Alzheimer's Disease International
The global voice on dementia

June 2014
Volume 24 No. 2

Global Perspective

A newsletter for Alzheimer's Disease International: The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.

29th International Conference of Alzheimer's Disease International

Working together in Puerto Rico

In partnership with Asociación de Alzheimer y Desórdenes Relacionados de Puerto Rico, ADI hosted the 29th International Conference of Alzheimer's Disease International in San Juan 1–4 May 2014

Henry Ostiana and his wife Mireya Ostiana-Wijman from Sint Maarten shared their experiences of living with dementia

John Sandblom from Dementia Alliance International during the *Living with Dementia* session in which stigma was discussed

Hundreds of delegates including people with dementia, professional and family carers, researchers, clinicians, scientists, and staff and volunteers of national Alzheimer associations from around the world united in Puerto Rico's capital to exchange knowledge and experiences and take part in ground-breaking discussions.

This year's theme was *Dementia: Working Together for a Global Solution*. The conference featured plenary sessions on topics such as new technologies, improving care and quality of life, advocacy and risk reduction and prevention. Keynote speakers from around the world presented. A particular highlight was a panel discussion which debated whether or not people should be informed of their risk of developing dementia.

ADI members were provided with several opportunities to participate in sessions before and during the conference, including a Fundraising Alzheimer University and advocacy workshops for ADI associations in the Latin America and Caribbean regions.

These workshops addressed global advocacy actions and work by the WHO in the region as well as the development of national dementia plans. Dr Anselm Hennis, Director of the Department of Noncommunicable Diseases and Mental Health at the Pan American Health Organization (PAHO) joined the group and shared his vision of how ADI and PAHO can work together in the region.

People with dementia played an important role in the conference with a strong delegation from Dementia Alliance International. People with dementia presented in two of the plenaries and several parallel sessions including a session led by people with dementia. Julio Solier, from Puerto Rico, was one of those plenary speakers as well as being a member of the Local Conference Organising Committee.

The G8 Dementia Summit proved an important topic at this year's conference. Delegates were addressed by video by Dr Dennis Gillings, World Dementia Envoy, and Norman Lamb MP, Minister of State for Care and Support in the UK. Gill Ayling from the UK's Department of Health took part in several sessions and meetings with the staff of ADI member associations. The final plenary of the conference looked at the power of advocacy with international dementia experts including Scott Russell, who is living with dementia and recently chaired the Alzheimer's Association Advocacy Forum.

A busy exhibition and a varied poster presentation area brought together local and international delegates to share their new knowledge, network and to make connections, bringing the theme of the conference alive.

Alzheimer's Disease International

The global voice on dementia

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Send us your comments

If you have any comments about or items for the newsletter please contact the Secretariat. Articles for the next issue of *Global Perspective* to arrive by 31 July 2014.

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Editorial

Jacob Roy, Chairman

As we are heading towards our 30th anniversary, there is a lot of enthusiasm and expectation in the air. Suddenly, there are a number of events happening around the globe, most significantly the G8 dementia summit, hosted by the UK government. ADI has come to play a significant role in these events and a number of follow up events are being arranged. We hope this will be followed by a G20 meeting on dementia. There are now enough reasons for us to believe that governments are waking up to face the global challenge of dementia. We at ADI can certainly take credit for our consistent advocacy efforts.

In May we hosted a successful conference in Puerto Rico. Although the numbers were smaller than previous meetings, the active participation of the delegates made all the difference, along with the quality of presentations, representation from the Latin American region, and above all the warm hospitality. It was a special conference of which all of us will carry fond memories.

At the World Health Assembly in Geneva a side event on dementia was organised by the UK government. We had an active role in this and the Global Alzheimer's and Dementia Action Alliance was launched. What we are aiming for is to have a national dementia plan for every country. This is where our member associations have a big role to play.

Volunteers at the 29th International Conference of Alzheimer's Disease International with the conference Local Organising Committee

Events

12 – 17 July 2014
Alzheimer's Association International Conference (AAIC) 2014
Copenhagen, Denmark
Web: www.alz.org/aaic

20 – 22 October 2014
Alzheimer Europe Conference
Glasgow, Scotland
Web: www.alzheimer-europe.org/Conferences

23 – 25 October 2014
The 9th International Conference on Frontotemporal Dementias
Vancouver, Canada
Web: www.ftdvancouver2014.com

7 – 9 November 2014
17th Asia Pacific Regional Conference of Alzheimer's Disease International
New Delhi, India
Web: www.aprc2014-india.com

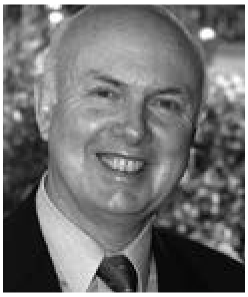
18 – 22 March 2015
The 12th International Conference on Alzheimer's and Parkinson's Diseases
Nice, France
Web: www2.kenes.com/adpd

