

Where would we be without research?

By Jim Mann

In the global sense, without research we wouldn't have computers or big passenger jets to take us on our holidays. But more importantly for those of us with a diagnosis of dementia, research has brought us our prescription medication.



A lot of the brochures available through the Alzheimer Society are based on research. Medical, quality of life - you name it, there has been research on it.

That's right, research hasn't found a cure for Alzheimer's but I know scientists around the world are working feverishly on Alzheimer's and related dementias. If research can uncover why some people get Alzheimer's or a related dementia perhaps that can lead to a cure or even better medications?

Personally I can get a bit jaded about research. I admit it. In my e-mail in-basket every day I get the Alzheimer's Daily News (www.alznews.com), which frequently details what research has uncovered. Often the items are noted with the word "may" as in "may delay Alzheimer's progression."

But then I realize that without research we can't develop new and better treatments for people with dementia. Only with more research will we learn to identify those most at risk for dementia and be able to initiate treatment before symptoms occur.

As you read the articles in this issue of Insight, I hope you feel some optimism and pride in the research that is being done locally, nationally and globally. It is exciting.

Jim Mann is the Honorary Editor of *Insight*. He 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.



Alzheimer's Drug Therapy Initiative

The Alzheimer's Drug Therapy Initiative (ADTI) was created to address the lack of clinical evidence to support PharmaCare coverage for a group of drugs known as cholinesterase inhibitors and allow individuals affected by Alzheimer's disease to access these medications without the restrictive cost.

Through the ADTI, individuals in the mild to moderate stages of Alzheimer's disease are now eligible to receive PharmaCare coverage of the following three medications:

- Donepezil (Aricept®)
- Galantamine (Reminyl®)
- Rivastigmine (Exelon®)

These drugs do not cure Alzheimer's disease but may slow its progression in some people.

Patients' cognitive abilities are reassessed every six months to ensure they continue to benefit from treatment. PharmaCare is monitoring the changes and building a profile of individuals who show benefit.

B.C.'s leading experts in the fields of dementia and aging are conducting research associated with the ADTI. The results of their research will provide PharmaCare with the information it needs to make decisions that support British Columbians affected by Alzheimer's.



Frequently Asked Questions

Question: *If I'm already taking a cholinesterase inhibitor, can I apply for coverage under the ADTI?*

Answer: Yes, if you meet the following criteria:

- a. You have PharmaCare coverage.
- b. Your physician submits a PharmaCare ADTI Special Authority request.

Question: *Who should I talk to if I am interested in participating in the ADTI?*

Answer: You can discuss your eligibility with your physician.

Question: *How can I find out more about participating in the research studies?*

Answer: Please call 1-866-511-2594 for information on the follow-up studies being

coordinated through the University of Victoria's Centre on Aging.

IMPORTANT INFORMATION FOR EXELON® PATCH USERS

- Strictly follow instructions on patch usage given by your doctor.
- Only one patch should be applied per day.
- If you have any questions, always speak to your doctor.

Information on “Brain Boosting” Supplements

There is an abundance of natural supplements on the market that claim to boost brain functions. Before purchasing these products, here is some information to keep in mind:

- Manufacturers of nutritional supplements are not required to provide the Food and Drug Administration (FDA) with any evidence of a product’s safety or effectiveness. Note: in Canada, some natural health products are licensed for safety and effectiveness by Health Canada. (www.healthcanada.gc.ca/lnhpd).



- Many brain boosters include Omega 3 fatty acids or ginkgo biloba even though **neither** of these compounds has been shown in large, well conducted clinical trials to be effective in treating Alzheimer’s.
- Sometimes, a substance may have undergone clinical trials for treating Alzheimer’s, but when results do not

show benefits, it may then be marketed as a supplement instead.

- Many people assume that if something is “natural,” it can’t be harmful, but some supplements do have negative side effects or interactions with other medications.
- **Always** inform your health care provider of any nutritional supplements you are taking.

Reference: "Understanding the Booming Business of Brain Boosters." Perspectives – A Newsletter for Individuals with Alzheimer's or a Related Disorder, Vol 15, No 2. Published by the University of California San Diego, Shiley-Marcos Alzheimer's Disease Research Center

Contribute to Insight!

We really want you to feel part of this bulletin. You can contribute in the following ways:

- Send us news from your support group. For example, what topics of interest or activities have you covered?
- Submit articles on how to live a full and meaningful life after a diagnosis of Alzheimer’s disease or a related dementia.
- Drop off photographs.

Send your contributions to the Alzheimer Society of B.C.

(Attention: *Insight*)

Fax: 604-669-6907

Email: info@alzheimerbc.org

Mail: Alzheimer Society of B.C.
300-828 West 8th Avenue
Vancouver, BC V5Z 1E2

My Hawaiian Cruise

By Norma Selbie

Have you ever wondered what to do with those dreary January days? Well this year inspiration struck when an old friend called me and we decided a break with some sunshine was needed. A few emails later we agreed that Hawaii would meet the bill, so the hunt was on for cruise deals. We found a repositioning cruise we could board in Honolulu that would take us around the islands with four stops, then sail back to Vancouver. This sounded like a winner to us.

Now let's get serious about what somebody like me needs to make the trip less stressful. Standing in long lineups is hard on me, and I get lost at the drop of a hat, so I asked to be met with a wheelchair at both the airport and ship entry and exits. I also mentioned that I was travelling with a caregiver. This ensures that you will go through short customs lineups together. These people also helped with my luggage.

