

# In the Loop

*Soci t *  
**Alzheimer**  
*Society*

NOVA SCOTIA

**FALL 2019**

MAKE YOUR COFFEE COUNT THIS FALL

A RISING TIDE LIFTS ALL BOATS

RESEARCH UPDATE: BIOGEN AND EISAI ANNOUNCE PLANS  
TO FILE FOR MARKET APPROVAL OF ALZHEIMER'S DRUG

THREE AWARENESS BREAKFASTS PLANNED FOR JANUARY



McInnes Cooper Coffee Break®

# FALL 2019

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# A Rising Tide Lifts All Boats

Contributed

Giving Tuesday is a global movement for giving and volunteering, taking place each year after Black Friday and Cyber Monday. In the same way that retailers take part in Black Friday, the giving community comes together for Giving Tuesday. Across Nova Scotia on Tuesday, December 3, Nova Scotians will do a bunch of good stuff! And you can join them!

The Alzheimer Society of Nova Scotia is asking that you kick off the ‘giving season’ by making a donation to support, inform, and educate those in our province on the dementia journey. You can make a donation by calling 1-800-611-6345 or online at [alzheimer.ca/ns](http://alzheimer.ca/ns).

There are over 50 countries participating in Giving Tuesday. Canada was one of the first, and the Alzheimer Society of Nova Scotia was one of the first charities in the province to participate.

“We have these two days of shopping – which is great for people to get deals on holiday gifts, or something for themselves! – but we always talk about this time of year being about giving back,” says Sarah Lyon, CFRE, Director of Philanthropy at the Alzheimer Society of Nova Scotia. “We signed on because we know that Giving Tuesday would be a great day to celebrate all the giving that happens in our province all year long. Giving Tuesday helps us celebrate because without our donors, we couldn’t do what we do to support the 17,000 Nova Scotians and their families who live with dementia.”

No one does philanthropy alone. That is why the Alzheimer Society founded and supports a Giving Tuesday civic movement called Nova Scotia Gives More. As a collective, this group of charities comes together to promote the day and asks you to do good stuff in any way you can, for whatever charity you choose. “We created NS Gives More because we think that asking Nova Scotians who may not have a charity of choice, to go to one website and learn about all the activities happening that day, would be useful,” says Lyon. “The information is found on [nsgives.ca](http://nsgives.ca), and we lead this movement because we believe a rising tide lifts all boats.”

A sentiment that is felt across the country. “We’re expecting millions of Canadians to participate in Giving Tuesday again this year. You can donate to your favourite charity, volunteer your time at a soup kitchen or any organization that is in need of hands-on-help,” says Lys Hugessen, President of GIV3. “The world needs more Canada right now – more Canada means more generosity and more kindness. Giving Tuesday is for everyone to find their own way to ‘Do Good Stuff’.”

Celebrate the season on December 3 and give.

**GIVINGTUESDAY™**

# Research Update: Biogen and Eisai Announce Plans to File for Market Approval of Alzheimer's Drug

Wenda MacDonald, Manager, Client Services, Research Liaison

Over the past ten years, we have seen many promising new drugs for Alzheimer's disease fail to meet hopes and expectations, most because they did not affect the disease as we had predicted, or the agents tested ended up being far too toxic to use. Many of these studies examined a class of compounds we call monoclonal antibodies (antibodies produced by only one single and specific type of cell, that all have the same activity). These antibodies can be made to recognize a specific protein, attach to it, and then let the body take over and dispose of it.

Most of us have probably heard that Alzheimer's disease is associated with a build-up of plaques and tangles in the brain. These plaques and tangles are made up of proteins that have gone awry. The Amyloid Cascade Hypothesis of Alzheimer's disease suggests that the abnormal folding and clumping of a protein called amyloid- $\beta$  ( $A\beta$ ) leads to the formation of plaques and that this in turn, leads to the destruction of nerve cells. This is what we see with Alzheimer's disease. With this hypothesis in mind, it is quite reasonable to propose that the removal of  $A\beta$  from the brain, and therefore plaques, could lead to a treatment or cure for Alzheimer's disease.