15 – 18 April 2015
30th Annual International Conference of Alzheimer's Disease International
Perth, Australia
Web: www.adi2015.org

VISIT WWW.ALZ.CO.UK/EVENTS FOR MORE CONFERENCES AND ANNOUNCEMENTS

News

Changes to the ADI Board



ADI's new Chair-Elect Glenn Rees

At the Council meeting in May, ADI member associations elected Glenn Rees, current CEO of Alzheimer's Australia, as Chair-Elect. Glenn will take over the chairmanship of ADI from Jacob Roy in 2015. Andrew Ketteringham, former Director of External Affairs at Alzheimer's Society (UK), was elected as ADI's new Treasurer, taking over from Martin Else, who has served a total of nine years in the position. Mariella Guerra from Peru and Gerry Sampson from the USA were elected to the Board, and Markus Löfström from Finland was re-elected, filling the roles left as Yasmin Raashid from Pakistan and Lonnie Wollin from the USA ended their second terms on the Board. ADI is delighted to welcome those new to the Board and looks forward to working with them.

For a full list of ADI's Elected Board visit www.alz.co.uk/elected-board

World Alzheimer's Month 2014

World
Alzheimer's Month
September
Alzheimer's Disease International

Preparations for World Alzheimer's Month 2014 are beginning to take place around the world, with members planning their events and activities for September. Tying in with the focus of the *World Alzheimer Report 2014* on risk factors and prevention, the theme for this year's campaign is *Dementia: Can we reduce the risk?* with promotion of physical activity, an active mind, good nutrition, a healthy heart and an enjoyable social life. As in previous years, ADI are preparing promotional materials to support the variety of events that will take place during the Month and on 21 September, World Alzheimer's Day.

To keep up to date be sure to visit www.alz.co.uk/WAM for more details as planning progresses

ADI joins NCD Alliance

NCD Alliance Chair Cary Adams with ADI's Marc Wortmann at ADI's 2013 conference in Taipei

On 1 May, ADI was delighted to announce that it has become the first new global partner to join The NCD Alliance Steering Group since the Alliance's formation in 2009.

Since 2011, ADI has been working closely with The NCD Alliance, a global advocate for the inclusion of non-communicable diseases in health policy, and has supported their ongoing campaign while calling for the recognition of shared risk factors between the four main non-communicable diseases and dementia.

ADI Executive Director Marc Wortmann now joins other Steering Group members, CEOs of the Union for International Cancer Control, the International Diabetes Federation, the World Heart Federation and the International Union between TB and Lung Disease.

Cary Adams, Chair of the NCD Alliance said of ADI's new membership, "as a global federation and a respected leader in the field of NCDs and dementia, we believe ADI is an ideal partner and adds significant value to the strategy and operations of the NCD Alliance".

To find out more about The NCD Alliance visit www.ncdalliance.org

Global Alliance launched

Together with the Alzheimer's Society and England's Department of Health, ADI launched the Global Alzheimer's and Dementia Action Alliance (GADAA) at an event during the World Health Assembly in Geneva. The Alliance is the first global body to bring together NGOs, professional associations, governments and other members of the wider civil society to raise awareness and tackle dementia internationally.

The Alliance is a response to the call for action of the G8 Summit on dementia that took place in London in December 2013. The Summit called for increased funding for research, improvement of dementia care and change of the societal attitude towards these diseases.

It will engage with broader civil society organisations to raise more awareness globally and change the attitude to dementia in as many countries as possible. This follows a clear commitment from the G8 Summit to reach beyond the G7 countries and to work with the World Health Organization and Organisation for Economic Co-operation and Development to support countries to strengthen health and social care systems to improve care and services for people with dementia.

Introducing the new World Dementia Envoy

This is an abridged transcript from a video message played at the 29th Annual International Conference of ADI in May 2014

Dr Dennis Gillings

Hello, I'm Dennis Gillings. I wanted to take a moment to introduce myself and describe my new role as World Dementia Envoy. There is a great deal that we can do to tackle this disease, one which is intensely personal for me as I'm sure it is for many of you. My mother developed Alzheimer's in her later years. I saw, first hand, the devastating impact that dementia has, both on those with the condition and the people who love and care for them. I was fortunate to be able to ensure that she had the very best available care, but as a scientist I was also acutely aware that the treatment options were more limited than we would like. So, a significant increase in funding to help to find a therapy or cure by 2025 means the world to me and, I'm sure, to you.

I am a biostatistician by training, with a particular interest in public health. I have devoted my career to the development of new medicines. So, I am extremely eager to work with the World Dementia Council in driving dementia innovation. The Council met for the first time on 30th April.

I also have a background in the world of finance. Developing new treatments is expensive. I am hopeful that a new investment fund will make a pivotal difference to synergise current efforts.

