



**Alzheimer's Disease
International**

The global voice on dementia

30 YEARS

March 2015
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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.

ADI founder Jerome Stone 1913 – 2015

It was with great sadness that the global dementia community learned that ADI founder Jerome Stone sadly passed away at the age of 101 on 1 January 2015.

Jerry's story with dementia is an inspiring one and one that we have heard on a local and national level a number of times. After his wife received a diagnosis of early onset Alzheimer's disease in 1970, Jerry took it upon himself to address the lack of support available for people with dementia and their carers both nationally, by founding the Alzheimer's Association in the USA, and internationally, with the creation of ADI. He did this by bringing together likeminded groups to share information and strengthen the cause. This objective is still very much at the heart of ADI's work today, 30 years after it was founded.



During those 30 years Jerry continued to follow and support ADI's work and, in 2006, he received the very first ADI Award at the 22nd ADI conference in Berlin. He gave his last formal presentation for ADI at the Alzheimer University on Public Policy and Campaigning in Chicago in 2010. **CONTINUED ON PAGE 7**

Associations gather in London

ADI's annual Alzheimer University programme for emerging associations took place in London in December, attended by representatives from Alzheimer associations in Bangladesh, Belgium, Bolivia, Kenya and Oman.

Presenters for the programme included Ann-Marie Evans and Kelly Butler from Alzheimer's Society (England, Wales and NI) who gave advice and guidance on working with the media, raising profile and awareness, and working with volunteers. Megan MacGarry from the International Alliance of Patients' Organizations (IAPO) highlighted the benefits of establishing collaborations and partnerships with other organisations, and ADI Honorary Vice President Nori Graham sat participants in a circle, support group style, to discuss setting up support groups.

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Participants and presenters discussing support groups at the Alzheimer University



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 30 April 2015.

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Editorial

Jacob Roy, Chairman



As we look ahead to our forthcoming international conference in Australia, I am entering the final months in my role as Chairman. The past three years have presented us with great challenges, but am I pleased that we have risen to them and made great progress. I am delighted that we now have greater presence within the Middle East and Africa regions with the regional conferences bringing us into contact with many new and emerging associations and interested individuals. Regional events in the English-speaking Caribbean have been a big step forward in improving communication with our member associations there and we are working closely with members in Latin America to strengthen their region. We have also worked with members across the Asia Pacific to strengthen this unique and varied region with the introduction of the regional office.

We continue to encourage our member associations to collaborate and our Twinning Programme has more recently seen the pairing of associations in Indonesia and the Netherlands, Germany and Turkey, and Nepal with Alzheimer's Australia Vic. It is encouraging to see that informal relationships are still forming as well in which a more developed association acts as a mentor, providing great support where it is very much needed. We have also worked alongside our members and like-minded organisations to create alliances in countries like Bangladesh and, in China, we have collaborated with the association to strengthen its secretariat.

A real turning point during my tenure as Chairman has been in global advocacy, particularly with the G8 Dementia Summit held in 2013. Since this original meeting we have seen the creation of the World Dementia Council and the appointment of the World Dementia Envoy, as well as follow-on G7 meetings and Australia leading the way in calling for dementia to also be addressed by the G20. We are also continuing our work with the World Health Organization and I am delighted that we will be actively involved in a WHO meeting of Health Ministers in March.

In April, Glenn Rees from Australia will take over the ADI helm. I am confident that, under Glenn's leadership, ADI will continue to grow its reputation and efforts worldwide. We still have much work to do and I am sure the legacy I leave behind me will be taken up and built upon in the coming years.

Events

16 – 18 March 2015
Dementia Care Innovations: Showcasing De Hogeweyk Dementia Village Melbourne and Sydney, Australia
Email: joannetan@ageingasia.com
Web: www.ageingasia.com/index.php/industry-trainings/australia/australasia-ageing-global-masterclass

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

15 - 18 April 2015
30th Annual International Conference of Alzheimer's Disease International Perth, Australia
Email: adi2015@mci-group.com
Web: www.alzint.org/2015

14 – 17 May 2015
9th Panhellenic Interdisciplinary Conference of Alzheimer's Disease and Related Disorders and 1st Mediterranean Conference on Neurodegenerative Diseases Thessaloniki, Greece
Email: info@alzheimer-hellas.gr

■ Meetings round-up

New alliance with DAI



Some of DAI's members at the ADI conference in 2014

ADI and Dementia Alliance International (DAI) formalised arrangements for a new partnership in January which would guarantee a greater presence of people with dementia in ADI's work and strengthening of both parties. The agreement will see DAI input on key ADI documents and position papers as well as people with dementia speaking at a number of ADI and other events throughout the year. An annual meeting of people with dementia will take place at the ADI conference each year and DAI will benefit from ADI's international connections.