The experience until now, however, has been heartbreakingly different. Many monoclonal antibodies designed to attach to and remove  $A\beta$  were put through the various standard phases of drug testing before being determined to be ineffective or toxic in humans. This spring trials of the aducanumab, the latest in this series of potential drugs, appeared to fail as well and testing was halted.

Last month, Alzheimer's Disease International (ADI) and the drug companies Biogen and Eisai announced that they were able to reevaluate the data after many more results became available. This re-analysis has given them reason to believe the aducanumab drug could indeed be effective, if used in large doses in persons with very early Alzheimer's disease. In fact, the data is good enough that the companies are going to file for drug approval in the United States. You can read the announcement by ADI here: <https://www.alz.co.uk/news/biogen-and-eisai-announce-plans-to-file-for-market-approval-of-alzheimers-drug> or find more details in the Alzforum newsletter here: <https://www.alzforum.org/therapeutics/aducanumab>

Will aducanumab work? Will it be found to halt the progression of Alzheimer's disease? We do not know. There is reason to be cautiously optimistic we hope. While earlier drug trials have failed for one reason or another, this one does hold promise, and researchers have learned much in the process. We have learned that we might have to target tau as well amyloid and perhaps we have to target more abnormalities as well. We have learned that treatment earlier in the disease process holds more promise. Lastly, we have also learned that it's okay to think we might one day prevent this disease with this type of research. We here at the Alzheimer Society of Nova Scotia will keep a close eye on developments and will update you when there's more research news.

## Phases of Drug Research and Development

### Pre-clinical Development

The drug is given to animals. If it can be shown that the drug causes no serious or unexpected harm at the doses required to have an effect, the company will proceed to clinical trials. These preclinical studies often take two to three years.

### Clinical trials – Phase 1

The objective of Phase 1 is to test if people can tolerate the drug. This testing starts the process of identifying common side effects, as well as finding out how high the dosages can be before adverse side effects occur. Phase 1 studies generally take at least one year to complete. If they look promising, they go into Phase 2 trials.

### Clinical trials – Phase 2

Phase 2 trials are carried out on people with Alzheimer's disease, who are usually otherwise healthy, with no other medical condition. In Phase 2, the objective of the trials is to continue to gather information on the safety of the drug and begin to determine its effectiveness. The drug is given for sufficient time to determine if it makes a difference, compared to people who are untreated or given another type of treatment. Side effects are identified and effective drug doses are determined. Usually it takes at least two years to obtain enough positive information to justify the much larger and more extensive Phase 3 trials.

### Clinical trials – Phase 3

If the results from Phase 2 show promise, hundreds or even thousands of people with Alzheimer's disease around the world will be involved, including those who have other medical conditions and those who are taking other medications. One group of patients receives the prospective treatment and a matching group receives a "placebo" (a harmless inactive substance or a comparable drug that is already on the market). It can take three years or longer to find out if the treated group does better than the untreated one and to confirm drug dosages that work without causing adverse side effects. If a drug successfully maintains its original promise right through to the end of the Phase 3 trial, it is submitted to the appropriate government agencies for their approval. Usually drugs are sent back for more studies in Phase 4 trials on people with other medical conditions in addition to Alzheimer's disease or in different age or sex categories. This phase may take another two to four years.

In summary, the treatment may be approved for administration by doctors approximately eight to ten years after human studies first began. See the Health Canada website for more information on how they authorize a company to market a drug and how you may be able to gain access to a promising drug before it comes to market.

## Maple Hill Manor Makes Memories Matter

Catherine Shepherd, Coordinator, Education and Outreach, Cape Breton

Every year, hundreds of Cape Bretoners join forces and participate in the annual IG Wealth Management Walk for Alzheimer's fundraiser. It's a fun day where you join the Alzheimer Society in raising funds and awareness for programs and services, family support groups, and education about Alzheimer's disease and other dementias in our community.

We all have our reasons for walking – whether it be for a family member or friend who has touched our lives. Recently I sat down with Kendra Baldwin, Administrator at Maple Hill Manor, to find out why Maple Hill Manor decided to get involved this summer.

