



**Alzheimer's Disease
International**

The global voice on dementia

December 2016
Volume 26 No. 3

Global Perspective

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

Over 70 countries unite for World Alzheimer's Month

Thank you to everyone who supported World Alzheimer's Month this September. The theme of 'Remember me' was successful in highlighting the campaign online with many people visiting the World Alzheimer's Month website in September.

Many organisations and individuals shared a #RememberMe photo or message to raise awareness of dementia and many more worldwide advocated for greater recognition of dementia through public campaigns, training and the launching of new services for people with dementia and their families. New Dementia Friendly Community initiatives were announced in the UK, Japan, Macau SAR and Indonesia.

The hashtag #WAM2016 gained more than 3 million impressions on social media with over 700 messages shared on Twitter. Videos by Alzheimer's Association Lebanon - 'Alzheimer's Moment' - and Confederación Española de Familiares de Enfermos de Alzheimer (CEAFA) - 'Give Memory' campaign - were viewed more than 8,000 times.

Ljubljana Castle in Slovenia, the National Monument in Indonesia and a giant experience sculpture in New Zealand lit up for the campaign and Memory Walks, conferences and activities for people living with dementia and their families were held in many more countries.

World Alzheimer's Day was marked by messages from around the world, including a tweet by the World Health Organisation (WHO) and a special appeal by His Holiness the Pope to remember those living with dementia and their families around the world.



Alzheimer's & Related Disorders Society of India - Kolkata chapter included people with dementia in art lessons and other activities for World Alzheimer's Month

ADI Executive Director Marc Wortmann attended several events during the month including the launch of the world's first Alzheimer's Tartan in Scotland and the ADI African Regional Conference in Nigeria while ADI Chair Glenn Rees presented on the importance of Dementia Friendly Communities during a World Alzheimer's Month event organised by Alzheimer's Disease Chinese and the Chinese Population Welfare Foundation.

James Smith, Communications and Administration Coordinator, attended the 50th Anniversary of Siemens where the Big Summer Cycle Campaign announced that more than \$30,000 had been raised in support of the work of ADI.

Read the Campaign Report from World Alzheimer's Month 2016 at www.alz.co.uk/world-alzheimers-month



Alzheimer's Disease International

The global voice on dementia

The views stated in *Global Perspective* are personal and do not necessarily reflect the views of ADI. Published by Alzheimer's Disease International, London, United Kingdom. Editor: James Smith. Design: David O'Connor. Printed by Vario Press Ltd. Copyright © Alzheimer's Disease International. All rights reserved. ADI is a not for profit organisation registered in the State of Illinois, USA.

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 30 January 2017.

Secretariat

Alzheimer's Disease International
64 Great Suffolk Street
London
SE1 0BL
Tel: +44 (0)20 7981 0880
Fax: +44 (0)20 7928 2357
Email: info@alz.co.uk
Web: www.alz.co.uk

Events

16-19 February 2017
LSE International Health Policy Conference

London, UK

Email: ihpc2017@lse.ac.uk

Web: www.lse.ac.uk/

LSEHealthAndSocialCare/events

23-24 February 2017
International Conference on Services to the Elderly

Hyderabad, India

Email: Jaishree@cimglobal.net

Web: <http://heritagefoundation-iahsa.net/>

26-29 April 2017
32nd International Conference of ADI

Kyoto, Japan

Email: adi2017@mci-group.com

Web: www.adi2017.org

Join us on Facebook, and Twitter

 www.facebook.com/alzheimersdiseaseinternational

 www.twitter.com/AlzDisInt

Editorial

Glenn Rees AM, Chair



The likely adoption of a Global Plan of Action on Dementia by the World Health Organisation (WHO) in 2017 represents the single most significant opportunity for advancing the reach of dementia awareness and services globally. It is also the start of a longer journey in ensuring that the targets of the 7 areas of the plan, on policy, risk reduction, diagnosis, care, treatment, support and research, are delivered beyond the 194 member states of the WHO, to 50 million people affected by dementia worldwide.

It is absolutely critical that we are ready to face the new opportunities this historic decision entails by embracing all means possible to use the expertise of Alzheimer associations and the global dementia community to support the implementation of the plan long after its adoption.

