

Forget Me Not
Help for Today.
Hope For Tomorrow.

Alzheimer Society
BRITISH COLUMBIA

Contact

Summer/Fall 2005

Volunteers can help us advocate for change

The Alzheimer Society of B.C. (ASBC) believes caring for people with Alzheimer's disease ought to be an essential component of our health-care system. And with a provincial election to be held on May 17, 2005, now is an important time to get our issues across to the politicians and candidates.

Every year nearly 14,000 British Columbians are diagnosed with Alzheimer's disease or a related dementia. Approximately 61,000 people in this province currently have dementia. "They and their families have a voice that, together with ours, can make a difference in how government looks at Alzheimer's care," says Barbara Lindsay, ASBC Manager of Advocacy and Public Policy.

With the upcoming provincial election, the Alzheimer Society needs volunteers to support the Society's advocacy efforts,

says Barbara, and to continue these efforts after the election. "The most important thing is for you to help us voice our issues in your community and, as important, for you to bring issues forward to us."

"You can either be a victim, or you can do something."

— Marcia Stobbart, Mill Bay (Advocacy Committee Volunteer)

One person who has stepped forward is Marcia Stobbart of Mill Bay on Vancouver Island. Marcia's husband, Robert, now 69, has Alzheimer's disease and she is his primary, full-time caregiver. Marcia's weekly column in her local community paper, *The Cowichan Citizen*, advocated on several occasions on behalf of Alzheimer's – drawn from her personal knowledge and that of others.

She has also met with her local MLA

and other government representatives to protest the lack of government funding for Alzheimer medications, and educate them about issues experienced by people affected by Alzheimer's. Not only does she volunteer for the ASBC as a

representative for those who cannot speak out, she intends to make her voice heard through her vote.

"You can either be a victim, or you can do something," says Marcia, urging others to step forward and help advocate for change. "The government has to look at the long-term difficulties facing caregivers and the fact that costs

(Volunteers continued inside)

Calendar of events

For a complete list of upcoming events, visit our Web site at www.alzheimerbc.org.

MAY

Forget Me Not Golf Tournament

May 12 Surrey, B.C.
A leading charity event, held at Northview Golf and Country Club. For info call Linda Forrest at 604-681-6530 or toll-free at 1-800-667-3742.

Educational Conference

May 19 Williams Lake, B.C.
Conference for families and health-care workers. For info call the Alzheimer Resource Centre at 250-377-8200 or 1-800-886-6946.

(Calendar continued back page)

Breaking ground on a new Alzheimer centre

When Michael Czorny died of Alzheimer's disease 20 years ago, his daughter Marilyn Stewart made a commitment to do whatever she could to help others touched by the disease. In January 2005, Marilyn and her husband Chick Stewart were on hand to help toss the first shovels of soil as construction started on a project that began as a dream all those years ago.

The Stewarts, the Alzheimer Society of B.C., and the Fraser Health Authority have partnered to build and operate the Czorny Alzheimer Centre – dedicated to the memory of Marilyn's parents. The Centre will offer residential care and outreach that the Stewarts hope will stand as a partnership and care model that can be replicated elsewhere in the province.



Chick and Marilyn Stewart with an architectural rendering of the Czorny Alzheimer Centre.

The Centre is the first stand-alone residential care facility in the Fraser Health region designed specifically to meet the needs of individuals with Alzheimer's disease. It will have 36 residential beds – arranged in three

(Alzheimer centre continued inside)

(Volunteers continued)

for long-term care far outweigh the costs of Alzheimer medications.”

Helping support the Alzheimer Society’s public policy efforts can take on many forms. You can help educate government, political parties and candidates by:

- Becoming familiar with the issues the ASBC is working to make public. This can be done by reviewing the ASBC Election Kit, available online at www.alzheimerbc.org, or in print format through your local Alzheimer Resource Centre. Advocating will continue to be relevant post election.
- Writing, calling or e-mailing your MLA or candidates in your area. Templates of letters are contained in the Election Kit, as is a step-by-step guide to setting up a meeting with your candidate, or your MLA after the election.
- Sharing your personal experiences with dementia, either as a caregiver or as a person living with the disease, with your local media and with the ASBC.
- Joining the ASBC Advocacy Committee.