**“Getting involved with the walk was an easy decision for us to make. I've participated in many community walks after 20+ years working in long term care and I've seen firsthand how beneficial they can be for residents,” Baldwin shared.**

One of the key driving forces behind them joining was advocating for their residents. “We wanted to keep that link between our residents and the community. Just because people have dementia does not mean they aren't living active and healthy lives,” Baldwin explains.

With the flexibility of Walk Where You Are event, Maple Hill Manor was able to plan their walk during New Waterford Coal Dust Days. “It was advertised in the community brochure and the response from the public was fantastic. The walk got to be part of the community's week long celebrations and many community members attended.” Baldwin said.

On the day of the walk when I arrived, I could feel the buzz of excitement in the air. There were over 50 residents, staff, family members, volunteers, and community members there to support those walking. Everyone was smiling, laughing, and mingling among one another as they enjoyed a barbeque lunch. During the walk each resident was paired up with family, friends, staff, or a volunteer so everyone that wanted to participate got the opportunity to. One of my favorite parts of the walk was community members driving by and cheering us on as we went, and residents waving back. “It was great to see the community support the walk and get involved in any way they could,” said Baldwin.

For those considering hosting a Walk Where You Are, Baldwin shares the following advice: “It wasn't as much work as you would think to plan. Staff were excited to join in and it didn't take long for 30 people to sign up. We had posters and brochures, made custom t-shirts, and had a barbeque. For a little bit of work there's a big benefit!”



If you couldn't make it to our walk in Sydney this May, follow in Maple Hill Manor's footsteps and grab a group of friends, family members, or co-workers and lace up your walking shoes and walk 5 kilometers. Pick a date that works for you this fall and we will send you everything you need to start fundraising – it's that easy.

For more information on how you can Walk Where You Are in your community, please contact Mark Frank, Coordinator of Community Giving, phone: 902-422-7961 ext. 241 or email: [mark.frank@asns.ca](mailto:mark.frank@asns.ca).



**IG** WEALTH MANAGEMENT

**WALK FOR ALZHEIMER'S**

Alzheimer Society  
NOVA SCOTIA

**Save the Date!**

We'll see you at our IG Wealth Management Walk for Alzheimer's this May in four locations: Halifax, Sydney, Truro, and the Annapolis Valley

**Shannex™**

Alzheimer InfoLine | 1-800-611-6345



*We're here to help*

The Alzheimer InfoLine is a confidential phone service provided by our team of knowledgeable and caring staff.

We provide information, support, and referral for persons with dementia, families, caregivers, and professionals.

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# Being Prepared, More Than Just for Girl Guides

Sarah Lyon, CFRE, Director, Philanthropy

There have been many surveys over the past couple of years asking Canadians if they have a will. The result? Over half of Canadians do not. Of course this data changes depending on who you are talking to. “A significant number say the reason they haven’t written a will is that they’re ‘too young’ to worry about it (25%),” a written statement by the Angus Reid Institute, which conducted the poll, said. “(A)nd almost as many say they don’t have enough assets to make a will worthwhile (23%).”

Taking the time to write a will at any age, is an investment for the future. It’s for your family, friends, and any charitable organizations you may want to support. Below you will find five reasons why making a will – and November is Make a Will Month – is important. If you have questions about making a will you should speak to a lawyer or a financial advisor.

## 1. Have your wishes respected.

When you die without a will, you are said to have died intestate in the eyes of the law. That means that your estate will be distributed in a standardized way according to the law in your province. These rules—which dictate who gets what, and how much—are non-negotiable.

## 2. Your partner is taken care of.

Married couples and domestic partners have the same rights regarding estates in Nova Scotia. Common law partners have few rights regarding estates, so if your common law partner passes away without a will, you would not inherit anything.

## 3. You get to decide who takes care of your dependants.

Did you know that the only place you can appoint guardians for your children or dependents is in your will? Should you die without a will and leave behind minor children or dependents, it’s up to the government to appoint someone to care for them—and it may not be the person you would have chosen.

## 4. You get to appoint an executor.

When you die without a will, you miss the opportunity to appoint an Executor – someone you trust - to administer your estate. Without an Executor, no one has an automatic right to make decisions for your estate. This may create a difficult situation for your family, who will face a number of administrative and legal hurdles as they attempt to manage your estate.

