



Alzheimer's Disease
International

The global voice on dementia

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Global Perspective

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

World Alzheimer's Month 2015



Memory Walk with Iran Alzheimer Association

The theme for this year's World Alzheimer's Month campaign was **Remember Me**, encouraging people from all around the world to learn to spot the signs of dementia, but also not to forget about loved ones who are living with dementia, or who may have passed away. Alzheimer associations around the world focused campaigns on advocacy and public awareness with a busy month of activities.

September's campaign was kicked off by the launch of the World Alzheimer Report 2015, putting the spotlight on the global impact of dementia. On World Alzheimer's Day, ADI issued a statement calling for stronger international commitment, urging the World Health Organization (WHO) Member States to adopt a resolution on dementia. The statement also highlighted the need for dementia

to be included in international development aid programmes to support low and middle income nations, countries which will account for 68% of the total global prevalence by the middle of the century.

September is a time for action, a global movement united by its call for change, but it is also a time to think about the impact of dementia, a disease that will affect more and more people as the years pass. Turn to our Members forum, World Alzheimer's Month special on pages 4 and 5 to find out more about some of the activities that took place.





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 January 2016.

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Season's Greetings

The ADI team would like to wish *Global Perspective* readers all the best for the season and a very successful 2016.

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Editorial

Dale Goldhawk, Vice Chairman



As I write this on a dreary autumn day in the northern hemisphere, I think about my father. I can see him standing silently, staring out the window, looking at something I could not see. His dementia was gaining a foothold every day. I thought of it as a thick, heavy curtain shrouding his mind.

My kind, caring, full-of-life, life-of-the-party father, a man who filled every room he entered, was living behind that curtain. We caught only the occasional glimpse of him when the curtain momentarily and inexplicably parted.

Of course, we loved him just the same, and included him in every family discussion, even well after he had become non-verbal. We hoped what we said somehow got through to him.

After seven years on his Alzheimer's disease journey, my father died in 1984.

I have always been consoled by the fact that 1984 was the year pioneers in the United Kingdom, the United States, Australia and Canada, with a lot of hard work and imagination, created Alzheimer's Disease International (ADI). ADI now has 83 member countries around the world.

The disease has grown, as well. More than 46 million people are living with dementia. The number will climb to an alarming 131 million by 2050 unless effective treatments, better approaches to care, quality of life and prevention, can be found.

ADI is now part of a global movement that involves the World Health Organization, the G7 countries, the United Nations, the Organization for Economic Cooperation and Development and many more.

The millions of families that have been touched by Alzheimer's disease and related dementias should know they are not alone. A growing movement of caring people are doing what they can to give help for today and hope for tomorrow.

My father would have been pleased.

Events

9-12 March 2016
14th International Athens/Springfield Symposium on Advances in Alzheimer Therapy (AAT)
Athens, Greece
Email: ahamilton@siumed.edu
Web: www.ad-springfield.com

17-20 March 2016
10th World Congress on Controversies in Neurology (CONy)
Lisbon, Portugal
Email: conypromotion@comtecmed.com
Web: www.comtecmed.com/cony/2016



21-24 April 2016
31st International Conference of Alzheimer's Disease International
Budapest, Hungary
Email: adi2016@tensi.hu
Web: www.adi2016.org

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

■ Meetings Roundup

8th Iberoamerican Congress on Alzheimer's Disease Rio de Janeiro, Brazil

The theme for the annual Iberoamerican Congress on Alzheimer's Disease was "Reinventing the long road:



ageing and longevity". A key topic was national dementia plans, in light of the recent announcement that the Pan American Health Organisation (PAHO) had voted unanimously to adopt a landmark regional dementia plan for the Americas (for more information, see page 12). ADI member associations from the region met for a half-day workshop, discussing how to make the most of this unique opportunity with their governments, how to become a stronger region and ways to strengthen existing member associations.

ADI's Deputy Executive Director Johan Vos met with Rio de Janeiro's State Secretary of Health, Mr Felipe Peixoto, who committed to develop a sub-national plan for Brazil's third most populous state. It is our hope that other regional Health Ministers in Brazil will now do the same.