The goal of this volunteer committee is to push forward issues of concern to people whose lives are affected by Alzheimer’s disease.

Getting our issues across to policy makers in government has been an ongoing focus for the Alzheimer Society. Steps we have taken include meeting with the key decision-makers in Victoria and ongoing communication with the Ministry of Health Services, government caucus committees and health authorities.

If you would like to help us advocate for change, please contact Barbara Lindsay, Alzheimer Society of B.C. Manager of Advocacy and Public Policy, at 604-681-6530, toll-free 1-800-667-3742 or e-mail blindsay@alzheimerbc.org.



Barbara Lindsay

(Alzheimer centre continued)

home-like cottages that are each built for groups of 12 – an adult day-care program, and an Alzheimer Society of B.C. Resource Centre.

“Families with a loved one affected by Alzheimer’s know all too well how deeply the disease can touch individuals and their families,” Marilyn says. The Stewart family has donated the land and capital funding to help see the Centre come to fruition.

The Alzheimer Society will be responsible for hosting a resource centre that will connect people to a community of information, services and support. “The Resource Centre will serve the people linked to the campus – caregivers, people living with Alzheimer’s and their families – as well as people in the greater community,” says Dan Eisner, Volunteer President of the Alzheimer Society.

The Czorny Alzheimer Centre is scheduled for completion in the spring of 2006.

Election May 17, 2005

Make your voice heard! Please go to our Web site at www.alzheimerbc.org. Look for the logo shown here. It will link you to our Government Relations section where you can read about the issues that are important to people whose lives are affected by Alzheimer’s disease and related dementias, and take action steps to make a difference.



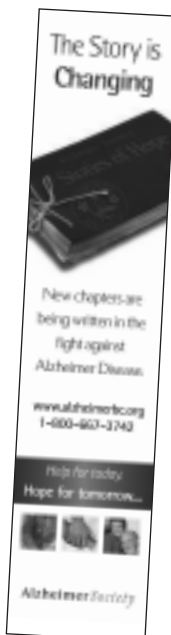
The Alzheimer story is changing

Throughout 2005, we will show you that there is hope and that the story is changing in B.C. for people whose lives are affected by Alzheimer’s disease or a related dementia.

Much progress has been made. In fact, 95 per cent of what we know about dementia today has been discovered in the last 15 years – so there is much hope for the future.

One in 13 Canadians over the age of 65 has Alzheimer’s disease or a related dementia; over the age of 85, this number climbs to 33 per cent, or one in three!

Get your FREE “The Story is Changing” bookmark, available through your local Alzheimer Resource Centre.



Here are the five top reasons why the story is changing in B.C:

1. Alzheimer’s disease is being diagnosed earlier. People are recognizing the signs earlier and doctors have better tools to diagnose the disease.
2. Medications are now available that can ease symptoms and improve quality of life. Promising new therapies are being tested.
3. Stigma around Alzheimer’s disease is decreasing and many people are seeking help from support groups, such as those offered locally by the Alzheimer Society of B.C.
4. New and updated programs and information offer help and hope to people whose lives are affected by Alzheimer’s disease.
5. Nationally, the Alzheimer Society and its partners invest more than \$3 million annually in research, and great strides have been made in the search for a cause and cure.

For help and information, contact your local Alzheimer Society of B.C. Resource Centre or go to our Web site at www.alzheimerbc.org.

Walk for Memories raises \$230,000

The third annual Walk for Memories, presented by Retirement Concepts, took place on Sunday, Jan. 30, as well as dates in early February. Almost 1,500 British Columbians laced up their walking shoes, helping to raise \$230,000.

Many communities across B.C. took part in the event including Chilliwack, Dawson Creek, Kamloops, Nanaimo, Penticton, Rossland, Vancouver, Vernon, Victoria, White Rock, and Williams Lake.

All the pledges raised from Walk for Memories will help fund community-based programs and services provided by the Alzheimer Society of B.C. Funds

raised will also support research to help find the causes and the cure.

