

Alzheimer Society

# By the numbers

**TODAY** 

## THE URGENCY

Canadians 500,000+ living with dementia

Cost of dementia to the Canadian economy and healthcare system

\$10.4 **BILLION**  2030

912,000

\$16.2



Of those living with dementia aged 65+



of Canadians are concerned about being affected by Alzheimer's disease

Of greatest concern is their fear of being a burden to others, and of losing their independence and the ability to recognize family and friends



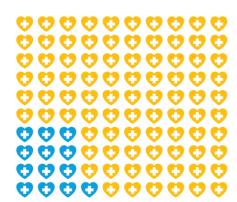




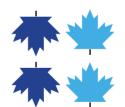




2 in 5 Canadians have experience caring for someone living with a form of dementia



of caregivers wish that more people understood the realities of caring for someone with dementia



Canadians admit they would feel ashamed or embarrassed if they had dementia

## THE PROGRESS



**MORF THAN** 

**MILLION** 

invested to date in research through the **Alzheimer Society** Research Program

# Working together for a brighter future



Kevin O'Shea



Ronan Ryan

It's a devastating reality that most of us have been touched by dementia, whether living with a diagnosis or watching someone we love experience the disease. While the world's attention turned to the global pandemic in early 2020, people living with dementia in Canada were enormously impacted. Across the country, crucial home and community support services for people living with dementia and caregivers were reduced, leading to social isolation and increased caregiving burden.

Because of you, Alzheimer Societies across Canada quickly responded to the increasing need for services by shifting many programs, services and ´sessions online and over the telephone. At the same time, the Alzheimer Society of Canada advocated that the unique needs and challenges of people living with dementia be at the forefront of the national pandemic response.

With our continued commitment to investing in dementia research, the Alzheimer Society of Canada has invested more than \$64 million since our research program began in 1989, focused on research areas including improving quality of life, early diagnosis and prevention, as well as big, bold and new ideas from emerging researchers across the country.

To achieve our mission, it's critical that people touched by dementia are heard. That's why people with lived experience of dementia are at

the heart of everything we do, engaging in all aspects of our work. For example, the Alzheimer Society of Canada's Advisory Group of People with Lived Experience of Dementia is a community of people living with dementia and care partners who provide critical input on our work and participate actively in education, advocacy and awareness-building.

We also listen to the needs of people living with dementia through the many letters, emails and calls we receive. Their voices help guide our advocacy efforts, shape what resources we develop, and push us to keep fighting for a better future for all people impacted by dementia in Canada.

Because of your support, we will continue to shine a light on the experience of living with dementia and ensure that the voices of people living with dementia are heard.

Kevin O'Shea

Board Chair, Alzheimer Society of Canada

Ronan Ryan

CEO, Alzheimer Society of Canada

# **COVID-19 and dementia**

Across Canada, people
living with dementia
and caregivers were
enormously impacted
by the pandemic, no
matter whether they
lived in a care setting or
at home. The Alzheimer
Society of Canada
introduced a series
of supports and took
action to support people
living with dementia, as
well as their families and
professional caregivers.

#### **COVID-19 Task Force**

In response to the pandemic, we convened a COVID-19 and Dementia Task Force that included leading researchers, clinicians, dementia specialists and people with lived experience of dementia to identify and address gaps in the healthcare system for people living with dementia and caregivers throughout the pandemic.

