

# Connections

Linking a community of dementia support



## The power of your voice and your story

With the 2017 provincial election approaching, it is the perfect time to speak to the electoral candidates in your community about dementia. By raising your voice, you can make a difference for people affected by Alzheimer's disease and other dementias.

Across the province British Columbians are speaking up. Many people think that their concerns won't matter in the eyes of a busy politician, but the lead up to an election is the perfect time to show your courage and share your story. The electoral candidates in your community want to hear from you!

To learn more about what you can do this election, check out the Alzheimer Society of B.C.'s [YouTube channel](#) after April 7, when we will be posting our spring webinar "Get Ready for the Provincial Election" which will highlight the tools available to help you share your story.

### Ask questions and get involved

Do you have more questions about speaking up about dementia this election? Email us at [advocacy@alzheimerbc.org](mailto:advocacy@alzheimerbc.org).

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# A warm welcome!

Welcome to the inaugural issue of *Connections*, the Alzheimer Society of B.C.'s flagship publication for people around the province who are affected by or concerned about dementia. This issue focuses on people who are raising their voices – as constituents and advocates, as caregivers, volunteers and fundraisers – to call attention to the disease, and to help build a society that is friendlier, more accepting and more supportive of people living with dementia.

Our vision is of a world without Alzheimer's disease and other dementias. Until this day comes, we are working towards a world in which people living with the disease are welcomed, acknowledged and included.

It'll take a movement to achieve this. It'll take a movement to support, to educate, and to advocate for

change. Whether you are a person with dementia, a caregiver, a volunteer, donor or health-care provider, you are part of the movement. Make dementia an election issue. Tell your story. Share awareness of the disease and work to change attitudes to lessen the stigma of dementia. Connect with the Society for support or information – or urge someone else to do so. There are so many ways you can get involved and help us move closer to our ultimate vision. Along the way, you'll make a difference in the lives of British Columbians who are affected by dementia. As always, thank you for your support of our work!

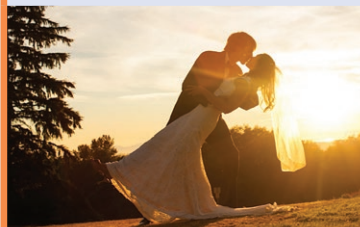


Maria Howard MBA, CCRC  
Chief Executive Officer  
Alzheimer Society of B.C.

## 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



*Investors Group 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 about all of our events, visit the [fundraising events page](#) on our website

# A student gives the gift of lasting memories

*Ruth Stewart, a caregiver and a former teacher, shares her story*

Serendipity allowed different people from different places to come together to create an amazing outcome.

One day, I was speaking to Brookwood Secondary School principal, Marcello Moino, about my experiences as a caregiver for a person living with dementia. We were discussing memories and the idea that family events and memories would be lost as the condition progressed, not only to the person on the dementia journey, but also to that person's children and grandchildren.

Not long before that, I had connected with a former Brookwood student who offered to interview and record my husband David's life stories. At a caregiver support group meeting, Ethel, a fellow attendee, had sighed to me and said "Oh, I wish I knew someone like that. My husband Larry has such a sense of humour and he is a great storyteller. The family would value his anecdotes so much."

I mentioned Ethel's request to Marcello, who was intrigued by the possibility of such an altruistic opportunity for a current student. In fact, he already had someone in mind.

Marcello approached Grade 10 student Conor Blackaby to ask if he would be willing to interview Ethel's husband Larry and record his life's story. Conor saw this as an exciting challenge and accepted. "It was a tremendous learning experience for me," admitted Conor. "I had no idea about the



From left to right: Ruth, Ethel, Larry, Conor and Marcello.

**What a team effort – and an amazing way to honour and record Larry's memories!**

technology needed to pull it off. I didn't even know how to use the video camera when I started."

Conor went above and beyond in accepting the challenge. At the end of the school year, we were all invited to view some of the clips that Conor had filmed and edited. Larry and Ethel were thrilled with what they saw. The result was indeed impressive. "We're going to go home, sit on the sofa, pop some popcorn and watch them all right through," joked Ethel.



At the end of the school year Conor received the prestigious Ike Sinden Stubbs Inspirational Award, which is awarded by the Brookwood Secondary School teaching staff to a Grade 10 student who exemplifies characteristics of altruism, service and citizenship.

What a team effort – and an amazing way to honour and record Larry’s memories! A win-win situation for everyone.

### Share your stories with us

We welcome submissions of personal stories, photography or original poems. Contact information is on the last page of this newsletter. Please provide your name, mailing address, phone number and/or email address if you would like to be contacted.



### New research professorship awarded

Earlier this year, we welcomed Dr. Robin Hsiung as the latest recipient of the Ralph Fisher and Alzheimer Society of B.C. Professorship in Alzheimer Disease Research at UBC.