For more information about the Walk for Memories, to find out the names of prize winners, or for more details showing where funds raised go, visit our Web site at www.alzheimerbc.org. Or contact the Alzheimer Society of B.C. at 604-681-6530, toll-free at 1-800-667-3742 or e-mail info@alzheimerbc.org.

PS: Save the date of Jan. 22, 2006 on your calendar – that's when the next Walk for Memories will take place, and we want you walking with us!



Photo by Flora Gordon

People of all ages came out to support the Alzheimer Society of B.C. at the third annual Walk for Memories.

Walk is personal for most people

When University of British Columbia professor Sultan Karim asked his pharmacology students how many of their families or friends' families have been affected by Alzheimer's disease, he saw most of the hands in his classroom rise into the air. But when he asked whether they had heard of Walk for Memories, the response wasn't as overwhelming.

"It was then that I told them I wasn't speaking to them as their professor, but as someone whose life had been personally affected by the disease," says Sultan; his wife Pitu was diagnosed with Alzheimer's 10 years ago. "That's why I asked them to take part in the Walk for Memories and fundraiser for a great cause."

And that is exactly what Sultans' students did.

Sultan led a 40-member team – the largest team out of all the Walks across B.C. – that raised \$10,000. The team included Sultan's students, family members, friends and neighbours. "Getting so many people out for the Walk felt great," Sultan says.

One of B.C.'s top individual fundraisers was Carol Edwards, who lives in Chilliwack. She personally raised \$2,100. Edwards' stepfather was diagnosed with Alzheimer's disease five years ago. "I walk because Alzheimer's disease affects so many people, and to take part in something like this helps us make people aware of the disease," says Carol, who has been taking part in Walk for

Memories since its inception in 2003.

When Stan Fryer of White Rock participated in Walk for Memories this year, he did so for one main reason – his wife. Shirley was diagnosed with Alzheimer's disease four years ago, and Stan is her primary caregiver.

"The most important thing for a person who is a caregiver is to give love and support," Stan says. "I know it makes my wife feel more secure and it gives her less anxiety to deal with."

Stan personally raised \$2,000, and had four friends accompany him at the Walk. "I think being a part of something like this is important because it helps promote a better understanding of the disease to the public."

Stan, a volunteer chaplain for Surrey Memorial Hospital, learned about the Walk for Memories last year during an



Stan and Shirley Fryer of White Rock. Shirley was diagnosed with Alzheimer's disease four years ago, and Stan raises funds and participates in the Walk for Memories in her honour.

Alzheimer Society of B.C. Caregivers Support Group meeting that he regularly facilitates in his community.

At his first Walk in 2004, Stan raised \$500. But this time around he says he had more time to raise funds, and that's why he managed to quadruple his donations.

Stan has already set a personal goal of \$4,000 for the 2006 Walk for Memories.

Donate securely online!

You can donate quickly, efficiently and safely to the Alzheimer Society of B.C. through our secure online option provided free by CanadaHelps. Within minutes of making a donation, you will receive a Revenue Canada-approved electronic tax receipt that is sent to the e-mail address you provide during the donation process.

CanadaHelps and the Alzheimer Society of B.C. abide by all the rules and regulations of the Canada Revenue Agency and the Personal Information Protection Act (www.alzheimerbc.org/privacy_policy). To make a donation online, look for the CanadaHelps logo on our Web site at www.alzheimerbc.org.

Donations can also be made by calling your local Alzheimer Society of B.C. Resource Centre, or toll-free 1-800-667-3742.

Making the Connection for professional caregivers

An estimated 61,000 British Columbians have Alzheimer's disease or a related dementia, and this is increasingly becoming a challenge for care facilities. The Alzheimer Society of B.C. is in a position to use its expertise to help educate professional caregivers.

Making the Connection is a new Alzheimer Society program, which was piloted for the first time with a group in Vancouver in mid-March.

"The goal of this program is to cause a

change in practice when staff go back to work," says Angela Johnston, the program developer and workshop facilitator. *Making the Connection* uses a simulated dementia experience to help participants understand what a person with dementia feels, hears and sees. The workshop that follows provides professional caregivers with practical help and advice.