Dementia is a ticking time bomb. You will all know that the number of people with dementia is due to double every twenty years. We have not yet risen to this global challenge. Research and development efforts have made limited progress. We have yet to produce an effective cure.

But all is not lost. We need to mobilise a worldwide assault on dementia. We should pool the best of our knowledge, experience and expertise and encourage earlier and better innovation in dementia right across diagnosis, treatment and care.

My role as World Envoy with the support of the Council places me in a unique position to champion the cause. I think there are five main areas of focus:

1. The regulatory framework: a robust regulatory framework is essential if drugs are going to be efficacious and safe. We need to work closely with regulators around the world to challenge existing regulatory frameworks so that patients get promising new treatments earlier without compromising robust data gathering.

2. Reimbursement, pricing and incentives: the market opportunity for investing in dementia research and development will be heavily influenced by the reimbursement environment, tax policies and the level of competitive advantage to be gained. Policy makers face a major task in balancing cost containment, access to medicines and rewarding innovation.

3. Increased clinical research: there needs to be a greater harmonisation of clinical trials involving industry and the scientific community. Moreover, the simplification of clinical trials would benefit translational research in dementia enormously. We need to introduce more safe treatments into the clinic and, in turn, eliminate them quickly if they do not show an effect. There is a need for greater public-private partnership in investment to share risk and reward, including the creation of a new fund or financial mechanism which draws upon philanthropic, social and commercial capital.

4. Promoting enterprise and talent: small biotech companies face significant challenges in accessing private finance to pursue dementia research. We should explore the use of financial incentives and remove all the disincentives: lowering the cost of approval processes and the use of collaborative funding mechanisms. I am also keen that we continue to attract the best talent into dementia research.

5. Societal contribution: we need to introduce more technology, such as the smart phone, to help elevate the quality of dementia care that can be brought to patients. Communities are very receptive to lending support to families and patients with dementia. This must be encouraged further to make the battle to fight dementia one in which we all participate. We should seek to involve the public more in dementia innovation through awareness training, the better linking of research, treatment and care, the use of dementia action alliances, and employing crowd-sourcing techniques.

In short, I strongly believe that we must build a global infrastructure to enlist and coordinate expertise and resources. We can't afford to waste time. We need to beat dementia and together we can.

Find out more and read the first newsletter from the Council at http://dementiachallenge.dh.gov.uk/category/wdc

■ Member profile

Norwegian Health Association

Lisbet Rugtvedt, secretary general of Norwegian Health Association

Nasjonalforeningen
for folkehelsen

Norwegian Health Association (NHA) is the only organisation in Norway that works for the interests of people with dementia and their carers. We are a voluntary organisation, founded in 1910 as a pioneer movement against tuberculosis, and were involved with fighting tuberculosis until its decline in Norway, after the Second World War. Since the late 1940's NHA has also taken on new challenges concerning non-communicable diseases. Today the organisation's goals are to combat cardiovascular disease and dementia.

Our focus on dementia started in the early 1990s. Norway has a population of five million, approximately 70,000 have dementia, and more than 300,000 relatives are involved. NHA has nearly 150 local dementia groups, and many of our other nearly 400 local groups are also involved in different capacities. They offer support, activities and raise funds and awareness.

Over the years NHA has built a strong voice, and is now in regular consultations with politicians, academia and health services. Since the late 1990s we have had a support line where people can call or send an e-mail to get advice or talk to someone about dementia. We also have a magazine with a circulation of 32,000, widely used webpages, as well as profiles on Facebook and Twitter.

Norway was among the first countries to have a national dementia plan, which was launched in 2005, and NHA has put down a lot of work, both before and since, to focus the interests of people with dementia. Right now we are campaigning to raise political awareness of the benefits individuals and society can get from giving people with dementia the opportunity to engage in activities on a regular basis. Our goal is that the government will regulate this as a right that people with dementia have, and that local communities must offer this.

Since the present national dementia plan only runs to 2015, we are also campaigning for a new plan, and for greater involvement of people with dementia in the planning process.

Last year was an important milestone in NHA's work. In October 2013, the Norwegian National Broadcaster selected NHA's dementia work as a beneficiary of its annual Telethon. The event raised €10 million, which will be used to improve the daily life for all affected by dementia, strengthen research and raise public awareness of the needs of people with dementia.

We are now in the process of starting a project called *Activity Friends*. As many people with dementia can still participate in activities, with a little bit of support and assistance, we want to offer a befriending service for this. We will provide basic training and guidance for volunteers who seek to support people with dementia to continue to participate in mutual leisure interests. We have recently hired twelve regional coordinators to implement the project and support and supervise the volunteers over the next four years.

