DASN International

The Dementia Advocacy and Support Network

We believe that shared **knowledge** is **empowerment**

We believe that our strengths provide a **supportive network**

We are **autonomous** and **competent** people

We are **a voice** and a **helping hand**

www.dasninternational.org

Alzheimer's Disease International

MAREP

Supported by ADI and MAREP

The Dementia Advocacy and Support Network (DASN) was opened on the Yahoo website on 8 November 2000 by Lorraine Smith, for people with early-stage dementia and their care partners. She registered it as a non-profit organisation in Montana. Its first annual meeting was held on 6 October 2000, during the Heartland Memory Walk in Kansas. The second annual meeting was held in Montana in June 2001, and 12 of the then 82 members attended in person, while others kept in touch by email and in chat. DASN International was formed and a new website **www.DASNInternational.org** was developed. Of those 12 people that met in Montana, 11 are still active and in contact.

The Montana meeting set the scene for changes in Alzheimer's Disease International by putting a proposal to ADI in July 2001 for greater recognition of the needs of people with dementia and their care-partners. From this emerged a suggestion that people get together at the forthcoming ADI conference in New Zealand to look at ways in which the Alzheimer's movement might become more inclusive of people with dementia.

The October 2001 ADI conference in Christchurch, New Zealand, was an extraordinary event because of the input of people with dementia. Christine Bryden, from Australia, gave the opening plenary presentation. She was the first person in the world with a diagnosis of dementia to present at a major international conference. This was the first time people with dementia attended the international conference as full participants. Twelve people came from Canada, United States, Australia and New Zealand – amazingly most were able to contribute personal profiles for a 10-year update. Their contributions made the conference an amazingly challenging and inspirational event - for conference delegates and the wider public.

People with dementia showed irrefutably that not only does life continue after diagnosis but also that people with dementia have much to offer the dementia movement.

People with dementia participated throughout the conference, from the delivery of a standing-ovation opening address to oral presentations, running workshops and media interviews. The DASNI booth was a magnet in the exhibitors' hall, and its brochures were in high demand and quickly became "collectors' items" for the delegates.

A group of people with dementia (all members of DASNI) and Alzheimer's Disease International (ADI) executive and staff was formed at this conference to work through strategies for Alzheimer's associations around the world to be more inclusive of people with dementia. The ADI conference in Barcelona in October 2002 was the second milestone of change for people with dementia. Peter Ashley gave an inspiring presentation on living with, not dying from, dementia. For the second year running, he too got a standing ovation.

Ashley was also the only person with dementia on the executive or board of a national Alzheimer's association, so he drew on his personal experience to give invaluable assistance to the working group on factors that could affect a governance role.

The Council decided to seek ways to increase the participation of people with dementia in ADI itself through a joint DASNI/ADI working group. This recommended that up to two people with dementia be elected on to the Board of ADI.

The working group's recommendations were approved in principle by the ADI Council at the 2003 Dominican Republic conference, when a member of DASNI, Christine Bryden, was nominated by her member country, Australia, for a Board vacancy. It was a great thrill for her to hear her name announced after the votes were counted. Since 2010 Lynda Hogg of Scotland has been the elected person with dementia on the ADI Board.

The inclusion of people with dementia on the Board of ADI is a gigantic step forward - a step that was once thought impossible. Credit for this turnaround goes to members of DASNI and other active campaigners with dementia who have worked hard to be recognised within the Alzheimer's movement.

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DASNI Founders - Personal Profiles

Some remarkable people with dementia made a huge difference 10 years ago: they got together on the internet, and gathered in Montana USA. Then they took their concerns to ADI, and made a big impact at the ADI conference in Christchurch in October 2001. They are all still here, except one person who attended the Montana gathering but has sadly since passed away.