Members of ADI have been working for this opportunity for many decades and it is essential that this includes a continued effort to support the 60% of people living with dementia in low and middle income countries. In many more, people living with dementia continue to face a lack of access to services, appropriate care and human rights. Stigma surrounding dementia remains a global issue.

It is not too early for ADI Members and others to ask themselves how they may be able to take advantage of the resolution, by:

- Seeking discussions with your government to get their support for the resolution and producing the evidence needed to support your priorities.
- Considering what can be achieved by systemic change and better coordination within the health care system.
- Reviewing what role your organisation is positioned to play in working with government? For example, in respect of helplines, training, support for family carers and awareness.
- Identifying the roles that people with dementia and their family carers could play in supporting advocacy and forming a national alliance or partnerships to support advocacy by your organisation.
- Consider how ADI can help to support your advocacy.

ADI for its part will consult members on how we can best give support to their work, for example through a document on national indicators to monitor dementia plans and an update to publications on different approaches to dementia friendly communities.

The Recommendations of the *World Alzheimer Report 2016: Improving healthcare for people with dementia* will also be a useful resource in identifying ways of scaling up the healthcare system in your country while reducing the growth in costs.

I thank you for your continued support and hope to see many of you at the International Conference in Kyoto.

■ Meetings Roundup



Alzheimer associations across Asia Pacific meet at the regional meeting ahead of the ADI - Alzheimers New Zealand Regional Conference in Wellington

Alzheimers NZ Biennial Conference and 19th Asia Pacific Regional Conference of Alzheimer's Disease International

ADI and Alzheimers New Zealand hosted the 19th Asia Pacific Conference of ADI in November, including sessions on the impact of dementia in the region, the latest advances in dementia care and research, and dementia friendly communities. The conference included presentations by speakers living with dementia, including a keynote address on day one of the conference by Mick Carmody, and a presentation by Kate Swaffer, Chair, CEO and Co-founder of Dementia Alliance International on the global contribution of people with dementia. This was followed by a focus on human rights and the importance of the adoption of a Global Plan on Dementia by the World Health Organisation (WHO), by Chair of ADI Glenn Rees.

Representatives from 15 countries met before the conference to discuss the achievements of Alzheimer associations and best practice, at the annual Asia Pacific Region Business meeting. Members of ADI welcomed DY Suharya as the new Regional Director of the Asia Pacific Regional Office, following successful leadership of the region in the office's first three years by Francis Wong. The meeting included presentations on the highlights of each country's governance, World Alzheimer's Month activities and Dementia Friendly campaigns.

A special Alzheimer University training programme on the theme of advocacy was held in the days before the conference. It was led by ADI Global Policy Advisor Mike Splaine with a focus on member advocacy ahead of the potential adoption of a Global Action Plan on Dementia by the WHO in May 2017, and the importance of encouraging National Plans on Dementia. Examples of successful advocacy were provided by Member associations in TADA Chinese Taipei, Indonesia and Australia.

9th Alzheimer Iberoamerica Congress on Alzheimer's Disease

The 9th Alzheimer Iberoamerica Congress on Alzheimer's Disease was held in Costa Rica from 12-14 October on the theme of 'Promoting National Plans on Dementia'. The conference follows the adoption of the first Regional Strategy and Plan of Action on Dementia in the Americas in 2015 and the introduction of a National Plan on Dementia in Costa Rica in 2014.

The conference featured speakers from 15 countries, including the Vice President of Costa Rica, Ana Helena Chacón Echeverri, representatives of the Pan American Health Organisation (PAHO) and the Minister for Health for Costa Rica, Dr Fernando Llorca Castro.

Latin America and South East Asia will see the greatest increase in the numbers of people living with dementia by 2050.

This month, the conference will be followed by the adoption of a National Plan on Dementia by the government in Argentina, thanks to the efforts of the Argentinean Alzheimer association (ALMA).

Members' forum

SCOTLAND

Alzheimer Scotland unveils world's first Alzheimer Tartan

Alzheimer Scotland marked World Alzheimer's Day by unveiling the world's first Alzheimer's inspired tartan alongside a special bespoke tartan frock coat by award winning Scottish designer, Judy R Clark.

