff we are grateful for your past support and appreciative of your continued commitment.

We remain more hopeful than ever that we will, together, fulfill our vision of a world without Alzheimer's disease.

Our intent is to

- Lead in the field of dementia prevention and healthy aging
- Speak on behalf of those with Alzheimer's disease and other dementias
- Fundraise more effectively and invest our monies more strategically
- Be an integrated and effective organization

Research – Creating hope for an Alzheimer's-free world

Dr. Ekaterina Roegaeva, a principal investigator at the Tanz Centre for Neurodegenerative Diseases at the University of Toronto, is optimistic that in the next 20 years science will find ways to prevent dementia before it strikes. We hope we don't have to wait that long.

That's why in 2011 with the support of our generous donors and a commitment to prudent expenditures, we were able to contribute in total more than \$2.6 million to research. This figure represents 40 per cent of our overall revenue, and will help researchers pursue new theories about the causes of dementia leading to drug therapies that can prevent or even stop the disease.

Highlights:

- Contributed more than \$1.4 million to the Alzheimer Society Research Program, our nationally peer-reviewed program supporting biomedical and quality-of-life research
- Contributed \$788,000 to the Tanz Centre for Research in Neurodegenerative Diseases, our long-standing research partner, which this year celebrated its 20th anniversary. This money tops off our pledge of \$1.5 million over three years for a total of \$12 million since the launch of the Centre.
- Established a Research Advisory Council of researchers, medical experts, Board Members and staff to identify current research opportunities and make recommendations for increased funding that will positively impact those we serve.

Making a world of difference

In 1991, the Alzheimer Society of Ontario and a group of people led by Mark Tanz and Lionel Schipper co-founded the Tanz Centre for Research in Neurodegenerative Diseases. Within five years of opening its doors, the Centre discovered the mutated form of two presenilin genes, PS1 and PS2, responsible for the most aggressive early-onset form of Alzheimer's disease. At that moment, the Tanz's reputation for ground-breaking discovery was cemented.

"That discovery made the Centre famous and internationally-recognized," recalls Dr. Ekaterina Rogaeva, who helped find the genes. "After that, there were other good discoveries, but this was the starting point."

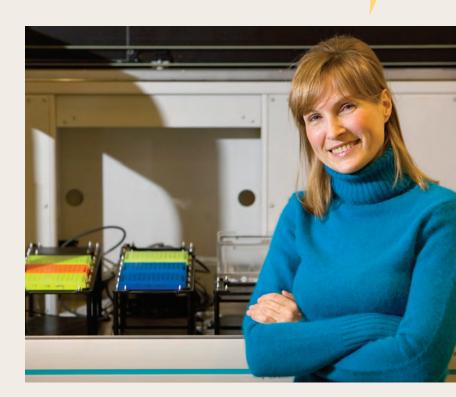
Soon after, the Centre, led by Dr. Peter St George-Hyslop, developed a mouse model for dementia. CRND8 or the "house mouse" is genetically altered to develop the brain plaques associated with Alzheimer's disease as early as three months of age, allowing researchers to more quickly test potential treatments.

In 2006 came another breakthrough - a naturally-occurring protein called TMP21 that inhibits the buildup of Abeta peptide, a neurotoxic protein that accumulates to cause Alzheimer's disease. This discovery was particularly exciting because up until then, attempts to block Abeta production resulted in brain inflammation and other dangerous complications.

A year later, the Centre made world headlines again, with the discovery of a mutated form of the gene SORL1 that increases the risk of late-onset Alzheimer's by 10 to 20 per cent. Dr. Rogaeva and her team painstakingly sifted through 6,000 DNA samples to uncover the risk. When the gene is working properly, it diverts the Abeta precursor protein (APP) into certain areas of inside brain cells where Abeta can't be produced. But in its mutated form, the gene tells APP to accumulate in a different region of the cell, where it then deteriorates into Abeta.

These discoveries are providing drug researchers with important clues. In the next two decades, they will almost certainly develop effective treatments for people before they start exhibiting symptoms. And more recently, research into biomarkers, such as genetic screening and imaging, may eventually be able to identify those at risk of developing dementia and tailor treatments to delay the disease or even stop it in its tracks.

"I'm very optimistic. Twenty years is a very generous time to put the puzzle together." - Dr. Ekaterina Rogaeva



Advocacy – achieving change

C indy O'Donnell, an insurance advisor in Barrie, knows all too well the heart-wrenching emotions and roller-coaster stress of caring for a family member with dementia - in her case, two family members. Cindy's father-in-law passed away from Alzheimer's and today, she deals with the daily, unpredictable struggle of her father who has mixed dementia. She wonders if more could have been done for her father-in-law, and if more can be done now for her father.