We call our story of surviving and thriving: the “DASNI Effect”. Through our advocacy efforts, and our support for each other, we were empowering ourselves. We did not anticipate how great the DASNI effect would be back in 2001, and that many of us would still be functioning at a high level today. But by being proactive in seeking social justice, and being active supporters of each other, we experienced a strong rehabilitative effect.

From reading these profiles you will see that we are all still very active and engaged with life, many are still advocating for people with dementia, and all are thriving, by not buying into the medical message of: ‘set your affairs in order, and go home to die’.

Peter Ashley, UK

As a graduate in computing and mathematics I was formerly Group Technical Director of a public computer graphics and communications company and have worked all over the world. After 3 years illness I was diagnosed with Dementia with Lewy Bodies in 2000 and started in the dementia movement in 2001.

In 2002 I became a Trustee of the UK Alzheimer’s Society and also joined the Dementia Advocacy and Support Network International (DASNI) **www.dasninternational.org**, as their first UK representative.

At the ADI Barcelona conference in 2002 I became the 2nd person with dementia anywhere in the world, following in the footsteps of Christine Bryden in 2001, to give a plenary presentation on “Living with Dementia”; I again gave another plenary in 2010 at the ADI conference in Thessaloniki, Greece.

I am a regular speaker in the UK and abroad on all mental health subjects but especially dementia.

In 2010 I was awarded an Honorary Masters from the University of Worcester for my work in the dementia movement. I now sit on their steering group for their Association for Dementia Studies.

Working with my international friends within DASNI has been a pleasure, fostering a broader understanding of the many dementia conditions that exist. It unites all of us living with dementia and enables mutual support. Lifelong friendships have been established all over the world and I have an extra special set of friends who live in New Zealand to whom I write and speak regularly; you can’t get much further away than that.

DASNI members are able to communicate by email every day either on a one to one basis or through our common bulletin email system. We go online for chats in our ‘Chat Room’, a virtual meeting room. With an increasing number of exhibitions and conferences worldwide a small number of us meet up from time to time. Funding is always a problem to attend such events but through the generosity of Societies and Associations along with pharmaceutical companies and others this is sometimes possible, usually our respective partners, our care family come along as well.

I have found working with academics highly rewarding and they have welcomed me always without question. Many have become firm friends and I’ve learned greatly from them about all aspects of the dementia condition.

At the time of my diagnosis a prognosis of 6 years was given, it is now 10 years and I’m still doing well.

I firmly believe that through working hard in the dementia movement I have offset the decline that normally takes place in people with any form of dementia, this, supported by a marvellous wife Ann and my children and grand children along with my international family of friends, have made a rewarding life – long may it continue.

Christine Bryden, Australia

I was a senior civil servant advising the Australian Prime Minister on science and technology, before being diagnosed with dementia in 1995. I attended the first meeting of DASNI in Montana, June 2001, then went to London to meet with ADI to seek inclusion of people with dementia.

I gave a plenary address to the ADI conference in Christchurch September 2001, with the support of my friends in DASNI. Since then, I have spoken at ADI conferences in Santo Domingo 2003, Kyoto 2004, Istanbul 2005 and Berlin 2006. Elected to the Board of Alzheimer’s Disease International in 2003, I stepped down in 2005.

I toured a number of ADI member countries in 2003, speaking in India, Israel, South Africa, France, Brazil, Taiwan and Japan. It was in that year I joined with professionals in Japan to change the culture of care and inclusion of people with dementia. This included appearances in print and TV media, including NHK documentaries, which have resulted in significant change.

The Japanese publisher of my first book (‘Who will I be when I die?’ HarperCollins 1998) commissioned the second book, which was released at the Kyoto conference in 2004. This was then published in English by Jessica Kingsley Publishers (‘Dancing with Dementia’, 2005). It has now been translated into Chinese and German.