For more information about DAI see page 8 or visit www.dementiaallianceinternational.org

Alzheimer University

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ADI adviser Jan Killeen attended the full programme, presenting sessions on how to set up an association and governance as well as screening a short film about people with dementia from the Scottish Dementia Working Group.

Additional sessions, presented by ADI staff, included providing information, fundraising and using social media. At the end of the programme the associations set three objectives to work on upon their return home, based on their learnings from the programme.

Twinning Programme

Alzheimer's Australia Vic and ARDS Nepal are the latest pairing of Alzheimer associations to join ADI's Twinning Programme with discussions taking place during 2014 to establish an action plan that would be of mutual benefit.

Following a visit to ARDS Nepal by Maree McCabe and Ann Reilly from Alzheimer's Australia Vic in June last year, the three key objectives were identified as: raising awareness in Nepal and encouraging government funding for education and services for people with dementia, sharing education resources to educate carers and health professionals about dementia, and enabling Alzheimer's Australia Vic to learn from the current activities in Nepal and how they might benefit from them. With many years of experience, Alzheimer's Australia Vic is able to offer examples of education programmes and resources, and successful service delivery models which could be modified for use in Nepal. They are also able to share their expertise in developing and leading services as well as working with governments and lobbying for funding.

In November, ARDS Nepal visited key ministers, officials and non-governmental organisations in Nepal alongside ADI Chair-Elect Glenn Rees. During this visit it was established that there is a severe lack of awareness and understanding of dementia, both in the country's administration and in society, as well as a distinct lack of services for people with dementia. These meetings enabled ARDS Nepal to see the real need for greater awareness raising, the creation of a diagnostic centre and dementia resource centre, and support of the existing services that are struggling.

ADI is committed to supporting ARDS Nepal and Alzheimer's Australia Vic in this work through the Twinning Programme and is confident that this partnership will be strong and hugely beneficial to both associations.

For more information on ADI's Twinning Programme visit www.alz.co.uk/twinning

Alzheimer Europe EPAD collaboration

Alongside 34 partner companies and institutions from across Europe, Alzheimer Europe announced in January that a 5-year programme, the European Prevention of Alzheimer's dementia (EPAD) initiative, would begin testing new treatments with the aim of preventing Alzheimer's disease.

In order to carry out the work, a Europe-wide register of around 24,000 people will be gathered from existing registers, with 1,500 individuals invited to take part in a trial. The trial will be delivered from around 30 sites within six countries or regional areas. The data from the trials will be collected and made publically available for analysis.

Jean Georges, Executive Director of Alzheimer Europe, said of the initiative, "Preventing the development of dementia in biomarker-positive people would be a fantastic step forward in our fight against Alzheimer's dementia. The EPAD project and its novel trial concept will hopefully help speed up the drug discovery progress and bring us closer to this ambitious aim."

For more information about EPAD visit www.ep-ad.org

■ Policy Update

World Dementia Council update

The World Dementia Council (WDC) announced in January that it has appointed a person with dementia as a new member, a move that has been welcomed by the global dementia community. Hilary Doxford, who lives in the UK, was diagnosed with early onset Alzheimer's disease in 2012 and appeared in videos shown at the G8 Dementia Summit in 2013. In the video Hilary describes her need for more information about what her future holds while her husband, Peter, calls for the media to help increase awareness of dementia. Hilary's appointment to the WDC is an important step forward in the inclusion of people with dementia in global advocacy.

Meera Pattabiraman, Chairperson of the Alzheimer's and Related Disorders Society of India, was also appointed to the WDC recently, adding to the number of members from low and middle income countries.

Based on a review carried out by Harry Johns, President and CEO of the Alzheimer's Association (USA) and member of the WDC, a statement was issued by the WDC in January about dementia risk reduction. It was announced that, although more research is needed in the area, there is growing evidence of risk factors in dementia and the topic will now be one of their five priority areas of work.