Another large part of the funds from the 2013 Telethon will be put towards research. We have recently appointed the board for the upcoming Dementia Research Program. Former Minister of Education Tora Aasland is to head the board. The other four elected board members are Professor Menno Witter from the Kavli Institute for Systems neuroscience, Ole Andreassen, professor in Psychiatry at the University of Oslo, Peter Johannsen, associated professor at Copenhagen University and Wenche Frogn Sellæg, former minister and Member of Parliament and, at present, head of Norway's senior citizens advisory board.

The board will allocate research funding, work towards a broader international cooperation and stimulate interdisciplinary cooperation within dementia research. In September the programme's first allocations will be announced.

NHA's local groups are also developing new activities all over Norway with funds from the Telethon. In the first five months they have received financial support to realise almost 250 large and small activities. So far about 80 percent of the local activities are different kinds of arenas for people with dementia and their carers to meet. These are physical activities, outings, dementia cafes, singing and other musical groups, cultural activities, reminiscence and learning courses. About 20 percent has been allocated to different kinds of information activities, mostly open meetings in areas where there is a need for higher awareness of dementia.

To find out more about the work of Norwegian Health Association visit www.nasjonalforeningen.no

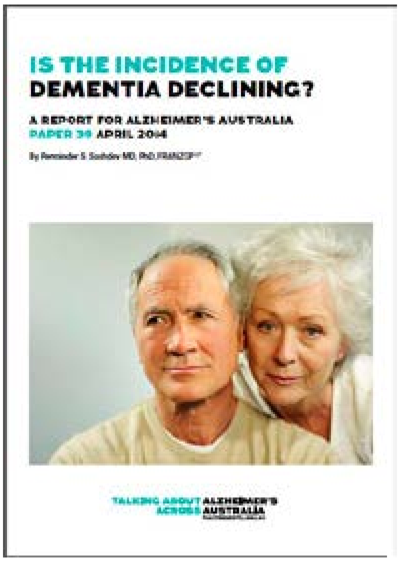
Members' forum

ADI members: do you have news to share with the global dementia community? Please contact us

AUSTRALIA

Risk reduction report

In partnership with the Centre for Healthy Brain Ageing (CHeBA), Alzheimer's Australia launched the report *Is the Incidence of Dementia Declining?* in April. The report highlights research that suggests improvements to environmental and lifestyle factors could lower the risk of dementia. It aims to inform the large percentage of the country's population who are not aware of the connection between dementia and other major chronic diseases of the risks. The report also explains that, while it may be possible for younger generations to reduce their risk, the number of people with dementia in Australia will continue to rise due to the increasing number of older people.


IS THE INCIDENCE OF
DEMENTIA DECLINING?
A REPORT FOR ALZHEIMER'S AUSTRALIA
PAPER 39 APRIL 2014

To find out more about the report visit the Alzheimer's Australia website www.fightdementia.org.au

NETHERLANDS

Dementia: then what?

Alzheimer Nederland is benefitting from a new film, produced by esteemed documentary maker Ireen van Ditshuyzen, with all proceeds from the film going to the association. Over a period of two years, Ireen filmed five people with dementia and their carers at various stages, including diagnosis, coping with moving into a care home and end of life decisions. The film also looks at aspects of research, continued enjoyment in physical activities, and the role of GPs and specialists. It aims to show professionals, carers and others with an interest a new way of looking at dementia.

To watch the trailer visit https://vimeo.com/84388261 and use the password DenD

Dementia newsflash

■ Germany

A campaign, developed by Deutsche Alzheimer Gesellschaft and social association VdK, to call for reform in the country's long-term care system has gained significant support from the general public. Launched in March, the *grosse Pflegereform jetzt!* (Big care reform, now!) petition received over 150,000 pledges of support within the first 10 days, 100,000 more than predicted. Based on this unprecedented support, a public hearing at the German National Petitions Committee will now take place.

■ Bermuda

Julie-Kay Darrell from Alzheimer's Family Support Group Bermuda received a certificate of appreciation from St George's Rotary Club in March, after sharing information about dementia.

■ India

The Alzheimer's and Related Disorders Society of India were visited by a delegation from Dubai in May who are looking to learn from their work for replication in Dubai. The group, in their research for the Dubai health authority, chose to visit India as care arrangements in the two countries are very similar, with care provided by family members rather than in institutions.

■ Ireland

The Alzheimer Society of Ireland hosted a series of 20th anniversary Alzheimer's Tea Day parties across Ireland on 1st May with a number of additional parties organised by individuals. The annual campaign aims to raise funds and recognise those living with dementia and their carers.

BANGLADESH

Dementia management seminar

On 26 May, the Alzheimer Society of Bangladesh (ASB) hosted a seminar titled *Management Update on Dementia* at Rangpur Medical College hospital. Speakers at the event included the founder of ASB alongside the principal of Rangpur College and professors of medicine, gastroenterology, cardiology, neurosurgery and neurology. The event was attended by more than 100 professors and doctors who received the presentations with great interest and enthusiasm.

