

# ANNUAL REPORT

2019/2020

#### A MESSAGE FROM OUR DIRECTOR AND PRESIDENT

The impact of dementia is far-reaching. From the stronger together because of the support of our and the stigma persists.

One thing that is undeniable, is the fact that there is strength in numbers. The more people who choose to For each of you who made the choice to raise your family care provider, who make a donation or about dementia, and those who have cared for a son living with dementia at the heart. From investing our heartfelt appreciation. time in developing our team to ensure that those who come to us have the best possible experience, to expanding our programs and services, to working together to create values to help guide our work, our ASNB staff and volunteers are committed to improving the experience of those with dementia.

This year's annual report looks back at the year behind us as we celebrate our impact. What you will read about in the pages that follow are stories of strength in numbers. You will read about how we are

person diagnosed, to their spouse and immediate incredible donors, partners and fundraisers. You will family, the extended family, the workplace, the also read about how the Alzheimer Society Research community and the health care system, the web cast. Program is investing in hope for tomorrow. What you by dementia is far-reaching and can be isolating, will ultimately read is how the Alzheimer Society There is so much we still do not know about dementia, depends on the support of the community. After all, it will take the whole community working together to impact real change for those living with dementia.

learn about dementia, who make offers of support to a hand in support by donating, volunteering, or learning volunteer with the ASNB, the better the experience is family member or a friend living with dementia – your for the person diagnosed. At the Alzheimer Society of contribution matters and you are making an incredible New Brunswick, every decision we make has the per- difference. On behalf of our staff and Board, we offer



Chandra MacBean Executive Director



Shelley Shillington President

### **BOARD OF DIRECTORS**

Shelley Shillington, Saint John, NB—President Adam Thornton, Nerepis, NB—Vice President Ashley King, Fredericton, NB—Past President Chandra MacBean, Charters Settlement, NB—Staff Michel Haché, Inkerman, NB André Savoie, Saumarez, NB

Debra Ward, Fredericton, NB Renée M. Roy, Dieppe, NB Becky Lyons-Standring, Miramichi, NB Guylaine Boudreau, Dieppe, NB Tyler Belyea, Fredericton, NB

## FEDERATION STRATEGIC PLAN

In 2019, the Alzheimer Society Federation partners came together to approve a new Strategic Plan that was the culmination of just over a year of work. The new represents people from coast to coast, including persons living with dementia, family and caregivers of those living with dementia, staff and volunteers from the Alzheimer Society, boards of directors, as well as community partners and lead Canadian researchers NB representatives brought

MISSION

Alleviate the personal and social consequences of Alzheimer's disease and other forms of dementia and to promote the search for causes and a cure

VISION

A world without Alzheimer's disease and other dementias

**VALUES** 

Accountability, transparency, collaboration, integrity, respect & teamwork.

#### Prevent/reduce risk

Prevent and reduce risk of AD and other dementias

We inform Canadians on brain health and preventative strategies for those at risk of AD

#### Advocate

Advocacy through engagement and partnerships

We advocate for enhanced quality of life for individuals impacted by AD and other dementias

#### Research

Strengthen research

We strengthen research on AD and other dementias to advance the search for causes, a cure, treatments & to enhance quality of life

#### Critical success factors

Financial and other resources grow to meet increasing and emergent needs

Alzheimer Society Federation Excellence

forward the unique NB lens in our conversations and amplified the voices of those in our province.

The result was a collaborative and comprehensive plan that includes investing in prevention and risk reduction programs, quality programs for those impacted by dementia, as well as advocacy and research. The plan lays a strong foundation for leadership and meaningful change for people living with dementia.

## **ANYTHING FOR ALZHEIMER'S**

In 2019, we made a major change to our fall fundraising campaign to make it even easier for New Brunswickers to support those living with dementia in our province. **Anything for Alzheimer's** is a do-it yourself campaign that enables creative, dedicated people to take their own unique activity and turn it into a fundraiser for the ASNB.



We would like to make special mention of a few fundraisers that went above and beyond, like Paulette Noël from Tracadie who organized a multi-day book sale that raised over \$3000, and Bob and Jane Eaton, a couple from Moncton both celebrating their 80<sup>th</sup> birthday, who asked their family and friends to make a donation in lieu of birthday gifts. Bob generously matched their donations, which enabled them to raise a total of \$5,382!