ADI Chair visits Singapore and China



ADI Chair Glenn Rees and former ADI Board Member Robert Yeoh with representatives of ADC and staff from the Community Health Centre in the Haidian district of Beijing

Glenn Rees, Chair of ADI, travelled to Singapore and China in October to discuss the impact of dementia in Asia. In Singapore, Glenn took part in a symposium about Dementia Friendly Communities, highlighting the importance of involving people with dementia in the development of these programmes. In China, Glenn spoke at the 25th anniversary celebration of Alzheimer's Disease Chinese (ADC), and met with senior officials to discuss the possibility of China developing a National Dementia Plan and supporting global advocacy for action on dementia in the WHO and G20.

Alzheimer Europe Conference

Ljubljana, Slovenia,
2-4 September 2015



ADI staff members Marc and Anastasia

The 25th Alzheimer Europe Conference "Dementia: putting strategies and research into practice", was attended by ADI staff members and Board member Birgitta Martensson. The event was hosted by Alzheimer Europe together with Spominčica - Alzheimer Slovenia and dedicated to the memory of Dr Aleš Kogoj, founder of Spominčica.

Plenary sessions gave a good overview of the latest research and European Union policy developments. As well as the plenaries, conference delegates were also able to attend 21 parallel sessions about legal, ethical and scientific aspects of living with dementia. In addition, three special symposia focused on the EPAD (European Prevention of Alzheimer's Dementia) project, the INTERDEM research group and the activities of the European Working Group of People with Dementia.

The 26th Alzheimer Europe Conference will be held in Copenhagen, Denmark, from the 31 October - 2 November 2016.

Members' forum

World Alzheimer's Month special

Each year, more countries take part in World Alzheimer's Month. Thanks to Alzheimer associations around the world, awareness of dementia is improving. It is these organisations who provide support to millions of people and who fight all year round to help improve the quality of life for people living with dementia. It is this dedication that makes World Alzheimer's Month a success.



MALAYSIA • Memory Walk



INDIA • Awareness event



SRI LANKA • Sri Lankan Cricket Captain Angelo Mathews launches Dementia Friends programme



NETHERLANDS • Dementia Friendly Award



MOROCCO • Fundraising event



KENYA • At Home Healthcare Kenya



GHANA • Talking to the media



FINLAND • Light of Memory campaign



PUERTO RICO • Information stand



SOUTH AFRICA • Fundraising run



BARBADOS • Health fair in Bridgetown



BELGIUM • Alzheimer Cafe Day



CAYMAN ISLANDS • Casual for a cause



BANGLADESH • Schools project



CHILE • Memory Walk



INDONESIA • Schools project

Over on Twitter,
#WorldAlzheimersDay and
#DíaMundialAlzheimer
 were two of the most popular
 hashtags on 21 September,
 as many people took to social
 media to reflect on the impact
 of dementia and discuss how
 we can better support
 people living with the
 disease.



News

Associations meet in London for Alzheimer University



At the start of September, ADI welcomed Alzheimer associations from Puerto Rico, St Kitts and Nevis, Pakistan, Norway, South Africa and Indonesia to the annual Alzheimer University training programme in London, a series of workshops to help strengthen and develop dementia organisations.

The sessions were led by speakers from ADI, the Alzheimer's Society, the NCD Alliance, Alzheimer Scotland and Cass Business School. At the end of the programme, participants also took part in a Dementia Friends session run by ADI Honorary Vice President and Dementia Champion, Nori Graham.

Over 100 countries have taken part in the Alzheimer University to date. The aim of the Alzheimer University is to give participants the tools to identify their association's aims, provide information, raise money and awareness, effectively govern their association and influence public policy. This year,

participants also took part in a special World Alzheimer's Month session to workshop event and campaign ideas.

Sara Benade, Regional Director for Alzheimer's South Africa KwaZulu-Natal chapter, said: "The highlight of the University was the excellent and interactive presentations which provided us with the opportunity to identify some objectives to strengthen our respective organisations upon our return home. Interacting and learning from our fellow delegates was a motivating experience."

