



ANNUAL REPORT 2012 – 2013

Alzheimer Society
CANADA

Our vision

A world without Alzheimer's disease
and other dementias.





Our mission

The Alzheimer Society of Canada identifies, develops and facilitates national priorities that enable its members to effectively alleviate the personal and social consequences of Alzheimer's disease and other dementias, promotes research and leads the search for a cure.

Leading the charge for a brighter future

Mimi Lowi-Young
CEO



Today, there are 747,000 Canadians living with Alzheimer's disease and other dementias and that number will continue to rise as our population ages. By 2031, there will be 1.4 million Canadians living with dementia and even more people required to provide good quality care for them. We know the pressure on family caregivers is overwhelming. They already spend 444 million unpaid hours per year caring for someone with the dementia. We also know our health-care system is unprepared to manage the growing needs of Canadian families and individuals living with this disease. But we can change the course of this disease if we drastically shift our approach.

The Alzheimer Society of Canada, with our provincial and local Alzheimer Society partners across the country, is committed to advancing the cause and speaking with one strong voice for all Canadians affected by dementia. We also work with a myriad of others including dementia experts, government officials, health-care providers and researchers. Our partnerships make us stronger and more hopeful that real change is possible.

In 2012-2013, we continued to invest in our Alzheimer Society Research Program to accelerate improvements in early diagnosis, treatment, care and ultimately a cure. We collaborated with politicians and community and health-care leaders to advocate for legislative change and to make dementia a national health priority. We acknowledged it is time to talk more openly and honestly about dementia so we launched an awareness campaign to address stigma. At the Alzheimer Society of Canada, we understand the courage it takes for someone to say, "I have Alzheimer's disease."

We are proud of our accomplishments. This annual report highlights our efforts to change the face of this disease. It is a collective story, just as it is a collective fight – one that belongs to all of our partners, donors, sponsors, advocates, volunteers and staff who share our mission. Thank you for all your support. We cannot do it alone.

Leslie A. Beck
President,
Board of Directors



A handwritten signature in black ink, appearing to read 'Mimi Lowi-Young'.

A handwritten signature in black ink, appearing to read 'Leslie A. Beck'.

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* replaced mid year

The Alzheimer Society of Canada thanks the following companies for supporting the programs featured in this year's annual report.



“ It made sense that the money go to the Alzheimer Society because of their strong commitment to research. Our father, who lived with this devastating disease, would have been proud to know that this money will provide more opportunities for finding a cure. ”

– Michael Higgins
Co-CEO Mother Parkers Tea & Coffee Inc.



A million reasons to celebrate research

In 2012, one of Canada's long-standing brands, Mother Parkers Tea & Coffee Inc. celebrated 100 years in business. To commemorate the anniversary and the legacy of their father Paul Sr., the founder, his sons Michael and Paul Higgins Jr. launched the *Mother Parkers Remembers* campaign and put their family's historic rail car, the *Pacific*, back into service. They partnered with the Alzheimer Society of Canada to help raise awareness of the need for more research into finding a cure for the disease. As the *Pacific* made her journey to cities across Canada, donations poured in from Mother Parkers' loyal customers and suppliers, employees, friends and family, totaling over one million dollars.

Proceeds from the campaign benefit the Alzheimer Society Research Program (ASRP). Research funded by the ASRP continues to make discoveries on topics such as genetic mechanisms, risk factors, early detection

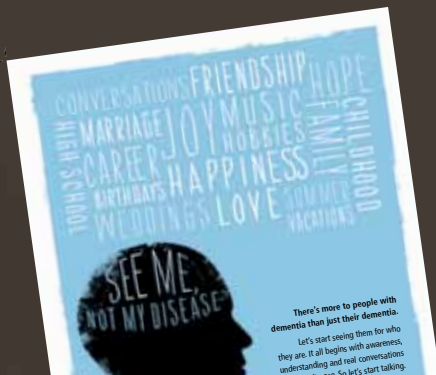
and new treatments – including non-pharmacological methods to slow the disease progression and improve quality of life. Each year the Society funds those applications that have the greatest scientific merit, as determined by experts from across Canada and the United States. However, with our current resources, only 50 per cent of the most promising research projects are supported. Clearly, we have a tremendous opportunity – if only we could support all the fundable and potentially groundbreaking projects that could bring us closer to a future without Alzheimer's disease. To make this possible, we need more friends to follow the lead of the Higgins family.

"A million dollars is a powerful gift of hope," says Mimi Lowi-Young, CEO Alzheimer Society of Canada. "It could one day lead to the breakthrough we so desperately need."

ASC thanks **Mother Parkers Tea & Coffee Inc.** for championing the Alzheimer Society Research Program.

Taking the stigma out of dementia

A diagnosis of Alzheimer's disease was the last thing Elizabeth Allen expected. What made the news even more devastating was the reaction of those around her. One of the hardest challenges faced by anyone after being diagnosed with Alzheimer's or dementia is the fear of social stigma. Losing friends and feeling isolated is hurtful to those with the disease. Stigma also prevents people from seeking a diagnosis, disclosing it and reaching out for help. Elizabeth, a retired corporate computer instructor, was one of many spokespeople who put a human face to this disease during our awareness campaign in January, *See me, not my disease*. Let's talk about dementia. Elizabeth wrote and read the following open letter on CBC national radio. She hopes others will be inspired to learn more about dementia and speak up.