Our supporters took on this new challenge and hosted game nights, bake sales, karaoke, paint nights, and lemonade stands. A total of 105 events were hosted and raised over \$46,000! Each activity truly made a difference in the lives of those affected by Alzheimer's disease and other dementias.

## ADVOCACY ON A NATION-WIDE LEVEL

We need to address dementia as a nation, and the June 2019 release of Canada's first-ever national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire*, follows years of advocacy by the Alzheimer Society of Canada (ASC) and the input of key stakeholders, including people with lived experience.

The announcement of the strategy was made by former Minister of Health and current Member of Parliament for Moncton-Riverview-Dieppe, the Honourable Ginette Petitpas Taylor. The strategy's three national objectives are to prevent dementia, advance therapies and find a cure, and improve the quality of life of people living with dementia and their caregivers. The federal government invested \$50 million in Budget 2019 to support implementation of key elements of the national dementia strategy.

Lobbying to ensure that people living with dementia are fully included in disability public policy continues to be a focus of the Society's federal advocacy work. Canada was the first member country in the United Nations to formally recognize dementia as a disability in the Convention on the Rights of Persons with Disabilities (CRPD). Advice to federal policymakers resulted in cognitive impairment being added to the definition of disability in the *Accessible Canada Act*, which became law in June 2019.

The Alzheimer Society of Canada has been able to capitalize on its advocacy success and positive working relationship with the federal government, but there is still much work ahead to ensure that the national dementia strategy is fully funded and implemented and Canadians with cognitive impairments are covered by disability discrimination legislation.

# The Impact of a Single Testimony

Denis Langevin and Louise Giguère from Saumarez, NB, lived a perfect life until 2013 when Louise was diagnosed with Alzheimer's disease. Immediately, Denis wanted Louise to know that they were in it together. "There was no question of giving up. I made it clear to Louise right away that it was not her illness, but OUR illness and that we were going to get through it TOGETHER."

When Denis shared their beautiful story as part of our campaign for the IG Wealth Management Walk for Alzheimer's, he could not have imagined the impact his story would have. In addition to being approached in their community by old friends and strangers alike, Denis and Louise's story has reached nearly 33,000 people on our Facebook page. It has been shared nearly 500 times and has received 238 comments.

A single testimony created a wave of compassion and support throughout an entire community. This is a perfect example of how one story can make an impact felt across the province.



## DEMENTIA-INCLUSIVE RESOURCE CENTRE



In 2019, when the opportunity arose during a planned renovation to our Resource Centre in Fredericton, our team decided to embark on a journey to create a dementia-inclusive office to offer an engaging, comfortable and safe environment for those living with dementia.

Many people living with dementia experience complex symptoms such as memory loss, visio-spatial changes, changes in depth perception, impaired reasoning, and difficulty with wayfinding. Throughout the renovation, we incorporated elements of dementia-friendly design that would cater to these challenges, and were very deliberate when making decisions around movement, navigation, visual cues and design.

In addition to offering an inclusive space for those living with dementia, our intention is to show others simple, practical changes they can adopt to make their own spaces dementia-friendly. So far we have welcomed over 300 people into our Dementia-Inclusive Resource Centre and offered several informational presentations on the space. We look forward to sharing this information with more people in the years to come.

## ENHANCING CARE CONFERENCE

In five short years, we have grown our one-day workshop into a two-day, multi-themed conference with internationally-renowned speakers focused on providing person-centred care.

On April 3 & 4, we hosted the first two-day Enhancing Care Conference, with an additional day to provide extended clinical and leadership focus. We welcomed plenary speakers such as Allan Manning and Jim Kinsey from Planetree, both international experts on the implementation of practices in institutions and the development of innovative approaches to person-centred care. Attendees were offered interactive workshops and



breakout sessions on topics such as music therapy, disenfranchised grief, policy and culture. We also heard the testimonies of Reverend Faye Forbes and Brian LeBlanc, two individuals living with Alzheimer's disease who provided a first-hand look at what it means to live with the disease.

We were thrilled to welcome 180 participants over two days, as well as 22 sponsors and exhibitors, making this our largest event to date.