"Interacting and learning from our fellow delegates was a motivating experience."

Samuel Rawlins, a volunteer for the Alzheimer's Association of St Kitts and Nevis, reflected: "We came to understand that whether we were working in a small island community with a population of just 50,000, like St Kitts and Nevis, or in a country

of over 191 million people, like our colleagues in Pakistan, to be effective, we must work hard to achieve our key objectives."

Margaret Hodge, also from St Kitts and Nevis, added: "The training session made me realize how much has been achieved worldwide, and we will continue to strive to do everything we can."

Throughout the year ADI runs several Alzheimer University events, often as part of regional conferences and meetings. These events are often focused on specific topics, such as advocacy or fundraising, enabling ADI to tailor sessions to the needs of participating associations. ADI is exploring the possibility of running online webinars to maximise the involvement of members in these sessions.

At the end of the programme, participants set themselves 3 key objectives for developing and strengthening their associations. ADI will now work together with the participants to help them achieve these aims.

Member profile

Cuba

By 2030 Cuba is predicted to have the highest proportion of older adults in any Latin American country. Today around 19% of the population is aged over 60, but in just 15 years' time this will rise to 30%. Cuba is a middle income country, but has health indicators similar to those in high income countries, and a life expectancy at birth of 78 years.

As a result of the rapid aging of the Cuban population, it is estimated that the number of people living with dementia, currently standing at around 150,000, is expected to double by the year 2030. If a cure is not found in the next few years, this number will rise to 300,000 by 2040. During the next 30 years, it is expected that there will be a tenfold increase in the demand for long-term care for people living with dementia.

The Cuban Section on Alzheimer's Disease, in Spanish Sección Cubana de Alzheimer (SCUAL), was founded in April 1996 and its main objectives have been to give information about dementia and educate family members and professionals, as well as to improve medical care for people living with dementia. In 1999, SCUAL became a member of ADI.

Over the past 8 years, SCUAL have participated in a national program to assist people who are living with a disability,

and to promote early diagnosis of dementia and risk reduction programmes. To date, more than 40,000 people over the age of 65 have taken part. The programme also helps to support families and training for health professionals. SCUAL has also developed an intervention program called 'Helping carers to care', which provides basic education about dementia and specific training on managing behaviours.

“SCUAL undertakes a wide variety of activities to help improve awareness about dementia in Cuba.”

SCUAL also participates in the work of the 10/66 Dementia Research Project, a network of over 100 active researchers from more than 30 low and middle income countries who are studying the prevalence and impact of dementia. In Cuba, more than 3,000 participants have been interviewed so far. SCUAL is now supporting a new project by the 10/66 team, to help understand changes in prevalence and incidence over a 10 year timeframe. The project also focuses on the social impact of dementia and how best to identify underlying risk factors and implement care packages.



Memory Walk in Matanzas organised by SCUAL

The Cuban National Dementia Strategy has been developed by SCUAL in partnership with the Ministry of Public Health, working together with researchers from several fields and with families and caregivers of people living with dementia. The plan has recommended that the strategy focus on increasing awareness, developing support services, promoting early diagnosis and risk reduction, quality assessment and implementing good clinical practice guidelines. It also asserts that there should be an increase in the availability of specialists in primary healthcare and in investment into dementia research.

SCUAL undertakes a wide variety of activities to help improve awareness about dementia in Cuba, including an annual conference and a campaign for World Alzheimer's Month and the World Alzheimer Report, including an annual Memory Walk on September 21, World Alzheimer's Day.

To find out more information about the work Cuban Section on Alzheimer's Disease please visit: www.alzheimer.sld.cu



■ Dementia Alliance International

Dementia: From words to action

Recently, Dementia Alliance International (DAI) appointed DAI member Professor Peter Mittler as its Advisor on Human Rights. He has a wealth of expertise in the disability sector on which we can draw in claiming access for people living with dementia to the UN Convention on the Rights of Persons with Disabilities (CRPD).