Dear brother, sister, son, daughter, friend,

I have Alzheimer's disease. I know you don't know what to say, or what you should do. I don't have all the answers – but I hope this letter will help.

First of all, please don't offer me platitudes. "You're fine," people will tell me. "Don't worry. Forgetting where you put your keys is just a natural part of aging." I'm sure you're trying to cheer me up, but that's not a fair acknowledgment when I've just confided in you that I have an incurable disease, and that my brain is dying.

As soon as people know I have Alzheimer's they think I don't understand or I have nothing to say. Don't dismiss me. Include me in your conversations and ask me questions like you mean them: "What were some of your symptoms?" "Are you taking any medication? Is it helping?" or "How are you doing?" In other words, let's have an open and honest conversation. Ask me questions as you would if my diagnosis were cancer or any other illness. I'm still me.

Alzheimer's is a progressive disease. There are many stages in the journey between diagnosis and the person you may visualize at the later stages. I'm the same person I was before you knew about my diagnosis. See me as the person I am now, and not who you think I'll be in the future.

And we're not all the same. Accept each of us in each phase of our unique journey and enjoy us for all the things that we can still do. Let me feel useful. Let me make mistakes until I come to terms with the fact that I'm not as perfect as I used to be.

Don't run away from this disease. If you're having trouble accepting me as I am, learn as much as you can about the disease. The Alzheimer Society was there for me and they are there for you with the information and support you need. And this is very important ... if you have concerns about your own health, see your doctor NOW. Early diagnosis and medication can make a world of difference to your well-being. And if you do have Alzheimer's, learn to ask for help. It makes life so much easier for you, your family and your friends.

You can help me and many others like me in our journey by seeing us for who we are.

My name is Elizabeth Allen and I have Alzheimer's disease.



Improving the experience in
long-term care

Today, 57 per cent of seniors living in a residential care home have a diagnosis of Alzheimer's disease or other dementia,¹ and 70 per cent of all individuals diagnosed with dementia will die in a long-term care home.² As more Canadians develop dementia, the compelling need to provide high-quality care in long-term care settings will increase.

Since 2008, the Alzheimer Society of Canada (ASC) has been working with others who, like us, want to improve the experiences of people with dementia in long-term care homes. We call this our "Culture Change Initiative". Culture change requires re-thinking all aspects of how care is delivered through a person-centred approach. Person-centred care recognizes that individuals have unique values, personal history and personality and that each person has the right to dignity, respect, and to participate fully in their environment.

Support of a person-centred approach in programs and practices by staff, management and owners of long-term care homes leads to better outcomes and enhances the quality of life and quality of care for

people with dementia and their families. Health-care providers can learn from family, friends and other care staff about the person's needs, interests, likes and dislikes. What gives her joy and comfort? What makes life meaningful and fun? What makes him smile or laugh?

What can long-term care homes do differently to give each person with dementia the best day possible? In 2012-13, ASC conducted research in six long-term care homes across Canada, which were selected because they provide aspects of person-centred care to their residents with dementia. ASC's research report will highlight essential elements of person-centred care, advice on how to implement these elements and some lessons learned.

We will share these findings widely in 2013-14 to encourage a different conversation about long-term care for people with dementia. "Our goal is to work with others to make person-centred care the norm rather than the exception in long-term care homes across Canada" explains Mimi Lowi-Young.

¹ Canadian Institute for Health Information, *Caring for Seniors with Alzheimer's Disease and Other Forms of Dementia*, August 2010.

² Mitchell S, Teno J, Miller S, Mor V: *A national study of the location of death for older persons with dementia*. JAGS 2005, 53:299-305.

The Alzheimer Society works right across Canada to offer help and support to thousands affected by Alzheimer's disease and other dementias. We also promote public education and awareness to ensure people know where to turn for help. But we can't do it alone; our corporate and industry partners are integral to the work we do to extend our reach, raise our voice and make a greater impact.



Extending our reach through corporate partners

"We are grateful for organizations that show leadership and engage employees and customers to rally support and ultimately raise funds that provide a brighter future for people living with dementia," says Mimi Lowi-Young.

Here are a few recent examples of how our partners are championing our cause in communities across Canada:

In the fall of 2012, Revera Inc. held their biggest ever fundraising drive, giving more than \$100,000 to Alzheimer's disease education and community support. Across Canada, 250 Revera homes held *Celebrating Memories* events in recognition of World Alzheimer's Day in September. Events included everything from bake sales to clothing drives to garage sales. "Giving back to the communities in which we live and work has always been important at Revera," says Jeff Lozon, President and CEO of Revera Inc. "This year, through *Celebrating Memories*, we harnessed the power of our collective efforts and are very proud of the contribution we have made to this important cause."