"The experiential portion of the training enables them to walk a mile in the shoes of a person coping with the

disabilities of aging and dementia. It creates an understanding that profoundly affects their approach to support and caregiving," Angela adds.

This program will continue to be piloted over the next year as the curriculum is refined.



Angela Johnston

Shaping the Journey – learning to live with dementia

Learning you or a loved one has dementia is just the beginning of an often intimidating process. Many myths surround Alzheimer's disease and dementia, and often, people diagnosed with dementia know little more than what they've seen or read in the media.

Shaping the Journey helps put you on the right path. This educational series, provided by the Alzheimer Society of B.C., is aimed directly at those who have recently been diagnosed and are in the early stages of Alzheimer's disease or a related dementia. With recent advances in diagnosis and treatment, people with dementia are being diagnosed earlier, at a time when they can still participate in the decision-making process on their own behalf.

The six-week program covers:

- Learning about the disease
- Diagnosis day
- Learning about treatments and wellness activities
- Life after diagnosis: my feelings and reactions
- Life after diagnosis: maintaining me
- Practical tips: what others have found useful
- Other implications of the diagnosis
- Planning ahead: Legal and financial implications

The first pilot series was held in Victoria with good response, and we will begin to make it more widely available in 2005 and 2006. As we expand *Shaping the Journey*, new dates and venues will be posted on the Events Calendar on our Web site, www.alzheimerbc.org.

Newsletter offers *Insight*



Norma Selbie

This spring, an innovative newsletter will begin circulating in British Columbia, under the auspices of the Alzheimer Society of B.C. Written by people with dementia, for people with dementia, *Insight* provides inspiring personal stories as well as hints and tips that offer daily coping strategies.

"This newsletter is designed specifically to deal with our own concerns and interests," says Norma Selbie, a Kelowna woman diagnosed with Alzheimer's disease several years ago, who is the

first Honorary Editor of *Insight*. "It offers a second line of support – with the first being the Alzheimer Society's Early Stage Support Group – that shows people with early stage dementia that we are important and valued."

The first edition of *Insight* includes the beginning of a series called "It's a family affair" as well as an inspirational story from someone with the disease, and tips on coping strategies.

Insight will be distributed to members of the Alzheimer Society's Early Stage Support Groups across the province, and will also be posted on our Web site at www.alzheimerbc.org/newsletter.php.

Newsletters at your fingertips

The Alzheimer Society of B.C.'s Web site, www.alzheimerbc.org, attracts more than 13,000 visitors each month. Many of our visitors go to one of the most popular parts of our Web site – the Newsletters section.

The Newsletters section was launched in August 2004, and houses the Alzheimer Society's main external publications. The section includes: our Annual Report; our twice-yearly *Contact* newsletter that keeps people up-to-date on activities, events and how donor dollars are being used; *In Touch for Caregivers* that offers tips, information and advice; and our new *Insight* newsletter (see related article this page).

Our Web site offers an easy and efficient way for people to read our



publications in their entirety, or by select article. The Web is especially convenient for those who may not be near an Alzheimer Resource Centre, or who prefer to connect with us online.

If you would like to go directly to the Newsletters section of our Web site, go to www.alzheimerbc.org/newsletter.php. For more information, contact your local Alzheimer Resource Centre – an entire contact list is posted on our Web under Contact Us.

Two easy ways to leave a legacy

Ask yourself: Would you rather leave a final legacy to a) the tax department or b) your favourite charity? Hopefully, you've answered b) the Alzheimer Society of B.C. rather than the taxman.

And there is an easy way to ensure your wishes are carried out: by naming the Alzheimer Society of B.C. (ASBC) as the beneficiary on any new registered retirement plans you are purchasing, or by changing the beneficiary on your existing plans to ASBC. Changing your beneficiary does not require a lawyer, but is a simple bit of paperwork that is done through your financial institution/advisor.

Your registered retirement plans can be in the form of a Registered Retirement Savings Plan (RRSP) and/or a Registered Retirement Income Fund (RRIF). When you first purchase your RRSP or RRIF, you are required to write down a beneficiary on the paperwork. Usually, people name their spouse, children, or their estate.