## 5. Lower the taxes on your estate.

Without a will, you miss opportunities to plan in ways that can be advantageous for your estate. Although the basic rules for tax on your estate are the same whether you die with or without a valid will, estate planning, including making a will, offers you the chance to minimize income taxes and probate fees for your estate. Leaving a gift to charity in your will, for example, could be claimed against your tax bill.

If you would like to talk about leaving a gift in your will to support future families facing dementia, please call the Alzheimer Society of Nova Scotia at 902-422-7961 ext. 227.

# Five Tips for Planning Holiday Gatherings

ASNS Staff



Holidays are often a nostalgic time of year, full of social gatherings, decorations, good food, and of course, spending time with family and friends. Participating in these events are important to help people with dementia feel connected and maintain relationships. This is also an opportunity to create new memories and reminisce about one's past memories.

When planning for your holiday festivities, it is important to keep in mind that although most people with dementia still enjoy socializing, some preparation should be considered. Social gatherings, particularly a larger gathering, can be especially challenging for people living with dementia. The extra stimulation may be difficult to manage. Friends and families may also feel uncertain in what to say or how to act.

To help ensure a fun social gathering, here are five helpful tips to help both people with dementia, and their families and friends:

1. Ask the person with dementia if he/she would like to contribute. Even if he/she can no longer bake cookies, perhaps he/she can stir batter or add ingredients.
2. Involve the person living with dementia in planning a dinner or talking about whom to invite.
3. Choose to take part in the occasions/traditions that are most important to you and your family.
4. Plan ahead; have a family discussion and set realistic expectations. It may be a good time to start a new family tradition.
5. Plan festivities on a day and time that suits the person with dementia.

\*Some content sourced from the Alzheimer Society of Canada

# Three Awareness Breakfasts Planned for January

ASNS Staff



**ALZHEIMER AWARENESS BREAKFAST**  
**DEMENTIA: WE CAN HELP!**

**JOIN US JANUARY 2020**  
**SYDNEY ▪ SOUTH SHORE ▪ HALIFAX**

Mark your calendars for the Alzheimer Awareness Breakfasts! Held in three locations throughout the province, they take place in January as part of Alzheimer Awareness Month.

The Alzheimer Awareness Breakfasts engage community members, physicians, nursing home employees, home care agencies, and businesses in education on Alzheimer's disease or other dementias.

The Breakfasts provide an important chance to come together to learn about Alzheimer's and other dementias. This year the theme of all three breakfasts will be "Dementia: We Can Help" where you will hear about local resources, tools, and strategies available.

Details are below and tickets can be purchased by calling the Society at 1-800-611-6345 or online at [www.alzheimer.ca/ns](http://www.alzheimer.ca/ns).

## Sydney Awareness Breakfast

**Location:** Membertou Trade and Convention Centre

**Date:** January 15, 2020 | 7 a.m. - 9 a.m.

## South Shore Awareness Breakfast

**Location:** Best Western Plus Bridgewater Hotel & Convention Centre

**Date:** January 24, 2020 | 8 a.m. - 10 a.m.

## Halifax Awareness Breakfast

**Location:** Casino Nova Scotia Schooner Room

**Date:** January 30, 2020 | 7 a.m. - 9 a.m.

## Make Your Coffee Count this Fall!

Mark Frank, Coordinator of Community Giving

Coffee Break® is where friends, co-workers, and customers gather in communities across Nova Scotia to raise funds for the Alzheimer Society. Participants at these events make a goodwill donation in exchange for a cup of coffee. It's a fun and simple way to support the Alzheimer Society. No event is too big or too small, and we can provide everything you need!

if you're interested in getting involved, please contact Mark Frank, Coordinator of Community Giving at 1-800-611-6345 ext. 241 or [mark.frank@asns.ca](mailto:mark.frank@asns.ca).