The tartan was released in support of people with dementia everywhere, including the 90,000 people living with dementia in Scotland. The design was donated to the association by the Scottish Tartans Authority, featuring vibrant shades of purple and other colours associated with Alzheimer associations globally. The new tartan was released to support the mission that nobody should face dementia alone.



Alzheimer Scotland ambassador and Game of Thrones actress Kate Dickie wears a bespoke coat featuring the world's first Alzheimer Tartan

The stunning frock coat is the first piece of clothing made from the new tartan and has already collected pin badges from many supportive dementia organisations across the world including: Alzheimer Scotland, Alzheimer's Disease International, Alzheimer's Disease Chinese, Alzheimer Slovenia, Association Alzheimer Maurice (Mauritius), CEFA (Spain), Croatia, Alzheimer's Society (England, Wales and Northern Ireland), Italy, Japan, TADA Chinese Taipei, Iran, Germany, Finland, Australia and Turkey.

Anna Devine, Director of Fundraising and Marketing at Alzheimer Scotland, commented: "Scotland is the home of tartan and as we develop our work with international partners around policy and good practice, it seems right that we should share the tartan to benefit people living with dementia everywhere."

Find out more at www.alzscot.org/tartan

MACAU SAR

Government of Macau SAR adopts Dementia Policy on World Alzheimer's Day



The government of Macau SAR has become the 27th to adopt an official dementia policy. The policy was launched by Dr Alexis Tam, Secretary for Social Affairs and Culture, in collaboration with the Macau Alzheimer's Disease Association (MADA) and health professionals at a special event on World Alzheimer's Day, 21 September.

ADI congratulated the government on the introduction of the policy, which includes a 10-year strategic framework to establish a dementia friendly community. MADA has supported the first milestone of the project through the establishment of the Dementia Medical Centre of CHCSJ Government hospital during World Alzheimer's Month.

The policy will be added to the list of dementia plans at www.alz.co.uk/alzplans in the coming weeks.

Visit www.mada.org.mo to find out more.

Share your campaign

Get in touch to share news of your activities and campaigns for the next edition of *Global Perspective*, by contacting info@alz.co.uk

Members' forum

UK

Global Launch of Dementia Friendly London



Chief Executive Jeremy Hughes with London Deputy Mayor Joanne McCartney, Professor Alistair Burns, Paul Burstow and Tim McLachlan, Operations Director for Alzheimer's Society London.

Alzheimer's Society marked the launch of Dementia Friendly London during World Alzheimer's Month with more than 100 attendees from the National Health Service, faith groups, businesses and transport, retail, housing and emergency services pledging their commitment to supporting dementia friendly initiatives. Alzheimer's Society Chief Executive Jeremy Hughes spoke at the event along with the Deputy Mayor, Assembly Members and a carer of a person affected by dementia.

These exciting plans to make London Dementia Friendly were started earlier this year when Alzheimer's Society worked alongside people living with dementia to engage key stakeholders and develop plans on what a dementia friendly London would look like.

The Society aims to make London one of the world's first Dementia Friendly Capitals where every person with dementia can live as full a life as they choose. A city as dynamic as London can and should be a global leader in dementia care and dementia friendliness and stakeholders at the event were encouraged to set up working groups to turn plans for the Dementia Friendly city into reality.

Roundtable discussions taking place over the coming months will include topics of health and care, transport, young people and housing.

The project slogan, *The strength of not being alone*, was chosen to reflect the sharing of a common effort to ensure that no one is left alone to deal with dementia.

You can contact Alzheimer's Society about supporting the initiative, or becoming a Dementia Friend, at: DFLondon@alzheimers.org.uk

LEBANON

Karaoke campaign encourages support for World Alzheimer's Month

Alzheimer's Association Lebanon marked World Alzheimer's Month with the launch of a campaign video that has been viewed almost 10,000 times.

The video, 'Alzheimer's Moment', recorded the reaction when members of the public realised that words to familiar songs had changed mid-performance during a Karaoke evening. Their reactions help demonstrate the confusion, disorientation and uncertainty that is often experienced by people living with dementia. The video reminds the viewer to remember those living with dementia or seek support by contacting the association on +961 76 030 083.

