AlzheimerSociety

# **2017** REPORT TO THE COMMUNITY

# BUILDING CONNECTIONS

## **OUR VISION**

Our vision is a world without Alzheimer's disease and other dementias.

We offer *Help for Today* through our programs and services for people impacted by dementia and *Hope for Tomorrow* by funding research.

# OUR MISSION

The Alzheimer Society of Alberta and Northwest Territories brings awareness to Alzheimer's disease and other dementias; helps alleviate the personal and social consequences of the disease; provides education and support programs; and promotes and funds research into the cause, prevention and cure.

# **CONNECTING** OUR VOICES **CONNECTING** OUR VISION

This past year, the Alzheimer Society of Alberta and Northwest Territories provided more help for today and more hope for tomorrow to more individuals and families than ever before. We were able to accomplish this by building strong connections. We connected more individuals, families and care partners to more programs, services, health professionals and resources in the community. Our researchers connected more dots in their quest to discover a cure. And, we connected more people with each other to help build understanding, gain strength and bring hope for a better tomorrow. We couldn't have made all of these valuable connections without our partners and generous supporters. We'd like to thank the Government of Northwest Territories, the Government of Alberta and Alberta Health Services for their continued support and the important work being done for those affected by dementia. We also thank our Board of Directors for their dedication and wisdom in governing our organization. And, to our staff, volunteers, donors and everyone else who has helped us throughout the year — thank you.

David Westaway, PhD President

Michele

Michele Mulder Chief Executive Officer

#### **BOARD OF DIRECTORS**



President: David Westaway, PhD

Past President: Donna Neumann

Vice-President: Jim Rivait

Secretary/Treasurer: Rosemarie Scarrow

Directors: Ray Biggs Samuel Gargan Matthew Hanrahan Karen Horsley Chris Lane Jenna Villeneuve Darcy Yamada

CEO: Michele Mulder

# **CONNECTING** FAMILIES AND COMMUNITIES

The Alzheimer Society of Alberta and Northwest Territories is a provincial\* organization with offices in Edmonton, Fort McMurray, Grande Prairie, Lethbridge, Medicine Hat, Red Deer and Yellowknife, NT. Our programs and services complement the existing healthcare system by addressing the support and educational needs of families and care partners on an ongoing basis.

\*Programs and services in Calgary and area are provided by the Alzheimer Society of Calgary.

#### What is Dementia?

Dementia is not a specific disease. It is a collective term to describe brain disorders with symptoms that may include memory loss and difficulties with thinking, problem solving or language. Dementia is severe enough to reduce a person's ability to carry out day-to-day activities and it can cause changes in personality and behaviour.

We know that living with Alzheimer's disease or other dementias is often demanding and isolating for those with the disease and their care partners. Through our programs and services, our regional offices provide care and support on an individual and family basis for those living with the disease.

**Dementia is a disease.** Early diagnosis is important to live well for longer and to make important decisions with family members and care partners.

# ADVOCATE SERVE INNOVATE

At the Alzheimer Society of Alberta and Northwest Territories, we *Advocate, Serve and Innovate* on behalf of people with dementia, their families and everyone involved with our organization. These principles guide us with a strategic focus to provide greater service and assistance to more people. Statistics tell us that the impact of dementia is far reaching. That's our reality. But, our knowledge, our understanding and our resolve to make life better for those affected by this disease makes us more determined than ever to make a difference.

> SOMEONE IN THE WORLD DEVELOPS DEMENTIA EVERY 3 SECONDS

### **ADVOCATE**

### **BUILDING** PARTNERSHIPS

This year we created the framework for a Community Dementia Ambassador program

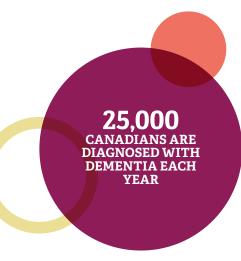
to provide ongoing information and support for people in rural or remote communities living with or caring for someone with dementia.



Martha MacLellan, NT Alzheimer staff member, Health Minister Glen Abernethy and Michele Mulder, CEO

"The Alzheimer Society provides resources, education, support and raises public awareness about Alzheimer's disease and other dementias. Seniors are the fastest growing demographic in the NT and its 33 communities. The Alzheimer Society is a valuable partner in supporting our residents and their care partners to successfully 'age in place' in or as close to their home community as possible."

Honourable Glen Abernethy, Minister of Health and Social Services, Government of Northwest Territories.