For many Canadians, their spouse may have already predeceased them, they have no heirs, or their heirs are already provided for in other ways. Donating retirement plans to a charity like the ASBC is another way to offset taxes. If you don't leave your registered retirement plan to a spouse or a charity, approximately 50 per cent of the value of your RRSP/RRIF will go to the tax department.

Albert of Surrey is one person who has chosen to change the beneficiary named in his RRIFs from his estate to the ASBC. Though he has children and grandchildren, he says they will be well-provided for in other ways. Donating his RRIF to the ASBC allows him to honour the memory of his wife, who passed away from Alzheimer's disease, and give back to the ASBC, which has helped him in many ways. "If my donation to the Alzheimer Society of B.C. will benefit someone else and the work the Society is doing, then it's a good thing," he says.

Naming the ASBC as the beneficiary of your RRSP/RRIF not only supports the Society's ongoing work, it has many advantages to you, the donor: It allows you to leave a lasting legacy in your name to a cause you believe in. By making ASBC the beneficiary, the funds in your RRSP/RRIF will not go

through your estate. Therefore, probate fees will not need to be paid on the RRSP/RRIF.

When you designate a beneficiary for your RRSP/RRIF, your wishes cannot be contested.

The tax receipt issued by ASBC will be used by your executor to offset final taxes.

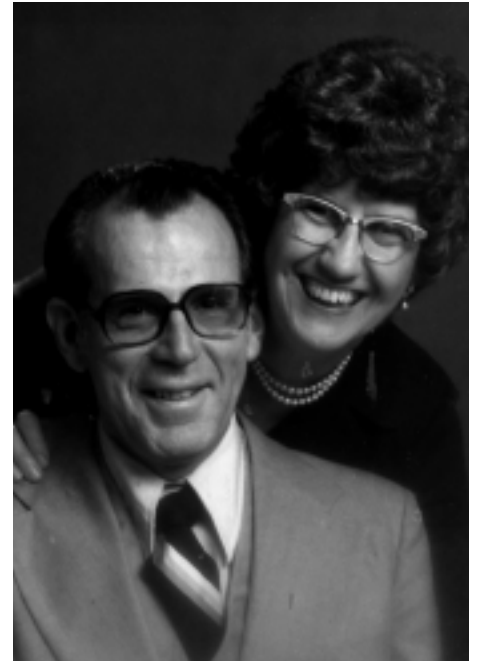
There are many other options, including designating the ASBC as a co-beneficiary or a default beneficiary should something happen to an heir. Please call Yolanda Bouwman (see inset box) for a telephone consultation.

Life Insurance

Another way to leave a legacy is by naming the ASBC as the beneficiary of your life insurance policy, or transferring ownership of the policy to us.

Rather than cancel an "old" policy, consider changing ownership of the policy to the ASBC. Depending on the type of policy you transfer, you may receive an immediate tax receipt. If you don't do this and decide to cancel an "old" policy, then all those years of paying premiums are lost ...only the life insurance company wins. Instead, if you transfer this old policy to the ASBC, you'll know your life insurance policy is being used to help others who are affected by Alzheimer's disease.

Most people purchase life insurance to ensure dependents will be taken care of should something unforeseen happen, says Yolanda Bouwman, Major and Planned Gifts Officer with the Alzheimer Society of B.C. "But has it ever occurred to you that a charity you have supported faithfully for years has become dependent on you as well? When the children are grown and independent, and the mortgage is paid, consider transferring



Ed and Paula Jakeman. Ed passed away from Alzheimer's disease at age 54.

your life insurance policy to that other dependent... the ASBC."

That's the case for Bryan Jakeman of White Rock. As a certified financial planner, he not only advises clients about the benefits of planned giving, he practices it too. Both he and his mother Paula have named the ASBC as the beneficiary of their individual life insurance policies, motivated by the support given to the family when his father, Ed, was diagnosed with Alzheimer's at age 48; he passed away six years later at 54.

"It's a way to make certain there's something in the estate to give back to the Alzheimer Society of B.C.," says Bryan. "Many people who have a desire to give don't always have the means. Transferring a life insurance policy is a way to make a difference."



Hello, my name is Yolanda Bouwman.