First WHO dementia conference announced

At the time of going to press, we were just weeks away from the First World Health Organization (WHO) Ministerial Conference on Global Action Against Dementia, to be held on 16 and 17 March in Geneva, Switzerland. This meeting is the WHO's response to the recent G7 efforts and will bring together health ministers worldwide to discuss the current global and national impact of dementia, governments' roles and responsibilities in the area and how they can work together to bring about change and improvements in dementia care and research.

It is expected that the event will be webcast by the WHO and a full report on the conference will appear in the next issue of *Global Perspective*.

G7 legacy event held in USA



ADI Executive Director Marc Wortmann presented during a meeting following the event

On 11 February, the fourth G7 dementia legacy event took place in Bethesda, USA. The event was attended by representatives from the G7 countries, the European Union, World Health Organization (WHO), Organisation for Economic Development and Cooperation (OECD) and members of the World Dementia Council. During the half-day meeting updates were given on the WHO's research prioritisation project and from each of the G7 countries on progress made since the last legacy event in Japan in November.

Among the updates was news that joint cohort studies will be carried out by Canada, Japan and the UK into multiple chronic diseases including dementia and risk factors. The Canadian government announced that they would be working with the Alzheimer Society of Canada to introduce a Dementia Friends programme, inspired by those in Japan and the UK. Germany have started to introduce local dementia alliances, with more than 1000 local sites already enrolled, and Dementia Care Managers who bridge the gap between people with dementia and the health system. Both Italy and Japan launched national plans to improve research and services for people with dementia and their families while France shared news of their new plan for addressing neurodegenerative diseases, including dementia.

The OECD presented figures on current dementia research budgets from the G7 countries, which clearly showed that, while the USA has the largest budget it still falls far behind the amount spent on other major disease areas. As a result of its ongoing research programmes, the European Union is spending a large amount on dementia research and patient organisations are now involved in its policy making.

After the event, ADI and the Alzheimer's Association (USA) hosted a meeting with non-profit organisations who fund research in the USA and Europe. The Association has set up the International Alzheimer's Disease Research Portfolio, a database of studies currently taking place around the world, and in some cases this has already led to a number of cross-border collaborations.

Since the event, the UK government has announced a commitment of £300 million to fund dementia research over the coming 5 years. In addition, they have committed to ensuring that all National Health Service staff receive dementia training.

Member profile

Still a lot to be done



The German Alzheimer Association (Deutsche Alzheimer Gesellschaft) celebrates its 25th anniversary



German Alzheimer Association's staff

Founded on 2 December 1989, the German Alzheimer Association celebrated its 25th anniversary last year. "Considerable progress has been made concerning the quality of life of people with dementia in Germany," says chairperson Heike von Lützu-Hohlbein, "but there is still a lot to be done."

The association is rooted in the principle of self-help of people with dementia and their families. Support groups, organised and run by volunteers, still constitute the heart of the organisation. They provide support and counselling in the communities. To further their cause politically and to raise awareness for the disease, the national association was founded.

In the beginning the association had to build its own structure, raise funds, establish connections into the government and form alliances with other non-governmental organisations. Today the German

Alzheimer Association is head of 137 regional Alzheimer organisations all over Germany. The office in Berlin employs 14 people, maintains a dementia helpline and provides information to people with dementia, their families, care professionals and volunteers. 2,000 people visit the association's website every day.

The German Alzheimer Association funds research that benefits people with dementia in their daily lives. A training programme is offered to volunteers and a national conference organised every two years. In October 2006 the German Alzheimer Association hosted the 22nd conference of Alzheimer's Disease International in Berlin.

Seeking exchange with others, the German Alzheimer Association is committed to international cooperation with Alzheimer associations. It has established close connections to ADI. The German association has been part of ADI's World Alzheimer's Day working group and is taking part in

the Twinning Programme with the Turkish Alzheimer Association. As a long-time member of the board of Alzheimer Europe it takes part in the effort of representing people with dementia within the European political realm.

The German Alzheimer Association has been successful in informing society about dementia, providing support for the self-help network and putting dementia on the agenda of law makers. Today the organisation is able to represent the interests of people with dementia in a number of national committees. Heike von Lützu-Hohlbein is vice-chair of the National Alliance for People with Dementia that is working towards a National Dementia Strategy.