Cindy counts among our remarkable network of more than 100 volunteer advocates who, this year, raised their voices and issues important to them during the 2012 Provincial Election. Side-by-side with local Alzheimer Societies, they successfully met with candidates, organized public events and spoke with media. Their actions were also supported by an online forum where they exchanged news and ideas with fellow advocates and kept track of their progress.

We also increased our face-to-face meetings with multiple levels of government and expanded our circle of health, community and science partners to improve dementia care.

As a result, our collective efforts culminated in significant legislative change for people impacted by dementia:

- Introduced a bill to create an eight-week leave for caregivers
- \$40 million dollar investment in the Behaviour Supports Ontario project, a three-way partnership between the Alzheimer Society of Ontario, the Ministry of Health and Long-Term Care and the province's 14 Local Health Integrated Networks, to hire and train staff in care settings to manage complex behaviours of people with dementia
- A wandering prevention program to help reduce the number of people with dementia who may wander and become lost

"Canada's health-care system needs to act, awareness of dementia must increase and positive change needs to happen, now."

- Cindy O'Donnell



First Link®

20,000 Ontarians touched by dementia were able to guickly access the right care in their communities through First Link. The program connects patients to health and social resources, including the Alzheimer Society. Research shows that timely information and support helps people with dementia and their families live well beyond diagnosis. First Link is currently available in 86 per cent of Ontario. Our goal is to increase this number to 100 per cent.

"It's a sad ending to anyone's life and an incredibly sad way for families to see their loved ones live out their remaining years. What we put into Alzheimer's research will go a long way to ensuring future generations don't have to endure what so many of our family members have lived."



Matt Barr

Fundraising – increasing donors and revenue

When Matt Barr, Toronto, got on his bike to raise money for Alzheimer's research, it was anything but freewheeling. In the wet and cold, the 32-yearold cycled 1,000 KM from Hanoi to Hoi An, Vietnam. He raised \$3,500 in memory of his grandfather, "Fast Mo," who had Alzheimer's, and to help his grandmother who currently has the disease. Matt recruited two of his buddies for moral support, and together, they paid for their own way to Vietnam.

Matt's incredible journey is just one of the amazing stories of our do-it-yourself fundraisers who have signed up onto our Memory Makers for Alzheimer's website. Launched in October with a generous grant from the Edwards Foundation, this fun and interactive hub gives groups and individuals the tools and resources to help them fundraise in unique and creative ways. Activities include everything from endurance events to bake sales. Funds can be designated to research or Alzheimer Society programs. Either way, they are critically important to anyone impacted by dementia. Within its first five months, Memory Makers has generated over \$26,000 in online donations, and we expect to raise significantly more in the coming year.

Memory Makers is also one of the ways we've been growing our donors and revenue, while keeping costs low. By diversifying into new marketing channels such as the internet, we increased our fundraising revenue by 27 per cent.

Organizational effectiveness – building a sustainable future

"Our goal is simple - to reinvigorate our organization by implementing the highest levels of excellence in governance and management practices, while expanding and enhancing our respected community and support services to reach thousands more Ontarians impacted by dementia."

- Rosemary Corbett, Co-Chair, Organizational Effectiveness Committee

angible results of our Organizational Effectiveness work are taking shape. This is demonstrated by many of the Alzheimer Societies, which are working to maintain a consistent brand and voice, especially in the delivery of services, fundraising, data collection and reporting. In addition, eleven Societies are currently investigating the possibility of integration, with the work partially funded by the Ontario Trillium Foundation. The benefits of amalgamation are already evident at the Alzheimer Society of Peterborough, Kawartha Lakes, Northhumberland and Haliburton, two former Societies that formally joined in April 2010 where according to CEO David Webster, services have improved and are available more equitably across the communities it serves.

That Ontarians receive quality and consistent care no matter where they live remains a priority of our work as we look to the future. We aim to achieve this through integrating our resources, while using best practices and economies of scale. This is essential if we're going to keep pace with the growing prevalence of dementia and evolve with the expanding needs of those we serve.

We've also developed parameters and benchmarks to improve how we collect and measure our data and have delivered a sustainability service tool to local Alzheimer Societies.

There is great passion and commitment among our colleagues to lead change. We are setting the stage for our future.



What's your lasting legacy?



Leaving a legacy is a meaningful way to support a cause you believe in and provides multiple tax savings at the same time. We launched two new booklets this year providing answers to common guestions about estate planning: Estate Planner and the Estate Planner Guide. It can be as simple as naming the Alzheimer Society in your will, or making an insurance arrangement. Whatever you choose, you will have the satisfaction of improving the quality of life and finding a cure for people living with dementia. Funding for the booklets was generously provided by Investors Group.

