



Alzheimer's Disease
International

December 2012
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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 2012

The first global World Alzheimer's Month took place in September with national Alzheimer associations and likeminded groups and individuals in numerous countries extending their activities across the 30-day period. Continuing to mark World Alzheimer's Day on 21 September gave associations the opportunity to host a pinnacle event or activity.

World Alzheimer's Month 2012 showcased some truly creative events, developed by national Alzheimer associations, including a cardboard boat race in Gibraltar, Raffle Draw in Sri Lanka, cycle rally in India and a cake sale in Curaçao. The North West branch of Alzheimer's South Africa visited a nursery school where children spent the day experiencing what it would be like to live in their grandparent's shoes with the help of a puppet show, while in Gauteng

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The Central Bank of Barbados, Barbados Alzheimer's Association and Rotary Clubs launched a national One Cent Drive to retrieve one cent coins. By the end of September 5 million cents had been collected and the aim is to now reach 10 million before the end of the year. The bank will donate an amount equal to that received in cents to the Association.

New awards for Dementia Care Education

With the generous support of MetLife Foundation, ADI is pleased to announce three new awards to recognise the success of Alzheimer association projects around the world that promote better dementia care through providing training programmes. The MetLife-ADI Awards for the Best Dementia Care Education Project consists of three awards, each of \$10,000, with one covering the Americas, one for Europe, the Middle East and Africa and the third being awarded for the best project in the Asia Pacific region.

The application process is open to Alzheimer associations who wish to showcase their effective dementia care training programmes, or programmes from others they are involved with. Applications will be reviewed and judged by a panel of experts from the dementia field, including a carer and a person with dementia. The award winners will be announced at the ADI International Conference in Taipei in April 2013.

More details and submission criteria will be available on the ADI website at www.alz.co.uk/award in early January.



Alzheimer's Disease International

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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 2013.

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



The ADI team would like to wish you all the best for the season. The office will be closed on 25 and 26 December and 1 January. The team look forward to working closely with you towards a successful 2013

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Editorial

Jacob Roy, Chairman



The last nine months since I took over the Chairmanship have been filled with various exciting events. Starting with the WHO-ADI dementia report in April, this was followed by the announcement of consultative status for ADI with the UN, and new initiatives in the Caribbean – especially with Rotary and Lions Clubs. In addition we have had the first African regional meeting in Mauritius, successful regional conferences in China and Chile, participation in the Alzheimer Europe conference, and the first Middle East and North Africa regional meeting in Egypt. We are reaping the fruits of the seeds planted by my predecessors. Obviously all these additional activities have created more work for the ADI staff. I must say that all of them are doing a great job. There is a sense of excitement in the air! We are mindful of the hard economic times that we are living in and we are compelled to look for resources outside traditional sources.

For ADI to be stronger, our members should grow stronger. As we are in the process of developing the Strategic Plan for 2013-16, this is one important area that we must consider. We should also look into ways of strengthening the regions.

We are looking forward to participating in the first International Conference of ADI to be held in the Chinese-speaking world. The conference will take place in Taipei, where the organisers are working hard to bring together an unforgettable learning experience.

We are looking forward to an exciting year ahead when we hope to work more closely with governments to make dementia a public health priority.

Events

2013

6 – 10 March
11th International Conference on Alzheimer's Disease & Parkinson's Disease (AD/PD 2013)
Florence, Italy
Web: www.kenes.com/adpd

11 – 14 April
7th World Congress on Controversies in Neurology (CONy)
Istanbul, Turkey
Email: cony@comtecmed.com
Web: www.comtecmed.com/cony/2013

18 – 20 April
28th International Conference of Alzheimer's Disease International
Taipei, Chinese Taipei
Email: adi2013@mci-group.com
Web: www.adi2013.org

3 – 5 October
23rd Alzheimer Europe Conference
Valleta, Malta
Web: www.alzheimer-europe.org/EN/Conferences

17 – 20 October
8th International Congress on Vascular Dementia (ICVD 2013)
Athens, Greece
Email: vascular_dementia@kenes.com
Web: www.kenes.com/vascular

11 – 14 December
16th Asia Pacific Regional Conference of Alzheimer's Disease International
Hong Kong SAR and Macau SAR
Email: headoffice@hkada.org.hk



Speakers at the
1st Africa Regional
Conference in
Mauritius held in
September 2012.
See next page for
details

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

Regional conferences 2012

Africa

In partnership with Alzheimer Association Mauritius, ADI hosted the 1st Africa Regional Conference on 27 to 28 September. The landmark event was well-received and provided ADI members in India, Mauritius, Nigeria and South Africa with the opportunity to present their work and current challenges they face with others in the region.

