Dementia Research

The tagline of the Alzheimer Society of B.C. is Help for Today. Hope for Tomorrow…®. This hope refers to the efforts to find treatments and a cure for Alzheimer’s disease and other dementias, and these advances can only happen through research.

This edition of *Insight* includes updates about some of the latest research in the field of dementia, information about how to interpret the results of research studies, and how you can get involved in research and the work of the Alzheimer Society of B.C.

Research Updates

“What is the latest research happening about Alzheimer’s disease?” This is one of the most common questions the Alzheimer Society of B.C. receives from people with dementia. The field of dementia research is constantly evolving, and lots of progress is being made. Here are some recent updates that may be of interest to you.

2014 Alzheimer’s Association International Conference

This annual conference is considered the world’s premier forum for groundbreaking research on the causes, diagnosis and treatment of Alzheimer’s disease and other dementias. This year’s conference took place in Copenhagen, Denmark, and more than 100 Canadian researchers gave presentations. Some conference highlights include:

- Taking steps to manage heart health risk factors and improve nutrition, physical activity, mental stimulation and social activity together may provide cognitive benefits, according to a new study.

- Playing games such as cards, checkers, crosswords or other puzzles may improve cognitive abilities and increase the size of several areas of the brain involved in Alzheimer’s disease. To learn more about steps you can take to maintain and improve the health of your brain, visit [www.alzheimerbc.org/healthy-brain.aspx](http://www.alzheimerbc.org/healthy-brain.aspx).
Both eye examinations and smell tests have the potential to detect Alzheimer’s disease early. Beta-amyloid is a protein that is found in Alzheimer’s disease plaques that occur in the brain. The build-up of this protein in the eye may be one way of seeing if it is accumulating in the brain. Decreased ability to identify odors is also associated with loss of brain cell function and progression to Alzheimer’s disease. In the future, these less invasive tests may improve how we diagnose Alzheimer’s disease and monitor how it progresses.

Advances in positron emission tomography (PET) imaging technology now allow researchers to identify deposits of tau proteins in the brains of persons living with Alzheimer’s disease and experiencing memory decline. In the future, this technology may be used for early detection and to help select participants for research studies.

A protein known as TDP-43 may play an important role in Alzheimer’s disease in addition to the well-known beta-amyloid and tau proteins. TDP-43 has previously been known to be involved in amyotrophic lateral sclerosis (ALS) and some forms of frontotemporal dementia, but not Alzheimer’s disease.

More highlights from the 2014 Alzheimer’s Association International Conference can be viewed online here: www.alz.org/aaic/about/highlights.asp.

**International Conference on Frontotemporal Dementias in Vancouver**

The Alzheimer Society of B.C. was proud to sponsor the 9th International Conference on Frontotemporal Dementias in Vancouver earlier this fall. Held only every two years, this conference was an important opportunity for clinicians, researchers, persons with dementia and caregivers from around the world to share knowledge, with the goal of improving care for individuals with frontotemporal dementias. There were more than 600 international attendees.

The conference featured an all-day session open to persons with frontotemporal dementia, caregivers, families and others. Medical and scientific experts took questions from the audience and provided up-to-date information about frontotemporal dementia research, diagnosis, treatments, care and family support. Almost 200 attendees were able to interact directly with one another and with the speakers during coffee breaks, lunch and an evening social event. You can download copies of the slides from this session and other helpful resources on frontotemporal dementia by

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visiting the website of the U.S.-based Association for Frontotemporal Degeneration at www.theaftd.org.

The presenters talked about how frontotemporal dementias are very good targets for developing new treatments because research has made remarkable advances in understanding these forms of dementia in the past decade. But frontotemporal dementias are very rare, so researchers need to work together internationally to understand the genetics of these diseases. It was inspiring to hear them speak about how they collaborate to expand our knowledge of frontotemporal dementias.

While the conference was happening, the U.S. National Institutes of Health announced more than $5.9 million in funding for research into frontotemporal dementia. The University of British Columbia (UBC) Hospital Clinic for Alzheimer’s Disease and Related Disorders will be participating in some of this research. Important advances in this area have already been made at UBC, including two major discoveries into the genetics of frontotemporal dementia.

To learn more about frontotemporal dementia, go to www.alzheimerbc.org, click on Alzheimer’s Disease and Dementia, and then find Frontotemporal Dementia under Types of Dementia.

