

Summer 2019

Insight

Alzheimer Society
BRITISH COLUMBIA

For people living with dementia

alzheimerbc.org



Changing the future

To change the future of the disease, the Alzheimer Society of B.C. champions dementia-friendly research to ensure people affected by dementia are meaningfully and respectfully included in the process. We support research through funding, as well as acting as a source of information and a bridge between researchers and the broader community.

In this issue of *Insight*, member of the B.C. Leadership Group for People Living

with Dementia Mario Gregorio shares why participating in research is important to him. We also hear more about how you can participate in research and learn about the First Link® evaluation, a research project to help make the Alzheimer Society of B.C.'s programs and services more meaningful for people using them. We'll also share our 2019 handout on research and a webinar on research by Dr. Julie Robillard.

Above: Panelists from the dementia-friendly research workshop hosted by the Alzheimer Society of B.C. at the 2018 Canadian Association on Gerontology conference.

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Why I participate in research

“I want a cure.” This was the first thing that came to my mind when I was asked to participate in research after I was diagnosed with dementia. Little did I know that this new door would lead to exciting and challenging opportunities that have enriched my dementia journey.

The first thing that comes to many people’s mind when they hear the word “research” is that they will have to take drugs. This is what I thought, until I attended a student symposium at the University of British Columbia. Here I learned about the many different parts of research, the impact it can have and the important role people living with dementia play when they participate. Many exciting breakthroughs in dementia research would not have been possible without the help of people living with dementia.

Lots of the research I’ve read has recommended simple ways to improve quality of life, like a change in lifestyle, a comprehensive look at nutrition or social engagement with your community. Some of the learnings have helped me to live well over the more than ten years since I was diagnosed.

Recently, I even came across some ongoing research that theorized that simply brushing your teeth correctly, using a mouthwash or an oral rinse might help prevent the progression of dementia. How cool is that?



I have had fun participating in research projects including:

- Using assistive technologies like robotics.
- Exploring inclusive financial decision making for people living with dementia.
- Seeking ways to prevent the progression of the disease.

I may be long gone before we find a cure for dementia, but it makes me happy and gives me a sense of achievement knowing that the research projects I’ve been involved with may benefit others who are living with dementia.

Mario Gregorio
B.C. Leadership Group of People Living with Dementia member

Interested in research?

The Society’s 2019 research handout is an accessible way to learn about the world of dementia research. Follow this link to read the handout:

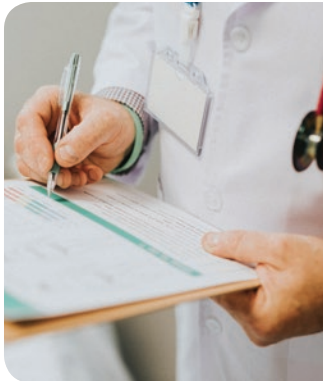
alzbc.org/2019research-handout

How can you participate in research?

Research helps improve the ways we understand, treat, diagnose and manage the risk of developing dementia. Participating in research can offer hope for oneself and for others. It can also be a great way to keep active and engaged in the community.

Before participating in research, it is always important to check with your primary health-care provider to see if it's a good fit for you.

The following studies are currently recruiting participants from B.C.



A medium chain triglyceride intervention for Alzheimer's disease (University of British Columbia)

- Details: alzbc.org/MINT
- Looking for: People living with mild to moderate Alzheimer's disease, with a care partner able to participate with them.
- Contact: Penny Slack at 604-822-6379 or pslack@mail.ubc.ca



Shared decision making about living well with dementia to the end of life (University of British Columbia).

- Details: alzbc.org/shared-decision-making
- Looking for: Anyone living with dementia in the community.
- Contact: Dr. Gloria Puurveen at 604-822-4150 or gloria.puurveen@ubc.ca



Dogs for people with dementia (University of Laval, online study)

- Details: alzbc.org/dogs
- Looking for: People living with dementia who live with a caregiver and either have a dog as a pet, have a dog as a service dog or would like to have a service dog.
- Contact: Frederic Dumont at 418-529-9141 ext. 6033 or Frederic.dumont@cirris.ulaval.ca

For more studies recruiting participants, visit our "Participating in Research" web page, check with your local hospital or health-science centre or contact your health-care provider (e.g. family physician or specialist).

Dementia research 101

On April 17, Dr. Julie Robillard, Assistant Professor of Neurology at UBC and Scientist in Patient Experience at BC Children's and Women's Hospital, partnered with the Society to give a "Research 101" webinar.

Dr. Robillard illuminated the basic research process, what to expect when you participate in a study and how to spot unreliable research.

Dr. Robillard highlighted the importance of being a knowledgeable consumer of research. When we have access to high-quality research, as well as news about this research, we are able to make informed decisions that may improve our health. However, poorly designed, unreliable research and inaccurate news stories can have negative impacts on our choices and our health.

Thank you to Dr. Robillard for sharing her expertise with us and increasing awareness about the world of research!



Learn more

Watch the full webinar here:
alzbc.org/research-webinar2019



Left: Krista James, National Director of the Canadian Centre for Elder Law along with members of the B.C. Leadership Group for people living with dementia Jim Mann and Mario Gregorio talk about the importance of lowering barriers for participation in dementia research at the 2018 Canadian Association on Gerontology conference.