## Recruitment Request for Research Participants!

Wenda MacDonald, Manager, Client Services, Research Liaison

In this issue of In the Loop you will see a recruitment request for research participants for a study called: *Living and Dying with Dementia: Let's talk about it!*

The Alzheimer Society receive requests from researchers interested in recruiting participants from among our clients and readers. Before these requests are accepted by us to share with you, they are vetted through our Research Advisory Committee to ensure they are being conducted by qualified researchers, are ethically and scientifically sound, look at important issues, and are not expected to pose harm to participants. Whether or not you participate, your response will remain confidential and are never known to the Alzheimer Society.

\*For more information about MAiD and the Alzheimer Society's position statement regarding MAiD, please visit [www.alzheimer.ca](http://www.alzheimer.ca)

## RESEARCH PARTICIPANTS NEEDED



### Living and Dying with Dementia: Let's talk about it!

A new study targeting **CARE PARTNERS** of people living with dementia will soon be launched throughout Canada. A **care partner is someone who spends the most time and resources helping another person, with one or more activities, among all those involved.** It can be a family member, a close friend, a neighbour, etc. Family ties do not count as an eligibility criterion.

The study focuses on **Care Partners' Attitudes toward Extending Medical Assistance in Dying to People Living with Dementia.** It will investigate the **beliefs** underlying care partners' **attitudes** on this issue, the **value** they attach to proposed safeguards as well as assessing **the impact of caregiving and unmet support needs.**

The study will be launched these coming months. The recruitment has already started. **To receive your questionnaire, please refer to the person whose name and contact information is listed at the bottom of this poster.** At your request, you will be sent either the survey questionnaire in a print form to fill out or the online link to its electronic version.

Your opinion on this delicate issue is crucial. Resulting findings will help determine how society should respond to people living with dementia or to their families asking for assistance in dying.

The study is led by Prof. **GINA BRAVO**, PhD, from the Université de Sherbrooke

Coinvestigators and International Collaborators: **MARCEL ARCAND**, MD, MSc (Université de Sherbrooke, Quebec)  
**JOCELYN DOWNIE**, SJD (Dalhousie University, Nova Scotia)  
**SHARON KAASALAINEN**, RN, PhD (McMaster University, Ontario)  
**CEES HERTOIGH**, MD, PhD (Amsterdam, The Netherlands)  
**SOPHIE PAUTEX**, MD (Geneva, Switzerland)  
**LIEVE VAN DEN BLOCK**, PhD (Brussel, Belgium)

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**Mondays, Tuesdays, and Wednesdays**  
Email: [informal.caregivers@usherbrooke.ca](mailto:informal.caregivers@usherbrooke.ca)



Centre de recherche  
sur le vieillissement  
Research Centre  
on Aging

This research study has been reviewed and approved by the  
*Comité d'éthique de la recherche du CIUSSS de l'Estrie - CHUS* [REB protocol number Project #2020-3397]  
and is funded by Alzheimer Society of Canada

# Care for the Caregiver

Connie VanBerkel, Manager, Community Development

Across Nova Scotia is a network of Alzheimer Caregiver Support Groups which offer support and education to caregivers of people living with dementia. From Neil's Harbour to Annapolis Valley, these groups meet monthly and are instrumental in helping people navigate their own dementia journey. Groups provide a respectful and open atmosphere, welcome caregivers at all stages of the journey; spouses caring for each other, children caring for a parent, friends supporting friends, and siblings supporting siblings. Members say they find the groups to be a safe space for sharing, and for accessing reliable and updated information on Alzheimer's disease and other dementias.

Each group is facilitated by one or two dedicated volunteers who give freely of their time and resources. In Truro, the Caregiver Support Group has been running for over ten years. The group is co-facilitated by Rosemarie Clayfield and Ruth Slack. Both are experienced Behavior Resource Consultants with the Nova Scotia Health Authority. Together they bring a wealth of knowledge and experience to their volunteer roles, helping members navigate an often overwhelming healthcare system.

Some people attend to learn more about the disease, while others may be considering a move to full time care. Common topics often include: trying to get a diagnosis, how to talk with your doctor, managing homecare and when to access Continuing Care, what other care partners are doing successfully, suggestions for challenging situations that caregivers are experiencing, or where to get additional help. Members can also share their experiences if they wish or just listen to others sharing similar stories – everything discussed in the group is confidential.