#### Key initiatives included

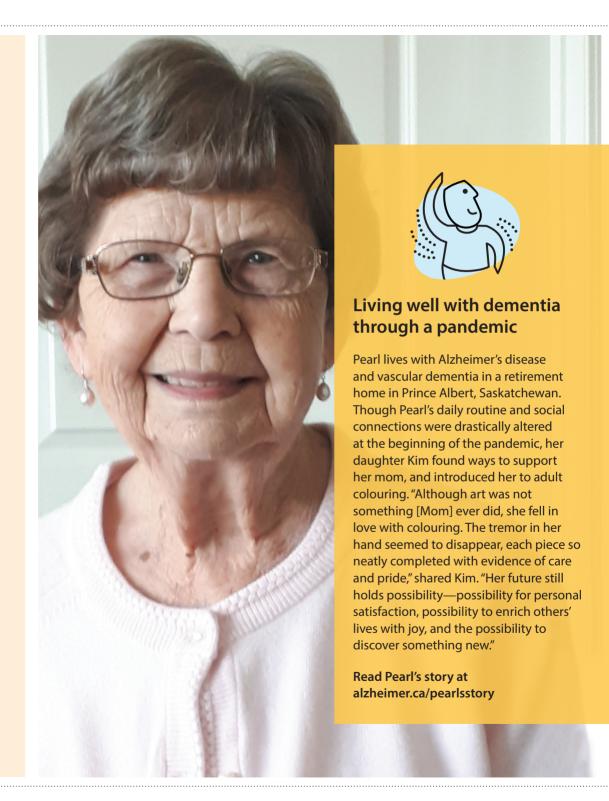
- Introducing guidelines for acute care settings to allocating scarce resources to people with dementia during a pandemic (provided to all acute care hospitals in Canada)
- Providing recommendations for family physicians on virtual cognitive and behavioural assessments
- Recommendations on improving end-of-life care in long-term care homes for people living with dementia.

The task force presented its recommendations to the Dementia Policy Secretariat at the Public Health Agency of Canada, the Federal/Provincial/Territorial Coordinating Committee on Dementia (one of the governance tables attached to the national dementia strategy) and to the Chief Science Advisor to the Government of Canada. Work continues in this area to improve healthcare for people living with dementia now and beyond the pandemic.

# COVID-19 tips for caregivers & people living alone with dementia



Recognizing that many community and support services were paused due to the pandemic, we introduced tips for both caregivers and people living alone with dementia. These online and print resources provided ideas on how to stay safe, incorporate activity and connection into daily life, and how to take care of both physical and mental health.



# Our research will change the future of dementia—because of your support.

Dementia is not a normal part of aging. It is causing Canadians to die early after enduring poor quality of life and deteriorating for many years. Every year, about 76,000 Canadians are diagnosed with dementia, all destined to slowly lose themselves while their family and friends helplessly watch.

But the devastation does not stop there. Families are put under tremendous strain with immense mental, physical, and financial stresses that last long after their loved one is gone. By 2031, there will be nearly one million Canadians living with dementia and two million Canadians supporting them as caregivers.

#### THERE ARE NO CURES.

We are not certain what causes dementia. We do not know how to prevent it from occurring or how to stop it from progressing. And for over 16 years, there have been no treatment breakthroughs.



#### **BIG, BOLD, NEW IDEAS ARE NEEDED.**

The Alzheimer Society Research Program is one of Canada's leading hubs for dementia research and is laser focused on funding high-impact projects to unlock innovative solutions.

Only dementia researchers with the best ideas receive our funding so they can figure out which new areas show promise and deserve further investigation.

To ensure projects that receive our funding will truly make a difference, we engage world-renowned experts in dementia along with people with lived experience of dementia in our peer review process. These "citizen reviewers" offer unique, first-hand perspective on dementia to help guide us to areas of greatest impact.

## **ELIMINATING DEMENTIA**WILL SAVE LIVES.

This is our vision for the future. But it will take time. That is why we also support projects that help people with the disease now to live the best and longest life possible. We fund research in eight priority areas:

#### **Prevention and Cures**

- Cause
- Risk and prevention
- Diagnosis and detection
- Epidemiology

#### Living with Dementia

- Therapy
- Improving care for people with lived experience
- Translational
- Developing treatments

## Some recent projects we funded were aimed at:

- · Restoring memory
- Understanding genetic risk factors
- · Reducing falls
- Reducing disease progression

Diagnosing dementia earlier, slowing its progression, and maintaining ability improve the quality of life of people living with the disease and ease the stress and strain on families and caregivers. Every step makes a difference.