The Vice-President and Minister of Social Welfare of Mauritius were in attendance alongside the Minister of Health who, during the closing ceremony, recognised the need for a national dementia plan. All government officials showed great respect for the work being undertaken by national Alzheimer associations within the region and some very positive meetings took place relating to future conferences in the region and closer collaboration with the 10/66 Dementia Research Group.

Latin America

Around 600 delegates attended the VI Congreso Iberoamericano de Alzheimer conference, which took place from 18 to 20 October in Santiago, Chile. The conference programme, which covered all aspects of dementia, included speakers from across the Latin America region as well as Canada, Spain, USA and UK.

ADI hosted a one-day Alzheimer University programme on fundraising and national Alzheimer plans, attended by representatives from ten national Alzheimer associations in the region. Recent developments towards national plans in Mexico and Peru were highlighted and fundraising techniques and guidance on the creation of a fundraising plan was shared.

Middle East and North Africa



The 1st Middle East Regional Conference included a range of discussions on future collaboration

ADI's 1st Middle East and North Africa regional conference was held on 28 and 29 November in Egypt. During the conference meetings involving national Alzheimer associations in Egypt, Lebanon, Morocco, Saudi Arabia and Tunisia took place with lively discussion on future regional collaboration. A full programme followed, including sessions on caring for people with dementia and research developments as well as a workshop focussed on national dementia plans.

At the conference a Cairo Declaration was announced calling for governments across the region to make dementia a public health priority and encouraging the World Health Organization's Eastern Mediterranean Regional Office to continue collaboration with Alzheimer associations.

Asia Pacific

The 15th Asia-Pacific Regional Meeting of ADI took place in Beijing, PR China from 26 to 28 October. The event, which ran alongside the 2012 Annual Conference of Alzheimer's Disease Chinese (ADC), attracted around 500 delegates with a strong programme.

The event marked a turning point for awareness and policy in China with the launch of the recent *Dementia: a public health priority* report from the World Health Organization in Chinese. Coverage of the launch appeared on national television featuring interviews with ADI's Executive Director Marc Wortmann and Dr Tarun Dua from the World Health Organization.

A particular highlight of the event was the presentation of awards to those people with dementia and carers who had spoken out during World Alzheimer's Month.

Alzheimer Europe

The 22nd Alzheimer Europe Conference was held in Vienna, Austria from 4-6 October in collaboration with Alzheimer Austria. The event drew around 500 delegates from 42 countries, including 15 people with dementia from 12 countries thanks to special financial support from Alzheimer Europe.

Austria's Federal Minister of Labour, Social Affairs and Consumer Protection, gave reassurance during the conference opening ceremony that Austria would develop its own national dementia plan within the next five years. This set in motion the strong focus throughout the conference on the need for national plans. Other topics covered included changing perceptions of dementia and medical and clinical aspects of dementia as well as social and care issues.

ADI attends WHO regional meetings

In recent years ADI representatives have attended a number of the annual meetings hosted by the World Health Organization's regional offices. This year was no exception with ADI attending five of the six meetings in September and October.

Hussain Jafri and Yasmin Raashid from Alzheimer's Pakistan joined Diane Mansour from Lebanon at the Eastern Mediterranean Regional Office meeting in Egypt. Hussain reported that strong connections were made at the event, which will ensure greater collaboration between ADI's members within the region and the WHO's regional office in future (see page 3 for more details).

ADI's Executive Director, Marc Wortmann, attended the European meeting in Malta alongside Charles Scerri from the Malta Dementia Society. The WHO's report on

dementia, released in April this year, was well-known among the meeting's participants and the launch of a large healthy ageing programme, which referenced both the WHO and ADI's reports, signalled a positive step.

ADI Policy Adviser Mike Splaine, and Raymond Jessurun from Sint Maarten Alzheimer Association attended the Pan American Health Organization (PAHO) meeting in Washington, DC. After ADI's statement was delivered, PAHO officials asked for ADI's assistance in preparing a separate action plan on dementia for the region to be completed by 2014. A request to attend a meeting on mental health hosted by the government in Panama was also taken up.