#### The Community Dementia Ambassador Program

This year we created the framework for a Community Dementia Ambassador program to provide ongoing information and support for people in rural or remote communities living with or caring for someone with dementia. The program will be led by volunteer ambassadors who create and nurture relationships where cultural values about dementia and community norms can be addressed at a local level. We look forward to partnering with the Northwest Territories Seniors Society and the Government of Northwest Territories in piloting this initiative.

#### **Supporting Dementia Advice Service**

Individuals and caregivers living with dementia are benefiting from Alberta Health Services specialized dementia advice service through **Health Link.** Caregivers, family and friends are encouraged to access advice on dementia by calling 811 in Alberta. Specialized dementia nurses provide an in-depth assessment to gain an understanding of each individual situation and provide personalized support and advice, as well as connect callers to available community services and supports. **Since launching provincewide in May 2016, the Alzheimer Society has received 54 additional referrals to our First Link\* program from the service.**  **Dementia doesn't discriminate -** friends, families and members of our communities all experience the personal and social impact of dementia.

#### **Awareness Month**

Throughout the month of January, we asked individuals to be **#InItForAlz** - so they could recognize the warning signs of dementia and support vital research to eliminate this disease. This campaign took aim at changing the conversation about a disease that continues to be shrouded in silence.

As part of Awareness Month, science communicator Jay Ingram, along with Alberta Innovates funded researchers, presented free lectures titled *The Alzheimer's Mystery* about the challenging science behind the disease and the research that is underway. The presentations were well attended and highlighted the importance of meaningful support for individuals with dementia and their families.

# **CONNECTING** BY SERVING EACH OTHER



**Thank you to all our volunteers** for assisting in the delivery of our programs and services. From facilitating support groups to ensuring information and materials are collated and distributed, we couldn't do it without you!

#### **Support Groups**

Support groups provide a safe environment to share ideas, introduce coping skills and offer encouragement to individuals and families facing similar situations. Specialized groups have been established to meet specific needs such as young onset, adult children and male care partners.

Activity based groups such as the Alzheimer Café, Memory Trekkers, and Art in the A.M. have also been created throughout the regions. These groups focus on social activities where participants can express themselves in an environment that promotes active participation.

We also offer telephone support groups and online support groups on ASANT Café.

This past year 32 unique support groups were offered monthly through our regional offices.

# Turning an extraordinary challenge into hope

Chris Nelson is an amazing individual. She is a mother, a wife, a volunteer and though she admits she's slowed down a bit, she still enjoys an active life, including going to Aquafit. As a matter of fact, Chris believes her healthy lifestyle has been key to her living well with dementia.

Fifteen years ago Chris was diagnosed with Frontotemporal dementia. While dealing with her own symptoms of dementia, Chris learned her mother was diagnosed with Alzheimer's disease. During this difficult time, Chris turned to the Alzheimer Society for help and started attending a support group for care partners. Years later, after her mother passed away, Chris continued to attend the support group—inspiring others and sharing a story that was truly unique. "I went to the care partner group while caring for mom and told them that I had dementia," says Chris. "Everyone was very supportive and I feel like I was able to make a difference in helping families relate to loved ones living with the disease." Chris was able to express how the smallest details can make a difference to people with dementia. "I was able to help a lot of people understand that too much clutter makes us confused.

How extra cutlery on the table gets us confused." She now gains personal strength and comfort by providing love and understanding to those in the group. Being able to share details of her life has made a significant impact on the lives of hundreds of people in her community. Chris is very open and shares her successes living with the disease as part of the Seeds of Hope: Family Learning Series. Being personally involved with support groups and acting as a spokesperson for the Alzheimer's Society has been very gratifying for Chris. Always one to care for others, she made the commitment to make a difference, and for everyone who has met her, she's left a lasting impression proving that you can still live a life of quality while living with the dementia.



Health Minister Sarah Hoffman and Michelle Mulder, CEO

"Strengthening supports for Albertans living with dementia, their families and their care partners is a priority for this government. The Alzheimer Society of Alberta and Northwest Territories is a tremendous resource for people in this province who are affected by dementia and I am pleased this grant will ensure the First Link<sup>®</sup> program is available to all Albertans." Honourable Sarah Hoffman, Deputy Premier and Minister of Health, Government of Alberta

#### **First Link**<sup>®</sup>

First Link<sup>®</sup> is an early intervention program that connects people living with dementia and their care partners to the Alzheimer Society for services and support. The program removes barriers by ensuring people are connected directly to key supports at the time of diagnosis or as soon as possible after a diagnosis is made.