President of Alzheimer's Association Lebanon, Georges Karam, said "The video had a major impact to raise awareness on Alzheimer's Disease, as people were able to experienced first-hand what it feels like to be confused in public! Thanks to that video, we noticed an increase of people calling our hotline as well as increase of followers on our social media platforms."



Watch the campaign video at: www.facebook.com/AlzheimersAssociationLebanon/videos

Members' forum

SLOVAK REPUBLIC

8th International Scientific Conference held in Bratislava, Slovakia



Slovak Alzheimer's Society held awareness events and an International Conference in Bratislava in support of World Alzheimer's Month 2016

During World Alzheimer's Month, the Slovak Alzheimer's Society held the 8th International Scientific Conference on Alzheimer's Disease in Bratislava, including presentations by Slovak and international lecturers from the Czech Republic, United Kingdom, Spain and Israel on best practice in dementia care.

The conference on 'Senior's Training and Non-pharmacological Intervention for Alzheimer's Disease' was held on 22 and 23 September and featured 14 lectures and 5 experiential workshops on a range of topics including care home worker and resident relationships, and the standard of care and post-diagnostic care for people with dementia in Europe.

The EURAG Memory Training Center and 13 volunteers were among 178 participants from various professions attending the conference, including psychologists, therapeutic pedagogues, therapists, social workers, nurses and carers of people living with dementia.

You can watch a short video of the conference at: <http://youtu.be/S0-rmnsNXdl>

FINLAND

The right to a good life

The Alzheimer Society of Finland celebrated the traditional Memory Week from the 19-25 September with the theme, *The right to good life*.

On World Alzheimer's Day the Society also published a new and extended edition of *The criteria for good care for people with memory disease*, which is an important part of the implementation of Memory Strategy in Finland.

The Society also awarded its committed volunteers: the Brain Health Ambassador of The Year, Taimi Piippo, and the Memory Friend of The Year, Toivo Takalo-Eskola (pictured).

The 44 Memory Associations held events including awareness talks, conferences, Take care! walks, memory cafes, exhibitions and memory masses all across Finland.

"Memory Week is the most important week of the year for us. We want to spread the word about memory-related diseases so that no one would be left alone or without continued support. Our member associations have again done an amazing job organizing hundreds of happenings and increasing awareness about these diseases", said Eila Okkonen, the Executive Director of The Alzheimer Society of Finland.

Contact the Society at: www.muistiliitto.fi/en



Taimi Piippo was awarded Brain Health Ambassador of The Year and Toivo Takalo-Eskola was awarded Memory Friend of The Year. Photos by Mikko Törmänen

■ How associations help

Advocacy for better Dementia Care

Maggie Lee, Executive Director, Hong Kong Alzheimer's Disease Association (HKADA)



Representatives of HKADA meet with officials from the Food and Health Bureau

Strengthening primary care and medical-social collaboration are the key foci of our advocacy efforts in realising early detection, early treatment and early planning for dementia. The Lee Hysan Foundation has been our strategic partner and sponsor since last year, which has facilitated us to network and implement Project Sunrise – a district-based community shared care model in Tsuen Wan, Hong Kong.

Through collaboration between primary care and social services, people with dementia symptoms received comprehensive pre-diagnostic assessments, attended diagnostic assessment by trained General Practitioners in the community and started both medical and non-medical interventions within 3 months. This enabled people with dementia to grasp a 'golden treatment period' by shortening waiting times as well as bridging service gaps in the delivery of care.

We are now holding active discussions with policy makers, including those within the Hong Kong SAR



A team attempt to trace memories 'lost' on the street

Government, to encourage the adoption of this model long term.

During World Alzheimer's Month, the association followed the importance of this approach with a press conference on the launch of the *World Alzheimer Report 2016; Improving healthcare for people living with dementia*. Recommendations from the report were shared 12 times following the launch, including in newspapers, radio and online media. At the same time, we proposed a continuous and holistic dementia care pathway which can be adopted in Hong Kong.