The Alzheimer Society of B.C. and the UBC Hospital Clinic for Alzheimer Disease and Related Disorders have a shared goal of supporting research to find the causes and cures of dementia. To learn more, visit the [Research](#) page of our website.

## Advocate

# Share your experiences about health-care consent!

*You can help make a difference for people affected by dementia across B.C.*

This April and May, the Canadian Centre for Elder Law and the Alzheimer Society of B.C. are holding discussions in communities across B.C. to learn about people’s experience of consenting to treatment and medication. By enhancing our understanding of health-care practices, we hope to identify how to

improve the law and help people better understand their rights.

If you are a caregiver or substitute health-care decision-maker for a person with dementia, we want to hear from you!

### Learn more or participate:

To find the date and time of the meeting in your community, please contact Lee Segall at 604-742-4938 (toll-free 1-800-667-3742) or email [lsegall@alzheimerbc.org](mailto:lsegall@alzheimerbc.org).

# What is advocacy?

*According to the dictionary, an “advocate” is one who defends or maintains a cause or proposal. Advocacy is an important part of the dementia journey.*

### What is advocacy?

Advocacy simply means speaking up for yourself or for somebody else. This provincial election is a great time to advocate for large-scale change for people affected by dementia. However, from time to time, you may also need to personally advocate for yourself or the person you are caring for.

People with dementia are often unable to make their needs and wishes known. So it is not unusual that a person with dementia will need an advocate to help them. This role can mean speaking to doctors, caregivers, health-care providers and other professionals.

Usually, a person’s advocate is their spouse or another family member, but sometimes it’s a friend or a volunteer from the community. The advocate’s main job is to communicate with the intention of having the person’s best interests met.

### Advocacy tips

Here are some things to remember if you are acting as an advocate for someone:

- There may be times when your beliefs or choices are different than those of the person you are advocating for. You are representing another person whose beliefs, values and wishes are critical. There can be a very big difference between doing what you think is best for somebody else, and doing what they want.
- Let the other person speak for themselves as much as possible and make whatever decisions they can.
- Respect the other person’s privacy.
- Get all the information you can before making decisions.
- Keep careful records. To learn more, see the [Alzheimer Society of B.C.’s Advocacy Fact Sheet 2: Getting Organized](#).



### Learn more and access resources

We have developed [ten Advocacy Fact Sheets](#) on advocating for a person with dementia. Each fact sheet covers a different topic you may encounter along the dementia journey. To download the fact sheets or to learn more, visit [alzbc.org/become-advocate](http://alzbc.org/become-advocate), or call the First Link® Dementia Helpline at 1-800-936-6033.

# “Spirit Unforgettable” – Honouring a legendary Canadian couple



## *A spotlight on Spirit of the West’s John Mann and his wife, Jill Daum*

John Mann is a founding member and lead singer of the iconic Canadian music group Spirit of the West, as well as a solo singer-songwriter and musician with a long list of national music awards and honours. His wife Jill Daum is an actor and a writer, a co-creator and performer in the internationally-acclaimed *Mom’s the Word* trilogy of plays.

In 2014, John received the Access to Music Foundation of B.C.’s Beautiful Heart Award for his many charitable efforts. A survivor of colon cancer, John has volunteered with the B.C. Cancer Agency and the B.C. Cancer Foundation. He travelled to Swaziland three times to work with the Bulembu Project, assisting children orphaned by the AIDS epidemic.

Music fans across the country were saddened to learn in 2014 that John had young onset Alzheimer’s disease. John kept performing with Spirit of the West until April of 2016, and he continues to perform benefits for Alzheimer Societies across the country.

“We want people to know how difficult Alzheimer’s is: the relentless, painful impact it has on a family,” says Jill. “There is so much more research to do.”

John and Jill are committed to doing whatever they can to diminish the stigma around Alzheimer’s disease and other forms of dementia. They’ve agreed not to “hide at home,” even as he gets sicker, she says. “Even though it may be awkward and uncomfortable for people, we’re still going to stay out in the world. We’re not going to silently disappear.”

She says the Alzheimer Society of B.C. is an organization “that is there when you don’t know who else to turn to. They’re caring and sensitive, because they’re experts in this subject, so they’re truly helpful. It would be terrible if they weren’t there, even though I wish we didn’t have the Alzheimer Society – I wish we had a cure instead and we didn’t need them anymore. But since we do, I’m so grateful they’re there.”

Jill Daum and John Mann are the 2017 *Investors Group Walk for Alzheimer’s* Vancouver honourees.

### Walk or sponsor someone else

The *Investors Group Walk for Alzheimer’s* takes place Sunday, May 7, 2017 in 22 communities around B.C. Visit [walkforalzheimers.ca](http://walkforalzheimers.ca) to read your local honouree’s story and learn how you can register and fundraise.