For more information about ASB visit http://alzheimerbd.com

PUERTO RICO

New President welcomed

Asociación de Alzheimer y Desórdenes Relacionados de Puerto Rico held their annual assembly in May and were delighted to appoint Julio Solier as President of the association's board for the next two years. Julio was diagnosed with Alzheimer's disease in 2003 after experiencing increasing memory problems, which are now being successfully treated with medication. Julio will be supported in his role by his wife Jennie Betancourt Solis and the rest of the association's board. ADI wishes Julio and the new board great success in their ongoing efforts.

Julio Solier

UK

Dementia Friends

A new advertising campaign from Alzheimer's Society, in collaboration with Public Health England, appeared on television screens across the UK in May. The advert aimed to promote the Dementia Friends initiative to increase public awareness and understanding. While individuals can still register to attend a 40 minute awareness session, it is now possible for those living in England to become a Dementia Friend online. Alzheimer's Society hopes to have recruited more than one million Dementia Friends from across England by March 2015. The Dementia Friends programme also exists in Wales and Northern Ireland and at the time of going to print the campaign had just been launched by Alzheimer Scotland.

For more information about Dementia Friends visit www.dementiafriends.org.uk

Participants from ARDS Nepal during the Alzheimer University in London in 2012

ADI membership reaches 84

At the ADI Council meeting in Puerto Rico in May, membership was granted to five Alzheimer associations who will join ADI's existing membership of 79. New members are Association Marocaine Alzheimer et Maladies Apparentées (AMAMA) in Morocco, AMPA in Monaco, Alzheimer and Related Dementia Society Nepal, Monaco, Nasjonalforeningen for folkehelsen in Norway (see page 5) and Spomincica – Slovensko zdruzenje in Slovenia. ADI are delighted to welcome these new members and hope they will benefit greatly from their new international connections.

For a full list of ADI member associations, visit www.alz.co.uk/associations

Living with dementia

Trevor Jarvis, UK

Trevor Jarvis is an Alzheimer's Society Ambassador living with vascular dementia. He attended, as a delegate from the Society, the ADI Conference in Puerto Rico, ably accompanied and supported by his wife and carer Ann. Trevor spoke in two sessions at the conference. First, in a workshop series on creating dementia friendly communities, he spoke of how he had inspired the creation of a 'dementia friendly charter' for the UK financial services sector. Delegates also saw a staff training film produced by Lloyds Bank, and featuring Trevor. He spoke in the closing plenary of the conference.

After the conference, Alzheimer's Society Chief Executive Jeremy Hughes spoke to Trevor about his experiences at the event:

JH: *What was your overall impression of the conference?*

TJ: The conference was well organised and got across what we needed to know. I can see all action to support people with dementia worldwide going forward thanks to this conference. Everyone I spoke to wanted to listen and learn from what I have been doing as an Alzheimer's Society Ambassador and Dementia Friends Champion.

JH: *One of the sessions you attended was on nutrition and dementia, based on a recent report commissioned by ADI. You asked a question of Prof Martin Prince who presented the report.*

TJ: Yes, I did. I said that studies have shown that food colourings, for example in sweets, have an effect on the behaviour of children. Have there been any studies looking at the possible effects on people with dementia? The researcher said this hasn't been looked at and it was a very good suggestion for a study. He would go away and see if this could be set up. It made me realise that it is important people like me with dementia attend these conferences and ask questions based on our own experiences of living with dementia.

JH: *What was the feedback you got from the session you did on tackling the banks?*

TJ: It was explosive! I hadn't realised the impact telling my story of using a signature card (as opposed to a PIN number) would be. Many delegates, including those from Japan, New Zealand, USA, Canada, Aruba and Australia said they wanted to start a programme with banks in their own country. They all want to get a copy of the Lloyds Bank video and use it to inspire their own banks to develop staff training on dementia awareness. Even before the end of the conference, the Alzheimer Society of Canada had made contact with one of their leading banks.

JH: *What did people say about you being an Alzheimer's Society Ambassador and Dementia Friends Champion?*

TJ: People asked about the impact we are having in the UK. It made me understand how far ahead we are in England compared with so many other countries. The Alzheimer's Society and the Prime Minister's Challenge have really got things going and many want to set up something similar in their own countries. People said, 'Listening to you Trevor is very interesting and inspiring. We want to follow your lead and go down the same road'.

JH: *You met other people living with dementia from around the world.*

TJ: Yes, we joined in the whole conference but also had two meetings of our own in our quiet room. These sessions were a real eye-opener. It made me realise how lucky we are in the UK. In some countries people with dementia are really struggling. For example, in the USA you don't get the same health services support we get in the UK. There you have to be >

Trevor's closing plenary speech

Good morning. This is the shortest speech I have given! Thank you ADI for giving us with dementia the opportunity to be involved with the conference. We know that you will listen to us and I know it will help us go forward in getting a better understanding about Alzheimer's and dementia.