Tami Tamitegama from Lanka Alzheimer's Foundation in Sri Lanka was present at the South East Asia meeting in Indonesia with Jacob

Roy, ADI Chairman. There was great awareness of the WHO report on dementia among health ministers at the event and meetings took place with representatives from a number of countries. Tami, who has attended the meeting each year on behalf of ADI, reported that there is strong evidence that the continued efforts of ADI are starting to be recognised.

ADI Board member Robert Yeoh was joined in Vietnam by Henry Shie from Hong Kong Alzheimer's Disease Association at the Western Pacific regional meeting. Robert delivered a statement on behalf of ADI and highlighted the current lack of knowledge about the WHO's report on dementia at the meeting. It is hoped that the launch of the Chinese translation by Alzheimer's Disease Chinese on World Alzheimer's Day will generate greater awareness.

Members' forum

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

ADI at 6th Croatian Congress



Marc Wortmann gave a presentation on the global impact of dementia at the conference

ADI's Executive Director, Marc Wortmann, attended the 6th Croatian Congress on Alzheimer's Disease, which took place in Primošten from 10 to 13 October. The biennial meeting, hosted by Alzheimer Croatia, highlighted the latest research advances and best practices in care with a particular focus on encouraging a holistic approach to dementia care.

The event opened with a photograph exhibition containing 113 photos, which were displayed through a projected presentation for the duration of the conference. A large number of poster presentations appeared at the event and Marc joined a panel of judges who selected the three prize-winning posters at the end of the conference. An award was also given to ADI for the successful developments with the World Health Organization.

Member profile

Alzheimer's Association of Trinidad & Tobago

The Alzheimer's Association of Trinidad and Tobago has been in existence since 16 June 2000 and became a full member of ADI in 2004.

Its vision is a life of dignity, with acceptance, support and security. Its mission is to respect the persons with dementia and their caregivers and to improve their quality of life through support, information education and research.

From its inception the Association has liaised with PAHO/WHO country representatives, the Ministry of Health, the Division of Ageing of the Ministry of the People and Social Development, the Ministry of Community Development, and the University of the West Indies.

In 2003, a partnership was formed with Alzheimer Society of Canada and this was formalised in 2006 with ADI's Twinning programme. A strong bond of friendship continues to exist.

In Trinidad and Tobago there are now four support groups which meet monthly in Port of Spain, San Fernando, Tobago and Arima.

During the year the Association facilitates and participates in:

- Several educational/outreach programmes
- Lectures throughout the country
- Seminars
- Radio and TV interviews
- Public fora of the Division of Ageing
- Health fairs of the Government ministries and other organisations.



His Worship the Mayor of Arima, Alderman Ghassan Youseph, at a seminar in Arima with Carlota Simon Rodrigo, Chairperson of the local group, and Norma Inniss, President of the Alzheimer's Association of Trinidad and Tobago

In observance of the Association's 12th anniversary, a weekly programme of activities for persons with dementia/Alzheimer's disease was launched.

On 16 April 2012, the Association was invited to the Launch of the project *The Prevalence and Economic Cost of Dementia in Trinidad and Tobago* held in collaboration with the Dementia Awareness and Research Group of Trinidad and Tobago (DARTT) of the Faculty of Medical Sciences University of the West Indies and the HEU – Centre for Health Economics – of the Faculty of Social Sciences University of the West Indies.

Professor Robert Stewart delivered the main address *Prevalence Studies around the*

World. Information from the WHO dementia report was included in the presentation. The project is on-going and is expected to be completed in one year.

The biggest awareness events for the year are the activities held for World Alzheimer's Month and Day in September which usually ends in October as each group has their own programme. The theme used, *Dementia: Living Together – Eliminating Fear and Stigma*, was very well addressed by Psychiatrist at St. Ann's Hospital Dr Rajev Khaja, and received by participants at the seminars in Port of Spain and Arima. It was also aired on the radio on World Alzheimer's Day.

Looking to the near future it is proposed to start programmes for children and teenagers in schools.

For more information about the work of the Alzheimer's Association of Trinidad and Tobago contact nebinniss@gmail.com

Members' forum

World Alzheimer's Month CONTINUED FROM FRONT PAGE



To launch the new Chinese name for 'dementia' Hong Kong Alzheimer's Disease Association hosted a press conference and launch ceremony followed by a bus parade to provide information and raise awareness of the new name



In Limpopo, South Africa, a large event took place with Dr Norma Mabasa, Member of the Limpopo Executive Council for Health and Social Development, with 600 participants. A further 600 people joined their 5km Fun Walk.