# Turn your fitness goals into fundraisers!

*Have you resolved to improve your health and fitness this year? Do you want to get more involved in supporting your favorite charities? Combine your health and wellness goals with fundraising through Anything for Alzheimer's!*

*Anything for Alzheimer's* makes it easy to take your unique idea and make it a fundraising success. Anyone with a creative idea, talent or passion can make a difference by registering a fundraising event or challenge through our website.

This spring, one of our *Anything for Alzheimer's* fundraisers, [Gary Haukeland](#) is taking on "the toughest footrace on earth." Gary will run the Marathon des Sables, a 250-kilometre journey across the Sahara Desert, carrying everything he'll need for a week. He's doing it to raise \$25,000 for the Alzheimer Society of B.C.!



**Gary Haukeland will be running across the Sahara Desert – and raising money for the Society – later this spring.**

But maybe grueling challenges in inhospitable environments aren't for you. Instead, you could sign up for a marathon or triathlon, host a golfing or bowling tournament, or even hold an old-fashioned dance party! Or, you could simply challenge yourself and make a pledge to reach your personal best in a sport or fitness activity of your choosing.

Whatever your health and wellness goal is, consider turning it into a fundraiser! Your support provides help and hope to the estimated 70,000 British Columbians currently living with dementia and the people who care for them.

### Do your thing!

Visit [anythingforalzheimers.com](http://anythingforalzheimers.com) to see what other fundraisers are doing or to register your event. To learn more about how we can help support your fundraising goals, contact us at 1-800-667-3742 or [info@alzheimerbc.org](mailto:info@alzheimerbc.org).

## Did you know?

*Our Circle of Hope program honours those who've planned a future gift to the Society. The circle is a symbol of kinship, connecting family and friends to each other – and connecting the past to the future.*

Almost 20 per cent of our donations are gifts from a person's will. Thoughtfully planned gifts form much of the financial foundation for our work, from education programs and support services to funding

## May is Leave a Legacy month

for research. To many people, legacy gifts make a statement about their values and how they want to be remembered.

### Thinking of your legacy?

To learn more, visit [alzbc.org/lasting-legacy](http://alzbc.org/lasting-legacy), call 1-800-667-3742 or email [info@alzheimerbc.org](mailto:info@alzheimerbc.org).



# Meet Oladele Atoyebi

*He's one of the Society's newest volunteers.*

Oladele ("Dele") Atoyebi volunteers as an Early Stage Support Group facilitator at the Society's Vancouver Resource Centre. His compassion and care for the people he supports is evident.

A physician, Dele served as a public health clinician in Nigeria before coming to Canada. With a particular interest in social and rehabilitative medicine he studied the experiences of rural and urban seniors as they aged in their communities.

Dele moved his young family to Vancouver in 2016 to enroll in Simon Fraser University's Gerontology program. He was adjusting to a new country and a new professional challenge – and he was determined to get even more involved. "I wanted to give back to my new community and integrate into my new home," Dele says. His research at SFU is enriched by his experience



**Volunteer Oladele Atoyebi with Manager of Regional Services Sara Wagner**

as an Early Stage Support Group Facilitator. He runs a support group with about 10 members, and he is struck by the level of honesty and acceptance they show him and each other.

Dele's volunteer contributions have another effect. "When I talk about volunteering at the Alzheimer Society of B.C. in class, people listen." Amongst his fellow gerontology students, Dele has become an advocate who is raising awareness about what people in the early stage of dementia need from the medical professionals who work with them. Dele is one of 160 Support Group Facilitators who run groups across B.C.

**Read and learn more**

Please visit the [Volunteer section](#) of our website to learn more about volunteering with the Society.

## About Connections

*Connections* is a quarterly print and digital publication produced by the Alzheimer Society of B.C. Articles cannot be reproduced without written permission.

**Contact us to contribute content or to subscribe to receive *Connections* regularly.**

- Online at [alzbc.org/connections-newsletter](http://alzbc.org/connections-newsletter)
- Email [newsletter@alzheimerbc.org](mailto:newsletter@alzheimerbc.org)
- Call 604-681-6530 or toll-free 1-800-667-3742
- Mail to the Alzheimer Society of B.C.  
300-828 West 8th Ave., Vancouver, B.C., V5Z 1E2

You can help us reduce our costs by choosing to receive *Connections* by email.

### Are you a person with dementia?

We also publish *Insight*, a publication for people living with dementia or cognitive impairment. For more information, visit [alzbc.org/insight-bulletin](http://alzbc.org/insight-bulletin).

### Need additional support?

The First Link® Dementia Helpline is a confidential province-wide support and information service for anyone with questions about dementia, including people living with dementia, their caregivers, friends, family, professionals and the general public.

**Phone:** 604-681-8651 (Lower Mainland) or 1-800-936-6033 (toll-free) – Monday to Friday, 9 a.m. to 4 p.m.

**Email:** [supportline@alzheimerbc.org](mailto:supportline@alzheimerbc.org)