We are also especially delighted with the commitment from Glenn Rees, Chair of ADI to this Convention and its relationship to 'dementia friendly'. His recent speech in Singapore declared; "I detect that the concept of dementia friendly communities is being given practical expression in at least four different ways. The first of these is Human Rights". Glenn also said, "... the Board of ADI has asked the CEO to

approach Alzheimer Scotland with a view to setting up a working group on human rights, together with people with dementia. The aim is to develop a strategy on the recognition of dementia within the Convention."

Peter Mittler has been appointed as a member of this group representing DAI which is fully committed to working in close cooperation with ADI to make full use of the CRPD. What follows now is Peter Mittler's introduction to the Convention, with suggestions on how we can begin now to get to know how we can benefit from it.

Kate Swaffer, Co-chair, Co-founder and editor, Dementia Alliance International

The time has come for people living with dementia to work in partnership with the wider disability community in claiming their basic rights, as well as those specific to their needs and impairments.

Many fine words are spoken about the human rights of people living with dementia. But very little has been done to enable us to hold governments to account for a recent OECD report that dementia receives the worst quality of care in the developed world.

The UN Convention on the Rights of Persons with Disabilities (CRPD) can do just that. It is the first Convention to have been written in full and equal partnership with the people it is designed to benefit. 17 of the 18 members of the UN CRPD Committee that monitors its implementation are themselves people with a disability.

By ratifying the CRPD, 159 governments have made a commitment in international law to implement its General Principles and Articles.

People living with dementia across the world are now asking why they seem to have been excluded from this

Convention. The simple answer is that they have every right to use it but that only Alzheimer Scotland has done so to secure a funded guarantee from the Scottish government for a year's post-diagnostic support. Any Alzheimer association could do the same.

At the recent WHO Ministerial Conference on Dementia, Kate Swaffer set the ball rolling at the opening session by including 'Access to CRPD' as one of DAI's demands. The conference later endorsed a human-rights based resolution proposed by Marc Wortmann on behalf of 34 national Alzheimer's associations. This was reflected in the Concluding Call for Action by WHO Director Dr Margaret Chan that "policies, plans, programmes, interventions and actions are sensitive to the needs, expectations and human rights of people living with dementia and their caregivers".

A new European Commission Dementia Strategy led by Scotland will begin in 2016 and the Pan-American Health Organisation has just published its plan for the whole region. All these plans mention human rights but none refer to the CRPD as a means of underpinning policies and monitoring outcomes.

What can be done now to prepare us to use the Convention?

1. Read the EHRC User's Guide to the Convention: http://www.equalityhumanrights.com/sites/default/files/publication_pdf/uncrpdguide_0.pdf
2. Regular updates on CRPD – and the post-2015 Sustainable Development Goals (SDGs) are on the UN Disability website: www.un.org/disabilities
3. Reports of the UN CRPD Committee on 23 countries are on: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx> – go to Sessions in top right corner.

Peter Mittler



■ Living with dementia

Living with dementia in Nigeria

Dr Adeyinka Babatunde Agbebiyi

Dr Agbebiyi is a member of a new support group in Nigeria that has been set up by Dementia Alliance International (DAI) and the Dementia Nigeria and the Dementia Care Society of Nigeria (DCSoN). Here, Dr Agbebiyi reflects on his experience of living with dementia in Nigeria, a country where sadly many people do not receive a diagnosis until they are in the later stages of dementia, and where only the very lucky or affluent end up receiving any kind of formal care or support.

"I am Dr Adeyinka Babatunde Agbebiyi. I am a Yoruba from the traditional historical town of Oyo in the western area of Nigeria. I have to keep telling people how to pronounce my surname correctly, even some Yoruba people. You know that Yoruba is a tonal language, and the wrong accent in the wrong place in a word can change the meaning of that word. Agbebiyi roughly translated can be broken down: "Agbe" is a kind of bird with dark blue colour; "Biyi" – gave birth to this. So my name means this bird gave birth to this boy. There is a story behind this, it will take too long to tell it. Ask any Yoruba person to translate the following Yoruba saying: "Agbe l'o l'aro, Aluko l'o l'osun, Lekeleke l'o l'efun". You will understand what my name means if you understand the saying. There is even a song about it. "Lekeleke" is a white bird, like a dove. "Aluko" is a red bird, "Agbe" is a blue bird, I don't know its English name. It is blue all over and it has a crown on its head like a Mohican hair-cut.

