

Connections

Linking a community of dementia support



Changing the future

Building a dementia-friendly province means fostering change. That change takes many forms. Through building awareness, we change the conversation. We can change the experience of people affected by dementia through programs and services offered as part of First Link® dementia support. We advocate to change policy and work with health-care providers to change practice. We also strive to change the future for people affected by dementia by supporting research.

To change the future of the disease, we champion research through funding, investing in people and acting as bridge between researchers and the community.

When we champion research, we also advocate for dementia-friendly research. Dementia-friendly research meaningfully engages people living with dementia and their caregivers. It invites them to participate, collaborate and advise on projects. Research that keeps people with lived experience at the forefront produces more meaningful results and improves their lives.

Learn more

Dementia research can be complex. You can learn more about it in our resource, "A focus on research": alzbc.org/2019research-handout

Photo: Participants discuss dementia-friendly research in a workshop hosted by the Alzheimer Society of B.C. at the 2018 Canadian Association on Gerontology conference.

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Imagine a better tomorrow with us

Welcome to the summer issue of *Connections*, the Alzheimer Society of B.C.'s publication for people affected by or concerned about dementia.

Our vision is for a world without Alzheimer's disease or other dementias, and that world begins with a more dementia-friendly province, where people affected by dementia are acknowledged, supported and included.

Summer is when events like the Alzheimer's Association International Conference happen. Here, experts in dementia research come together from around the world, and we turn our eyes to what the future could look like, and why both biomedical and quality-of-life research are important.

In this issue, we're talking about dementia research and the role the Society plays in supporting it to help change the future for people affected by the disease. We'll meet a doctoral student at Simon Fraser

University involved in dementia research and share tips on how to increase your understanding and be an informed consumer of research. We'll get an update on the Ralph Fisher and Alzheimer Society of B.C. Professorship in Alzheimer Disease Research and we'll profile one of the volunteers responsible for Minds in Motion®, a program we offer to people in the early stages of dementia that demonstrates the link between fitness, social engagement and brain health.

Research is key to changing the future for people living with dementia. I know this issue of *Connections* will inspire you to think about how you can help us take a step towards our vision.



Maria Howard MBA, CCRC
Chief Executive Officer
Alzheimer Society of B.C.

Events at a glance

We host signature events throughout the year to raise awareness and funds to help provide programs and services in communities around B.C. Here's a taste.

Anything for Alzheimer's
Year-round



Breakfast to Remember
February/March



IG Wealth Management
Walk for Alzheimer's
May



Scotiabank Vancouver
Half-Marathon & 5k
June



Climb for Alzheimer's
September



Coffee Break®
September/October



Learn more
or get involved

For more information
visit our events page:
alzbc.org/society-events

Dementia-friendly communities – A researcher's perspective



Kishore Seetharaman

Kishore Seetharaman is a first-year Ph.D. student in Gerontology at Simon Fraser University. His background is in architecture and environmental psychology. His current research focuses on the design of neighbourhoods

and working with the built environment – including signage, street furniture and parks – to create dementia-friendly communities.

When did your interest in dementia begin?

I remember first learning about dementia through movies like *Away from Her* and *Still Alice*. I was moved and intrigued. However, my interest in dementia as a topic for research came later, growing from various experiences during my master's program – including a seminar by Dr. Bill Thomas, a geriatrician responsible for long-term care projects like the Eden Alternative. He spoke about long-term care and the importance of understanding dementia through a person-centred lens.

What are you currently working on?

I'm working on the Dementia-Friendly Care Homes research project, a collaboration between the BC Care Providers Association, the Alzheimer Society of B.C. and Simon Fraser University. The project aims to define criteria for dementia-friendly long-term care in B.C. It is compiled from research and materials

like reports from organizations or governments at local, national and international levels and focuses on staffing, training and education as well as the physical environment. I am also currently developing my doctoral research proposal which will look at how the design of our neighbourhoods affects how people living with dementia are able to get around their communities.

What do you hope to achieve with this research?

The findings from the Dementia-Friendly Care Homes research project will help guide advocacy efforts for the creation of programs and guidelines for providing person-centred dementia care in B.C. My doctoral research could help inform the design of neighbourhood environments as several communities in B.C. establish Dementia-Friendly Community Action Plans.