To learn more about what to consider before participating, consult:

- The Alzheimer Society of Canada guide to participating in research:
alzbc.org/research-participation-Canada
- The Alzheimer Society of B.C. webpage on the topic:
alzbc.org/research-participation-BC

Glossary of research terms

Active/experimental group: Many studies separate participants into at least two groups. The active (or “experimental”) group will receive the intervention being examined (for example, a new drug).

Case study: A study based on a very small number of participants who are studied in detail. This can be a starting point for research but generally cannot reveal anything about cause and effect.

Control group: This is the group in a study that will be compared to the “active/experimental” group. The group may receive a placebo (e.g. a sugar pill), the normal treatment for the condition being studied or no intervention at all. This group is essential to ensure that the intervention being tested has an effect and that it is better than the established treatment.

Correlation: This means that two factors are related in some way. It does not mean that one of them causes the other; more research is needed to make that link. For example, a study may show that there is a relationship between exercise and dementia, but we do not know what the relationship between them is.

Dependent variable: This is how researchers measure the effects of the independent variable (defined below). For example, the number of words in a list remembered after an hour or happiness level could be dependent variables.

Double-blind study: This means that neither participants nor researchers know if a participant is in the active group or control group during the study.

Experiment: A research design used to establish a cause-and-effect relationship between an intervention (for example, a drug) and a result (for example, improvement in symptoms).

Hypothesis: This is what the researchers are testing in their study. It can generally be stated in one sentence. For example, “Walking a mile every day will make you happier.”

Independent variable: This is what is being tested in a study, such as a drug or intervention. It should be the only difference between the active/experimental and control groups.

Population: The entire group being considered in a study, for example “people living with dementia.” A **sample** is the small number of people from the population being studied that take part in the study.

Randomized controlled trial (RCT): This is considered the gold standard for any kind of treatment. It is a type of experiment in which people are chosen at random to receive an intervention or a placebo.

Significance: If results are statistically significant (often just called “significant”), this means the results have passed specific mathematical tests the researchers have put them through. It doesn’t necessarily mean the treatment works, or has a large effect, but rather that it is unlikely that the result occurred due to random chance.



Thank you, British Columbia!

Thank you to our incredible participants, donors, patrons, volunteers and sponsors for taking part in the 2019 IG Wealth Management Walk for Alzheimer's. A special thank you to our event honourees and their families for sharing their stories.

Together, we make memories matter!

To date, we have raised over one million dollars to support Alzheimer Society of B.C programs and services across the province, and to enable research into the causes and cures of the disease.

National title sponsor



Provincial sponsors



walkforalzheimers.ca
1-800-667-3742

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Improving First Link®

As an organization whose focus is supporting people affected by dementia, the Alzheimer Society of B.C. is continuously working to improve our dementia support programs.

In 2019, Dr. Robillard of the University of British Columbia will be evaluating the programs and services offered through First Link® dementia support, including support calls, dementia education, support groups and Minds in Motion®. In order to ensure the evaluation reflects the needs of people living with dementia, one of the first steps was inviting people living with the disease to advise the research team on their methods.

One of the advisors is Myrna Norman, who is living with dementia. As a veteran of groups like the Purple Angels and Dementia Advocacy Canada, as well as the Society's B.C. Leadership Group for People Living with Dementia, Myrna keenly appreciates the role that advocates living with the disease can play in inclusion and leadership of people with lived experience. "Taking part is a responsibility and a privilege," Myrna says. "Especially when the goal is to improve services offered through First Link®."

Myrna's role as an advisor for the First Link® evaluation is to work with Dr. Robillard's team to provide guidance on the survey being sent out to people living with the disease and their caregivers.

"Living with dementia gives me a unique insight that is valuable for projects like this evaluation," she says. Her feedback helped the research team develop questions that will provide meaningful



information to guide program development, and questions that would be clear and concise and reduce barriers to participating.

The evaluation is just one of the ways that Myrna has been involved in research. Among other projects, she has recently been involved with a project that looks at dementia and writing poetry. "My voice as someone living with dementia has become my passion," she says. She hopes that researchers will continue to find ways to work in partnership with people to change the future of the disease, together.

Help us make First Link® better

Your feedback is valuable and will help British Columbians affected by dementia. If you would like to help make First Link® services as meaningful as possible for people affected by dementia, sign up to be contacted by our external research partners by visiting: alzbc.org/FL-evaluation

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- Subscribe online at alzbc.org/insight-newsletter
- Call 604-681-6530 or toll-free 1-800-667-3742

Contribute

We welcome contributions, such as personal stories, photography or original poems, from people living with dementia. Please provide your name, mailing address, phone number and/or email address if you would like to be contacted. All submissions will be considered based on theme and space.

- Email Insight@alzheimerbc.org
- Call 604-681-6530 or toll-free 1-800-667-3742
- Mail to the Alzheimer Society of B.C., care of *Insight*:
300-828 West 8th Avenue
Vancouver, B.C. V5Z 1E2

Call the First Link® Dementia Helpline

A confidential, province-wide support and information service for anyone with questions about dementia, including people living with dementia, their caregivers, friends, family, health-care providers and the general public.

- English: 1-800-936-6033.
- Punjabi: 1-833-674-5003
- Cantonese or Mandarin: 1-833-674-5007
- Hours: Monday to Friday, 9 a.m. to 4 p.m.
- Email supportline@alzheimerbc.org

Are you a caregiver?

Connections is a quarterly print and digital publication produced by the Alzheimer Society of B.C.

To subscribe:

- Visit our website at alzbc.org/connections-newsletter
- Call 604-681-6530 or toll-free 1-800-667-3742



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