# **FORGET ME NOT TOUR:**

## IN SEARCH OF A VILLAGE

The forget-me-not appears in my memory as a child know them to be caring and open-minded and fishing in the alder choked brook running through my always looking toward new advancements in grandparents farm in rural NB. I can still picture it in preventing the disease and with equal importance, in my mind, like blue polka dots in a sea of green with tiny yellow eyes you have to squint to see. It appears in my garden, in fact throughout my entire yard. It appears as a logo on the bright vellow shirts that I have worn almost every day, all summer and fall. Let me explain.

Every summer for the last 10 years, I do a solo bicycle ride to raise awareness and a bit of money for a worthy charity. For the last two years I've been pedaling and peddling for the Alzheimer Society in NB and PEI.

My mom Julia faded away three years ago after being diagnosed with the disease and it opened a window on a whole new world for my family and me. We knew nothing about the symptoms, the care, or the toll it takes. The day Mom was diagnosed her life changed dramatically. She was living alone up to that point in a little house and enjoyed cooking and gardening. Her days were filled with things to do and choices to make.

My wife Theresa volunteers at an outreach program in our neighborhood nursing home and pays weekly visits to the Care Facility where my



spent mom last her months. have also come to know the people who work at the Alzheimer Society.

creating a high quality of life for those who must enter our nursing homes.

So in July, I was in search of an activity whereby I could help raise some awareness and maybe some donations. Theresa and I met with the Executive Director of the Alzheimer Society of New Brunswick at their office in Fredericton. Jim, the owner of their building was there and during the course of the conversation I learned of a "Dementia Village" that was soon to open in Langley, BC. It was inspired and patterned after De Hogewejk in Weesp, near Amsterdam. That was it for me. I just happened to have meetings in Abbotsford so I borrowed a bicycle and pushed off from there to Langley. Next I booked a flight to Brussels to cycle to Weesp and added a few hundred kilometers by cycling PEI and included Saint John, NB, to Yarmouth, NS, to attend the communities in bloom conference and awards. In total I was planning to travel 2000 km and raise a bit of awareness and money in the process.

I consider myself blessed that at 60+ years old I have the health, the wealth, the time, and the understanding attitude of my wife that allows me to sit myself upon my bicycle and travel about. Please don't picture me as a cyclist. I don't match the image. My chicken type legs have never seen the sun, nor has spandex ever been in contact with my skin. The vision I want you to have is more that of a hobo... on a bicycle... with a credit card. Even though I enjoy cycling for the sake of cycling, I extract even more pleasure if my travels have a purpose. A reason to go from point B to point A. My September "Forget-

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Me-Not Tour," provided all of that.

The first stop on my journey from Brussels to Amsterdam was Zundert in Brabant province near the Belgian border. In Langley the villagers who live in the Dementia Village live in houses that are settled into a residential area just south of the City, on the site of a former school. Food is prepared in their houses and they can go outside to tend the garden if they wish. There is a barn with animals. There is a restaurant and a pub/café on site as well as a place for visiting families to spend the night. It makes for a more comfortable transition for those who need care.

At Veesp's Vivium Hogewey it is a bit different. It is very much like any dutch town. Within the facility, there is a barber shop, a music venue, large restaurant. It is very hard to distinguish the difference between what is inside the walls from what is outside. I arrived at noon, parked my bicycle, went inside and asked at reception if I could go inside and look around. "I'm sorry but no". I anticipated this, as I was told that tours needed to be scheduled in advance. Due to the fact I was cycling and was not sure when I might arrive, I didn't heed the advice. I could come back in a few days. That was my backup plan. Tours needed to be booked about three weeks in advance. I said that I understood, for this was where people lived, not a tourist attraction. Truly, I was just happy to have made the journey. It gave me and my Forget-Me-Not Tour purpose. I had struck out in search of a village, and found it.

The gentleman standing with me in reception was Eloy, facility manager and founder of the village. Serendipitously, my mom had placed him in the room with me. He explained further why I could not come in and I told him I understood completely, and I was not upset in the least. We then spent the next hour and a half guiding me through the streets, the shops, the history and the future plans to take this model throughout the world. Eloy used one word to describe what they were trying to achieve:



deinstitutionalization. Think about that for a moment. Do you or anyone you know want to be in an institution? They achieve this by allowing meals to be cooked in the residences, by having pets on the property, by allowing the residents to dig in the earth and plant and harvest crops, by giving them choices on the live music or the conversations they might enjoy. There are nurses and staff present, but they just blend in with the crowd.