Alongside their annual World Alzheimer's Day conference, Fundacion Alzheimer de Venezuela organised a very successful Memory Walk and symposium



The Alzheimer's Disease Association of the Philippines ran post-graduate courses for nurses and physicians. Participants were given the opportunity to experience how it might feel to have dementia. The Association also hosted a Memory Walk with more than 2000 participants.

Paws for People dog therapy joined the branch on a visit to a care home.

Teaming up with the online auction and shopping website eBay, the Alzheimer's Association in the USA hosted celebrity auctions and a *Give at Checkout* option. In addition, the Association raised \$1.1 million from 32,000 people through direct marketing and were congratulated on their important efforts by President Obama's Administration on the White House blog. Their *Go Purple to End Alzheimer's* campaign was a great success with strong celebrity and media support.

Reports from ADI's member associations in various parts of the world, including those in Curaçao, Finland, India, Peru, Sri Lanka and Turkey, highlight the strong media coverage they also received through the month. Spominčica – Slovensko združenje in Slovenia received more media coverage than ever before and Alzheimer's Australia reached an audience of more than 20 million people as a result of the launch of their new programme, *Your Brain Matters*, which marks the world's first publicly funded initiative to promote brain health as well as a healthy body and heart.

Many more associations recognised the powerful opening that World Alzheimer's Month provides for the launch of new programmes or initiatives. In Russia, the association founded the school for caregivers of people with dementia during the month. CEAFA in Spain co-launched the *kNOW Alzheimer* initiative, which will detect the current concerns of those associated with dementia, including carers, pharmacists, primary care physicians and geriatricians.

The creation of national Alzheimer plans in Peru and Belgium tied into their World Alzheimer's Month schedule. APEAD in Peru received strong media coverage and support

of their preparations for the country's Alzheimer's draft law. Ligue Alzheimer in Belgium launched their *Alzheimer national plan* that will lead to the creation of an action plan by May 2013. *Dementia Alliance Belgium* was also formed to feed into the action plan. The UK government also chose 21 September to announce a new media campaign that would encourage people to speak to loved ones if they are concerned about dementia and access help.

Great recognition was paid to the outstanding efforts of carers of people with dementia. Alzheimer's and Dementia Association of The Cayman Islands hosted a carer's dinner with live music and prizes donated by corporate sponsors. Alzheimer's Association Korea organised a ceremony to award four carers which was attended by 600 people and ZARDA in Zimbabwe invited people with dementia and carers to join a Morning Tea Party. Iran Alzheimer Association chose to celebrate the commitment of their volunteers by organising an awards ceremony for them, where the winner of their hugely successful photography competition was also announced.

Memory Walk maintains its status as the most popular activity with incredible awareness-raising potential. This year walks took place in many countries, including Cuba, Indonesia, Nigeria, Mpumalanga in South Africa, Trinidad & Tobago and the UK. The Alzheimer's Association also continued their hugely successful *Walk to End Alzheimer's* with countless walks taking place across the USA throughout the month.

Other activities hosted in a number of countries included memory screening, Alzheimer Cafés and widespread dissemination of information. The Alzheimer's Disease Association of Nigeria sent a mass



Alzheimer's Disease Chinese (ADC) hosted an advocacy event to reduce stigma and donated education packs to primary care settings. ADC worked closely with News Center of China (CCTV) throughout the month

SMS to medical professionals about the existence of the association and its support groups. In Singapore, Alzheimer's Disease Association hosted three public forums in English, Mandarin and Malay covering three topics. These events, which have been a great success in recent years, attracted almost 400 participants.

Slovak Alzheimer's Association hosted their annual conference with participation from Austria and Czech Republic while Alzheimer's and Related Disorders Association of Thailand conducted an educational day for medical and nursing students and professionals. Asociacion Dominicana de Alzheimer in the Dominican Republic hosted a public meeting in a central park while the Turkish Alzheimer Society and Foundation organised a training programme for police officers to enable them to better understand and respond to people with dementia they may encounter in their duties.

World Alzheimer's Month and World Alzheimer's Day allow for a great number of creative and informative activities to take place. In Germany alone, around 200 activities took place and in the Netherlands Alzheimer Nederland's branches

organised 55 activities in total, including special events at their Alzheimer Cafés, an initiative they founded fifteen years ago that has since been replicated in a number of other countries.

ADI would like to thank all of its members for their great efforts and MetLife Foundation for their support of World Alzheimer's Month.



