

TWENTY-FIVE
YEARS
of MEMORIES
1981-2006

HELP FOR TODAY, HOPE FOR TOMORROW

Alzheimer *Society*
BRITISH COLUMBIA

ACKNOWLEDGEMENTS

The Alzheimer Society of B.C. wishes to extend grateful acknowledgement and thanks to the hundreds of volunteers, supporters and donors, and staff (past and present) who have all had a part in helping form and build the Society into the organization it is today.

While this 25-year retrospective is unable to name or acknowledge every person who had an impact on the Society, we sincerely hope everyone will accept our heartfelt appreciation and recognition.

Preparing our history proved quite challenging, especially since the Society has moved several times and many historical records have been lost. Instead, we became reliant on old newsletters, annual reports and a few interviews to piece together our history.

SPECIAL ACKNOWLEDGEMENT GOES TO:

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MISSION STATEMENT

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



VISION STATEMENT

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



THE ALZHEIMER LANDSCAPE IS CHANGING

*Rosemary Rawnsley is the Executive Director of
the Alzheimer Society of B.C.*

Celebrating 25 years as an organization means we have reached a milestone. The story that you'll read in these pages outlines the progress we've made in our mission to support those impacted by Alzheimer's disease. The achievements have been significant, made possible by the support of dedicated volunteers, donors and staff.

Our history also shows how important it is to change with the times. In recent years, as a result of earlier diagnosis and changes in attitudes, we have been able to expand our services by providing support to people who are in the early stages of the disease. That ability to have direct input from those affected, plus the opportunity to involve them in the activities of the Society, has enriched our work significantly.

We have reached another milestone – the point where the Alzheimer landscape is changing. There is real hope and progress, not only in the field of research but also in the support services and education programs available. There is also a growing realization of the significant impact Alzheimer's disease and related dementias will have in the next years. That is evident through increased interest from the government and the health

authorities, and we are partnering with them to bring about positive changes.

Furthermore, the Alzheimer Society of B.C.'s Board of Directors has approved a plan to reach out to people earlier in the process (early intervention). We know that moving in this direction will provide opportunities for better planning and support for those affected. This move will also call for a more proactive approach for those who have been diagnosed, along with a greater partnership with the medical and support community. We will also be reaching out to more people through a TV partnership with the Knowledge Network. We will be ensuring that people can access accurate information from us on brain health. As well, we are committed as an organization to ensuring that individuals are celebrated for their lives as a whole.

It is valuable to look back, acknowledge and celebrate what has taken place in the last 25 years. It is equally critical to build on our foundation and recognize the challenges we will face as the incidence and impact of dementia increases.

We at the Alzheimer Society of B.C. look forward to your support in this important time of change.



BE A PART OF OUR FUTURE HISTORY

Nicole Bertrand has been a volunteer with the Alzheimer Society of B.C. for more than four years. She currently serves on the Board of Directors.

On behalf of the Board of Directors of the Alzheimer Society of B.C., I would like to extend our utmost gratitude to all the volunteers who have dedicated their time and effort over the last 25 years – from those who helped create the Society and lay its foundation, to those who helped build it into the entity it is today, and will become tomorrow.

The passion and devotion of staff and volunteers past and present have enabled us to offer help today to those that are impacted by Alzheimer's disease or a related dementia, and to bring hope for tomorrow by keeping alive our vision of a world without this disease. The good news is that we know so much more than we did 25 years ago, and there is greater hope for people impacted by the disease.

I first became involved with the Alzheimer Society as a user of its services after my mother was diagnosed with Alzheimer's disease. Now, as a volunteer, I want to make a difference and make sure I do everything in my power to keep the Alzheimer Society strong and viable so that anyone who has to face the Alzheimer journey can, like me, turn to their local Alzheimer Society office for support, help, education and information.

Being a volunteer is gratifying, rewarding and fulfilling. And yes, it can be demanding and time consuming. But the return can be incredible – as it has been for me.