## PROMISING RESEARCH IS GOING UNEXPLORED.

It is imperative that we continue to fund high-impact research to unlock solutions, but there are more qualified projects than we can fund. And one of them just may contain a discovery that will make the progress that is so desperately needed.



# We urgently need your help.

To make sure the potential of the best ideas and brightest new researchers are realized, we must double our research funding over the next five years. And we can't do it without you.

Your investment in Alzheimer Society research will touch the lives of millions across Canada. Learn more at alzheimer.ca/research.

# Translating research into support

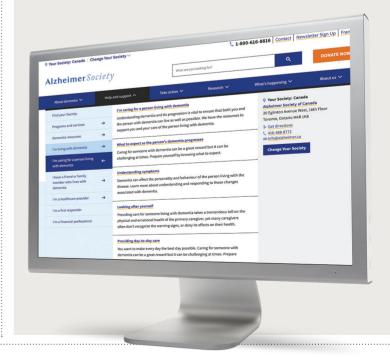
100+ new online and print materials created by the Alzheimer Society of Canada to support people living with dementia, caregivers, and front-line staff across the country

## 2,000 Subject Matter

**Experts,** including people living with dementia, engaged to review materials

Nearly **1,000,000 materials** printed and delivered to local Alzheimer Societies in the last year

**300,000** downloads of dementia resources from our website, <u>alzheimer.ca</u>



# **Knowledge** is power

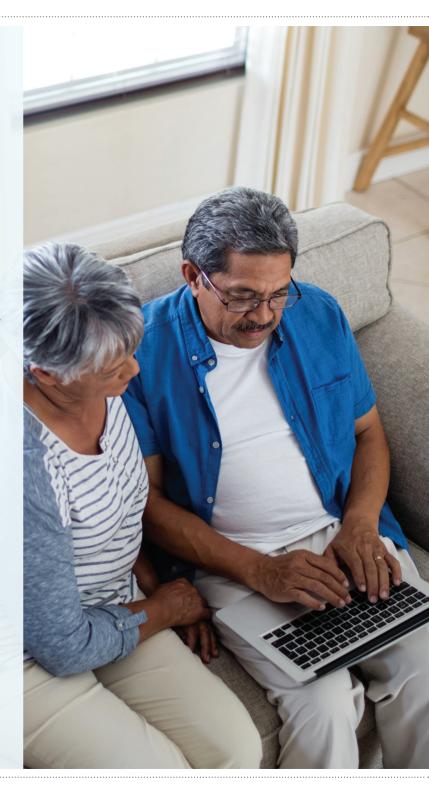
When faced with a dementia diagnosis, having the right information can help you feel connected and empowered. When you and your loved ones have a meaningful understanding of your condition, and support along every step of the journey, you can truly live well with dementia

Your support enables the Alzheimer Society of Canada to research, produce and update our website—Alzheimer.ca—as well as print resources at local societies across the country. People living with and affected by dementia count on these educational resources to help them understand and navigate the disease. These tools are used daily by people living with dementia and caregivers, as well as our frontline teams.

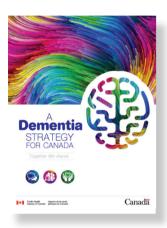
After hearing feedback from people across Canada—people living with dementia, families, caregivers, researchers and our staff—we've relaunched alzheimer.ca with a new look and ease of navigation. If you visit our website today, you're likely looking for support with a challenge you're facing right now, so we've created quick access to topics that speak to you if:

- · You're worried you might have dementia
- You're worried someone you know might have dementia
- · You have recently been diagnosed or are living with dementia
- You are caring for someone with dementia

Visit alzheimer.ca for the latest facts and news about dementia; to access help and support close to you; to take action on stigma and raise awareness; or to learn more about dementia research.