My pace of life has slowed significantly since Berlin 2006, although I did speak in Sapporo in 2007, and in Australia in 2009 and 2010. I now delight in two grandchildren, and in doing new activities such as vegetable growing, and have seen one of our daughters married! All things I did not think I would live to see when diagnosed at the age of 46 back in 1995. Now aged 62, dementia seems more appropriate, and less alarming, as I enjoy life in the slow lane. I continue to rely on my dear husband Paul for continued care and support, and hope to be able to participate in ADI in the coming years.

For more information see my website **www.christinebryden.com**

Morris Friedell, USA

I’m 70. I have two children and seven grandchildren. I’m a retired sociology professor.

In 1998 disturbing weaknesses in following conversations, remembering and problem-solving led me to get a “working diagnosis” of early Alzheimer’s disease. That made me think of emulating Viktor Frankl. As David Shenk wrote in The Forgetting: “Before being taken prisoner by the Nazis, Frankl wrote extensively about the human ability to retain dignity under extreme conditions. Then, in the concentration camp, he faced the ultimate personal test of his own ideas. Now, after years of studying him, Morris was echoing Frankl’s life. In the freezing, foodless, lice-ridden barracks of Auschwitz, Frankl survived and maintained his dignity. Morris wondered if he could do the same as he was thrown into the dark cave of forgetting.”

My second career became “dementia activist,” and I was a co-founder of DASNI.

DASNI Founders - Personal Profiles continued

Now, twelve years later, my mind works slowly and is easily overloaded and fatigued by complex interaction with the environment in real-time (games, conversation, etc.). This is consistent with the bitemporal hypometabolism in my brain PET, but it is not certain whether pathology is present, or whether the possible pathology is Alzheimer's or microvascular.

Regardless, my work and that of others has affirmed that the lessons learned from spiritual resistance to the Holocaust by persons like Frankl apply as well to the trauma of dementing disease. The Nazis' idolization of biology has again been found wrong.

For more of my story visit **www.morrisfriedell.com.**

Alan Gibb, New Zealand

Alan Gibb, 77 Y.O., retired at 60 in 1993, 42 years in the electricity design industry. Married to Gwynneth with a "pigeon pair". Diagnosed in 2000 with "probable" Fronto-Temporal Dementia after disturbing changes in short-term memory recall, depression and emotions.

I joined the local Wellington Branch of the New Zealand Alzheimers Association which not only served the needs of carers but was also a pioneer of the inclusion of Persons With Dementia in their activities. Here, taking part in an "early diagnosis" support group I learnt about the internet support group DASNI and the ADI Conference to take place in Christchurch in 2001.

Rashly, I said "If they want to know something about Dementia they are asking the wrong people".

This challenge resulted in an invitation to present a paper, "Life and Living with Dementia", two forums and advocating what I have come to believe; that with the appropriate medications, behavioural strategies and intimate support, many of us are able to give significant insight into this affliction and to support each other.

Thus began a journey in which I met many wonderful people and received wonderful care and support from family, close friends, DASNI internet friends, (many of whom I have been able to meet) and the very forward-looking and inclusive N.Z. Alz. Ass'n.

Recently at the 2010 N.Z. Alz. Ass'n Wellington Annual Conference I was privileged to take part in a Discussion Panel which included Richard Taylor, Ph.D., also of DASNI.

Now, my life revolves around contact with family, near and far, keeping physically and mentally fit, agile and active. I gym and swim 3 days a week, walk most days, do Sudoku and word puzzles daily and enjoy the computer and metal and wood work.

As the stresses and strains of my care rose I moved to a flat attached to rest-home. Now instead of going there for respite care, we now phone daily and visit other each once or twice a week for a more agreeable "respite".

Phil Hardt, USA

Phil Hardt was diagnosed with Huntington's Disease (HD) Dementia in 1997 while working for AlliedSignal Aerospace, Aircraft Engines Division. I still remember fondly Montana and the beginnings of DASNI, doing the incorporation for it, and the privilege serving as President for it.

Since our humble beginnings I branched off and advocate strongly for those with HD, being proactive in my own treatment and helping others with HD or who are at risk.