We arrived in Honolulu where Jeanne, a Dementia Advocacy and Support Network International chat line friend, greeted us with beautiful leis at the airport. Dinner at an authentic Hawaiian restaurant featuring talented blind musicians made for a fun evening. The musicians were delighted to hear that they had five gorgeous women sitting next to them. It was a lovely end to a long day of travel.

Our first full day in Honolulu began with snorkeling in an extinct volcano. Perhaps it would be more honest to say swimming, since I can no longer remember how to breathe through my mouth. Perhaps most exciting was a chance to see giant green turtles sunning themselves on the sand. A fond farewell to our new Hawaiian friends, plus half a dozen T-shirts for the family and we were off to the cruise part of our vacation.

Rhapsody of the Seas is not considered a large ship though she takes 2400 passengers and a crew of 800. For somebody with a poor sense of direction this was plenty big enough for me, and I stuck pretty close to my friend for the first 5 or 6 days until I was confident that I could find my way back to the cabin.



Norma with her friend Jeanne in Hawaii

Phyllis Dyck, who heads up the Kelowna Alzheimer Resource Centre, sent me off with a lanyard so I could always have my sea pass and cabin number with me. This was a great help because the sea pass is also your cabin key, and is used in place of money for any purchase made aboard ship. Many ladies wished they had my lanyard instead of always carrying a wallet or purse. Another good tip is to pack a nightlight. An inside cabin can be very dark when you turn the lights off.

There was a casino with card games and slot machines for those who like this kind of fun. But when I put twenty cents into a machine and didn't get any money back, I decided this was not for me. Truth of the

matter is that I didn't even know what buttons to press.

We circled the islands, stopping at four of them, and enjoyed a tour on each one, and I always managed to help the local economy with more souvenirs. One glass bottomed boat excursion was particularly interesting when we found ourselves in the middle of a school of spinning dolphins. That was an interesting experience.

Now for our biggest thrill of all. It was seeing the Kilauea Volcano spewing lava down into the sea at night. From far off it

looked like a city of lights on a hillside. Then as we came closer you could see great plumes of steam rise as lava plunged into the ocean.

Well, all good things must come to an end. Even though our cabin steward assured us that we had enough clothes to take us through the Alaskan cruise that was to follow, we knew it was time to head for home. Once again, I am reminded that we live in a wonderful land of opportunity. We can enjoy the luxury of a delightful cruise, then come home to dream of another year's exotic vacation.



On December 17th, the North Fraser Early Stage Support Groups came together to recognize accomplishments and group participation. They worked in teams to assemble and decorate gingerbread houses, trees, and trains!

We asked the Burnaby Early Stage Support Group: *Where did your name come from?*

<p>John: I was named after my great uncle John and I am happy with my name!</p>	<p>Dennis: I was named after a famous 1930's singer. My parents admired Dennis Day.</p>
<p>Sharon: I have my mother's name for my middle name – "Fern". In early years I did not like it but over time I have come to see the good part of it – "Fern" is restful.</p>	<p>Mario: In the Philippines, Catholics name their children after saints. I have noticed when giving my name that people expect me to be Italian.</p>
<p>Bill: My name comes from my middle name "William" and my first name is Blythe. I changed high schools and decided to go by William as I was not so happy with Blythe. As time has passed I have come to see that it's not so bad!</p>	<p>Julien: When my family registered by birth at the local church, they changed the spelling from the typical spelling of the French name Julian. I grew up helping at that church.</p>
<p>Joy: My first name is Ethel and I was named after my grandmother. I turned out to be a "Joy" to my family!</p>	<p>Mary: I was named by the schoolteacher living with my family at the time. The Chinese pronunciation is "Lin".</p>

Notes and Events

DEMENTIA HELPLINE


 Alzheimer Society
BRITISH COLUMBIA

1-800-936-6033
(Lower Mainland 604-681-8651)

Helping people with dementia, their friends, and their family members to build the confidence to maintain quality of life when facing dementia.



Our Vision

Our ultimate vision is to create a world without Alzheimer's disease and related dementias.

Our Mission

The Alzheimer Society of B.C. exists to alleviate the personal and social consequences of Alzheimer's disease and related dementia, to promote public awareness and to search for the causes and the cure.

The Alzheimer Society of B.C. relies on the generosity of individuals and the community to ensure families have access to the knowledge, skills and tools they need to live well with dementia. Your donation will help make the journey easier for families impacted by Alzheimer's disease or related dementias.

Shaping the Journey



This six-session educational series is designed for people experiencing the early symptoms of Alzheimer's disease or a related dementia, as well as a care-partner, family member, or friend. It is this joint learning environment that makes the program unique. Contact your local Alzheimer Society of B.C. Resource Centre to find out when it will be taking place in your area. Go to www.alzheimerbc.org to find out more.

Healthlink BC – Call 811

Speak with a nurse, consult a pharmacist, or get healthy eating advice from a dietician. This service is free of charge and available 24 hours a day and 7 days a week. Simply dial 811 for health information and answers to non-emergency questions. Information is also available online at www.healthlinkbc.ca

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 Alzheimer Society
BRITISH COLUMBIA

#300 – 828 West 8th Avenue
Vancouver, B.C. V5Z 1E2
Tel: 604-681-6530
Toll-free: 1-800-667-3742
Fax: 604-669-6907

Email: info@alzheimerbc.org
Website: www.alzheimerbc.org