***“For members there is great relief in knowing this is a safe space to just be able to talk freely or cry with no judgement. Participants have expressed feeling supported by being able to share their concerns with others that can understand what they are going through,” said Rosemarie.***

Often members have questions about what is happening in the brain of those they are caring for, and Rosemarie and Ruth are able to answer their questions and explain why persons living with dementia may exhibit certain behaviors due to these changes. For caregivers, understanding the changes in the brain can go a long way to improving care outcomes.

On occasion guest speakers are brought in to speak about issues and resources related to dementia. Some groups have had guest speakers from pharmacies, law firms, social workers, and others who can provide information on caring for someone living with a dementia.

Caregiver Support Groups are offered free of charge to anyone who is interested. The Truro group meets the third Wednesday of each month, from September to June at 7:00 p.m. To learn more about support groups meeting near you, call 1-800-611-6345.

# The Impact of Support Groups

Dawn Kehoe, Manager, Community Giving



Barb's mother, Margaret, liked to be busy. Forever "on the go" with taking care of her home, family, and just being a wonderful volunteer in her community of Inverness. Margaret showed her love through food and was well known for her great cooking and baking.

Then things started changing. She was forgetting to put the sugar in her wonderful rolls, her biscuits were not rising, and she was misplacing things. In 2012, Margaret was diagnosed with Alzheimer's disease.

Life changed for the MacLellan family. There were a lot of challenges. It was hard to understand what was happening to Margaret. Most people assume that after you receive a diagnosis, everything starts to make sense and things get easier. But Barb was still struggling. She didn't know how to improve the situation, until the Alzheimer Society entered her life and changed everything.

Barb, a lawyer, was invited to speak at an Alzheimer Society six week education series. She was asked to discuss matters of the law for people who are sick: Wills, Personal Directives and Power of Attorney. After she finished contributing her expertise, she decided to stay and participate in the course. From this she learned about Margaret's behaviours and how to communicate with her. The experience made her realize the value and importance of the Society. She wanted to do more. She wanted to give back. Barb became co-facilitator of the Fall River Caregiver Support Group.

The six week course gave Barb knowledge and understanding, but the Support Group gave her clarity and peace. This is where Barb says she found her "peeps". Week after week, Barb and her co-facilitator Sharron Paattinen (whom Barb lovingly refers to as the driving force of the group) gather people together for advice, discussion, and support. It is a safe space. It is Barb's way to continue to feel connected to her mother and to also help others.

**Support Groups depend on dedicated volunteers like Barb and Sharron, and generous donors like you.**

We want all Nova Scotians to have access to these resources. We need your help to do that. Because Barb was able to find help through the Alzheimer Society, she now has the clarity needed to deal with her grief and even see some beauty from her mother's experience. "In a world where we all chase the idea of 'mindfulness' I saw my mother's ability to just be in the moment. She could not dwell in the past, or worry about the future. She lived in the now and saw joy all around her."

OCT19

# Soci t  Alzheimer Society

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SPECIAL REPLY FROM:

Name: \_\_\_\_\_

Full Mailing Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



YES! I want to help people like Barb and Margaret! Please accept my gift of:

\$100    \$50    \$25    \$15    \$ \_\_\_\_\_

**Please check your preferred payment method:**

\_\_\_ An enclosed cheque made payable to the Alzheimer Society of Nova Scotia

\_\_\_ Please process my: \_\_\_ VISA   \_\_\_ MasterCard   \_\_\_ AMEX

Card # \_\_\_\_\_

Expiry: \_\_\_\_/\_\_\_\_

Phone# \_\_\_\_\_

Email \_\_\_\_\_

**Do you have a similar story to that of Barb and her family? Would you like to share your story?**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thank you. Please return in the enclosed envelope.  
**You can also make your donation at [www.alzheimer.ca/ns](http://www.alzheimer.ca/ns)**

## Hope for Tomorrow.

Thank you for supporting Nova Scotians today. Did you know that by leaving a gift in your will, to continue your legacy of giving, you can support Nova Scotians living with dementia in the future? We want to say thank you if you've made arrangements for a gift. We are also happy to answer any questions you may have.

\_\_\_ I have made a gift in my will

\_\_\_ I would like to learn more about making a gift in my will

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