In support of World Alzheimer's Month, since 2014, HKADA has also initiated an experiential education and fundraising event called "Memory Hunt". Corporate organisations and members of the public were invited to sponsor and form team of 6-8 participants to compete in the Hunt in September 2016. A total of 10 participating teams formed by corporate individuals, young people, caregivers and health care professionals accomplished different missions to retrieve 'lost memories', in order to experience the emotional ups and downs experienced by people living with dementia.

Contact the Association at: www.hkada.org.hk

Launch of Dementia Friends Hong Kong

With the assistance and support of Alzheimer's Society, HKADA is excited to launch the 'Dementia Friends' movement in Hong Kong in spring, 2017. An official announcement for the campaign was made during a Dementia Friends event for World Alzheimer's Month. Our first group of Dementia Friends supporters, including family caregivers, corporate organisations, secondary and tertiary schools attended the event and pledged their participation.



Supporters of Dementia Friends Hong Kong include a range of professionals, caregivers and family members



■ Dementia Alliance International

Human Rights and Disability Rights news

Kate Swaffer, Chair, CEO & Co-Founder of Dementia Alliance International



Dementia Alliance International's Human Rights work has continued to develop as the year has passed, and a number of DAI members, and many others living with dementia have been working tirelessly locally, nationally or globally

to ensure a human rights based approach is taken for all people with dementia, and that our rights to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) are acted upon. The Ontario Dementia Working Group have made a number of submissions to the Senate in Canada on human rights, people with dementia through the Dementia Engagement and Empowerment (DEEP) Think Tank in the UK have produced a book on human rights, and we are currently working with our American members on a human rights publication relative to USA legislation.

This year, DAI has produced a number of publications, including in May, *The Human Rights of People with Dementia: From Rhetoric to Reality*, which has already been translated into Spanish, Italian and Arabic, and is currently being translated into Portuguese, Indonesian, Japanese, French, Polish and Russian. We also released in October our *Supporting and Accommodating People with Dementia at Conferences and Other Events* booklet to assist event organisers to better support us to attend. In partnership with ADI, we also produced a position paper *Access to CRPD and SDGs by Persons with Dementia*, and submitted a flyer and video for the CBR 2nd World Congress

in Kuala Lumpur in September. They can be downloaded on our publications page, at www.dementiaallianceinternational.org/resources/publications/

Earlier in the year, we produced a formal *Peer to Peer Support Group Information and Guidelines*, and our *Code of Conduct Protocols for Board members, volunteers and staff* for our members, which has been downloaded or referred to by many organisations. 2017 will see a number of new publications, including one on Dementia Friendly Communities, and publications on Engagement and Dementia Language.

As a newly appointed Ambassador to ADI for the South East Asia Region, I hope to support the membership of both DAI and ADI in that region, which will enhance the work we are already doing in low and middle income countries, where access even to a diagnosis of dementia is difficult.

DAI has just farewelled a number of outgoing board members at our AGM in November, and we thank them for their commitment to DAI, and to all people living with dementia. I personally continue to be humbled by the passion, loyalty to the rights of all people with dementia and the contribution people with dementia are making in their own communities, and now, on the global stage. We will soon introduce you to our new board in our first Annual Report, to be released this month. As always, we welcome new members and are finding the growth of our support groups, a unique free global service, is actively supporting and empowering our members to live with a higher quality of life. Find out more at www.joinadai.org

Supporting and accommodating people with dementia at conferences and other events

DAI have published guidelines for supporting people with dementia at professional conferences and other events, acknowledging that people living with the condition are 'experts on the lived experience of dementia'.

The guide suggests ways to ensure that inclusion of people with dementia at events accommodates the difficulties that may be faced by individuals and their care partners, in a manner that promotes respect and understanding, and that supports disabilities of those of any age. Download the guide at: www.dementiaallianceinternational.org/publications

■ Carer's story

A Good Decade

Rebekah Churchyard, aged 27, speaks about her Grandfather's dementia

I was fourteen when my Grandma told us that Grandpa was diagnosed with 'semantic dementia'. She carefully explained that this was a type of cognitive disorder where he would gradually lose the ability to do things like plan, make decisions and talk.