You are going on a journey now, but like all good engines you need fuel to get there. That is where you all come on board. Without your shared information, we would not be moving as fast as we are. So please keep sharing your information. We started on a minor road, but now we are on the highways and motorways. There is no stopping us now.

Trevor's three letters are C A R: Care – Assist – Respect.

And finally, enjoy life. Get out of it what you can. Adventure before dementia!

■ Carer's story

Each carer is an expert

Pat Murray, Scotland

It was so strange to be told Phil had dementia because it had taken us over three years to get that diagnosis and I knew it was coming. I had been told without the words actually being said. So I knew it was coming and yet it was a painful shock for me. It's so weird to explain. I think there was an element in me that just desperately didn't want it to be true even though I knew it was. I was still hanging on to a shred of hope. So when the diagnosis came it was quite devastating. I think I was in shock for a long time because it meant that not only did Phil's life have to change, but mine had to change beyond all recognition. I found the future very frightening. I'd never ever been, what I would call, a carer and I actually had been thoroughly enjoying my life as it was. The idea of having to face what would certainly happen in the future was extremely frightening and very shocking.

I had never known anybody who'd had dementia before. I just saw things in the media and I couldn't see any way forward. I was in shock. What helped me most was to meet a superb woman whose husband had had dementia for a few years. I remember meeting up with her and she was smiling and laughing and they seemed to have a good life. That was a revelation to me. Somehow this wonderful woman just gave me some strength and I was able to ask her questions and she said you adapt and you keep your spirits up. He had been diagnosed seven or eight years before and there they were still functioning; still involved in things. That was the big thing for me: meeting another person who was in the same situation as me.

The Carers Exchange was the other best thing. It's amazing to think that even three and a half years ago there was very little there for us. The diagnosis was given and it was pretty well 'goodbye' and then you're left. Phil has behavioural fronto-temporal dementia, so all of the books we had on Alzheimer's didn't fit anything that was happening in our lives. So I was really struggling. I'd had a lot of help from the Voluntary Services Aberdeen carer support because, by this stage, we had been down a long, bewildering road. One of the carer support workers phoned me up one day and said 'I've got somebody else here whose husband has been diagnosed with dementia. Can I put her in touch with you? I think maybe you could help each other.' So, this woman, Helen, and I met up and we realised that we were in exactly the same position and we felt that what we needed was a way us carers could meet, where we could talk freely, ask questions and get answers instead of always being presented to. That's what the Carers Exchange has done. We form networks with each other, so many of us keep in touch at the monthly meetings or by email or text message. Also, it's amazing how each of us is an expert and we have people asking us what it's like to care for someone who has dementia. I think the Carers Exchange is a lifeline. Anything that's networking, that helps us connect up with each other, is so important because of that enormous support we give each other.

For the future I would like seamless transition along this path with support at each stage from the necessary services because, for sure, we can't stop the dementia's progress. The disease is going to take its own course and it's a great deal of worry for me now. Rosewell, the respite centre Phil goes to, does not have a secure unit so they will only take people while they are well-behaved and as soon as there's any aggression, disruptive behaviour or attempts to escape that's it, they can't go anymore. Phil can be very impulsive and has huge mood swings. The drugs he's on are beginning to wear off, but they can't be increased. I want Phil at home for as long as is possible and I do know of people in this situation whose loved ones are having to go into care because there is no respite available. One person I know said 'I could have carried on, all I needed was a break' and her husband is now in care. There just aren't enough respite services where the staff are trained to deal with dementia as it progresses. What we need, once Phil is no longer able to go to Rosewell, is a care home that could also be a respite home so the transition from home to a care home is gradual. That would be perfection.

> really on the street with no money before anyone will help you. The conference was a good opportunity for all of us with dementia to get support from each other. The Australians are doing really well on involving people with dementia. We all agreed we should increase our work together as people with dementia from different countries.

JH: *What advice would you give someone with dementia attending next year's ADI conference?*

TJ: Prepare well for what you want to talk about. Have confidence and write down what you want to say so that you don't let yourself down. Know your subject. People will want to listen to you – have confidence in yourself.

How associations help

Associations supporting self-advocacy

Kate Swaffer, Australia

Associations can help people with dementia by offering the same inclusive services they offer our carers. The time has come for our voices to be heard and for every organisation, conference, committee, or event about dementia with a mixed audience, to include us. Not in a tokenistic way, but in the same fully inclusive way as everyone else. 'Nothing about us, without us' has been the catch phrase for so long, but it has not been realised for people with dementia.

In 2001, the Scottish Dementia Working Group was set up, and it took 11 years before the European Dementia Working Group was to follow. After meeting the Scottish group members at ADI's 2011 conference, I then instigated the Alzheimer's Australia Dementia Advisory Committee, and this group held its inaugural meeting in Canberra during Dementia Awareness Week 2013.