# Advocating for change across Canada



The Alzheimer Society of Canada continues to advocate for the rights of people living with dementia and caregivers through several federal advisory roles. We won't stop until people living with dementia are represented at every table where care and policy decisions are made.

This year, the Society's Chief Science Officer, Dr. Saskia Sivananthan, was appointed to the Ministerial Advisory Board on Dementia, which provides

advice to the Federal Minister of Health on Canada's first national dementia strategy, A Dementia Strategy for Canada: Together We Aspire. She also spoke on unpaid work from a caregiving perspective at the Status of Women Standing Committee.

As the national dementia strategy is in its second year, we continue to push for full and sustainable funding so that the strategy may fully realize its goals. Along with many other national health organizations, the Alzheimer Society of Canada has recommended that the federal government increase its initial investment of \$50M over five years to \$150M to ensure measurable and timely progress of the strategy.

Investment in dementia research in Canada falls well below that of other G7 nations. Through the Society's pre-budget submission and several meetings with federal representatives, we continue to advocate for more funding for dementia research.

## **OUR VISION**

A world without Alzheimer's disease and other dementias.

### **OUR MISSION**

To alleviate the personal and social consequences of Alzheimer's and related diseases and to promote the search for causes, treatments and a cure.

### **OUR VALUES**

#### **COLLABORATION**

We work together and with partners to fulfill our mission and achieve our goals, to ensure Canadians receive personal and responsive services throughout their dementia journey.

#### **ACCOUNTABILITY**

We measure our performance and follow a process of continuous improvement. We are wholly accountable for our actions and must account to our stakeholders for our use of the financial and human resources. available to us.

#### RESPECT

We set for ourselves the highest standards of honesty, trustworthiness and professional integrity in all aspects of our organization and carry out our work with the utmost respect for the dignity and the rights of the people we serve.

#### **EXCELLENCE**

We strive to engage stakeholders in meaningful ways. To inform, listen and be attentive to those we work with: people living with dementia, families, community partners, donors, volunteers and staff members.

# **Dementia does** not stop and neither do we

The IG Wealth Management Walk for Alzheimer's breaks records





When the global pandemic was declared on March 11, 2020, just weeks away from the annual IG Wealth Management Walk for Alzheimer's, it was unclear if the Alzheimer Society would be able to deliver the event. Most national organizations and charities opted to cancel their fundraising events.

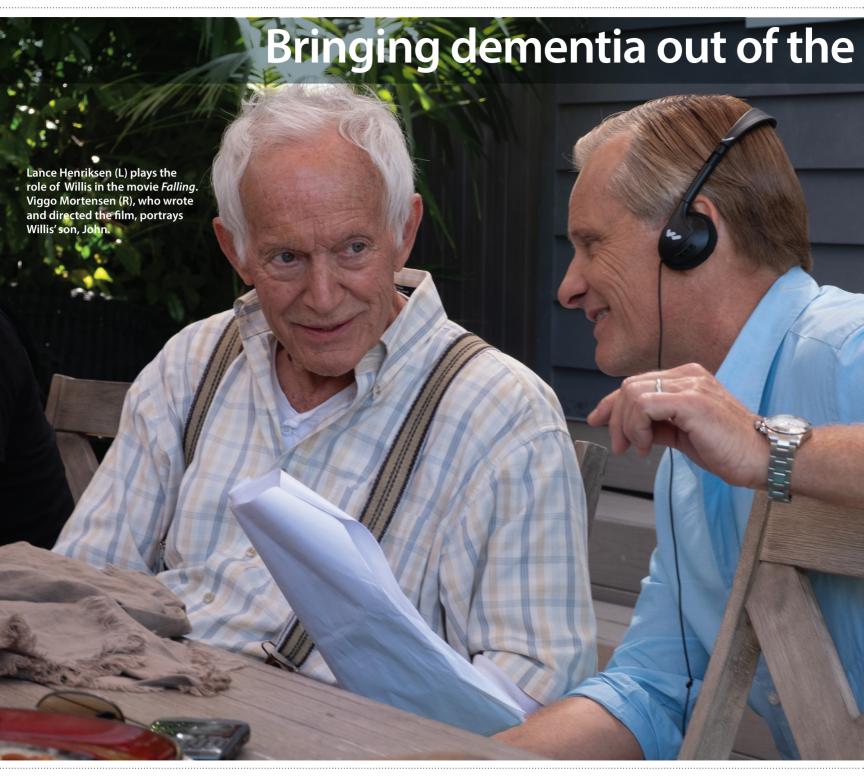
The IG Wealth Management Walk for Alzheimer's is Canada's biggest event in direct support of people living with dementia. In 2019, the event raised more than \$6 million, enabling Alzheimer Societies to provide vital programs and services for hundreds of thousands living with a diagnosis and their caregivers. It was clear the need for those services would not diminish in a pandemic. Dementia is an isolating disease, and people living with a diagnosis and their caregivers were already enduring mental and emotional isolation. The pandemic had already started to add to their isolation, with widespread stay-at-home orders issued across the country, and many support services suspended.