However, "People with dementia still face many challenges and they need our support," says Heike von Lützu-Hohlbein, "the outdated representation of people with dementia within the German Long-Term Care Insurance has to be reformed. The general level of diagnosis for people with dementia needs to be improved, as well as the treatment of patients with dementia in acute care hospitals. Despite all these political and judicial problems we should keep in mind what a person with early onset dementia said on our conference 2008: 'There is a life after diagnosis.'"

For more information about the work of the German Alzheimer Association visit www.deutsche-alzheimer.de

Members' forum

ADI members: do you have news to share with the global dementia community? Please contact us - info@alz.co.uk

ALZHEIMER IBEROAMERICA

8th conference for regional group



Alzheimer Iberoamerica (AIB) will host the 8th Ibero-American Congress on Alzheimer's Disease from 15-17 October in Rio de Janeiro, Brazil this year.

Under the theme *Reinventing the Long Road: Aging and Longevity*, topics up for discussion will include older people and society, nutrition and physical activity, assistive technology in caring

for people with dementia and the status of national dementia plans across the region. Abstract submission for the event will close on 30 April and reduced rate registration will be available until 31 May.

Confirmed speakers so far include Daisy Acosta and Martin Prince, who have both played an important part in researching dementia across the region through the 10/66 Dementia Research Group. The event will also include the XII Meeting of the AIB member associations. For more information about the event visit www.aibbrasil2015.com.br

Dementia newsflash

Caribbean

At the time of going to print, the Regional non-Latin Caribbean Conference was taking place in Curacao, incorporating an ADI workshop on Public Policy and celebrating the 15th anniversary of Stichting Alzheimer Curacao. A full report on this event will appear in the next issue.

Germany

Heike von Lützu-Hohlbein, first President of the German Alzheimer Association (DAIzG) and current Chairperson of Alzheimer Europe, was awarded for her ongoing voluntary commitment in Germany. She received her award from Bavarian Health and Care Minister Melanie Huml in November.

Venezuela

Fundación Alzheimer de Venezuela announced a new fundraising collaboration with the bank Banplus in January. Known as "the unforgettable account", bank users can donate to the Fundación using the account number 0000-0000-00-0000000000 (20 zeros).

AUSTRALIA

New CEO takes the lead



In December, Alzheimer's Australia welcomed Carol Bennett as their new Chief Executive Officer. Carol has over 15 years' experience in senior management roles in national and state health organisations, such as the Consumers Health Forum of Australia. She has recently been appointed a Board Director of the International Alliance of Patients Organisations and holds similar posts with numerous other national and international policy groups.

Carol's appointment as CEO of Alzheimer's Australia follows the stepping down of Glenn Rees who will take over as ADI Chairman in April. We are sure that, with her past experience, Carol will provide strong leadership and great knowledge. ADI wishes her well in her new role and looks forward to working with her and the Alzheimer's Australia team for many years to come.

For more information about Alzheimer's Australia visit www.fightdementia.org.au

Members' forum

IRAN

New centres for care and research

On 13 January, Iran Alzheimer Association (IAA) hosted a fundraising event to support the completion of their new centre, which is currently being constructed after land was donated by Tehran Municipality. The event was filmed by four television channels and coverage was broadcast seven times. At the event, IAA's new Honorary Patron, Prof Majid Samii, announced that he had signed a Memorandum of Understanding with the country's Ministry of Science and Technology to establish a new research centre in Tehran. Although this development is still in its early stages, it is hoped that the centre will eventually carry out research into a number of areas, including dementia. Prof Samii has already established a neuroscience centre in Tehran and plans to allocate a ward in the centre to people with dementia.

For more information about the work of IAA visit www.iranalz.ir

IRELAND

National strategy launched

Three years after declaring its commitment to developing a National Dementia Strategy for Ireland, the country's government released the final document on 17 December 2014. The Strategy, which The Alzheimer Society of Ireland had played a large part in progressing, states three priority areas to receive increased funding: intensive home care supports, GP education and training, and dementia awareness.

A year after the government had announced their plans to address the needs of people with dementia and their carers in 2011, The Alzheimer Society of Ireland was given the opportunity to make a submission to the Department of Health with recommendations for the key areas to be addressed. A working group was formed by the Department of Health in 2013 to advance the strategy, working on the core elements of the plan as well as an implementation plan. The Alzheimer Society of Ireland hosted two roundtable discussions, bringing together those on the strategy working group with people with dementia and their carers to ensure their voices were heard.