Let's face it!

"I have Alzheimer's but it doesn't have me."

Public awareness – getting the word out

" have Alzheimer's disease, but Alzheimer's doesn't have me." That's the motto by which Jim Finkbeiner lives, a 67-year-old Exeter resident who was diagnosed with early-stage Alzheimer's three years ago. And that was the underlying message of this year's Alzheimer Awareness Month – *Let's face it! Get the facts. Know for sure*. We engaged real people whose inspiring stories are changing the face of dementia and reducing stigma.

In collaboration with the Alzheimer Society of Canada, our Marketing and Communications team was instrumental in creating an integrated social media campaign to promote the month focussing on the importance of early diagnosis. Launched on January 4, the campaign incorporated Jim and others in a suite of public service announcements, video testimonials, YouTube streaming, tweets and Facebook postings. The campaign had an overall audience reach of 2.2 million and generated over 600 media impressions, including front page news of the Globe and Mail and the lead stories on Global and CTV national news. In Ontario, we were responsible for 40 per cent of total coverage.

Canadians shrugging off dementia signs as 'old age'

This year's Awareness Campaign was based on alarming new information as a result of a survey conducted by the Alzheimer Society. One in four Canadians waited a year or more to see their doctor after noticing the first signs of dementia. Of these, 16 per cent waited two years. Overall, 50 per cent of Canadians continue to associate memory loss as the only sign of dementia. Behavioural changes such as repeating words and increasing agitation are also signs.

Would you be able to recognize the warning signs? Visit http://alzheimerletsfaceit.ca

Increasingly, we're harnessing the power of social media and social networks to market our brand, expand our reach and engage more voices. Most notably, we launched a dynamic new national web portal so every Canadian receives consistent support and information across the country. Our Marketing and Communications team contributed to the structural and content redesign of the portal, while Alzheimer Societies in Ontario were among the first to migrate to the new site.

Other highlights:

- Successfully launched a new blogging site
- Expanded our Facebook followers to 665, up by 90 per cent over the previous year; increased our daily reach from 500 to more than 1,900
- Collaborated with major media on a variety of stories, including Global National's compassionate care series and the Toronto Star's investigative reports on nursing home neglect and driving and dementia.

Alzheimer Society of Ontario

Summarized statement of financial position

(Year ended March 31, 2012)

	2012		2011
ASSETS			
Current assets	3,295,974		2,921,448
Capital assets	134,468		189,519
Long term investments	1,929,614		1,905,729
	\$ 5,360,056	\$	5,016,696
LIABILITIES AND NET ASSETS			
Liabilities	2,015,524		2,122,763
Net assets	3,344,532		2,893,933
	\$ 5,360,056	\$	5,016,696
Statement of operations, year ende	ed March 31, 2012	2	
	2012		2011
REVENUE			
Net fund development revenue	6,777,944		5,566,379
Investment income	65,088		142,277
Grants - government	342,951		467,959
Other	187,409		57,840
	\$ 7,373,392	\$	6,234,455
EXPENDITURES			
Alzheimer Society of Canada			
operating cost assessment	1,701,027		1,544,082
Public policy and program initiatives	977,596		830,449
Marketing and communications	277,917		289,336
Finance and operations	284,293		258,064
Governance	328,866		327,231
Grant expenses	342,952		467,959
	\$ 3,912,651	\$	3,717,121
Operating surplus	3,460,741		2,517,334
Member Chapter contributions to research	292,643		186,880
			(1,495,511)
Research contribution	(2,618,340)		
Research contribution Net surplus	(2,618,340) 1,135,044		1,208,703
			1,208,703 (1,037,343)

On behalf of the Board:

Bryon Lero

Bryon Gero President

I Evano

Gale Evans Treasurer



Memory loss isn't the only sign

The following pays tribute to Lou Grieve who died from complications of her Pick's disease, a form of dementia. We are grateful to Lou and Wayne Grieve for participating in our 2012 Awareness Campaign.

Two years is a long time to wait between the first symptom of dementia and a diagnosis – precious time when 62-year-old Lou Grieve might have received medication and made plans for her future.

The time lapse wasn't because she and her husband Wayne consciously put off seeing a doctor. It was because the couple didn't understand that her mood and behaviour changes were classic symptoms of dementia.

"The old Lou was chatty and engaged," says Wayne. "It was a way she processed things, she was just a verbal person."

Memory loss isn't the only sign

When Lou began coming home from work exhausted, Wayne chalked it up to the stress of her job.

But when Lou struggled to use her employer's automated phone system to call in sick, a red flag went up.