My Grandpa was a well-known teacher in Ontario, Canada. "Did you know I was a teacher? It's funny, I never wanted to be a teacher...", he would say.

To generate extra income for their retirement, my grandparents operated a Christmas Tree Farm. They became well-loved community figures. Grandpa spent the days on his tractor in the fields, pruning and baling trees. We knew things would change when he put water where oil is supposed to go in his chainsaw. It was scary for my Grandma.

Grandma did a wonderful job accessing support and resources available, especially from the Waterloo-Wellington Alzheimer Society. Grandpa did not enjoy attending Day Programs and Grandma hired personal support workers or asked family and friends to stay with him. He would regularly greet guests and say, "You know my brain's no good anymore". At first, I responded with, "I still love you". In time, I learned to respond in a more caring way with, "I'm sorry, that must be so difficult. It's very nice to see you, I love you."

Times with Grandpa are some of my favourite memories. We would watch baseball, hockey or play cards. He would hold up his milk mug and ask if I want "some of that". He offered to microwave me Jamaican patties. I do not usually eat Jamaican patties (neither did he), but these were some of the most delightful meals I've ever had.

I am grateful for Grandma's honesty. She expressed a new tenderness in her husband that she hadn't known, paired with agonizing grief at the changes in her life partner. I felt guilty. Although my Grandma, mother and aunts were his primary caregivers, I think anyone caring for someone living with a neurocognitive disorder feels responsible for their wellbeing.

Grandpa moved to long-term care. He had a private



Rebekah with her grandfather in Ontario, Canada

room close to the dining area that faced the garden and the forest beyond. It didn't matter what others said; he hated it there. He asked to go home every time we saw him and even offered us money. My heart is heavy remembering how hard it was to say no.

Grandpa was more affectionate in his last year than ever before. Other changes were harder to accept, such as spitting and increased sensitivity to noise which would make him cry. He could no longer listen to Grandma play the piano. He was often frustrated by his dependence on her. She was the one thing he didn't ever forget, but he blamed her for much of his lost freedom.

Grandpa had been living with dementia for over a decade. Suddenly and unexpectedly, my Grandma died in April 2014. Grandpa, who now spoke very little, began to ask "Where is the girl?" He stopped asking about going home. He did not want to eat, sing or be around people. Sometimes we would sit in mutual silence, searching for conversation.

In August 2014 I was preparing to move for graduate studies when Grandpa died. The difference between my Grandma and Grandpa's funerals were striking. During his years living with dementia he had lost most of his community.

My final memories of Grandpa are the sweetest. He gave the softest goodbye hugs and would say "Goodbye sweetie pie". I would answer, "Bye bye, have a good day," and he would reply, "Have a good decade", and rub his cheek against mine.

My engagement with *World Young Leaders in Dementia* is to ensure that progressive research includes advancement in current models of care for people living with dementia. Joyful moments of human contact with care partners need to be supported in workplace policies, and all people need time to simply be together. To me, these interactions are more important than the best medicine.

■ Living with dementia

Regaining my confidence, and helping others through online support

Mick Carmody, Vice Chair and Global Support Group Manager, Dementia Alliance International



My name is Mick Carmody. I live in Brisbane with my wife Sue. Prior to my diagnosis of younger onset dementia I spent 25 days in two hospitals. I was told that I should be happy because I don't have epilepsy.

I was referred to a

geriatrician who sent me to have a MRI and a SPECT scan. The doctor explained that I had Fronto-Temporal Dementia. He explained every aspect of the disease but the only thing that resonated with me was being told of the 5-7 years' life expectancy. That was almost 4 years ago.

He asked my wife and daughter what led them to believe I had dementia; their answers shocked me. They'd all had to walk on eggshells for some time just so I would not get cranky. I had refused to believe that my driving, concentration, stability and forgetfulness were a problem, or that they were getting worse.

We shed many tears and discussed the future, including my attitude and my mood swings. I apologised to all of my family and now listen to Sue. My attitude has changed. For some time I had sat in my chair and refused to go anywhere, continuously thinking what is the use as I will not live much longer anyway.