As we salute our past and present volunteers, we need to look towards the future. To deliver on our promise to support, educate, advocate, raise awareness and funds for research, we need even more passionate people with the desire to make a difference. I invite you to join us, to be a part of our future history by becoming a volunteer, or renew your commitment to your volunteer work with the Society.

And if you can't give your time, then please give generously by making a donation to the Alzheimer Society of B.C. Money raised supports local community programs and services provided by the Society, and funds important research to help find the causes and the cure.

Thank you volunteers, thank you staff, thank you Alzheimer Society of B.C. The passion and ability to make a difference is truly within each and every one of us!





Phyllis Forsythe of North Vancouver was one of the founders of the Society and served as its first official President. She cared for her husband who was diagnosed with Alzheimer's disease.

FOR 25 YEARS, THE ALZHEIMER SOCIETY OF B.C. has played an important role in the lives of people with Alzheimer's disease, their families and caregivers. From humble roots starting off in a North Vancouver home, the Society has grown tremendously over the years and has blossomed into an organization active in communities across the province. Staying true to its goals, the Society continues to provide help for today and hope for tomorrow to those whose lives have been impacted by dementia.

THE GRASSROOTS

In 1978, a group of caregivers held meetings at a North Vancouver home. Facing the responsibility of caring for a family member diagnosed with Alzheimer's disease, the caregivers found it a good venue to share the stresses and challenges they faced daily.

Over the years, as they shared their experiences, the group realized there was a lack of information and support available in the province.

In February 1981, they formed a volunteer steering committee and met to initiate the process of establishing a formal association to provide support to Alzheimer caregivers. These volunteers, many of whom travelled around the province encouraging others to form their own support group, played an integral role in the Society's formation.

Finally, on November 17th, 1981, the Society was incorporated as a non-profit organization and named the Alzheimer Support Association of B.C.

Phyllis Forsythe, a resident of North Vancouver whose husband was diagnosed with Alzheimer's disease, served as the first President. At one time, Phyllis described life after her

husband's diagnosis as a nightmare. "My family's story is not unique," she wrote in 1982 in correspondence to members of the Alzheimer Support Association of B.C. "It is representative of the intense agony and the immense catastrophe that strikes the victim of dementing illness and their families."

Phyllis was joined by Barbara Rolls of Victoria as first Vice-President, Sara Searl of Vancouver as second Vice-President, and Brenda J. Clarke from Vancouver as Treasurer.

Under the Board of Directors' guidance, the newly formed organization was active in reaching out to the public. Conferences featuring prominent researchers like Dr. Mel Ball (who is active in neurology research at the University of California, Davis) were organized. The Society was also invited to take part in health fairs held in the Lower Mainland to impart information on Alzheimer's disease. The Lieutenant Governor, Sir Henry Pybus Bell-Irving, contributed to the effort by proclaiming November 24th, 1982, as Alzheimer's Awareness Day in British Columbia.