I was chosen as the Huntington's Disease Society of America's (HDSA) 2001 Person of the Year and was the past Executive Director of the HDSA Arizona Affiliate and Director of their Annual HD and Juvenile HD Retreats for 8 years.

I was one of six persons who had the privilege of testifying about HD in front of the National Institute of Health's committee on Genetic Discrimination in October 2004. My testimony was picked up by Senator Ted Kennedy and other Congressmen, used as examples on the Senate and House Floors and was part of the reason why GINA got passed! I spend 40-50 hours per week getting people with HD off the streets, out of jail, and onto benefits and into safe places to live.

I have developed guidelines to help thousands of people with HD to successfully apply for Social Security Disability on the first go round. I also had the privilege of organizing three humanitarian trips to Colombia, South America where I was able to connect homes of those with HD to running water, electricity, provide them medications, clothing, pigs and chickens, and also provide them with the first information on HD they had ever received.

I have written dozens of articles to help educate and encourage those with HD on how to live positively with HD. You can contact me at **phardt1@cox.net** or **+1 602-309-3118**.

Candy Harrison, USA

I was a Physician Assistant before my diagnosis in 2001. I'm now getting into my 62nd year. So much has happened since our meeting in Montana.

While I continue to have Mild Cognitive Impairment, I probably no longer face the worsening diagnosis of Alzheimer's Disease.

I continue to take the medications, but addressing a secondary health issue of low oxygen at night, has helped my brain considerably. I believe that there are others out there with memory loss that may also have a mixed diagnosis of sleep apnoea. My issue was a variation due to a central brain injury.

By getting the medications, oxygen at night and staying active, I look forward to a happy and full filling life. I "embrace my limitations" and allow myself to have the down time I need. I continue to work with DASNI and advocate with those newly diagnosed to get proper evaluations. My extensive medical background and personal experience helps with this. I am often amazed with the discussions with the initial members of DASNI, as to how much time has evolved in all of our lives, with great functioning ability yet. By not buying into the 'set your affairs in order, and go home to die', we are thriving. This is the message!

My current activities include Trustee at our local District Hospital, organization and doing the Federal and State Tax program assistance for e-filing taxes for seniors and low income, playing bridge once a week, and other outside activities.

Lynn Jackson, Canada

I was a Registered Nurse and then I went into Sales and Marketing with a Medical Supply company. In 1999 I was diagnosed with the early stages of dementia and became medically retired.

Since retirement I have become a staunch advocate for people with early stage dementia. In June 2001, along with a few people I had met through an online support group called Dementia Advocacy and Support Network, I attended a

DASNI Founders - Personal Profiles continued

2 day meeting we called the "Montana Summit" Later that year I helped co-found Dementia Advocacy and Support Network International (DASNI) **www.dasninternational.org**, an internet based organization by and for those diagnosed with dementia.

In the early days my time was spent corresponding and supporting other people in the DASNI email community. Each evening I would spend an hour in the chat room with others going through the same problems and situations as I found myself in as a person newly diagnosed with dementia. In Vancouver where I live, I founded and co-facilitate an Early Stage Support Group at the Alzheimer Society of B.C.

Between 2002 and 2008 I was on the planning committee for the annual "A Changing Melody Forum" hosted by MAREP that took place in Toronto for people with early stage dementia and their partners in care. Again, this year 2011, I have been on the same planning committee for the International A Changing Melody Forum.

Currently, I am on the Advisory Committee for the Centre for Research on Personhood in Dementia at the University of British Columbia, as well as sitting on the South Fraser Residential and Community Ethics Group.

I have spoken many times locally, nationally and internationally (Spain, Dominican Republic, Japan, Czech Republic, Ireland, Turkey, Germany and the USA) in an effort to promote better diagnosis, access to treatment, and inclusiveness. My particular interest is in breaking the worldwide stigma surrounding a diagnosis of dementia. I have participated in numerous Alzheimer's Disease International working groups helping its member countries become more inclusive of people with dementia.