Asociación Costarricense de Alzheimer y otras Demencias Asociadas in Costa Rica launched a campaign to raise awareness of the 10 warning signs of dementia



Iran Alzheimer Association organised an event to thank their volunteers and announce the winners of their successful photography competition

Dementia newsflash

■ Australia

Alzheimer's Australia's successful *It's not a disgrace...it's dementia* documentary series has recently been extended to include films for Arabic, Serbian, Spanish and Ukrainian communities. The full series of short films, can be viewed on Alzheimer's Australia's YouTube channel.

■ France

New French President, François Hollande, announced on 21 September that he will prolong the country's *Plan Alzheimer*, adding that the plan will be evaluated to test its effectiveness.

■ Iran

In late October, Iran Alzheimer Association (IAA) met with the Health Ministry to follow up on the development of a national dementia plan. The Ministry reported that they had already begun to work on the project and had produced two booklets for family doctors and health professionals.

■ Italy

ADI were sad to learn of the passing of Ornella Salvini in October. Ornella played a key role in the work of Federazione Alzheimer Italia and was a regular presence at the Alzheimer Europe and ADI conferences. ADI offers condolences to her sister, Gabriella, and the rest of her family at this difficult time.

■ Mexico

On 12 November, Federacion Mexicana de Alzheimer (FEDMA) signed a landmark agreement with the National Institute on Aging and National Institute of Neurology that will see the formation of a national dementia plan.

Living with dementia

Different day, different diagnosis

Norman McNamara, UK

I was diagnosed with Lewy Bodies type dementia after being told I had the Alzheimer's type four years ago. I will explain to you what this means to me.

To be honest it didn't come as a shock as we had investigated this before but had just taken my old consultant's word on it (I now have a new one) so we did know a little about it. I can now say though that I know a lot more about it than I did and I must credit that to some of my wonderful friends on the internet who sent me some wonderful information on the subject. I have been given Exelon now to take alongside my Ebixa and I must admit to feeling a little 'spaced' at the moment but hopefully that will pass. It's the probable sickness I am not looking forward to as I am not a sickly person.

I must admit though to being knocked sideways when I heard the news. You would have thought I had become accustomed to it by now, but does anybody ever get 'used' to hearing the news they have dementia? I shouldn't think so. The more I read about this type of dementia the more worrying it becomes.

Have I become complacent in thinking I am ok and just got 'used' to my illness? The symptoms are very similar apart from the hallucinations, nightmares, smells and sounds. I must admit to thinking (fleetingly) 'How much more can anyone take!!', but then I just felt so selfish as I know it's my Angel, Elaine, who will suffer and my family will struggle seeing me imagine things that aren't really there.

Am I frightened? YES, absolutely terrified. But am I ashamed of having this awful illness ... CERTAINLY NOT



Norman McNamara is widely known in his community and in the UK dementia field for his efforts to raise awareness of dementia

We now have to look at this illness all over again. We have to think how we can change things, how we can do things for the future which will benefit all. Once again I will have to sit my family down and prepare them for the worst because the hallucinations began a while ago, only minor ones, but still. The nightmares still come thick and fast and I sometimes have trouble separating reality from dreamlike states. It's like starting all over again in some ways because some lifestyle changes will have to be made. Sleeping arrangements, respite for my darling Elaine and so forth. All these things have to be thought out, talked about and prepared for.

Yes, these are worrying times. There is no such thing as 'bad dementia' or 'better dementia', there is just DEMENTIA and no matter what

type it is, unless a cure is found, the outcome is just the same. You can't just have a 'touch of' dementia, that would be the same as being a 'little bit pregnant'! But, my friends, my resolve is just the same and my determination to beat this thing is still as strong, albeit a little more battered these days.

Me and my family will come together as one, as we always do, and plan for the future the best way we can. Am I frightened? YES, absolutely terrified. But am I ashamed of having this awful illness whatever type it is? CERTAINLY NOT, and never will be. And, of course, I couldn't finish without thanking each and every one of you who have supported, helped and befriended both my family and me; each and every one of you are my heroes, thank you and bless you all. All our love, Norrms, Elaine and family xxxxxxxxxxxxxx

■ Carer's story

Lessons for a full and good life from a 20th century father to 21st century child

A speech by Chris Ward, UK, delivered at his father's funeral in September 2012

I am having a good life in a different age to my dad – but when I have reflected over this week – and in fact over most of my life – the reason I have experienced some success at work, play and love is due to the critical lessons my dad taught me that have dictated the way I live my life.