As a participant in the landscape profession, I understand the satisfaction that comes with being connected to the soil, taking risks and to solving problems that mitigate those risks. The longer we can keep those tools sharp, the higher the quality of our lives will be. Let's continue our collective efforts to introduce future generations to nature and to plants. Show them the satisfaction that comes from being productive and hope that they are provided the opportunity right through to the end.

This article was written by Jim Landry of Landscape NB & PEI.

Jim raised \$5,900 for the Alzheimer Society of NB and PEI by cycling around the Maritimes, across the country and overseas to learn more about dementia-friendly communities.

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## MIND-BODY CONNECTION

In November of 2019, we piloted a monthly program tailored to the unique needs of those living with young-onset dementia and their care partners, hosted in our new Dementia-Inclusive Resource Centre. Segmented into two groups led by person-centred volunteers— one for those living with dementia and one for their care partner—Mind-Body Connection provides an opportunity to connect with others on the dementia journey.

When the group was first launched, participants were asked what they wanted, and sessions were structured accordingly. The Alzheimer Society was able to arrange various presentations, activities and social opportunities. This group is also about empowement. When one participant shared he felt that people judged him for living with young-onset and felt physicians were reluctant to give a diagnosis of dementia, the ASNB connected him with OPUS MD, a magazine for physicians that are members of the New Brunswick Medical Society, and arranged an interview for him to share his story.



After travelling the dementia journey on their own, members of this group were finally able to make meaningful connections with others on the same journey. The program is ongoing as the members of the group continue to work through their empowerment board.

80%

Of clients felt supported when using ASNB services

## MAKING MEMORIES THROUGH MUSIC

Making Memories through Music is an intergenerational and inclusive music program that promotes socialization, inclusion and the benefits of music. The program was piloted in Fredericton, in partnership with Royal Road Elementary School, Windsor Court Retirement Residence, and the Alzheimer Society of New Brunswick, and was funded by the Fredericton Community Foundation.

The project ran within the 2019-2020 school year in partnership with 12 students from the elementary school and 6 residents living with dementia at the local nursing home. The students visited the nursing home 3 times during the program. On the first and second visits, students were partnered with a resident and spent time connecting with them and learning about their taste in music. For the final visit, the students prepared a concert and presented the residents with an iPod and customized playlist. Not only were the residents loaned an iPod, they also received an iTunes gift card to continue to add to their personalized playlist.

"The memories through music program was fantastic. I think bringing dementia education to the students at the school was just as rewarding as bringing the kids into our home to do music therapy. The residents really enjoyed this partnership." -Sheri Green, Resident Services Manager at Windsor Court Retirement Residence

## PAULINE SPATZ LEADERSHIP AWARD

We find strength in change-makers like George Allen of Saint John. To recognize George's dedication to his community, he was awarded the Pauline Spatz Leadership Award in 2019.

Since 2013 when his dear wife of over 70 years, Joan, was diagnosed with Alzheimer's disease, George has strived to bring awareness to the disease and impact meaningful change for those that will travel the journey after him. George has helped amplify the voices of those on the dementia journey by consulting on the provincial Dementia Strategy and Action Plan, and by sharing his story with media, medical schools, and as part of the ASNB's 2018 Awareness Campaign.



George's greatest impact stems from his ability to empathize and connect with others. Through kindness and compassion, he offers support to his peers by sharing his own experiences, particularly the stories involving Joan, which he tells with a twinkle in his eye.

George lives a life of gratitude, service and kindness. He shows leadership by giving of his time, his passion, and his energy to make his community a better place.

## 5 Smooth Stones Leadership Award

The 2019 recipient of the 5 Smooth Stones Leadership Award, and ASNB trail blazer was Jess Baxter. Meant to recognize the efforts and successes of our staff, this award appropriately reflects the professionalism, loyalty, dedication and leadership she plays in our team. Jess joined the ASNB in 2016 and quickly became the glue that holds everything and everyone together. Her attention to detail and unlimited resourcefulness made her a



trustworthy reference point. Her passion, vision and creativity is admired and respected by her teammates, stakeholders and everyone who has the opportunity to work with her.

Sincere and thoughtful in her work, Jess also understands the importance of creating an inspiring work environment and is always ready to give a helping hand. She has provided our team with so much support over the past few years and we cannot foresee our future without her. We are so fortunate to have such a dedicated and hardworking member as part of our ASNB family.