For more information about the strategy and the work of The Alzheimer Society of Ireland visit www.alzheimer.ie

Remembering Jerome Stone CONTINUED FROM PAGE 1

To mark Jerry's passing, the following messages have been gathered by some of our past chairmen, those at ADI who knew him best.

Brian Moss: *It is indeed sad to learn of the passing of our founder, Jerome Stone, yet in our grief we must also celebrate what Jerry has accomplished for people with dementia and their families. Jerry inspired me to join with others in Australia and so began our journey to establish the Alzheimer's Association of Australia. Subsequently, together with other Australian representatives, it was a privilege to attend the inaugural meeting of ADI held in Washington*

DC in October 1984. We shall always be grateful to Jerry for his leadership and wise counsel which has contributed enormously to what ADI has become today.

Nori Graham: *He was such an important figure for the Alzheimer movement. It was his vision which created the American Alzheimer's Association. But he had a wider view of the needs of the whole world and went on to found ADI. I shall never forget how excited he would be each year when he used to come to the ADI council meetings and saw the increase in the number of countries around the table. I know he was very proud of our achievements. I shall miss him.*

Henry Brodaty: *Jerry Stone was the founding father of ADI. In 1984 Jerry had the vision and the energy to bring together a small international band that formed ADI. Jerry maintained a keen interest and careful oversight of ADI for the next 30 years! He attended many of the ADI annual conferences, always carefully reviewed the finances and was instrumental in the appointment of Princess Yasmin Aga Khan as our Honorary President. I was a huge admirer and fan of Jerry. He was the rock on which the Alzheimer's Association (US) and ADI were built. A great man! We miss him enormously. His legacy will endure and grow.*

Living with dementia

Dementia Alliance International

Kate Swaffer, Australia

Dementia Alliance International (DAI) is the first global group, of, by and for people with dementia, where membership will remain exclusive to people with dementia.

Dementia Advocacy and Support Network International (DASNI) was the first organisation set up in 2001 by people with dementia; however membership of DASNI did not remain exclusive to people with dementia and two thirds of their membership is now comprised of people who are carers or others without dementia.

In the last few years, the voices of people with dementia around the world have become stronger, led by some trailblazers including Christine Bryden, Peter Ashley and Richard Taylor. Ultimately a number of people with dementia met online, and finally sowed the many seeds of what was to become DAI, to give us back an autonomous voice, and to ensure issues such as social isolation, discrimination, stigma and exclusion are addressed. We started this group using the vast global networks of people with dementia now speaking and collaborating with each other over the Internet through blogs, Twitter, Facebook and other social media. We were established on 1 January 2014 to promote education and awareness about dementia, to eradicate stigma and discrimination, and to improve the quality of the lives of people with dementia.

The founding members of DAI are Richard Taylor, John Sandblom, Kate Swaffer, Steve Ponath, Janet Pitts, Dena Dotson, Susan Stephen and Amy Shives. Laura Bowley has also been a significant contributor to the emergence of DAI and its success, and we thank her for her support and passion. She has not been diagnosed

with dementia, but has advocated for our rights for a number of years, and we hope that eventually we can raise funds to support a paid executive administrative position within this organisation, who may be a person with, or without dementia. Our 2015 Board Members are Co-chairs Janet Pitts and Kate Swaffer, Treasurer John Sandblom, Secretary Sid Yudowitch, and Sue Stephen, Agnes Houston, Helga Rohra, Chris Roberts, Leo White and Scott Russell.

Dementia Alliance International have modelled themselves on the establishment of the first of the dementia working group where membership comprises people with dementia. The Scottish Dementia Working Group (2002) led the way, followed by Europe (2012), Australia (2013), Ireland (2013), Japan (2014) and currently Canada are developing their own Dementia Working Groups. As such, the voices of people with dementia are becoming more unified, and global, as membership is comprised of only people with dementia, and supported by their national Alzheimer's associations. DAI advocates for the voice and needs of people with dementia, and provides a global forum, aiming to unite all people with dementia around the world to stand up and speak out. By working with ADI, and all of these Dementia Working Groups, our vision; **A world where a person with dementia continues to be fully valued**, will be realised.