LOCAL, PROVINCIAL, AND NATIONAL

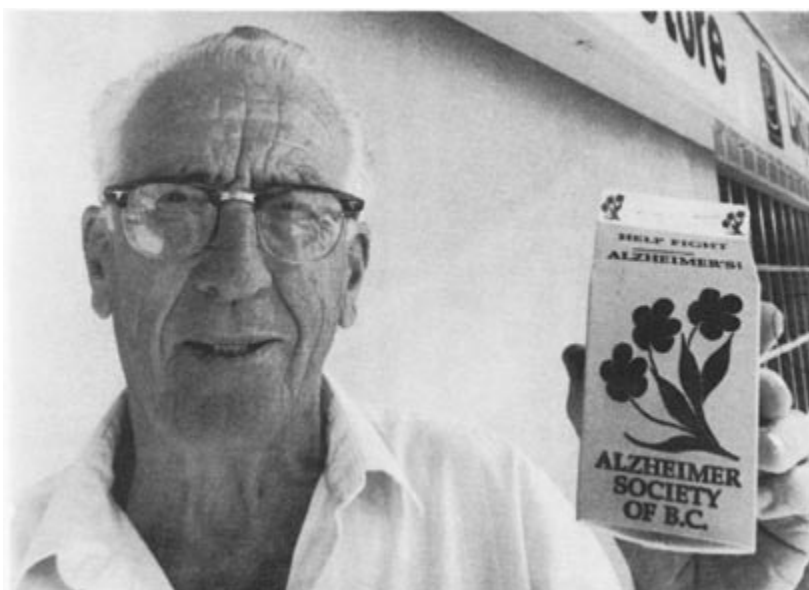
Over the years, many independent support groups across the province were invited to formally affiliate with the Alzheimer Support Association. In February 1984, the Society established a provincial office in Vancouver.

"By putting the association on a more business-like footing, we are now beginning to attain our purposes: support of caregivers, education and fundraising for research," wrote Johannes van den Hooven (President from 1984 to 1985) in the Society's newsletter.

In October 1984, Nancy Hable was hired to work out of the new provincial office. She was the first staff hired by the Society



Paul Olson, (left) manager of LaFarge Cement Ltd., Nanaimo, and volunteers Gloria Sommerville (centre) and Don Davies (right) stand in front of an Alzheimer Society promotional message (1997).



Jack Inkster, a member of the Langley Support Group, poses with a coin box placed in government liquor stores throughout B.C. in August 1991. The donations were used to provide daycare for Alzheimer patients while their caregivers attended one of the Society's educational workshops.

and was the organization's only staff person for three years.

"When I first started, it was incredibly challenging," Nancy recalled. "We had a tiny office but a ton of volunteers came in regularly." The dedicated volunteers contributed greatly to the Society's work and growth. With their assistance, Nancy was able to coordinate office activities to better fulfill the Society's mandate building on the four guiding pillars of support, education, advocacy, and research.

At the same time, more and more caregivers and other volunteers took the initiative to form support groups in their communities. The number of support groups affiliated with the Society across the province tripled from seven in 1982 to twenty-one in 1984.

Volunteers from the New Westminster Support Group demonstrated their dedication by holding what was called a Tag Day. On that day, volunteers armed with brochures went to shopping centres in Burnaby and asked the public to donate money in exchange for a button. The event raised a total of \$2,052.

In addition to expanding within B.C., in 1985 the Society began looking at affiliating with the national Alzheimer Society of Canada. The Alzheimer Society of Canada, the first organization of its kind in the world, was incorporated federally in 1978.

"It is apparent to us all that more can be accomplished for the victims of Alzheimer's disease and their families if we all work together," wrote Johannes in the Society's newsletter in 1985.

A series of meetings started the process, and the Boards of Directors from the two Societies worked diligently toward uniting the National and B.C. Society.

The year 1986 marked the fifth year of the Society's operation; it also marked great changes. After an extended period of searching for an office space that would allow the Society to provide more services to the community, a location was found at 1090 West 8th Avenue in Vancouver.

Marguerite Ford, a former medical librarian who had served as councillor to the City of Vancouver for a decade, was hired as the Society's first Executive Director later in 1987.

A NATIONALLY UNITED FRONT

In April 1986, the Alzheimer Support Association of B.C. legally changed its name to the current Alzheimer Society of B.C. The new name more accurately reflected the values and goals of the Society: not only was there a commitment to provide support, but also research, education, and advocacy were equally valued. Moreover, the name change was the provincial Society's first step to demonstrate the closer relationship with the Alzheimer Society of Canada.

Though the process of uniting the National and the B.C. societies was met with many challenges, representatives on both sides continued their work to connect the organizations throughout much of 1986.