Depression and thoughts of not wanting to live became my best friend and I sank into a black hole. During this time, for reasons unknown, I started to write poetry. I entered a poem into the Alzheimer's Australia younger onset dementia website and it was subsequently entered into the national quarterly newsletter. I was asked to join an Alzheimer's research network. Upon meeting the then co-chair Kate Swaffer, she realised that I was at my lowest point and asked me to join Dementia Alliance International (DAI).

Shortly after joining I was asked to attend a weekly online support group. I conquered my fear and trepidation and could not believe that I was going to be part of a group that was hosted by the great man himself, the late Dr Richard Taylor PhD. After sitting quietly and listening intently, Richard asked me to tell my story. I was absolutely blown away by the immediate acceptance from the group. I felt like part of a family that understood what I was going through because they were also living with a diagnosis of dementia.

"Whenever I fall back into that black hole of depression and despair, they help me want to live again."

As each week went by I went from the depths of despair to getting my confidence and desire to live back again. I have no doubt that being a part of the group has saved my life and I set about re-paying that debt the best way that I could. Richard and Kate helped me set up the first weekly support group in Australia, which I hosted. Richard Taylor became very ill and passed away in July 2015, but I had made a promise to him that his legacy would live on. DAI now has three online support groups in Australia, three in the USA and one in England, and has even hosted one in Nigeria, with more countries coming online during 2016. I now host a number of them as the Global Support Group Manager.

The weekly online support groups are hosted by people with dementia for people with dementia. To date I have been told they have saved four people from doing something stupid - just like me. It is my honour and privilege to run them, and to support others living with dementia. Whenever I fall back into that black hole of depression and despair, they help me want to live again. I am very proud that we have continued to fulfil the legacy left to us by Richard.

If any person with a confirmed diagnosis would like to join DAI and join our online discussion groups, both free, they can go to www.join dai.org

■ Research update

A positive note to end 2016

Dr Serge Gauthier, CM, MD, FRCPC, Chair of ADI Medical and Scientific Advisory Panel and Director of the Alzheimer's Disease Research Unit, McGill University, Canada



There have been an increasing number of publications on new medications for Alzheimer's Disease (AD). Results from the first study in mild to moderate stages of AD using the drug LMTM which inhibits the tau

protein aggregation were published in *The Lancet* (doi:10.1016/S0140-6736(16)31275-2), and results from a second study in mild AD were presented at the 9th Clinical Trials for Alzheimer's Disease congress (CTAD) in San Diego, California, December 8th-10th: although the analysis comparing low versus high doses in all participants showed no difference, there is the possibility that current AD drugs interfered with the LMTM actions.

Similarly, the 5-HT₆ receptor inhibitor antagonist idalopirdine which had shown encouraging results in people treated with donepezil (*Lancet Neurology* 2014; 13: 1092-1099) did not show efficacy in high doses, but there is still hope for the lower doses still under testing. Thus, it appears that current trial designs where drugs are simply added on to each other do not allow us to adequately measure positive (synergistic) and negative interactions. This is an important lesson as the field is planning combination therapies against various components of AD (*Alzheimer's & Dementia* 2016; 12: 623-630; *J Prev Alz Dis* 2016; 3: 164-172).

Results from a large-scale study using the anti-amyloid drug solanezumab in mild AD were also announced on November 23rd as negative for the primary analysis with more details provided at the CTAD congress. This antibody against the beta42-amyloid protein had shown encouraging results in mild AD using pooled analysis from two previous Phase III studies (*Alzheimer's & Dementia* 2016; 12: 110-120).

Results from a Phase II study using the antibody aducanumab demonstrated a reduction in the amount of beta-amyloid in the brain and a stabilization of clinical decline that was dose-related (doi:10.1038/nature19323); this has led to a large Phase III study, which is still enrolling. Drugs acting by inhibition of the enzyme β -secretase (BACE1 inhibitors) such as

verubecestat are showing encouraging results (*Sci Transl Med* 2016; 8: 363ra150), and there is even consideration of combinations acting on the amyloid protein in different ways (antibodies and BACE1 inhibitors).