One of DAI's major goals was to become the peak advocacy and support organisation for people with dementia, by people with dementia, and through collaboration with ADI we have now achieved that, and we are proud to be working with ADI, and to have more recently joined the Global Alzheimer's and Dementia



Action Alliance whose vision is *"To transform the lives of people with dementia and those that care for them through building commitment and actions at a national and international level and through the sharing of best practice and learning"*. ADI's Global Charter states; *"I can live well with dementia"*.

We share similar goals and vision, and many of our members are living well, alongside their diagnosis of dementia. With ADI, the members of DAI look forward to networking into all countries, as, for now, membership currently only represents seven countries, and to assist this process, our website has a very functional translation button on it.

Services include weekly online support groups in two time zones, hosted by members in the USA, UK and Australia. We have a number of educational videos on our YouTube channel, including recordings of our monthly webinar series, *A Meeting of the Minds*. Members are engaged in various other activities and projects, and we have a Circle of Friends of more active members. We run sub-committees to develop educational videos, provide members with a media watch, offer a speakers bureau and undertake fundraising. We welcome new members, and are always supportive of people without dementia becoming involved, either as volunteers, or to assist us with fundraising or other activities for members.

Membership is free for people with dementia, and anyone can subscribe to our newsletters or weekly blog, all on our home page at www.dementiaallianceinternational.org

What we can't do alone, we **can do** together.

■ Carer's story

“I care for her. She comforts me.”

Lili, Peru



Lili with her mother Ana

The lack of knowledge about dementia and family conflicts

Four years ago Lili went to see her mother Ana who lived alone in Trujillo, a Peruvian city. She noticed changes in her mother's behaviour, her memory and her speech. These changes caught her attention but she reassured herself that these were just changes that came with age.

Her mother would forget what she had been told, what she had seen or read. She would put money under her pillows and would shout and accuse people of robbery if she could not find it.

She would complain that someone was stealing her pots and pans, someone was shredding her sheets, and she would wear her keys hanging around her neck so as not to lose them. She would pay twice or three times when hiring a taxi and she would get confused when using money. She would forget about her medication, sometimes taking twice the doses and other times taking none at all. She had difficulties expressing herself and she could often not find the right words to use. She had been neglecting her personal appearance and hygiene.

Lili had noticed all of these changes and asked her siblings to visit her mother more often. She thought about having one of them move in with her. She was concerned her mother may need medical attention or someone to care for her. But her siblings got upset and said that she worried too much about an old woman being old. They said that they had no time to look after her. And so Lili went back to Lima where she lived; worried, frustrated and sad because, on top of all her family issues, she was going through a divorce.

After two years of coming and going to see her mother, Lili got an important phone call. It was her sister-in-law who sounded worried about her mother, “Ana is crying the entire time saying her children are all in prison and she is not able to see them. Her behaviour changes have increased and she hits her head and cries because someone is stealing her things.”

She would make her children look for her missing money for hours and this was making them extremely angry, and so they would not visit her often.

Lili took her mother to a hospital in Trujillo where a neurologist and a psychiatrist told her “it is part of the ageing process” and prescribed some vitamins. Lili felt they were mistaken. Full of doubt and fear she went to public and social security hospitals but was told they would have to wait for weeks or even months to get an appointment with specialists.

She decided to take her mother to Lima to a private clinic where another neurologist told her Ana has “brain reduction” secondary to high blood pressure and diabetes. Lili felt unconvinced with this answer once again, and she went to another private clinic where Ana was put through several evaluations and tests after which she was given the diagnosis of Alzheimer's disease.

Lili decided to move her mother to Lima to live with her. She even takes her to work with her. She says: “It hurts me deeply to see my mother suffer every time she wants to help. It seems unreal how she is not able to remember, when she gets confused. She sees me crying and she gives me comforting words, she cuddles me.”

“I do not mind if she cannot remember as long as she is happy. I want what is best for her. She always gave her best to us. It's just so unfair she has to go through this! I never thought I would be such a part of this disease as a main carer I have so many challenges.”

Nowadays Lili asks for help from her siblings who have labelled her as the “over worried” sister. She manages a very tight budget and her mother's pension is not enough to cover medical needs.

Lili feels she wants to learn more about this disease so she can cope better, especially with the behavioural symptoms her mother has that are difficult to handle. She is also worried about taking care of herself so she does not develop Alzheimer's.