In 1987, the Alzheimer Society of Canada and the Alzheimer Society of B.C. entered into a formal affiliation. The linkage brought the B.C. Society greater access to information, reading materials and advocacy. More importantly, it strengthened the work of the Alzheimer Society both nationally and internationally.

"We all stand to benefit from [the affiliation], especially if we want to make the point to Canada that we are a united front in our fight against Alzheimer's disease," said Kevin Keefe, then

Local dignitaries join members of the Alzheimer Society in celebrating the official opening of the Abbotsford Alzheimer Information Centre in January 1995.



Gordon Campbell, then Mayor of Vancouver, cuts the red ribbon on June 15, 1989 to officially open the Alzheimer Society of B.C.'s office in the Waterfront Station. Holding the ribbon are Dr. Patrick McGeer, Society President Jack McKeown, and past president Lanny Slade.

President of the Alzheimer Society of Canada.

In 1988, the Alzheimer Society of B.C. received funding from the Woodward Foundation and a New Horizons Grant from the federal government to establish an information and support centre. The funding was directed to support the Society's effort in recruiting, training, and coordinating volunteers to answer questions and offer support to those diagnosed with Alzheimer's disease and their families. The new support centre also housed a small resource library started by medical librarians and managed by volunteers. People were encouraged to borrow the audio, visual, and print materials.

STARTING THE YEAR OFF RIGHT

At the official opening of the support centre in January 1988, Gordon Campbell, then Mayor of Vancouver, took the opportunity to proclaim January as Alzheimer's Awareness Month as part of a national Alzheimer campaign. The awareness campaign's shift from November to January proved to be highly beneficial, as the Society's message reached more people with increased media coverage.

"It is important that the Society maintain a high profile in the community so that our services are known to the people who need them," said Executive Director Marguerite Ford in the Society's 1988 newsletter.

Dedicated volunteers across the province added to the effort by manning information desks and booths in hospitals, shopping centres and malls during the month of January

As the demand for information about Alzheimer's disease and related dementias increased, the Society decided to meet the need by hiring a support and education coordinator in 1989.

Linda Knight, the first person to take on the challenge, joined the Society to coordinate support and provide resources to educate the public about the disease.

By developing the position of a Support and Education Coordinator, the Society was able to improve awareness about Alzheimer's disease, the impact of the disease on individuals and ways to help.

Meanwhile, the Society continued to extend services to more communities in the province. In 1990, the first Regional Resource Centre planned and organized by the provincial Society was established in Langley based on the model of the Victoria Resource Centre (which was started by the Society's Victoria-based support group).

The resource centre provided information and resources about other local health agencies and services to people diagnosed with the disease, their families and caregivers. The new resource centre supplemented the support services from the provincial office by having volunteers and staff from the local community provide one-to-one help, both over the telephone and in person.

The Society soon realized that it needed to develop some key fundraising events in order to raise crucial funds to support its work, and to raise public awareness.

In January 1988, the Alzheimer Society of B.C. launched the first "Forget-me-not Ball," a gala fundraiser of the year with dinner, dancing and an auction. Up until 1994, the "Forget-me-not Ball" was the Society's major fundraising initiative.

Two of the Society's signature fundraising events – the Forget Me Not Golf Tournament and the Longest Day Walk/Run were inaugurated in 1995.

More than 50 businesses supported the first golf tournament held in Surrey. Under a wonderfully blue sky, 166 golfers

attended the event on May 25, 1995, raising a net total of \$171,000. After 10 years, the tournament is now a nationally renowned fundraising event and has raised \$3 million.

On June 23, the “official” longest day of 1995, more than 1,925 runners and walkers participated in the first Longest Day Walk/Run that took place at the University of B.C. in Vancouver, resulting in \$25,000. This event was made possible with the assistance of approximately 100 volunteers.

The Alzheimer Society of Canada launched the first national fundraising event, Coffee Break, on Sept. 20, 1996. In B.C., 550 people were recruited to host tea or coffee parties at their homes or offices and collect donations on the Society’s behalf. Approximately \$20,000 was raised in the first year; in 2004 that number had increased to \$113,000. Coffee Break celebrated its 10th anniversary in 2005.