Referrals from physicians or other health professionals to our offices provides early access to information, services and support and an ongoing connection throughout the progression of the disease.

We have seen the positive impact First Link<sup>®</sup> has had on the lives of thousands of families since it was first established in 2013. We were pleased to have received a grant for almost \$2 million over three years from the Government of Alberta in 2016 to enable the program to expand to all of Alberta.

> THE ANNUAL COST OF **CARING FOR DEMENTIA** IN CANADA IS **S10** RHIION

AFTER THE AGE OF 65, THE RISK OF DEMENTIA DOUBLES EVERY 5 YEARS



ASANT Café is an online education forum and community designed to help people connect, share, discuss and learn. It's a gathering place for individuals, family members, care partners, and friends - anyone whose life is affected by Alzheimer's disease and other dementias. Developed in 2014, ASANT Café provides access to our learning and educational series, discussion boards and a host of webinars on topics of interest to people affected by this disease. The Café was created to extend the reach of the programs provided in our regional offices to people across Alberta and the Northwest Territories. During the past year, on average, our site was accessed over 25 times daily and our online community membership has grown **38 per cent.** With a dedicated staff member assigned to oversee the ASANT Café, we have now formed partnerships with other Alzheimer Societies across the country to provide a virtual connection for people where support, discussion, and education resources can be found.

We connected with over 3500 individuals on 119 different occasions through our Community Outreach program this year.

#### Seeds of Hope: Family Learning Series

Seeds of Hope is an educational series that addresses the emotional and educational needs of individuals impacted by dementia. Offered online and in person, *Seeds of Hope* features 18 sessions that are designed to reflect the progression of the disease at all stages. **This year**, over 150 people attended our learning series in offices across the province.

#### **Brain Health Education Series**

A Brain Health education series for everyone wanting to keep their mind active and vibrant is offered on ASANT Café. Research has shown that keeping your brain active and making better lifestyle choices can improve the brain's ability to sustain long-term health. The Brain Health Series offers eight sessions with a number of modules with each session.

#### ASANTCafe.ca

### **INNOVATE**

# **CONNECTING** THE DOTS

Dementia research is without a doubt, our "hope for tomorrow". The Alzheimer Society is committed to promoting excellence in research, both bio-medical and non-clinical, to improve the quality of life for those with dementia and their care partners.

#### The Alberta Alzheimer Research Program

This program is a collaboration between the Alzheimer Society of Alberta and Northwest Territories and the Alberta Prion Research Institute. We have committed to fund up to \$500,000 over three years, to support Alberta-based dementia research. **Last year, seven investigators were awarded just over \$1 million in total funding.** 

#### **Alzheimer Society Research Program**

A national partnership, the Alzheimer Society Research Program is a collaborative initiative of provincial Alzheimer Societies, the Alzheimer Society of Canada, partners, and donors who support research directed at both eradicating dementia and improving the lives of those affected by the disease. In 2016-17, Alberta contributed over \$127,000 in funding to the program.

#### Healthy Brain Aging and Dementia Initiative

DEMENTIA CAN BE PRESENT IN THE BRAIN FOR UP TO

EFORE SYMPTOMS

Through our partnership with Campus Alberta Neuroscience, we supported the Healthy Brain Aging and Dementia International Symposium held in May, 2016. This event brought internationally renowned dementia and brain research specialists from around the world to share the latest findings in bio-medical and psycho-social dementia research. Our partnership also included our Society committing \$350,000 to a joint collaboration with Brain Canada, the University of Calgary and Alberta Innovates to fund a three-year research project.

Our involvement in non-clinical research has evolved and grown over the past year. While we have not provided funding to these projects, the Society does assist by recruiting people for studies, participating on advisory committees, and providing expertise. We have assisted in a number of projects ranging from web-based technologies in support of people with dementia and their care partners to digital storytelling research aimed at gaining a better understanding of the benefits of sharing stories and memories to those with dementia.

# Getting closer to a breakthrough everyday

Dr. Jack Jhamandas could possibly be the right person in the right place at the right time to be researching a breakthrough and cure for those living from dementia.