Because dementia doesn't stop, neither do we. Alzheimer Societies quickly reacted to the pandemic and found new ways to provide services. Funds were needed to continue those shifts, so cancelling or even postponing the Walk was not possible. The decision was made—the Walk would go on. With thanks to our committed partner, IG Wealth Management, the Alzheimer Society was poised to move forward.

The 2020 IG Wealth Management Walk for Alzheimer's was one of Canada's first mass fundraising events held under pandemic restrictions. For the first time, the Walk landed in the top ten list of peer-to-peer fundraising events in Canada. The event raised more than \$5 million so that the Alzheimer Society could continue providing urgent support to people living with dementia and caregivers. Because we couldn't gather together in communities like we normally do for this event, we instead asked supporters to "walk their way"—and that they did! Fundraisers across the country walked, ran, biked, swam, stood on their head, baked cookies, sang songs and even walked their neighbourhood in costume; and on May 31st the country came together through a nationwide broadcast which celebrated the creativity, generosity and remarkable support of all who participated in the Walk.

Watch the national celebration of the 2020 IG Wealth Management Walk for Alzheimer's at youtube. com/alzheimercanada





# shadows and onto the big screen

## Viggo Mortensen discusses his personal connection to dementia and his latest film

Oscar-winning actor Viggo Mortensen, like many of us, has been personally impacted by dementia. "Both my parents, my stepdad, grandparents, aunts, uncles, both sides. I've seen it a lot, up close," he shared when sitting down to talk about dementia and his latest film, Falling, with the Alzheimer Society of Canada.

Mortensen wrote, directed and starred in the awardwinning film. Falling depicts a caregiver's struggle to connect with his father, who lives with dementia. In his ASC interview, the acclaimed actor discussed his thoughts behind his new film, including the importance of getting an accurate portrayal of dementia on screen and how to show compassion and understanding when communicating with a person living with the disease.

In the film, conflict and frustration arise as father and son navigate how to effectively communicate their feelings to each other and mend their relationship. It was vital to Mortensen to depict these challenges accurately and to reflect a reality he and millions around the world live every day. He shared that dementia isn't always shown authentically on screen.

By offering a true portrayal of a family's struggles with dementia, Mortensen highlights some of the stumbling blocks many people experience with trying to engage with a loved one with dementia, such as trying to correct their observations and behaviour instead of adapting to their experiences.

"It's about communication," said Mortensen. "Whether you have dementia or not, it's important to be flexible with anybody that you care about."



Watch the interview at youtube.com/c/alzheimercanada/videos

# Changing how we see, discuss and learn about race and dementia

At the Alzheimer Society of Canada, we work to change the lives of people living with dementia. However, we need to do more to combat systemic oppression. Here is how we are changing.