These lessons were far more important than anything I learnt at school or through work. These are not the lessons of how to be cleverer or get more money – these are the lessons of how to live the best and fullest life.

1 Expect nothing more of your children than for them to do their best

Work hard and do your best at everything you try; homework, cycling, helping at home. Life doesn't owe you anything. This was Dad leading by example. Critically though – and this is how dad must have differed from many other fathers – there were no further expectations placed on us, if we did our best that was simply enough, nothing more was expected from us.

2 Anything is possible

Mum would often say "there's no such word as 'can't'" but dad really showed it to me when we went to see the careers officer at school. He came with me with his full backing while we told the careers officer I wanted to be ... a Formula 1 motor racing driver. To be fair to him the careers officer went off to investigate and a week later reported back that

we needed to be millionaires if that was to happen – which it didn't! But it showed me that my dad thought it was possible.

3 Watch the pennies

It seemed Dad loved the idea of beating the supermarkets at their own game (we didn't know it was out of necessity). I remember walking back and forth between Sainsbury's and Presto as Dad compared prices and made sure he got the best deal in town for the weekly shop.

4 Ride a bike

A bike isn't about getting you from A to B. A bike provides the opportunity to gain the most pleasure there is from life, to enjoy the simplicity that life should be about, to cycle through sunny country lanes, to keep fit, to pass the time with friends, to get away from all the stresses and strains for a few hours.

5 Eat more cake

Everyone likes cake. Cake makes you happy, you can't ever eat enough but the magic is if you cycle you can eat as much as you like – Dad did and so never had an ounce of fat on him.

6 Put family first / stay married

Mum and Dad always put us first. Dad made brilliant toys, Mum made brilliant dinners. They also put their marriage first. Everyone has stresses and strains in their marriage – but all us three children are still together in long relationships. This is a tribute to my mum and dad who so ingrained in us that we stick together – however hard it gets...



Chris cycled from one end of the Pyrenees to the other, covering 18 mountains in 100 hours around World Alzheimer's Day, in memory of his father, Roy

7 Embarrass your kids

My kids will verify I follow this lesson to the ultimate degree. Dad lived his own life and if that meant embarrassing us that was fine. The thought of being embarrassed is what stops most people attempting something new or doing what they want – Dad didn't have that, and much to my son's regret – nor do I!

8 Finally, with the onset of Alzheimer's came the last lesson and a side to Dad we hadn't often seen before. He started to show his emotions and feelings – on many levels. Alzheimer's is a horrendous illness – often more for the partner and carers than for the sufferer themselves. But, it was great to see Dad setting the example that it's alright for a dad to show his emotions. It took a lifetime to pass over from father to son – and one that I am still working on.

Dad had a great life and, following his guidance, his grandchildren will also get the same chance.

This is an edited version of Chris's speech. To view the full version visit <http://bit.ly/ULQyz8>

■ How associations help

Being a volunteer at ALMA

A path for service

Elsa Ghio, Argentina

I approached Asociación de Lucha contra el Mal de Alzheimer (ALMA) for guidance. I went with my relative who was diagnosed with Alzheimer's disease. We were greeted by Lidia Iriarte, a volunteer. I cherish three things from that day: first, good treatment, warmth and good information, second, the recognition of the dignity for my relative, and third, through the conversation the possibility emerged of forming an ALMA office in Corrientes. It was 2004 and I needed time to mature my connection with the disease. I took that time and returned in 2010 to offer my service as a volunteer.

Since then, I realised that what I had cherished from my personal experience back in 2004 coincided with ALMA's

commitment to the mission of the association, especially in regards to sharing up to date information and what can be done to improve the quality of life of the patient and family caregivers.

Perhaps the most valuable aspect was to discover that the task and mission of the volunteers matches my personal vocation: to serve others. I am very respectful of the history and value of the institution that was made by its founders and enabled ALMA in the country. Today I feel 'part of' and 'co-star' of the ALMA organisation, from my possibilities to reality. I am grateful for the opportunity. I am excited about the work I do and I'm learning more every day.

At present, I work with Norma De Nardi in coordinating the Family Support Group in the Zubizarreta hospital. I contribute to providing



Elsa Ghio has been volunteering with ALMA since 2010

personalised advice to family members at ALMA headquarters. I collaborated with the team to edit ALMA's 2011 magazine with Naomi Medina and Nevis Pazos, directed by Ana Baldoni. I am also working with Naomi in the design and programming of a Training Course for Coordinators of Family Support Groups.