Dr. Jhamandas is an Edmonton-based physician and scientist whose research focuses on studying misfolded proteins in Alzheimer's and Prion diseases. With funding through the Alberta Alzheimer Research Program, he and his team of researchers have discovered that a compound, known as AC253, has shown significant benefits against a rogue protein associated with Alzheimer's disease. The team's hope is to advance the research far enough to enlist pharmaceutical investment to help them develop a drug based upon AC253 for Alzheimer's disease. "I'm very optimistic about the future," says Dr. Jhamandas. "I feel like in the next 5 to 10 years, there's going to be a tremendous breakthrough. We may be able to find a cure for Alzheimer's or at least halt its progression."

But that's not all that motivates Dr. Jhamandas to continue his research. He is also encouraged by the work of his colleagues in the Alzheimer's research community. As a clinician, he sees first-hand how dementia impacts families, friends and the community. While there may be over 50,000 individuals directly affected by dementia in Alberta, he is quick to point out that the number is closer to 400,000 when you take into account everyone affected including families, friends and caregivers. "Alzheimer's is at the top of the list for the burden it places on individuals and society," says Dr. Jhamandas. "It often plays out in living rooms, kitchens and bedrooms and involves everyone from grandchildren and friends to spouses."

Dr. Jhamandas recognizes the value in the research conducted into maintaining a healthy lifestyle, brain health and the importance of the arts—as these have proven to be helpful for thousands of people living with dementia. With people like Dr. Jack Jhamandas at work right here in Alberta, we're all encouraged that the lives of those impacted by dementia will improve for people not only here at home but around the world.

We recognize and thank the hundreds of volunteers who give of their time and talents to ensure the success of our events. We couldn't do what we do, without their commitment, dedication and passion.

# **CONNECTING PEOPLE** ON A LARGER STAGE

Our events throughout the year truly personify our commitment to Advocate, Serve and Innovate. These events not only raise funds for our programs, services and research, they also provide a valuable opportunity to start a conversation about dementia. The more awareness we can create, the better equipped we will be to help to dispel the stigma of the disease. This in turn will help foster greater understanding and acceptance of those living with dementia.



The Face Off for Alzheimer's Pro-Am Hockey Tournament, now in its seventh year, is our signature fundraising event. Teams raise a minimum of \$25,000 each for the opportunity to lace up their skates and play with some of hockey's

greatest legends and raise money for Alzheimer's research. The weekend event pairs amateur players with members of the NHL Alumni in a friendly, yet competitive, round-robin tournament.

Through the amazing efforts of the hockey players and sponsors, the Face Off for Alzheimer's tournament has contributed approximately \$3.273 million and funded 22 research projects in Alberta since 2012.



The Investors Group Walk for Alzheimer's is a fun and family-friendly way to raise awareness and funds for the Alzheimer Society.

The Walk helps create positive memories while sending a message of hope to those living with dementia, and the thousands of friends and families who care for them. This year, our Walks attracted hundreds of people in 9 communities throughout Alberta, raising over \$222,000 so people with dementia and their families can access support groups and services from their regional Alzheimer's office.



Coffee Break is a long-standing event across Canada that raises awareness and funds and encourages a greater discussion about Alzheimer's disease and other dementias. **In 2016, over 200** 

individuals and organizations hosted a Coffee Break, raising \$26,577 for the Society.

# A big goal for Alzheimer's

Helping the Alzheimer Society has become second nature to Darren Cunningham. He's one of those caring souls who, because of a personal connection, wants to make a difference in the lives of people diagnosed with dementia.

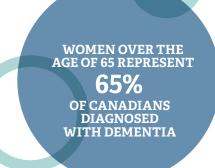
Darren watched his grandmother live with dementia and now his own mother has the disease. So Darren has made it life," says Darren. "Whether it's Alzheimer's or another his mission to raise money in support of dementia research. He has raised donations through the 'Wood to Remember' fund at his business and through his involvement in the Alzheimer's Face-Off hockey tournament. Darren got involved in the tournament with the help of his rugby buddies and now, as co-captain of the "Mayflowers" (named in honour of his mother, May), the team has raised over \$175,000 in three years.

"Everybody has something they are fighting for in their disease, everybody has something that has affected them personally. So for me, it's easy. I help raise money every year in honour of my grandmother and my mom."

Darren knows there is always the possibility that dementia may affect other members of his family, so he is doing what he can to support research to find a cure for the disease. With passion and commitment, Darren and his team are truly making a difference.