#### The Dementia Journey Survey

Physicians are insufficiently equipped to manage dementia, especially for Black, Indigenous, and People of Colour (BIPOC) who experience the healthcare system differently. We conducted a national survey to identify the experiences of people living with dementia, with an intentional focus on BIPOC communities. The data we captured will shape and deliver new resources to ensure family physicians are equipped to support all Canadians living with dementia.

### Our Advisory Group of People with **Lived Experience**

Knowledge of how BIPOC experience dementia and the healthcare system in Canada is woefully inadequate. Our first step to changing this is to grow the Alzheimer Society of Canada's Advisory Group of People with Lived Experience of Dementia. This group is vital to our work but is almost entirely white. We will grow the group with a specific focus and target to BIPOC communities.

#### We are changing how we hire our people, manage our business, and deliver our work

- To accelerate change within our organization, a major portion of our professional development budget will be dedicated to inclusivity and antiracism training. This development will remain a key, long-term component of our professional development budget and processes for our existing team, new hires, and our board.
- We will implement new recruitment standards to identify and remove any traces of bias, and to actively deliver a team and board that looks like Canada, and where marginalized people are not just safe, but can thrive and grow.
- We will build specific, formal relationships with diverse community groups and build partnerships requiring engagement by staff at all levels so we can listen, understand and be accountable for developing programs and services that are inclusive to all.



## **Remembering Claude**

"My wife's father, Claude (pictured), was diagnosed with a rare form of dementia whereby the initial symptoms presented as difficulties in communication. As his condition progressed and his mobility faded, his joyful, silly and upbeat personality never stopped shining through. He still managed to make us laugh and cry in a single moment. Since his passing at the age of 69 in 2018, he left an immense hole in our hearts. Though that void can never be filled, Angela and I are expecting our first child and found out just this week that we are having a boy! His due date is April Fool's day, April 1st, and we know Claude would have seen the humour in telling people the due date, thinking that it might be a prank. To pay tribute to his memory, we began donating to the Alzheimer Society of Canada. Our hope is that our donation can contribute in some small way to educating, supporting, and funding research on Alzheimer's disease and other forms of dementia. We miss you, Claude!"

—Dan Barker



# Thank you!

Your generous support is helping us to find a cure and identify potential new treatments for Alzheimer's disease, understand the different forms of dementia, and enhance quality of life, care and support for all those who are affected by dementia.

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<sup>\*</sup> denotes donors whose giving includes an estate gift

## Thank you, Valeria!

be hope for the future."

For Valeria Rosenbloom, caring about one another and society at large is a family priority. She and her family are focused on helping improve the lives of people who experience the challenges of health conditions through both professional practice and philanthropy.

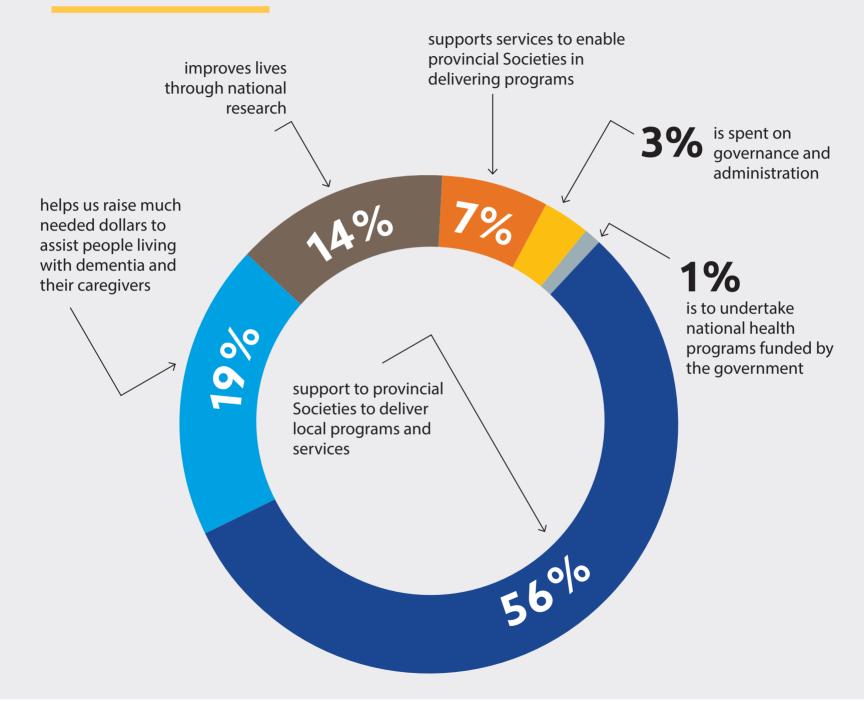
In her career as a physical therapist, Valeria often worked with patients who struggled not only with physical disabilities, but also with neurological issues. And her daughter works as a speech therapist, continuing the family tradition of caring and supporting others. Valeria remains active on the board of the Unicorn Children's Foundation that was started by her late husband, Mike, and his family to serve families with neurodiverse children from diagnosis through to adulthood.