Upcoming Tele-Workshop: Heads Up for a Healthy Brain
Monday, December 8, 2014, 7 p.m. (Pacific)

This tele-workshop for people with dementia, their caregivers and the general public looks at Alzheimer’s disease and how it impacts the brain, the latest research on reducing your risk for dementia, and everyday tips for improving brain health.

To participate in this one-hour tele-workshop, connect by:

Internet: momentum.adobeconnect.com/alzheimerbc (Enter as a guest)
and/or Phone: 1-866-994-7745 (Participant pass code: 1122333)

What are the tele-workshops?

Tele-workshops are free educational sessions on various topics related to dementia and caregiving. You can participate by listening on the phone, or through the internet to see the PowerPoint presentation and see and hear the presenters. Pre-registration is not required.

To learn more about tele-workshops, view previous sessions and receive notifications about upcoming sessions, visit www.alzheimerbc.org/tele-workshops.aspx.
Reading About Research: Things to Keep In Mind

It seems as though almost every week we hear about a new study that reports exciting progress in dementia research. There is so much work happening in this field and research is crucial to finding treatments and a cure. However, sometimes these studies have conflicting results and they can be hard to interpret. One study might tell you that a particular food or beverage is good for the brain, while another study might show a different result.

How do you know what to believe? It is important to stay objective when you read or hear about new research. There are several factors to keep in mind when thinking about how reliable and relevant a study may be.

Below is some information to help you understand and interpret the results of research studies:

**What is the source?** Is it a book, a scientific magazine, a popular magazine, a newspaper article, a government web page or a web page from someone with no relevant credentials? Anyone with an opinion can write an article on a web page, but only serious research is published in scientific magazine or peer-reviewed journals (publications reviewed by professionals working in the same field).

**Who did the research?** Legitimate research articles always state the name of the researchers, their credentials, the organization where they work, when the research was done, and where the research study was originally published.

**How was the study designed?** When reading a study, check the methodology (how the study was designed and conducted) to put the findings in perspective. If the methodology is not explained, it is hard to form an opinion on how valid it is. Here are some other things to consider about the methodology:

- **Animal or human?** Some studies may be conducted on animals rather than humans. However, testing something using animals does not mean that the same results will be found when the same test is conducted with humans.

- **How many subjects?** The higher the number of participants, the more likely the results will be representative of the population being studied. For example, a study with only 10 participants cannot claim to represent a large segment of the population, although it may indicate a potential direction for future research.

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• **The type of population.** Do the participants in the study represent the population at large? For example, if the subjects are all experiencing the early stages of Alzheimer’s disease, are the findings applicable to everyone with Alzheimer’s disease? What about other kinds of dementia?

• **Was there a control group?** Did the study include a group of participants (a control group) who did not receive treatment or participate in the activity that was studied? If so, did this group score worse, better or the same as participants who received the intervention?

**Beware of bias.** Who funded the study? If the funding agency has something to gain or lose by the results (such as having a product or medication approved or rejected), there is more potential for bias. If it sounds too good to be true, it probably is. Research funded by independent agencies and reviewed by other researchers who didn’t assist with the study is less likely to be biased. Reputable journals require authors to declare any conflicts of interest.

**Are the conclusions in line with the results?** Conclusions from the findings of a study should stay within the parameters of the research areas that were studied. Be wary of vague and sweeping generalizations, such as “everyone should take gingko biloba”. Did the study effectively demonstrate a “cause and effect” relationship between the findings and the conclusions? Things can be associated with each other without one causing the other. For example, the presence of aluminum in the brains of people with Alzheimer’s disease does not necessarily mean that aluminum causes Alzheimer’s disease. One possibility might be that aluminum is a by-product of the disease.

**How many studies have been done in this area?** One experiment is never definitive. While multiple studies can come to different conclusions, there need to be several studies done in an area to know we can trust the results. When enough research has been done on a topic, researchers can look at and combine all of these results to look for patterns.

A previous version of this article appeared in the April/May 2010 edition of In Touch.
Participating in Research

After learning more about dementia research, you may be thinking about what you can do to help this important work. Some people with dementia and caregivers want to participate in research. The Alzheimer Society of B.C. also wants to support the important research into Alzheimer’s disease and other dementias that is taking place here in this province and across the country. For both of these reasons, the Alzheimer Society of B.C. website has a section titled Participating in Research.