■ How associations help

Disaster preparedness



Alzheimer's Pakistan provided medical support to people with dementia and their families after the 2010 floods

Flooding, hurricanes, tsunamis and earthquakes are just some of the natural disasters that have affected countries across the world in recent years. For many, learning to cope during and after a disaster can be difficult enough, but for those living with dementia and their carers the upheaval is often multiplied. Recognising this added impact, many Alzheimer associations have taken steps to prepare themselves and support individuals in their preparation ahead of any disaster occurring.

Planning ahead

Each year the Atlantic and Eastern Pacific regions experience hurricane season. Advances in meteorology allow for some preparation time prior to a hurricane occurring and chapters of the Alzheimer's Association (USA), offer local advice to carers on how they can prepare ahead of hurricane season. The Alzheimer's Association's website contains information on how to prepare and what to do in an emergency situation, such as managing agitation in a person with dementia.

Some associations also offer enrolment for a person with dementia on a safety programme such as MedicAlert® + Alzheimer's Association Safe Return® in the USA or MedicAlert® Safely Home® in Canada, which could assist should a carer become separated from a person with dementia in the event of a disaster.

Relief on the ground

Faced with the worst flood in Pakistan's history in 2010 with more than 20 million people affected, Alzheimer's Pakistan staff and volunteers immediately saw the need to be at the front line of relief efforts. With a shortage of food, clean water, clothing, shelter and medicine for those affected, the vulnerability of the people with dementia involved increased considerably. Through ADI, Alzheimer's Pakistan sent out an appeal for funds to support their

relief effort and received a strong response from both associations and individuals alike.

Working alongside Jahandad Society for Community Development (JSCD), a non-governmental organisation with vast experience of disaster relief work, Alzheimer's Pakistan identified and registered those living with dementia among the affected population in the relief camps and surrounding areas. Along with their families, the people with dementia were then adopted by Alzheimer's Pakistan for eight months following the floods and were provided with a tent, food, blankets and bedding, clothing, as well as required medicines. In addition, Alzheimer's Pakistan carried out a targeted awareness campaign for healthcare providers and district management teams to highlight the issues faced by people with dementia and their carers. This campaign helped to identify people with dementia who had been affected by the flooding and created a referral network for families to receive the necessary medical services required for their loved ones.

In 2011, an earthquake caused a series of tsunami waves to hit the east coast of Japan, causing widespread devastation in the Tohoku region. After establishing that their regional branch was unaffected, Alzheimer's Association Japan (AAJ) set up a team to check that all AAJ members were safe while a call for donations to support relief efforts was sent out. AAJ also submitted a request to the country's government that support should be given to people with dementia and their families who had been affected.

February 2011 saw devastation in Canterbury, New Zealand when a 6.2 magnitude earthquake hit the city of Christchurch followed by numerous aftershocks in the months following. At the same time as managing their own situations following the earthquake, Alzheimers Canterbury staff and volunteers responded immediately by ensuring that those living with dementia and their families within the region were safe.

In the aftermath, key issues included a lack of planned respite with over 600 respite beds lost, the relocation of 500 care home residents, familiar landmarks no longer existing, having to leave their home, and needing to use a port-a-loo in the street. To address these challenges Alzheimers Canterbury established an Immediate Response Volunteer Team within two weeks of the earthquake taking place. Support from Alzheimers New Zealand's national office and other branches was also available. ➤

■ Research update

The Dominantly Inherited Alzheimer Network (DIAN) and Trials Unit (DIAN-TU)

Serge Gauthier, Chair of ADI's Medical and Scientific Advisory Panel



Serge Gauthier provides details of the Dominantly Inherited Alzheimer Network (DIAN), a study of people who have a 50% chance of inheriting younger onset Alzheimer's disease due to one parent carrying an abnormal gene, and the Dominantly Inherited Alzheimer Network

Trials Unit (DIAN-TU) which is looking at treatment of these individuals before symptoms appear.

The DIAN initiative is an observational study led by Dr John C. Morris at Washington University in St Louis for persons from families with autosomal dominant early-onset Alzheimer's disease. These volunteers are seen at regular intervals for clinical evaluations, neuropsychological tests, brain imaging and cerebrospinal fluid (CSF) measurements. This study has already led to a map of the clinical and biomarker changes over time, prior to the clinical manifestations of Alzheimer's disease. For example, amyloid build up in the brain is detectable by positron emission tomography (PET) scan up to 20 years prior to symptoms, as reported in a landmark

article by Dr Randall Bateman and the DIAN investigators in the New England Journal of Medicine (New Engl J Med 367, 795-804, 2012).