90%

Of clients felt more confident and informed managing dementia after attending an ASNB program

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# ALZHEIMER SOCIETY RESEARCH PROGRAM INSIGHT REPORT 2019

#### **FUNDING PRIORITIES:**

Starting in 2019, the Alzheimer Society Research Program (ASRP) shifted into an open competition that focuses on four new funding priorities: discovery, policy and health system change, evaluation of community programs, ethical and legal issues.

#### A DIRECT RESULT OF FUNDING FROM THE ALZHEIMER SOCIETY RESEARCH PROGRAM:

- > 100% of New Investigators continued working in academic research
- > 100% of Investigators continued working in dementia research
- > More than 80% of Investigators and trainees had published in journals



#### ONGOING WORK

94% of trainees in research work in dementia



#### STAYED IN THE FIELD

97% of investigators continued their careers in dementia



#### LARGER GRANTS

86% received larger grants after being funded by the AS Research Program



#### KICKSTARTED PUBLISHING CAREER

88% of investigators have journal publications85% of trainees have journal publications



#### NEW - PROOF OF CONCEPT GRANT: \$100,000 UP TO 5 YEARS

\$100,000 OF 10 5 TEARS

Supports investigators with innovative, high-risk, highyield approaches to research. (No existing hypotheses, pleasel)



#### NEW INVESTIGATOR OPERATING GRANT:

\$200,000 UP TO 4 YEARS

Supports new investigators within the first four years of their first faculty position.



#### POSTDOCTORAL FELLOWSHIP:

\$100,000 OVER 2 YEARS

Supports trainees within the first 18 months of completing their PhD program.



#### DOCTORAL AWARD:

\$66,000 OVER 3 YEARS

Supports students in the first 18 months of their PhD program.

"Funding from the Alzheimer Society Research Program has been absolutely essential to my career. Without it, I would be nowhere near where I am today. The professionalism of the Program's peer-revive committee is unique in Canada and is of utmost importance to conduct novel projects that are not necessarily mainstream"

- New Investigator Grant Recipient, 2013

# FINANCIAL REPORT

REVENUES	2020	2019	
Memorials and Bequests	\$272,100	\$112,284	
Public Support	\$324,077	\$370,963	75% of our
Investment Income	\$4,717	\$14,910	revenue comes from events
Education	\$262	\$1,266	and unsolicited donations
Government Employee Programs	\$47,833	\$33,167	donations
Project Funding—First Link	\$343,950	\$323,975	
	\$992,939	\$856,565	0.050 poorlo
EXPENSES			2,250 people contributed to our annual fundraising
Amortization	\$2,411	\$1,606	events
Administration	\$86,519	\$77,159	
Board of Directors	\$7,822	\$17,292	040/
Fundraising	\$181,807	\$157,258	61% of our revenue was
Service Delivery	\$746,864	\$670,492	allocated to service delivery
	\$1,025,423	\$923,807	and education
DEFICIENCY OF REVENUE OVER	(32,484)	(67,242)	
EXPENSES FROM OPERATIONS			We contributed \$76,753 to the AS
OTHER INCOME			Research
Alzheimer Society of Canada Revenue	\$239,191	\$179,054	Program
Alzheimer Society of Canada Assessments	(104,563)	(108,725)	
EXCESS OF REVENUE OVER EXPENSES	\$102,144	\$3,087	Over 2,300 people chose to donate to the ASNB

## RESOURCE CENTRES

For more information on programs and services, volunteer opportunities or ways you can donate, please contact the resource centre nearest you!

#### Fredericton

320 Maple Street, Suite 100 Fredericton, NB E3A 3R4 Phone: (506) 459-4280 amcnair@alzheimernb.ca

#### Moncton

1070 St. George Blvd, Unit 2B Moncton, NB E1E 4K7 Phone: (506) 858-8380 aking@alzheimernb.ca

#### Tracadie

203-399 rue du Couvent Tracadie-Sheila, NB E1X 1E1 Phone: (506) 600-7000 hduguay@alzheimernb.ca

#### Saint John

221 Ellerdale Street Saint John, NB E2J 2M1 Phone: (506) 634-8722 mharris@alzheimernb.ca

#### Edmundston

296 Victoria Street Edmundston, NB E3V 2H9 Phone: (506) 735-4248 smartin@alzheimernb.ca