This new web page includes information about what to consider when deciding to participate in research, including a checklist of questions to ask before you sign up for a study. It also includes links to information about research happening in Canada and around the world, including various studies recruiting participants from B.C. that might be of interest to you and your family.

To learn more, go to www.alzheimerbc.org and click on Alzheimer’s Disease and Dementia.

Important Update: Safely Home® Program Changes

Do you or someone you know have a Safely Home® identification bracelet? The Alzheimer Society of Canada has partnered with the Canadian MedicAlert Foundation to improve the program, incorporating the best features of both the Safely Home and MedicAlert services. The existing program will be changing on December 31, 2014 and, as a result, Safely Home bracelets (pictured below) will no longer be active.

All Safely Home members are encouraged to call 1-855-581-3794 to discuss the option of transitioning to the MedicAlert® Safely Home® program. Benefits include:

- MedicAlert is recognized by all emergency responders, not just police.
- MedicAlert provides a unique 24/7 hotline that quickly gives police and emergency responders the member’s physical description, personal contacts and critical health information.
- MedicAlert has specialists ready 24/7 to help reunite caregivers with the person who has wandered or experienced a medical emergency.

To learn more about the MedicAlert Safely Home program, call 1-855-581-3794 or visit www.medicalert.ca/safelyhome.
Consider Volunteering with the Alzheimer Society of B.C.

By Jim Mann

A lot is written about the need, after a diagnosis of dementia, to socialize, keep active and have a purpose in order to stay healthy and live well with our diagnosis.

Some may say, how is all that possible when I no longer work, I can’t drive and I feel really limited because of my dementia? I think I have an answer: volunteer.

Societies like ours rely on volunteers. Volunteers raise their voices as advocates so government officials can understand what it is like to live with dementia. Volunteers share their stories and experiences in this bulletin. Volunteers help with key fundraising events such as Ascent for Alzheimer’s (ascentbc.ca), even by becoming a team member and climbing Mt. Kilimanjaro.

I personally have found great support and satisfaction in the volunteer activities with the Alzheimer Society of B.C. And I think many of you would, too.

The most important volunteer role I had for six years – ending this past September – was as a member of the Alzheimer Society of B.C. Board of Directors. I sat at the table with other volunteers discussing the future of the Society and making important decisions. I was also Honourary Editor of this bulletin for a number of years, which I truly enjoyed.

There are many facets to volunteering, some more long-term or more intensive than others. There are many opportunities at the Alzheimer Society of B.C. for those who want to get involved, find something enjoyable to do and maybe just get out there a few times a month.

I encourage each and every one of you to give this some thought. If something seems interesting to you or you just want to talk about what opportunities there might be in the community, contact a staff member in your local Alzheimer Resource Centre or email volunteer@alzheimerbc.org.

Jim Mann is an active volunteer who advocates on behalf of and for people with dementia. Diagnosed with Early Onset Dementia in February 2007, at the age of 58, Jim is determined to help make a difference in the lives of people who are affected by the disease. As an experienced public policy professional, Jim provides critical advocacy advice to the Alzheimer Society of B.C. and the Alzheimer Society of Canada.
Are you a caregiver?
The Alzheimer Society of B.C. also publishes In Touch, a bulletin for caregivers of persons with dementia or cognitive impairment. To subscribe:

- Visit our website at www.alzheimerbc.org/bulletins.aspx
- Call 604-681-6530 (toll-free 1-800-667-3742)
- E-mail In-Touch@alzheimerbc.org

Contribute to Insight
Do you have a topic you would like to see covered in Insight?

Do you have content you would like to publish in Insight (personal stories, photography, original poems, etc.)?

- E-mail Insight@alzheimerbc.org
- Call Anthony at 604-742-4933 (toll-free 1-800-667-3742)
- Mail to the address below with attention to Insight

All submissions will be considered based on space and theme. Please provide your name, mailing address, phone number and/or e-mail address if you would like to be contacted.

Dementia Helpline
1-800-936-6033
(Lower Mainland 604-681-8651)
supportline@alzheimerbc.org
Monday to Friday, 9 a.m. to 4 p.m.

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

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