Two years later in 1998, the Alzheimer Society of B.C. created another major fundraising event: Ascent for Alzheimer’s – the Mount Kilimanjaro Climb. A team of participants took on the challenge of fundraising for the Society and then travelled to Tanzania, Africa, to hike Africa’s highest mountain. The trek to the summit was reflective of the daily mountainous struggles faced by persons affected by the disease. Each climber raised \$5,000 for the Society before they set off for Tanzania. Eight committed participants, including Ian Ross, the Society’s Executive Director from 1990 to 2001, were the first to reach the summit on August 29, 1998. They raised over \$70,000 in the first year.

Since its inauguration year, many notable dignitaries have participated in Ascent for Alzheimer’s including Gordon Campbell, Premier of British Columbia (then Opposition Leader), and his family in 1999.

Recognizing its grassroots and the fact that so much of the Society's success was a result of volunteer support, the Alzheimer Society established four awards to recognize volunteers: The Twigg White Award established in 1992, the Clyde and Lanny Slade Leadership Award started in 1998, the Mike Crowe Award of Hope launched in 1999, and the Lola Turik Community Service Award inaugurated in 2004.

The years 1997 – 1998 marked a first for the Society: the establishment of support and education programs for people in the early stages of Alzheimer's disease. The South Okanagan/Similkameen region offered a 10-week program, and the South & Upper Fraser Valley started a support group, based in Langley. Up until then, the Society had traditionally focused on supporting caregivers. The Society continues to develop support groups for people with dementia and caregivers across B.C.

The year 2000 was one of the Society's most successful in educating the public about Alzheimer's disease and the support available. On May 19, 2000, the Society was awarded the British Columbia Association of Broadcasters Humanity Award, which honoured an organization whose services to the public would be greatly benefited by a sponsored media campaign.

The Society was awarded the broadcast of a year-long campaign with an estimated worth between \$3 to \$5 million. The result was a television commercial titled, *Wedding Vows*, in which a couple pledged their love and devotion to each other for life, even when impacted by Alzheimer's disease.

THE STORY IS CHANGING

"We couldn't do what we do now without the building blocks of what volunteers and staff did to help form the Society," said Rosemary Rawnsley, the Society's Executive Director since 2001.

As the number of people affected by Alzheimer's disease and dementia continues to increase, Rawnsley said the Society is determined to build on the work that was started twenty-five years ago and continue to provide much needed services to people whose lives have been impacted by Alzheimer's disease and related dementias.

Under the Board of Directors' leadership, the Alzheimer Society of B.C. was the first in the nation to actively involve people with the disease when Elaine Wright joined the Board in 2002. Elaine has early stage Alzheimer's disease.

"My being part of the Board of Directors recognizes that having dementia doesn't preclude you from being active in family life and the community," Elaine said. "Having a person with dementia on the Board teaches others how to best support people with Alzheimer's and their families."

With advances in technology, the Society began to reach out to more rural communities. In July 2003, the Society completely revamped and relaunched its Web site at www.alzheimerbc.org. Through the Web site, the public may easily access information on Alzheimer's disease, resources, events in the community, and newsletters produced by the Society.

From a grassroots, volunteer-run association, the Society has expanded to a well-structured organization that ensures people whose lives are affected by dementia are connected to a community of information, services and support.

Still, much work is left to be done. Each year, about 14,000 people will develop Alzheimer's disease or a related dementia in British Columbia.

"The Society has to keep changing. We have to grow," said Rawnsley, stressing that ultimately the Society's vision is to create a world without Alzheimer's disease.

ASBC TIMELINE - AT A GLANCE

- 1978 · A group of caregivers meet regularly and hold meetings at a home in North Vancouver to share the stresses and challenges of caring for a person diagnosed with Alzheimer's disease.