Lately, I have been trying to spend more time concentrating on "me". For the last 10 years I have made a point to walk every day as I find it is important to keep the blood flowing to the brain. I visit with friends and family, try to keep up with emails and enjoy a slower pace of life.

Jeanne Lee, USA

I was diagnosed in 1995 after a 6 year search for a diagnosis. I have been a member of DASNI since right before our first meeting in Montana. After this came a new world of learning and teaching, a world of keeping in touch through chat and online messages with others in DASNI and even many others. My book "Just Love Me" My Life turned Upside-down by Alzheimer's was published and is doing well. Although not accepted by my own Alzheimer's Association, I have participated in the activities of other associations, including ADI, attending the 2002 Barcelona Conference.

Travels have been some of my blessings: visiting family (including two great-grand-daughters), cruising the Americas, Caribbean, Australia, and New Zealand.

I learned to use the computer after diagnosis and it keeps me alert. I choose to work my brain, help others, be social, eat healthily and have a glass or two of red wine. I am a believer, exercise, meditate and relax; counting my blessing for what a new place in this world this diagnosis has brought me.

I am amazed at what I have accomplished, despite having a slow downhill process. I have tried to convince others that I am the picture of early onset Alzheimer's, but they don't believe me in spite of all the tests. Why can't someone with early Alzheimer's lecture 280 times in a few years so as to help: people not to go through what she went through for 6 years (in and out of mental institutions); care-partners to know what their loved ones need; doctors to see inside their patients better? We live it, we want to stop it, and we have so much to share! I want to set the world straight on living with dementia and not dying of it (as stated by my dear fellow member Peter). Help us search for a cure. My life before and after diagnosis has been published, now I am still standing on my soapbox to see that we get our share of the money allotted for research.

Mary Lockhart, USA

I was diagnosed with dementia in 1995 at age 55. Right out of high school I went to work as a nurse's aide in a nursing home and later I worked in hospitals. In 1980 I opened up my own business working as a licensed day care home for infants. I did that until my diagnosis.

For the last ten years, I have continued the same things I've done for DASNI all along. I host chat each day, admit new members, and continue to blog to maintain a record of my life with Alzheimer's.

My husband and I have both faced a number of worsening health conditions.

For me, a desmoid tumor continues to spread in my foot, limiting my mobility more. I have asthma, possibly COPD, and macular degeneration. Dave's health difficulties have allowed me to take care of him now and then, as well as he has always taken care of me.

Dave and I moved six years ago from Oklahoma City to Piedmont, OK, in order to be nearer to family. I have a grandson with Asperger's there, for whom I wanted to provide more constant support and love. I am pleased to say that he is doing very well now and is successfully employed. We also adopted two new dogs, a Bichon and a Maltese. Until the last few months, Dave and I continued to travel in our motor home, but then we sold it to take a wonderful trip to Hawaii for the celebration of our 50th wedding anniversary.

Over the years, I have been able to visit face-to-face with many DASNI members, including Jan Phillips in Checotah, OK, Jeanne Lee in Hawaii, Ben, Lynne and Tom in Texas, Carole in Missouri, Sandy and Duchess in Ohio, Lynn in Canada and Chip and Sharon Gerber. And, of course, I was able to meet others as well when we had a DASNI reunion at Jan Phillips' KOA campground in Oklahoma several years ago.

My faithfulness, my caring and my ongoing role in encouraging people to stay positive and go on, even when spouses die, has been very satisfying. and those things help me stay active and positive as well as I wait for a cure.

Brian McNaughton, New Zealand

I was a pharmacist, and retired on medical grounds in 1997. I was first introduced to the crazy world of dementia through contact with the local Alzheimer's Association and by the gracious acceptance and understanding of the C.E.O. of Alzheimer's New Zealand.