Another activity that makes me very happy is to work towards providing new opportunities in other parts of the country where there are no family support groups established.

I believe I responded to the invitation offered by ALMA: 'Join us in ALMA with your soul' and I feel very happy!

To find out more about ALMA's work visit
www.alma-alzheimer.org.ar

ADI receives legacy of \$225,000

This spring, ADI received a legacy of US\$225,000 from a donor in Florida, USA. This donor had put ADI in his will back in 1992, together with three other international charities. As often happens with legacies, ADI was not aware of this, so it came as a big surprise when the letter arrived. It also came as a relief at a time when we had increased expenses in advocacy, particularly with the launch of the WHO report.

ADI does not actively solicit bequests because our members in each country already do so, particularly in the high-income countries. Legacy income is significant for some of our largest members. However, we appreciate it when it happens. In cases where someone is born in a country and now

lives in a different country, it could be a reason to donate to international causes like dementia.

Should you ever come across someone who is interested in doing this, make sure they use the right name and address of Alzheimer's Disease International. ADI is registered in the USA in the state of Illinois as a 501(c)(3) non-profit organisation with tax ID 36-3366783. In the UK, Friends of ADI is a sister charity, which exists to support ADI's work, so donations from the UK can be tax efficient. Friends of ADI is registered with the Charity Commission of England and Wales with registered charity number 1076992 and it has the same address as ADI (which can be found on page 2).

In other countries, it would be good to look at local legislation around this issue. ADI receiving a legacy has prompted me to think about my own Will (that is 20 years old) and how to include ADI as a beneficiary. Under Dutch law, in order to avoid inheritance tax, you have to leave your legacy to a tax registered charity, so an option is to put Alzheimer Netherlands in my will and ask them to donate half or all of the amount to ADI.

I hope the above will inspire you to consider leaving a bequest, or at least making a Will. And if you already have left a bequest, you might like to consider letting us know, so that we can acknowledge and thank you in person.

Marc Wortmann, Executive Director

■ Research update

Mixed results from Alzheimer's disease clinical trials

Reisa Sperling, Professor of Neurology, Harvard Medical School, USA

Researchers reported the results from several large Phase 3 Alzheimer's disease clinical trials at the American Neurological Association meeting in Boston and the Clinical Trials in Alzheimer's Disease (CTAD) meeting in Monaco, this October. The Phase 3 trials tested two different antibodies (blood immune proteins), bapineuzumab and solanezumab, designed to help clear amyloid out of the brain.

The bapineuzumab trials enrolled over 2500 people with dementia across the United States, divided into two studies: one trial for patients who have the most common genetic risk factor for Alzheimer's disease – apolipoprotein E epsilon4 allele – which tested only low dose bapineuzumab, and one trial for patients without the genetic risk factor.

Unfortunately, neither trial showed evidence of slowing the progression of clinical symptoms in Alzheimer's disease. However, there was evidence that bapineuzumab had some effect on the biological markers tested in the study. Patients treated with bapineuzumab showed less amyloid accumulation on PET amyloid imaging and less evidence of nerve cell injury in cerebrospinal fluid tests. Although these biomarker results were somewhat encouraging, researchers think we may be trying these drugs too late in the course of Alzheimer's disease, and that we

might have a better chance of slowing progression if we started treatment at earlier stages of the disease. It may also be that we need to give higher doses of these antibodies to lower amyloid, but bapineuzumab had some side effects that limited the doses in the study.

The solanezumab trials enrolled over 2000 patients in two studies conducted around the world. Unfortunately, these studies also did not demonstrate a significant clinical effect overall, but there was some evidence that those in the milder stages of dementia treated with solanezumab had a slower rate of clinical decline. Combining across the two trials, the mild dementia patients treated with solanezumab had slightly less decline in thinking and memory tests than the patients treated with placebo.

The PET amyloid imaging results showed a very slight treatment effect on the amount of amyloid in the brain but this was only clearly seen in one of the PET studies. There was no evidence of a positive effect on the cerebrospinal fluid measures of phospho-tau or tau (the markers of nerve cell injury), but there were some effects on the levels of cerebrospinal fluid amyloid peptides. Although the treatment benefits were small, the clinical results in the mild dementia group suggested that if treatments like solanezumab were started earlier in the course of Alzheimer's disease,

we might be able to have a positive impact on the disease.