Dementia-friendly care homes are about connecting with people affected by dementia and keeping them, their needs and their voices at the centre of the support that is provided to them. The Alzheimer Society of B.C. is proud to be collaborating with the BC Care Providers Association and Simon Fraser University on this Dementia-Friendly Care Homes project to improve quality of life for people living with dementia.

Stay tuned

Stay tuned for more on the project as it moves forward or visit alzbc.org/DFC for more information on dementia-friendly communities.

Dementia research 101



Julie Robillard

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. The webinar emphasized that researchers do not "invent" knowledge but rather explained how they systematically gather and analyze it from a variety of sources.

Participants learned about the different types of dementia research, some of which include:

- **Pharmaceutical:** Looks for drugs that might treat different forms of dementia.
- **Technological:** A new rapidly-growing field that includes how robots can help people affected by dementia.
- **Human factors:** Includes understanding the lived experience of people affected by dementia and how we can make society more dementia friendly.
- **Health-care system research:** Looks at how the system can better serve people living with dementia and their caregivers.

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. While ideally all research and reporting would be accurate, being able to identify good, well-conducted research studies can improve our lives and our health.

The webinar ended by explaining what "good" research looks like. A study, or a news report about a study, should have all these "green lights:"

- It should include the author and their qualifications.
- It should have been published within the past five years.
- It shouldn't try to sell you any products or services.
- It should encourage you to talk to your doctor.
- It should talk about findings cautiously and reference at least one identifiable scientific study.

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

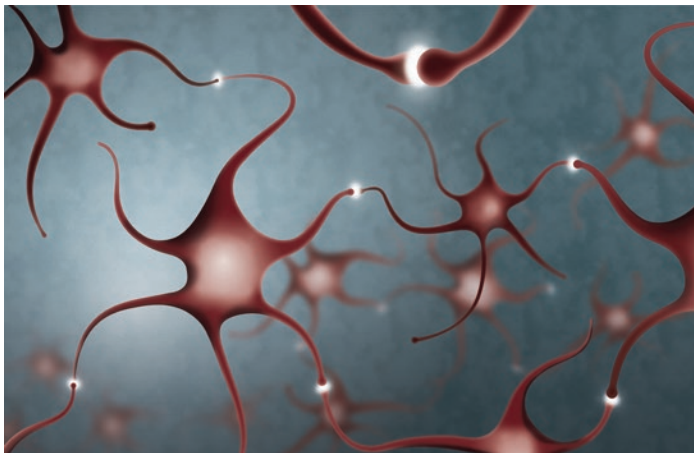
Learn more

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

Don't stop there

To watch other recordings on a variety of dementia-related topics, visit:
alzbc.org/webinar-recordings

Becoming research savvy



It can seem like we're constantly hearing about new and exciting breakthroughs in dementia research. While all research helps contribute to our growing knowledge about dementia, it's important to be critical and recognize that some articles or studies may not always tell the whole story.

Below are some tips for identifying reliable research:

Who did the research?

Legitimate research articles always state the names of the researchers, their credentials, the organization they work for, where the research study was originally published and when the research was done.

What kind of study is it?

There are many types of studies. A true experiment contains an intervention (for example, a new drug) and controls for variables (such as other health

conditions or age) so that the results will indicate the effect of the intervention. If a study is "observational" or references a "case study" it might indicate a new area to be studied but it can't claim anything about the effects of a treatment.

How many people are in the study?

The higher the number of participants in the study, the more likely the results will represent the larger population being studied. For example, a study done with only 10 people is not a good basis for a treatment.

Is it an animal or human study?

Research is often conducted on animals before humans to determine the effects of a treatment. However, promising results in an animal study do not always appear when the same study is done on humans.

How do they talk about their results?

Good researchers avoid words like "cure" or "prove" because they know that science is rarely that definitive, especially early on. Instead they should talk about their results as being evidence for something or suggesting a relationship.

Learn more

For more tips about how to become a better consumer of research news, explore the research section of our website:

alzbc.org/research

Participate in research to help others in your community

The Alzheimer Society of B.C. is committed to offering the highest quality services that also meet the needs of the people receiving them. To ensure this, the Society has contracted researchers at the University of British Columbia to evaluate all First Link® dementia support services (support calls, dementia education,

support groups and Minds in Motion®). Your feedback is valuable and will help improve services for other British Columbians affected by dementia. If you would like to give feedback and be a part of this research project, sign up to be contacted by our external research partners by visiting: alzbc.org/FL-evaluation



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

Alzheimer Society
BRITISH COLUMBIA

Supporting research excellence in B.C.