This looks like a lot of medication to be used potentially in a lot of people. Prevention of AD is thus clearly the way to go (*J Prev Alz Dis* 2016; 3: 160-163), and national plans in many countries are encouraging healthy lifestyles - ADI is monitoring these national plans in order to highlight what seems to work best. For the people at higher risk of AD, or those with early symptoms, "precision medicine" is being proposed, using the right medicine at the right stage of disease (<http://dx.doi.org/10.14283/jpad2016.112>).

A reduction in the number of people with dementia has been documented in the USA (doi:10.1001/jamainternmed.2016.6807), attributed to the higher brain reserve due to education. Another factor at play is reduction of strokes due to better treatment of vascular risk factors in mid-life.

So the end of 2016 is ending on a positive note, as highlighted by the excellent overall review by science writer Elie Dolgin, in his feature on how to defeat dementia (*Nature* 2016; 539: 156-158).

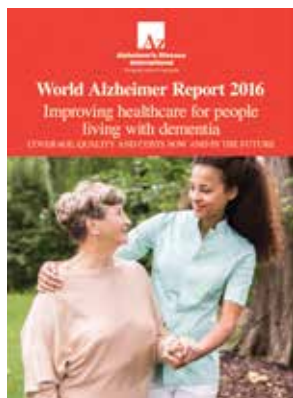


Dr Serge Gauthier presenting at the 31st International Conference of Alzheimer's Disease International in Budapest, Hungary, April 2016

■ News

Launch of World Alzheimer Report 2016

We have released the *World Alzheimer Report 2016*, calling for a global transformation in healthcare for people living with dementia.



The *World Alzheimer Report 2016*, 'Improving healthcare for people living with dementia: Coverage, quality and costs now and in the future' reviews research evidence on existing elements of healthcare for people with dementia and, using economic modelling, suggests how it should be improved and made more efficient.

The report shows that a greater role for non-specialist primary care staff could increase coverage of diagnosis and services for people with dementia and reduce the cost of care per person by up to 40% - but that healthcare systems must be transformed to provide dementia care that is continuous, coordinated and holistic.

The report was researched and authored by Prof Martin Prince, Ms Adelina Comas-Herrera, Prof Martin Knapp, Dr Maëlynn Guerchet and Ms Maria Karagiannidou from The Global Observatory for Ageing and Dementia Care, King's College London and the Personal Social Services Research Unit (PSSRU), London School of Economics and Political Science.

Read the report at www.alz.co.uk/worldreport2016

ADI submits joint response to Zero Draft Global Plan on Dementia

ADI, Dementia Alliance International (DAI), Alzheimer Europe and Global Alzheimer's and Dementia Action Alliance (GADAA) have submitted a response to the World Health Organisation (WHO) Zero Draft Global Plan on the Public Health Response to Dementia including feedback from ADI member associations in Sub Saharan Africa, the Americas, Europe, Middle East and Asia Pacific.

The plan identifies seven areas for global development in dementia care, treatment and research including a target for 75% of WHO member countries to develop or update national policies, strategies, plans or frameworks for dementia by 2025.

A final version of the Plan will be considered by the 70th World Health Assembly in May 2017.

Read the response at www.alz.co.uk/zerodraft

Alzheimer associations issue declaration at African Regional Conference

ADI and participants of the 3rd African Regional Conference issued a declaration to raise the priority of dementia in Sub Saharan Africa on World Alzheimer's Day. They called

for governments across the region to support the principles of the World Health Organisation Call for Action issued at the First WHO Ministerial Conference on Global Action against Dementia in 2015.

The conference was jointly organised by ADI and Alzheimer's Disease Association of Nigeria (ADAN), attended by delegates from 13 countries including individuals from the World Dementia Council, King's College London and World Young Leaders in Dementia (WYLD). The opening ceremony was graced by the Olubadan of Ibadanland, His Imperial Majesty, Oba Saliu Olasupo Adetunji, Aje Ogungunniso I.

Dementia affects more than 4 million people in Africa, and this is expected to increase to 14 million by 2050. The cost of dementia care in 2015 was estimated to be US\$ 21.6 billion in the African region - one of the greatest regional increases since 2010.



ADI Executive Director Marc Wortmann with dignitaries at the African Regional Conference in Ibadan, Nigeria