Overall, there remains debate about whether the 'glass is half full or half empty' regarding anti-amyloid treatments in Alzheimer's disease. There is a growing sense in the field that we need to start these interventions much earlier in the disease process, as evidence from both genetic-at-risk and clinically normal older individuals suggests that the brain changes in Alzheimer's disease begin more than a decade before the symptoms are apparent. The success in treating other major diseases, such as cancer, heart disease, HIV, and diabetes, is primarily due to prevention efforts and very early treatment. The good news is that we now have imaging and biomarker tools to identify very early Alzheimer's disease.

Secondary prevention trials, aimed at delaying the onset of clinical impairment in healthy participants at high risk for Alzheimer's disease, are starting next year. One of the 'bottlenecks' in finding a successful treatment for Alzheimer's disease is the many months and sometimes years, that it typically takes to fill the enrolment in large scale clinical trials. Thus, we need to find ways to rapidly enrol patients and healthy older participants into these new studies quickly, and look forward to reporting a positive result from an earlier treatment trial soon!



News

ADI conference wins Excellence Award



ADI's Membership and Events Manager, Jane Cziborra (centre), with representatives from MCI UK, the professional conference organiser

The 27th International Conference of Alzheimer's Disease International, held in London in March, has received the award for Association Congress of the

Year at Conference and Incentive Travel's (C&IT) Excellence Awards.

The conference was a landmark event, with a stream of sessions being run by people with dementia, a Memory Garden in the exhibition area and inspirational presentations from British celebrities, including Sir Terry Pratchett, who is living with dementia, and actor Ray Winstone.

ADI will host the much-anticipated 28th International Conference of Alzheimer's Disease International in Chinese Taipei in April 2013. To find out more visit www.adi2013.org

World Alzheimer Report 2012 launch

On 21 September, ADI launched the *World Alzheimer Report 2012: Overcoming the stigma of dementia*. The report is the fourth in a series featuring the latest global data and information about dementia. This year's report contains a review of survey findings on stigma associated with dementia and some of the successful programmes taking place around the world to address the issue.

The report was prepared by ADI alongside Nicole Batsch, who has 16 years' experience of developing ageing and dementia programmes across the USA, and Dr Mary Mittelman, Director of Psychosocial Research and Support



of the NYU Comprehensive Center on Brain Aging in New York. Essays were also contributed from a range of individuals within the dementia field.

The report contains findings from an international survey, conducted by ADI, of people with dementia and carers. Results of the survey, which was completed by over 150 people with dementia and more than 2000 carers, highlighted that 75% of respondents with dementia and 60% of family carers believe that there are negative associations for those diagnosed with dementia in their country.

A thought-provoking film was produced to accompany the launch of the report. ADI is grateful to Nutricia for supporting the production of the film and launch of the report and to those member associations that helped to promote it.

To view the *World Alzheimer Report 2012* and previous reports visit www.alz.co.uk/worldreport

The launch event for the report in London included presentations from the report's authors, a person with dementia and family carers

World Alzheimer's Month campaigns

This year ADI received great support from a number of individuals and organisations throughout World Alzheimer's Month. Two campaigns in particular played an important role in raising awareness.

Donate your Facebook timeline

On World Alzheimer's Day, 21 September, global PR firm Ogilvy chose to donate their services to ADI with a social media campaign to raise awareness of dementia. The campaign, called *Donate your Facebook Timeline*, enabled individuals with a Facebook account to install an application that, on 21 September when they visited their Facebook page, would remove all of their 'memories', including pictures, friends and previous posts.

The campaign attracted more than 20,000 visitors to its dedicated website over a 3 day period leading up to 21 September. A total of 4,873 Facebook users shared the campaign with their friends and it was mentioned in over 1,600 tweets from Twitter users. In total more than 700 individuals installed the application and experienced the loss of memories on the day. A supporting video was also made available on YouTube, which has to date received over 11,000 views.

ADI would like to thank Ogilvy for their valuable support.

How the times have changed

Australian-Maltese singer-songwriter Joseph Portelli generously offered for all proceeds from the sale of his song *How The Times Have Changed* to be donated to ADI and national Alzheimer associations. A number of ADI member associations signed up to promote the campaign, which is still ongoing, and results from sales in September are expected soon. Thanks go to Joseph for his continuing support of ADI. Visit www.alz.co.uk/WAMsong to buy the song.