"It is my pleasure to be a part of Alzheimer Canada's mission. Dementia is one of the most critical health problems we face not just as a country, but as a society. We want to see the Alzheimer Society of Canada succeed in its exciting new areas of research."

Because of Valeria's generosity and support of the Alzheimer Society Research Program, projects are being undertaken by the best and brightest researchers in the field of dementia to uncover knowledge that will lead to ways of preventing the disease, and eventually, cures.



## Your dollars at work



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## Alzheimer Society of Canada/Société Alzheimer du Canada Statement of Revenue and Expenses

For the year ended March 31	2021	2020
Revenue Support from the public		
Individual giving and direct marketing		\$ 10,212,462
Bequests	1,708,574	4,261,800
Corporate and foundation giving	2,074,248	1,937,790
Total support from the public	16,545,246	16,412,052
Government	223,718	114,421
Partner charities (Note 10)	10,760,938	10,981,589
Investment and other income (Note 3c)	1,360,081	693,753
Government subsidy (Note 16)	432,273	
Total revenue	29,322,256	28,201,815
Expenses		
Programs		
Services	1,988,897	3,138,177
Research	3,814,912	3,758,742
Partner charities (Note 10)	15,524,570	15,283,986
Government health programs	223,718	114,421
Total program expenses	21,552,097	22,295,326
Support		
Fundraising	5,301,476	4,910,830
Administration (Note 14)	768,108	497,928
Total support expenses	6,069,584	5,408,758
Total expenses	27,621,681	27,704,084
Excess of revenue over expenses before unrealized investment losses	1,700,575	497,731
Unrealized investment losses (Note 3d)	(53,541)	(696,725)
omediazed investment lesses (Note od)	(00,071)	(030,720)
Excess (deficiency) of revenue over expenses	\$ 1,647,034	\$ (198,994)

## Take the pledge **Take action** Give generously Learn more I PLEDGE TO: Join in your local Visit alzheimer.ca for Visit alzheimer.ca/donate **IG Wealth Management** helpful resources and to give online, or phone BE VOCAL if I hear a joke or Walk for Alzheimer's to locate the Alzheimer 416-488-8772 to speak with other conversations that Society in your community us about your goals Join our Advisory Group create stigma. of People with Lived **BE PATIENT if I encounter** Experience. someone with dementia. To get involved and learn **BE SUPPORTIVE to people** about other opportunities living with dementia and at the Society, please email their families. us at info@alzheimer.ca

#### **Alzheimer Society of Canada**

20 Eglinton Avenue West, 16th floor Toronto, Ontario, M4R 1K8

Phone: 416-488-8772
Toll Free: 1-800-616-8816
Email: info@alzheimer.ca
Website: alzheimer.ca