Dr. Robin Hsiung

Dr. Robin Hsiung, Assistant Professor in the Division of Neurology, Department of Medicine, University of British Columbia, and staff neurologist at the UBC Hospital Clinic for Alzheimer Disease and Related Disorders and St. Paul's Hospital.

Dr. Robin Hsiung holds the Ralph Fisher and Alzheimer Society of B.C. Professorship in Alzheimer Disease Research. Funding the professorship is an important way that the Alzheimer Society of B.C. supports innovative research in our province.

The professorship allows Dr. Hsiung to conduct research that furthers our understanding of dementia. He leads the frontotemporal dementia team in the Canadian Consortium on Neurodegeneration and Aging (CCNS), which focuses on researching the causes and potential cures for dementia, as well as ways to improve care for people living with the

disease. The current study is looking at ways of predicting the risk of dementia to allow for early intervention to slow the disease's progression.

Since 2018, Dr. Hsiung has been studying the effect of music therapy, building on a clinical trial he conducted in 2016 that showed the benefits of music on reducing the behavioural symptoms of dementia.

Dr. Hsiung is also the president of C5R (Consortium of Canadian Centres for Clinical Cognitive Research), which facilitates collaboration between pharmaceutical companies and dementia researchers across Canada.

The Ralph Fisher and Alzheimer Society of B.C. Professorship in Alzheimer Disease Research was created in 2007 through donations from the Ralph Fisher Foundation, the Alzheimer Society of B.C. and others to honour the memory of Ralph Fisher. By nurturing the brightest scientific minds in British Columbia, the professorship continues to move research and discovery forward.

Learn more

To find out more about Dr. Hsiung, the Ralph Fisher and Alzheimer Society of B.C. Professorship in Alzheimer Disease Research, visit: alzbc.org/professorship

Join us in the Charity Challenge
Scotiabank Vancouver
Half-Marathon & 5k
 June 23, 2019

604-742-4948 or gmountfield@alzheimerbc.org



Brenda Partridge: Keeping minds in motion



Brenda Partridge

Retired Kamloops nurse Brenda Partridge volunteers with Minds in Motion®, a fitness and social program for people in the early stages of dementia. Brenda volunteers because of her professional experience and her desire to give back. She believes

staying active and involved in the community has many health benefits.

Exercise and mental stimulation are good for you and your brain. “I not only see benefits for the person living with dementia but also their partner,” Brenda says. “We all know that exercise is beneficial. But there

is a ton of evidence that mild to moderate exercise may help maintain your health.”

For Brenda, social connection is key to Minds in Motion®. “The activity is great, and we encourage people to do more at home – but for the most part, I think [the value is] being around other people.”

Brenda is a people person, always willing to go the extra mile. “I like to bake, so quite often I’ll bake something to bring. The participants enjoy it, so it’s rewarding for me.”

What does Brenda enjoy most about volunteering? “I’ve gotten to know these folks well. I look forward to seeing them. It’s a social outlet for them but it’s also a social outlet for me.”

Read and learn more

Please visit the [Volunteer section](#) of our website to learn more about volunteering with the Society or call 1-800-667-3742.

Questions about dementia
or memory loss?

English: 1-800-936-6033

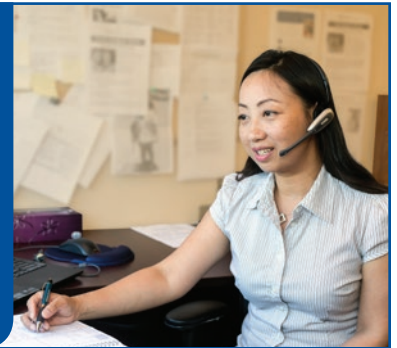
Cantonese or Mandarin: 1-833-674-5007

Hours: Monday to Friday, 9 a.m. to 4 p.m.

First Link®
YOUR LINK TO DEMENTIA SUPPORT

Punjabi: 1-833-674-5003

Learn more: alzbc.org/fldhl



About Connections

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

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Are you a person living with dementia?

We also publish *Insight*, a publication for people living with dementia or cognitive impairment. For more information, visit alzbc.org/insight-newsletter.



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