In October, Bulk Barn Limited presented the Alzheimer Society of Canada with a cheque for \$275,201, the largest one-year donation that the company has made since the start of their involvement eight years ago in the Coffee Break® fundraiser hosted by Alzheimer Societies across Canada each year. The campaign's success is owed in great part to the fact that for the first time on World Alzheimer's Day, Bulk Barn's corporate office and their franchises participated in a "dollar match" program to help celebrate their 25th Anniversary. For every \$1 donated by a customer to a local Alzheimer Society, both the corporate office and franchise each contributed \$1, tripling the donation to the Society.

The Alzheimer Society is a proud member of HealthPartners, and is pleased to be among Canada's 16 leading national health charities, reaching employees through workplace giving campaigns. This year the Society received \$859,486 in generous donations.

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* Multi-year pledge

The Alzheimer Society of Canada thanks the many businesses, employee groups, foundations, government agencies and individuals that contributed so generously in 2012/2013. Thousands of others have contributed to Alzheimer Societies in their province or community.

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We honour, recognize and thank donors who have made a provision for a future gift to the Alzheimer Society via their will, gifts of life insurance, annuities, charitable trusts or endowment funds.

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We gratefully appreciate the generosity of our donors. We make every effort to ensure that donors' names are correctly listed. If there are any errors or omissions, please accept our sincere apologies and please notify us at 1-800-616-8816 or info@alzheimers.ca

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Statement of Financial Position

As at March 31, 2013

ASSETS

Current assets
Long-term investments
Capital assets

LIABILITIES AND NET ASSETS

Liabilities
Net assets

Statement of Operations

Year ended March 31, 2013

REVENUE

Public support
Bequests and memoriams
Corporate and foundations
Investment income
Other

Expenditures

Research program
Public education
Fundraising
General and administrative
Board and committee

Excess of revenue over expenditures before partner transfers

Partner transfers

Revenue flowed to partners
Partner assessments

Surplus (Deficiency) of revenue over expenditures

	2013	2012
ASSETS		
Current assets	\$ 4,478,660	\$ 3,415,388
Long-term investments	5,568,456	5,129,445
Capital assets	171,447	268,493
	10,218,563	8,813,326
LIABILITIES AND NET ASSETS		
Liabilities	4,355,800	4,153,604
Net assets	5,862,763	4,659,722
	10,218,563	8,813,326
Statement of Operations		
Year ended March 31, 2013		
REVENUE		
Public support	\$ 9,077,022	\$ 9,060,208
Bequests and memoriams	2,636,909	2,921,416
Corporate and foundations	573,236	465,947
Investment income	510,199	218,095
Other	59,427	52,133
	12,856,793	12,717,799
Expenditures		
Research program	3,707,329	3,873,414
Public education	2,862,609	2,690,633
Fundraising	3,913,635	3,997,542
General and administrative	407,470	512,558
Board and committee	143,480	196,104
	11,034,523	11,270,251
Excess of revenue over expenditures before partner transfers	1,822,270	1,447,548
Partner transfers		
Revenue flowed to partners	(7,260,343)	(7,940,902)
Partner assessments	6,631,050	5,594,059
	(629,293)	(2,346,843)
Surplus (Deficiency) of revenue over expenditures	\$ 1,192,977	\$ (899,295)

Dale Goldhawk, Honorary Director of the Alzheimer Society of Canada Board of Directors, and Debbie Benczkowski, Chief Operating Officer, represented Canada at the annual Alzheimer's Disease International (ADI) conference in Taipei last April. As a co-founding member of ADI, the Society works with other world Alzheimer organizations, campaigning for policy change and improved care for people affected by dementia.



Advocating for change through partnership

The Alzheimer Society is the national voice for the 747,000 Canadians living with dementia. We raise awareness about the issues and concerns that matter most to them. We work with politicians, policy makers and other community and health-care organizations to advocate for change in legislation, policies and programs at all levels of government.

Key highlights of our recent work include:

- Influenced the Canadian Medical Association (CMA) to call on the House of Commons Finance Committee to establish a national dementia strategy. The CMA also unanimously passed a motion at their 2012 annual general meeting in support of our call for a strategy.
- Presented to the House of Commons Health Committee hearings on neurological conditions, and contributed to the study on the impact of chronic diseases on Canada's aging population.
- Successfully encouraged the Council of the Federations Health Care Innovation Working Group to incorporate dementia-related issues into their mandate.
- Contributed to the 2012 World Health Organization report, *Dementia: a public health priority*, calling on governments to implement national dementia plans.
- Partnered with the Mental Health Commission of Canada to review the impact of dementia on Canadian society.
- Continued to work with the Neurological Health Charities of Canada to influence legislative change for people with dementia and their caregivers.
- Continued to partner with the Canadian Institutes for Health Research on research projects of mutual and strategic importance.
- Gained endorsement of our anti-stigma campaign from the College of Family Physicians of Canada.

In 2013-14, we will be recommending that the Federal Government create and fund an arms-length, not-for-profit organization to establish an integrated national strategic plan to address Alzheimer's disease and dementia.

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C A N A D A