I am the Major and Planned Gifts Officer for the Alzheimer Society of B.C. I can help you with information or offer advice about the ASBC's legacy options, like the ones you've read here. I am just one phone call away, and I'm happy to talk to you on the phone or meet you in person. Please feel free to contact me at 604-681-6530, toll-free 1-800-667-3742 or e-mail me at ybouwman@alzheimerbc.org.

Calendar of events

(continued from front)

AUGUST

Ultimate For Alzheimer's

(DTBD) Vancouver, B.C.

A 24-hour exciting game of Ultimate. For info, contact Karen Koch at 604-681-6530 or toll-free at 1-800-667-3742.

SEPTEMBER

Coffee Break

Sept. 21 (World Alzheimer's Day)
Various B.C. Locations

The world's largest Coffee Break. For info, contact Karen Koch at 604-681-6530 or toll-free at 1-800-667-3742.

Ascent for Alzheimer's 2005

Team 1, Sep. 19-28
Team 2, Sep. 28-Oct. 7
Tanzania, Africa

Ascent to the summit of Mount Kilimanjaro. Spots still available. For info, contact Linda Forrest at 604-681-6530 or toll-free at 1-800-667-3742.

OCTOBER

Public Forum

Oct. 27 Kelowna, B.C.
"Keeping Your Brain Healthy".

For info, contact the Alzheimer Resource Centre at 250-860-0305 or 1-800-634-3399.

Educational Conference

Oct. 28 Kelowna, B.C.

Conference for health-care workers, family and friends affected by dementia. For info, contact the Alzheimer Resource Centre at 250-860-0305 or 1-800-634-3399.

FALL

Educational Conference

East Kootenay, B.C.

Conference for family caregivers. For info, contact Kern Windwraith at 604-681-6530 (Lower Mainland) or toll-free at 1-800-667-3742.

Summit to the roof of Africa

Ascent for Alzheimer's is a signature fundraising event for the Alzheimer Society of B.C. that takes two teams to the highest summit on the African continent.

In order to be a part of this non-technical climb to the top of Mount Kilimanjaro in Tanzania, Africa, participants raise funds to support the work of the Alzheimer Society of B.C. and pay all their own expenses.

This year, two teams will be trekking to the top. Team One heads up Sept. 19-28, while Team Two goes Sept. 28-Oct. 7. They are led by experienced and professional guides and porters. There are two spots available on Team One.

Janice Cole, who participated in 2004, says: "Ascent for Alzheimer's was the most amazing experience of my life. I was not a hiker or a mountain climber when I signed up, yet I enjoyed every minute of the journey! I encourage you to join Ascent for Alzheimer's team... it is a journey you will never forget."



Ascent for Alzheimer's symbolizes the mountainous journey both those with the disease and their caregivers face on a daily basis. Close to 150 Canadians have participated in this meaningful event in honour and in memory of friends and family who have experienced their own journey through Alzheimer's disease or a related dementia.

For more information about participating in Ascent for Alzheimer's 2005 or a future year, please contact Linda Forrest at 604-681-6530, toll-free at 1-800-667-3742 or e-mail lforrest@alzheimercbc.org.

Help us celebrate 10 years of Coffee Breaks

Wednesday, Sept. 21 marks the 10th anniversary of our annual event, Coffee Break. It's also World Alzheimer's Day. A Coffee Break is a hosted gathering where friends, neighbours, customers and co-workers have a coffee and make a donation to the Alzheimer Society.

Coffee Breaks now take place in communities across Canada. Last year, donations from every cup of coffee raised more than \$100,000 in B.C. alone. This money was used to fund services and programs to help people whose lives are affected by Alzheimer's disease or a related dementia.

Now we need your help to take Coffee Break to the next level, and help us celebrate the event's 10th year. We are looking for energetic and enthusiastic volunteers to coordinate Coffee Breaks in communities across B.C. by recruiting and supporting local Coffee Break hosts.

If you have a bit of spare time and want to join in to make Coffee Break an incredible fundraising event, or if you just want more information to help you decide, please contact Karen Koch toll-free 1-800-667-3742 or e-mail her at kkoch@alzheimercbc.org.



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OF BRITISH COLUMBIA

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