"Can you miss something you don't know is missing?"

I was a surgeon. I know I was a very good surgeon. My birthday is in December, I can't tell you what date right at this moment. I sometimes think I am in my twenties, though I know, and people keep telling me I am in my seventies. I think it is rude for people to want to know how old I am. I am also an ordained reverend of a Roman Catholic Church. Some people ask how I can be a reverend when I am married and



have children. That is another story, and it is nobody's business. I love singing hymns. I think I have a lovely voice. I love to read anything and everything, but I do not do much of that now. I just can't seem to concentrate on anything as much as I used to. They say I had a stroke and that I have vascular dementia, and that is why I forget things. I don't know whether to believe it. I know that things are not right. I put it down to me trying to forget bad memories, but they keep telling me it is the dementia that is taking away my memories. I prefer my theory. Maybe it is not a bad thing not remembering. I don't think I am missing out on the lack of memories. I am fine with what memories I am left with. Can you miss something you don't know is missing? I like meeting new people and making new friends. It's a good life."

■ Carer's story

Finding strength through support groups

By Anat Aviv, Israel

Alzheimer's Association of Israel, or EMDA, is a non-profit organisation founded by family members of people living with dementia, which aims to support these families. One of the services offered are caregiver support groups, where caregivers come to realise they are not alone in facing the challenges of caring for someone living with dementia. Through the groups, they can access information on the disease and how to deal with the health and social care systems.

The group sessions also provide an opportunity for caregivers to share their innermost thoughts and emotions in a supporting and understanding setting, receiving encouragement and drawing strength from one another. EMDA currently operates around 50 support groups throughout Israel that meet once a month, led by social workers or trained volunteers.

“The group sessions provide an opportunity for caregivers to share their innermost thoughts and emotions in a supporting and understanding setting.”

I attend meetings in Petah-Tikva. My father was diagnosed with dementia around three years ago. When it started, before his medication was balanced, I felt lost. I was looking for answers – how do I cope with this? What should I say? How should I respond? How does this affect my personal and family life? I came to call it finding ‘the right dosage for my involvement in my father’s journey with dementia’.

I was looking for answers online and that’s when I came across EMDA’s support groups. I phoned Ilana, who led the support group in my hometown and immediately found a sympathetic ear. Ilana invited me to a support group meeting with other caregivers who are in a similar situation. It felt like I got to the right place at the right time. I learned how to accept this situation, how to take in any moment I had with my father, even when some moments were very difficult. There were also times, unfortunately only a few, when I could say: that was fun. I cherish these moments.



My father passed away 5 months ago. Yesterday I attended another support group meeting. I came, for the second time since my father’s passing, in order to feel a sense of closure. The first time was right after he passed away and my mother and youngest son came with me. I wanted them to share their feelings and to meet the people who were there with me for almost three years.

I first felt closure when my mother, overwhelmed with emotions, shared her point of view as a spouse of someone with dementia. My son, 18 years-old, had a strong bond with his grandfather. Despite my father’s disease and the deterioration in his condition in the last years, their relationship hasn’t ceased.

Yesterday, I personally felt a sense of closure and thanked the leaders of the support group who were there for me during this difficult time of my life. On behalf of my family I’ve purchased several copies of the book *The Power to Go On* by Ayelet Saar. This book accompanied our family during my father’s journey with dementia and provided us with answers for many questions we had. We gave out copies of the book to other group members hoping it would be helpful for them and give them strength going forward.

I wish to thank the leaders of the support group of the group in Petah-Tikva, especially Ruthie and Ilana, who were always there for me.

■ Research update

The ENGAGE and EMERGE Studies

The information below has been provided by Biogen

Amyloid plaques are the primary pathological hallmark of Alzheimer's disease (AD). Amyloid peptides, particularly the amyloid beta (A β) 1–42 variants, are the predominant component of these extracellular protein plaques. Accumulation of A β is thought to play a central role in the neuropathogenesis of AD by initiating a neurotoxic cascade leading to formation of neurofibrillary tangles, neuronal dysfunction, and cell death.