As Chair of this new consumers group, I welcomed the initiative, and without the vision and goodwill of Glenn Rees, CEO of Alzheimer's Australia, it would not have happened. We need more associations to take the lead by supporting us and finding the funds to allow us to self advocate and to improve outcomes, quality of life and well-being for people with dementia. The Alzheimer's Australia Dementia Advisory Committee aims to determine the priorities of people with dementia, contribute to policy and advocacy work, promote dialogue between those with dementia, researchers and service providers with a view to promoting a better understanding of their social and care needs, and assist in refining and evaluating Alzheimer's Australia's national programmes.

I am also co-founder and Board member of a new group Dementia Alliance International (DAI). This is the first global group, of, by and for people with dementia, where membership is exclusive to people with dementia. Whilst Dementia Advocacy and Support Network International (DASNI) was the first organisation set up in 2001 by people with dementia, its membership is open to others. DAI advocates for the voice and needs of people with dementia, and provides a global forum, aiming to unite all people with dementia globally to stand up and speak out, by re-empowering them through advocacy and education to live better lives, and to provide support, and increase awareness and education of others.

Since being diagnosed with dementia at the age of 49, I have chosen to remain actively engaged. I have completed a Bachelor of Arts in creative and professional writing, and a Bachelor of Psychology, with support from the disAbility advisors at the University of South Australia, and am now attempting to complete a Master's of Science in Dementia Care! The SA Department of Health/ Domiciliary Care has produced a staff training video of my story to educate their staff about dementia. I am actively involved in at least ten Alzheimer's Australia consumer groups nationally and locally. I produced and performed in an Adelaide Fringe event in 2012, *My Unseen Disappearing World*, with an accompanying Youth Engagement Program Education Pack supporting Years 11 & 12. My blog, with a readership of many thousands, has been archived in the State and National libraries PANDORA collections. It is also a resource for a number of institutions including Edinburgh University, MSc Dementia: International Experience, Scotland, 3 Spirit Training and Consultancy, the NSW Department of Health Dementia e-Learning courses, and the University of Tasmania's Understanding Dementia MOOC course.

In the search for my own humanity, I have found reaching out to others through advocacy and volunteering has been paramount to my own emotional health, as it helps to keep my own life in perspective. Self advocacy, supported strongly by Alzheimer's Australia, has also helped me to live a good life, and to positively impact on the lives of others diagnosed with dementia.

People with dementia need to be supported in this way by their organisations, to help reduce the stigma, the social and professional isolation, and to help break down the myths of living with dementia. Dementia is in my face every day anyway, so to have other things to be involved in, works to support my quality of life and well being, and perhaps more importantly my positivity. Advocating, publishing, volunteering, and contributing as a consumer advocate in a number of Alzheimer's Australia advisory roles has ensured my sense of identity has been retained, well beyond the diagnosis of dementia. It ensures I do not live as a 'victim' or 'sufferer' but that I live well with dementia, as a person functioning and living to the maximum of my ability, focused on what assets remain, and not my deficits.

Research update

Palliative care for dementia

Stephen R Connor, PhD, Senior Fellow, Worldwide Palliative Care Alliance

In the United States in 2012, 12.8% of patients admitted to hospice programmes had a primary diagnosis of dementia. Twenty-five years ago 90% of hospice patients had a cancer diagnosis. By 2012 this had dropped to 38.4% meaning that nearly 62% of hospice patients now have a non-cancer diagnosis (NHPCO, 2013). The focus of palliative care has been shifting for many years to non-cancer patients. This change simply reflects the reality that most people die of something other than cancer. Projections are that US hospices will level out at about one-third cancer two-thirds non-cancer by 2020.

In the last twenty years there has been an effort to extend hospice and palliative care to more people with advanced dementias. In 1996 the National Hospice and Palliative Care Organization published Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases: 2nd Edition. This publication was intended to give guidance to hospices on what clinical findings should be considered when making a prognosis of six months or less, if the disease runs its normal course. One of the eight diagnostic groups was dementia.

The guidelines were essentially the same for Alzheimer's and vascular dementias, while noting that vascular dementia appears to progress to death more quickly. The guidelines contained many caveats but essentially suggested that people with dementia be at stage 7c or greater on the Functional Assessment Staging (FAST) scale (Reisberg, 1994). This meant inability to walk, bathe or dress without assistance, the presence of urinary and fecal incontinence, and inability to speak or communicate meaningfully. A number of problems with the predictive validity of the FAST scale have been noted meaning that this is not a reliable way to determine prognosis, however all these factors should be considered when making a prognosis as well as the presence of common medical complications including co-morbid conditions and difficulty eating.

When hospice and palliative care providers began to care for people with dementia there was prejudice against the practice. Government officials would say things like 'what's the point of serving them, they can't even communicate?' Hospice advocates responded with education about the heavy care burdens that people with dementia and their families experience, the need for more personal care and attention to feeding, the need for family respite, and the inherent fact that someone with dementia was still a person with dignity.