**OUT OF 4** KNOW SOMEONE WITH DEMENTIA





Many individuals and organizations choose to host their own fundraising events to support the work of the Alzheimer Society. These third party events raised over \$29,000 this past year.

One unique event that took place in June 2017 was *Ten Thousand Meters for Ten Thousand Dollars* – a cycling challenge that Gordon Jones embarked on to honour his mother, who was diagnosed with Alzheimer's disease two years ago, and to raise money for the First Link<sup>®</sup> program.

On completion, Gordon joined an elite group of cyclists who have completed the vertical climb, known as Everesting (riders must continuously climb until they hit the height of the world's tallest peak, Mount Everest, at 8,848 metres).

Gordon rounded up the distance, because as he said, 10,000 metres to raise \$10,000 seemed a nice round number. His goals were lofty, and though he did not cover the full 10,000 meters (the final stats were 8907 meters, 339 kilometers and 27 hours), his fundraising efforts surpassed \$22,500\* in donations.

We could not do the work we do in assisting those with dementia, their families and care partners, without people like Gordon.

\*monies raised will be reflected in the 2017/18 fiscal year



Gordon and his mother Moya Kavanagh on climb day.

**Thanks to the \$22,500 that Gordon Jones raised, 275 families** will receive the help they need through the intake process from a First Link° referral.

# **CONNECTING** WITH THE COMMUNITY

Over the past year we have helped hundreds of individuals and families in Alberta and the Northwest Territories because of the generosity of our donors. Every contribution is an investment in our programs, services and research, enabling us to support individuals and families impacted by dementia.

#### Leaving a Legacy

Planning for a gift to the Alzheimer Society in your will is an easy way to leave a lasting legacy and represents a significant contribution to support the work we do, while providing tax and estate planning benefits.

**This year we received 13 bequests totaling \$1,273,435.** Future planning makes a huge impact on the types of investment we can make into education programs, services, and research.

#### Thank you to our donors

Whether a gift is a direct donation, in memory of a loved one, or through pledges for the Walk or another event – they are all important and make a huge difference in our ability to serve those who come to us for help. We appreciate the generous gifts we receive from our donors who faithfully give financially to make us stronger.

> 564,000 canadians are living with dementia

# FINANCIAL HIGHLIGHTS

Statement of Operations for the year ended March 31, 2017

<b>REVENUE TOTALS</b>	2017	2016
Fundraising	1,624,308	1,766,125
General Donations	2,093,888	1,624,755
Government Grants	581,884	927,176
Investment Income	66,656	13,807
	4,366,736	4,331,863

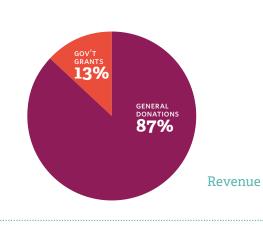
#### **EXPENSE TOTALS**

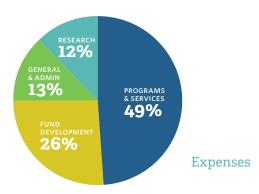
Programs & Services	1,980,714	1,714,474
Fund Development	1,031,828	994,141
General & Administration	547,611	676,513
Research	474,218	341,121
	4,034,371	3,726,249

332,365

605,614

#### Excess Revenue over Expenses





This information has been extracted from the Audited Financial Statements reported by our auditing firm, DeGraves Pallard & Associates, LLP. The full report can be found at alzheimer.ab.ca



# AlzheimerSociety

ALBERTA AND NORTHWEST TERRITORIES

# **OUR OFFICES**

#### **Provincial Office**

High Park Corner #308, 14925 - 111 Avenue NW Edmonton, Alberta T5M 2P6 Phone: 780-761-0030

#### Edmonton

10531 Kingsway Avenue Edmonton, Alberta T5H 4K1 Phone: 780-488-2266

#### Fort McMurray

The Redpoll Centre at Shell Place 1 C. A. Knight Way Ft. McMurray, Alberta T9H 5C5 Phone: 780-791-0077 Ext 3042

#### **Grande Prairie**

#102, 9823 - 116 Avenue Grande Prairie, Alberta T8V 4B4 Phone: 780-882-8770

#### Lethbridge

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#### **Medicine Hat**

#201, Medical Arts Building 770 - 6 Street SW Medicine Hat, Alberta T1A 4J6 Phone: 403-528-2700

#### **Red Deer**

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#### Yellowknife

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alzheimer.ab.ca 1-866-950-5465