Contacting DASN on the internet with my brand new computer took away a lot of the loneliness we were experiencing and it was through new overseas friends we came to attend that wonderful ADI conference in Christchurch in September 2001. We knew then we were part of something very special and had lots we could contribute.

This led to being invited to participate in the publishing of 'Remember Me' a small book showing most intimately how it is to live with dementia, profiling several couples and was distributed nationally.

The next highlight for Jean and me was a radio documentary for National Radio entitled 'Silence Speaking.' This was also a most intimate insight into our everyday living guided by a very empathetic interviewer, Helena Ogonawaska Coates. Her documentary received a gold medal award at an international convention. Publicity led to my being asked to speak locally, nationally and to have interviews on radio and in the national press over the ensuing years.

DASNI Founders - Personal Profiles continued

A latent talent for writing was awakened culminating in being asked to present a poster presentation at the ADI conference in Barcelona in 2008 including essays and poems which I entitled 'Writings from a different perspective.'

Changes in the National executive made it harder to keep in contact and over the last two years our lives have taken on a much more domestic profile. Other complicating health issues have also muddied the water.

All in all Jean and I have enjoyed these last ten years and give thanks for those early introductions into the world of dementia. We look forward to this new decade with much more confidence than we had in 2001.

Carole Mulliken, USA

Before dementia, I was an educator, a suicide crisis interventionist and a writer. All involved a desire to help people and to write. After developing dementia, I became unemployable, lived alone in a strange city, and was essentially housebound and clinically depressed. Yet through DASN International involvement, many things in my life slowly took surprisingly happy turns.

Being the DASNI message board's daily "hostess," for eleven years, I offered a constant flow of contributions and built closer member connections.

I also got cognitive therapies few others with dementia receive. Through the Department of Vocational Rehabilitation, I received months of computer-based neuropsychological rehabilitation to improve my attention skills and reaction times. I achieved minor functional improvements, but the insight I developed into how minds (and mine in particular) worked was enormous. Those understandings I have been able to share with DASNI over the years. I organized and led a DASNI reunion in Oklahoma in 2004. Approximately 35 people were able to attend this "family" reunion. A pilot project investigating the utility of neurofeedback in improving memory problems associated with early dementia included me. EEG biofeedback software and equipment were employed as I practiced maintaining proper blood flow to target areas of my brain through neurofeedback.

Rehabilitation gave me the confidence to volunteer with the homeless and then at an animal shelter. After a year I understood these non-profits' organizational needs enough to propose and get real, paid positions. Currently, I maintain the shelter's website and write email newsletters for a distribution list of 4,000. This spring I teach English again, but this time online for a college's distance education program.

My husband died, and then major bypass surgery last December put me in hospital facilities for six months, but my recovery has been nothing short of amazing. Post surgery, my family was told I would never be able to do anything more than move from the bed to a chair, and then only with the assistance of an aide. Yet today, I walk, swim, shop, clean house, see friends, write and help others again. Life is good!

Jan Phillips, USA

Anger and frustration turned to impassioned advocacy for people diagnosed with dementia soon after my diagnosis at the age of 45 in 1995. At that time support, counseling, etc, was only available for caregivers from the Alzheimer's Association in the USA, people with a dementia diagnosis were summarily dismissed after end of life counseling. I was able to find a community of like minded individuals on a web site founded by Laura Smith on the Internet.

Empathetic, forward thinking individuals in the Orange and Los Angeles County Alzheimer's Association also became partners and champions of our cause as early onset dementia patients, they also afforded me many opportunities to speak. Many of their programs were models for communities worldwide. I was honoured to be sponsored by them to represent DASN and the Alzheimer's Association in New Zealand at the ADI conference, and at Public Policy Forums in Washington D.C. With the advocacy of Maureen Regan and David Hyde-Pierce, DASN was promised representation as a seated member on the National Alzheimer's Association board, and they also promoted representation on local boards.