Over time the apparent need for palliative care for people with dementia has become more accepted. Surprisingly only recently was it acknowledged that dementia itself is a cause of death (Mitchell et al, 2009). Globally dementia is growing along with the ageing of the population.

The World Health Organization estimates that 676,000 people died from Alzheimer's and other dementias in 2011 (WHO, 2013). This number will rise dramatically in the decades ahead and will require increasingly more palliative care services. To meet this need we need to expand training for health care workers globally in the basics of palliative care and dementia and to have health professionals with advanced skills in caring for those suffering from dementia and their families.

Clearly there is a need for greater cooperation between hospice palliative care workers, and the greater health care system. Not every person with dementia may need a specialised palliative care programme. We need to do a better job of ensuring that all health care workers receive training in the basics of palliative care so that reliable palliative care is available in every setting where people with dementia receive care, especially in long term care. Many families want to be able to care for their loved one at home. Hospice palliative care is especially helpful in supporting families to provide this care at home. However the current system for hospice in the USA limits care to the final six months of life, which is noted to be difficult to predict, particularly in dementia. Families need care over a long haul if they are to succeed in avoiding nursing home care. What is needed is a more flexible care management system of long-term care in the home that utilizes rehabilitative as well as palliative support. People with dementia and their families deserve no less.

News

ADI Award 2014

Martin Prince with some of his 10/66 colleagues from Latin America

After 16 years at the helm of the 10/66 Dementia Research Group, Prof Martin Prince was nominated by ADI member associations across the Latin American region to receive this year's ADI Award for his coordination of research efforts within the region.

Since 1998 Prof Prince has overseen dementia prevalence, incidence and impact research in countries including Cuba, Dominican Republic, Mexico, Peru and Venezuela. His efforts have led to a greater understanding of dementia within low and middle income countries, an area which was previously uninvestigated.

To find out more about the work of the 10/66 Dementia Research Group visit www.alz.co.uk/1066

In the next issue of *Global Perspective*

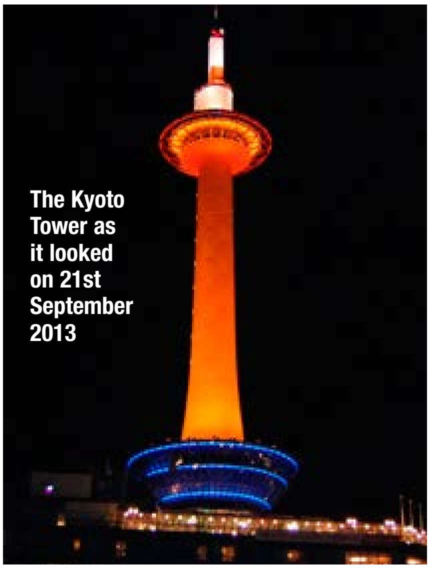
- **A look ahead to World Alzheimer's Month**
- **More details of the World Alzheimer Report 2014**
- **An update on the first follow-up meeting after the G8 summit**

Second MetLife Foundation–ADI Awards

At the conference in Puerto Rico, ADI announced the recipients of the 2014 awards for the best dementia care education programmes around the world, supported by the MetLife Foundation.

Now in their second year, the awards recognise successful projects run by Alzheimer associations around the world that promote better dementia care through training programmes. Thanks to the generous support of the MetLife Foundation, prizes totalling US$30,000 were given for the applications judged to be the most effective by a panel of experts from the dementia field, including a carer and a person with dementia.

In the high income category, Alzheimer's Association Japan (AAJ) was selected for their project *Color Whole Japan with Orange, Symbol of Dementia Support to Understand Dementia Care Better*. On World Alzheimer's Day 2013, AAJ "enlightened" the general public by lightning up Kyoto Tower in orange, while distributing educational leaflets and holding lectures on dementia across the country.



The Kyoto Tower as it looked on 21st September 2013

The winner of the low and middle income counties category was Alzheimer's Disease Chinese (ADC) for their project *Dementia Quality Care Online Training Programme*. This online training course, designed for professional care workers and family carers of people with dementia, was developed by ADC in collaboration with Peking University Institute of Mental Health and China Alzheimer's Project.

To find out more about runners-up and other entries for the Award visit www.alz.co.uk/metlife-adi-awards

First Carer of the Year announced

The first ADI – Home Instead Award for Family Carer of the Year has been presented to Rosabelle Dorothy Toyer from South Africa. Rosabelle went to great efforts to ensure improvements were made to the care and support of people with dementia in her area after her experiences following her husband's diagnosis in 2012.

The award was collected on Mrs Toyer's behalf at the 29th Annual International Conference of ADI in Puerto Rico.

Rosabelle's full story will appear in the next issue of Global Perspective.

The award was presented during the ADI conference in Puerto Rico