- 1981 · The caregivers form a Steering Committee that meets to initiate the process of developing an official support society.
 - The Alzheimer Support Association of B.C. incorporates on November 17.

- 1982 · B.C. Lieutenant Governor Sir Henry Pybus Bell-Irving proclaims the first Alzheimer's Awareness Day on November 24.

- 1984 · The Alzheimer Support Association of B.C. establishes a provincial office located on Granville Street in Vancouver
 - Nancy Hable, the first staff person, is hired. Twenty-two years later (2006), she is still working with the Alzheimer Society.
 - The first conference on Alzheimer's disease is held in British Columbia.

- 1985 · The Alzheimer Society of Canada and B.C. start discussions to form an affiliation.



Vivian Lam (left), Support & Education Coordinator of the Society's Chinese Resource Centre, stands with Pui-Man Li and Lydia Yan beside one of the Society's Chinese-language displays (1995).

- 1986 · A special resolution passes at the Annual General Meeting to change the organization's name from the Alzheimer Support Association of B.C. to the Alzheimer Society of B.C. (ASBC).
- The Society moves to a new office on West 8th Avenue in Vancouver.
- 1987 · The ASBC forms a committee focusing on advocacy.
- The ASBC enters into a formal affiliation with the Alzheimer Society of Canada.
- 1988 · The ASBC establishes a provincial Information and Support Centre.
- Alzheimer Awareness Month shifts from November to January.

- 1989 · The Society moves to a new provincial office at Waterfront Station in Vancouver. Mayor Gordon Campbell is the keynote guest at the ribbon-cutting ceremony.
- 1990 · The first regional resource centre under the ASBC umbrella opens in Langley based on the model of the Victoria Resource Centre (which was started by the Society's Victoria support group).
- 1992 · The Twigg White Award of Merit, the Society's first award to recognize volunteers, is given to its first recipient, Helen Wilson, past president of the Society.
- 1995 · The first ever Forget Me Not Golf Tournament tees off in Surrey, eventually becoming one of Canada's most successful charitable golf tournaments.
 - The first Longest Day Walk/Run fundraising event begins. British Columbians across the province raise funds and awareness of Alzheimer's disease and the Society. This event eventually changes into the existing Walk for Memories.
 - The nationwide Alzheimer Wandering Registry starts. This program, now called Safely Home, helps police find people with dementia who wander, and assists in a safe return home. In B.C., Safely Home is enhanced with the B.C. Photo Registry web-based database.
- 1996 · Inauguration of Coffee Break, an event in which volunteers hold coffee breaks at their homes or offices and collect donations on the Society's behalf. Ten years later, it's still brewing strong.

- 1997 – · First support and education groups for people in the early stage of Alzheimer’s disease start in the South Okanagan and the Fraser Valley.
- 1998 · Ascent for Alzheimer’s is launched. Participants fundraise for the Society and then travel to Tanzania, Africa, to tackle Africa’s Mount Kilimanjaro as a way to symbolize the mountainous struggle faced by those impacted by the disease. Ascent becomes a key signature event for the Society.
- 2000 · ASBC receives the British Columbia Association of Broadcasters Humanity Award which awards a year-long broadcast campaign worth an estimated \$3 to 5 million.
- 2002 · The ASBC moves the Provincial Office to its current location on West 8th Avenue in Vancouver.
- Elaine Wright is invited to join the Society as a director, and is the first person with Alzheimer’s disease to sit on an Alzheimer Society Board of Directors.
- 2005 · The Society launches a two-year Campaign of Hope Year One: The Story is Changing.
- 2006 · Year Two: Research – 100 years of discovery.
- The 100th anniversary since Dr. Alois Alzheimer described the symptoms of the disease that now bears his name.
 - The 25th anniversary of the Society’s establishment in British Columbia.

CELEBRATING *our* 25th ANNIVERSARY

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