BIIB037 is an investigational compound being developed by Biogen for the treatment of AD. It is a human anti-A β monoclonal antibody derived from a de-identified library of B cells collected from either healthy elderly subjects with no signs of cognitive impairment or cognitively impaired elderly subjects with unusually slow cognitive decline. BIIB037 is thought to selectively target aggregated forms of A β , including soluble oligomers and insoluble fibrils.

Biogen licensed BIIB037 from Neurimmune under a collaborative development and license agreement.

The Phase 3 BIIB037 program includes two global studies, ENGAGE and EMERGE, which are identical in design and evaluate the efficacy and safety of BIIB037 in patients with early AD. The primary objective of these studies is to evaluate the ability of BIIB037 to slow cognitive and functional impairment, as measured by changes in the clinical dementia rating sum of boxes (CDR-sb) score, compared with placebo. ENGAGE and EMERGE are currently recruiting and the first patients have recently been enrolled. An estimated 2,700 patients will participate in the trials, which will be conducted in more than 20 countries in North America, Europe, and Asia. For more information about ENGAGE and EMERGE, visit clinicaltrials.gov (NCT02477800 or NCT02484547) or write to clinicaltrials@biogen.com.

Join us for ADI's 31st International Conference



31st International Conference of Alzheimer's Disease International
Dementia: Global Perspective – Local Solutions

21–24 April 2016, Budapest, Hungary

ADI's International Conference brings together unparalleled value, knowledge and shared experience from the world's most prominent speakers. Our 30 years' experience in leading global efforts on dementia has enabled us to deliver an international conference experience like no other. Join us for an engaging programme of dynamic presentations, workshops and exhibits to learn about the latest dementia research and gain insight into innovations in dementia care.

Register before 31 January 2016 to save up to 30% with our early bird registration offers. ADI's conference welcomes all with an interest in dementia and our fees reflect that, with reduced fees for people living with dementia, family carers, students and people from lower and middle income countries. Visit www.adi2016.org for more information.

■ News

In memory of Peter Ashley



Peter presents at ADI's Conference in London, 2012

It is with great sadness that we inform you that dementia advocate Peter Ashley passed away on 10th November. Peter was diagnosed with dementia with Lewy bodies in 2000, and worked closely with the Alzheimer's Society in the UK both as a trustee and in developing a 'Living with Dementia' group. Peter was also involved in the formation of the Lewy Body Society (now affiliated to Parkinson's UK) and presented at numerous conferences.

Peter was a close friend of ADI and a tireless campaigner, writer and advocate for people living with dementia, coining the phrase "I'm not dying with dementia, I'm living with dementia". Peter will be greatly missed by all those whose lives were touched by his warmth and determination.

We extend our deepest sympathy to Peter's wife and family.

Regional NCD Alliance for Southeast Asia



ADI's Asia Pacific Regional Office (APRO) has joined forces with other NCD (non-communicable disease) organisations to form a regional NCD Alliance. The Alliance combines resources to create a core team committed to combat the NCD epidemic, putting health at the centre of all Southeast Asian health and development policies through targeted advocacy and outreach work. NCDs account for more than half of all deaths in the region, and they will be the leading global cause of disability by 2030.

Landmark regional dementia strategy for the Americas



Marc Wortmann delivers a statement at the PAHO meeting

The Pan American Health Organization (PAHO), the World Health Organization's (WHO) agency for the Americas, has become the first region to adopt a Regional Plan of Action on Dementia. The plan was voted for unanimously at the 67th Session of the Regional Committee of the WHO for the Americas, held in October in Washington D.C.

The PAHO Regional Plan of Action on Dementia obliges countries to develop national dementia plans, including the promotion of risk reduction strategies through public health programmes, ensuring a rights-based approach to the provision of care and support for people living with dementia and better training for health professionals, as well as more funding for research.

ADI is encouraged to see that PAHO has taken leadership on this issue, and hopes that other WHO regions will follow suit in taking action to help support people living with dementia and their families around the world.