I left Southern California in 2002 to pursue life! Fifteen years after my diagnosis I can proudly say I live for my abilities not my disability. At peace with myself that the online community of (now) DASNI (Dementia Advocacy And Support International) continues on as an incomparable source of support and information and a life-line for those of us continuing on this path. Alzheimer's Associations nationwide here in the USA, and ADI have heard our message and strive to continue to create responsive and caring support world wide.

Lorraine Smith, USA

Since the landmark 2001 conference there have been many changes in my life, some chosen, some not.

An exacerbation of Multiple Scleroses symptoms during the conference necessitated a reassessment of my lifestyle. And DASNI was up and running well in capable hands.

My very near and dear neighbor Morris Friedell was also reassessing his life style and relationships.

As a result both of us departed from cold, windy Montana in June 2002; he for Houston TX and myself for Nashville TN where I had friends. Warmer climes suit us both.

I have been taking Aricept for 12 years but added Namenda about 4 years ago. My particular form of dementia is due to excessive atrophy of the brain, especially of the temporal and frontal lobes. I took 15 mg of Aricept for many years but recently started taking the 23 mg dose of Aricept and find it helpful. The 23 mg dose helps me focus on the meaning of passages I read and facilitates the spontaneous flow of useful thoughts when I occasionally awaken early.

My life is complicated by the mixed blessings of a wheelchair and a Foley catheter.

One sad note; my beloved helper dog Border Collie Roy grew old and died peacefully at age 13 of natural causes last July. I miss him terribly but have 3 cats for companions.

An amazing test of Roy's homing skills came about in 2002 when I took him halfway around the large campground we were staying at in our RV (recreational vehicle) I said "Roy, RV" and he proceeded to lead me to it, not back along the road but straight across the campground, weaving among tents and vehicles to our RV. I treasure this memory.

Overall I feel quite well, my glass is still half full, I talk on the phone, use the internet to Google everything I think of, (chickadees most recently) and use Facebook under my maiden name Lorraine Smith. Find me among Morris' or Christine's friends and say "hello". I'd love to hear from you...

Nothing about us, without us!

Alzheimer's Disease International

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations around the world, in official relations with the World Health Organization. Each member is the national Alzheimer association in their country who support people with dementia and their families. ADI's vision is an improved quality of life for people with dementia and their families throughout the world.

People with dementia are at the heart of ADI's mission and in 2001, encouraged by a visit from Christine Bryden from Australia, ADI set up a people with dementia working group. ADI has since continued to involve people with dementia in a number of their activities and encouraged national Alzheimer associations across the world to do the same. People with dementia have actively taken part in ADI's Alzheimer University, the annual International Conference, advocacy work and, most recently, a seat on the ADI Elected Board has been reserved for a person with dementia.

www.alz.co.uk

Murray Alzheimer Research and Education Program

The Murray Alzheimer Research and Education Program (MAREP) is an innovative program that adopts an authentic partnership approach and integrates research and educational activities in an effort to improve dementia care practices in Canada and beyond.

Housed in the Schlegel-UW Research Institute for Aging in the Faculty of Applied Health Sciences at the University of Waterloo, Canada, MAREP brings persons living with dementia, family members, and a range of professionals together to identify the most pressing priorities and work together to address them. In 2002, MAREP began a strong partnership with the Dementia Advocacy and Support Network International (DASNI) on our A Changing Melody (ACM) project. Since then, DASNI has played a key role in the planning and implementation of five national ACM forums, the development of the ACM tool-kit, and most recently in the planning and implementation of the International ACM forum held in conjunction with the Alzheimer Disease International conference in 2011.

MAREP could not do the work we do without the willingness and support of the members of DASNI, who have contributed so significantly in creating a new face of dementia. Congratulations DASNI for all of your accomplishments!

www.marep.uwaterloo.ca

Supported by ADI and MAREP