When the exhaustion wouldn't go away, Lou visited her family doctor.

She and Wayne saw him several times over the next two years as Lou's symptoms progressed - from extreme fatigue to mood changes. The doctor's assessment was depression, an illness whose symptoms include exhaustion, mood and behavioural changes that can sometimes mimic those of dementia.

Lou scaled down to part-time hours. By March 2008, she was still exhausted and less interested in things that once animated her. That's when Lou decided to stop driving and stopped working altogether.

All the while, the Grieves sought counselling and nutritional advice from health professionals, hoping to bring Lou back to her old self.

"I felt we were still missing something," recalls Wayne. But they never suspected dementia. Like many people, the only symptom they associated with dementia was memory problems.

CAT scan reveals brain atrophy

In the fall of 2008, the Grieves were referred to a psychiatrist who ordered a CAT scan - it showed frontal cerebral atrophy.

In January 2009, a referral to a neurologist, along with MRIs and memory tests, gave them a formal diagnosis of Pick's disease, also known as Frontotemporal dementia. But by this time, the illness had progressed too far for Lou to make decisions about her care. Wayne, who's retired, cared for Lou at home up until her death.

Don't minimize symptoms

Earlier detection could have helped the Grieves better understand the disease and get the supports they needed sooner. If there's one piece of advice Wayne has for others - it's don't minimize the symptoms. Don't leave anything to chance.

Find out about the benefits of early diagnosis at http://alzheimerletsfaceit.ca

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"It's clear during this pivotal year that we're greater than our individual parts. We're moving toward a more comprehensive and coordinated action plan to tackle dementia. It's not just unifying, it's energizing. I'm confident this energy will continue to inspire our work in 2012 to make even a greater difference to Ontarians affected by this disease."

- Vic Prendergast, In-coming President

Meet our team

Chief Executive Officer (CEO) Gale Carey

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Development Officer, Gift & Estate Planning Colleen Bradley

Research & Policy Analyst Philip Caffery

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Chief Communications & Media Relations Officer Rosanne Meandro

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Alzheimer Knowledge Exchange: Joanne Bertrand Kathy Hickman Karen Parrage Tania Solomon Felicia White



One of the team -

Jacquie Micallef - Public Policy & Stakeholder Relations. For Jacquie, the most rewarding aspect of her work is "seeing the passion and resiliency grow in caregivers and people with dementia when they gain knowledge about the disease and speak up about concerns that affect them." Jacquie is curious and compassionate by nature and is passionate about social justice.

Thank you to our donors

Your generous gifts help find a cure for people living with Alzheimer's disease and other dementias and improve their care and quality of life.

Gifts of \$1,000 or more between April 1, 2011 and March 31, 2012

- Allan Slaight & Emmanuelle Gattuso Andrew & Valerie Pringle
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- Anonymous (1)
- Bill & Kathryn Troubridge
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- Bryon M. Gero
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· Helen Rotenberg in memory of my sisters Virginia Joseph and Rose Vasso

Estate of Thelma Margaret Schappert

Estate of Johannes Jozef Overmars

Estate of William Edwin Joseph Pinson

Is dementia the same as Alzheimer's?

It's a question we're often asked. There is a difference.

Dementia is a term used to describe a general category of brain disorders that are progressive, degenerative – and eventually terminal. Symptoms include memory loss, poor judgment and language difficulty. Sudden or unusual changes in behaviour and personality are also telltale signs. Although Alzheimer's accounts for over two thirds of dementia cases in Canada today, other common dementias include Vascular dementia, Frontotemporal dementia and Lewy body dementia.

The causes for dementia are not fully understood and a cure is yet to be found. That's why it's important to recognize the warning signs. Early diagnosis is crucial to living well with dementia. A doctor will first rule out other treatable conditions such as depression that often mimic the signs of dementia, or may refer the person to a neurologist or other specialist. The sooner the diagnosis, the sooner people can access the care and support they need to manage their symptoms and start planning for the future.

Watch for these signs:

- Repeating questions
- Forgetting recent events, conversations, appointments and faces
- Getting lost or confused in familiar places
- Having problems following simple instructions, operating appliances or even driving
- Confusing dates, having difficulty counting change or calculating numbers
- Showing signs of apathy, agitation, isolation or paranoia

Can Alzheimer's be prevented?

Not yet, but you can take protective steps. Your brain is like any other muscle so be sure to exercise it often and give it plenty of nourishment.

- Get moving. Physical activity keeps your heart pumping. A healthy heart means a healthy brain.
- Stay connected and challenged. Social and mental activity builds cognitive reserve.
- Eat right. A diet that benefits your heart is also good for your brain.



www.alzheimer.ca/on

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