Treatment against the amyloid build up before significant clinical changes is now possible, and the DIAN-TU is a randomized study led by Dr Bateman, also of Washington University, comparing drugs such as gantenerumab and solanezumab against placebo over two years, with regular measurements of the amyloid load in the brain using PET and CSF. More information about DIAN and the DIAN-TU is available at www.dian-info.org and www.diantu.info

From a personal perspective, the DIAN-TU study is a dream come true, since I moved into the Alzheimer field after meeting a 33 year-old woman with this condition, coming with her two teenage daughters and husband, who, after three years as caregiver, became the founder of the local Alzheimer Association. I have seen many of her close and distant family members since, and was hoping for a treatment protocol specific to their needs. We just enrolled this week our first such volunteer. I want to thank Drs Morris and Bateman for their dedication to the cause of families with early onset Alzheimer's disease.

Disaster preparedness

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Alzheimer's Marlborough sent a large number of quilts made during a "Quiltathon" to be distributed in Christchurch, which were welcomed by many at a time when they were concerned they had been forgotten.

Collaborative efforts

Providing help on the ground after any natural disaster requires great collaboration with other non-governmental organisations. Recently Iran Alzheimer Association signed a Memorandum of Understanding with the Iranian Red Crescent Society to support people with dementia and their families if natural disasters occur. Alzheimer's Pakistan is now working together with HelpAge Pakistan to develop a psychosocial and health intervention package for people with dementia to be used during emergencies.

Canadian honour for MSAP Chair

Dr Serge Gauthier, Chairman of ADI's Medical and Scientific Advisory Panel, received great recognition in January for his work to advance knowledge of Alzheimer's disease and dementia in his home country of Canada and further afield. Serge was appointed to the Order of Canada by His Excellency the Right Honourable David Johnston, Governor General of Canada, for his research efforts, including his setting up of the country's first multicentre study of tacrine as a treatment for Alzheimer's disease and the founding of the Consortium of Canadian Centres for Clinical Cognitive Research.

Serge said of the honour, 'I share this award with the patients and families across Canada and the rest of the world who are fighting Alzheimer's disease on a daily basis, and are hoping for effective prevention for their children'. ADI congratulates Serge on this honour and looks forward to continuing to work closely with him in the coming years.

■ News

25 years of your GP

This year marks 25 years since the launch of *Global Perspective*. Since the release of the first issue in April 1990, the newsletter has provided updates to the global dementia community on both the work of ADI and its increasing number of member associations worldwide. In more recent years personal stories from people with dementia and carers have become an important element of the newsletter and, in many cases, a regular reminder of why our joint cause is so important.

Throughout the year we will be bringing you the changing face of *Global Perspective* and stories spanning its 25 year history.



News from 1990: In our first issue of *Global Perspective* back in 1990, we reported on the development of our Medical and Scientific Advisory Panel, introduced our 15 member associations, and reported on our 5th International Conference in Dublin, Ireland.

To read back issues of *Global Perspective* visit www.alz.co.uk/newsletter

ADI's 30th International Conference www.alzint.org



Hussain nominated for WHO advisory role

In January it was announced that Hussain Jafri, founding Secretary General of Alzheimer's Pakistan, had been nominated by the World Health Organization (WHO) for the role of Vice Chair of their patient safety advisory group. The WHO Patients for Patient Safety (PFPS) programme was developed in 2005 to improve health care safety and reduce preventable harm in health care through advocacy, collaboration and partnership. The programme brings together more than 250 patients, care providers, policy-makers and those affected by harm as PFPS Champions to share their concerns in the area and advocate for safety improvements to be made around the world. ADI would like to congratulate Hussain on this important nomination and his ongoing work with the programme.



Recognition for Helga

For many involved in the global dementia field, the name Helga Rohra will be a familiar one. In recent years Helga, who lives in Munich, Germany and has a diagnosis of dementia with Lewy bodies, has become a true global advocate for people living with dementia. In December, her work in this area received the recognition it deserves when she was awarded the Deutschen Engagementpreis (German Prize for Civic Engagement) 2014 in the individual category. The award was given in her home country for Helga's tireless and fearless commitment to help others living with dementia and raise awareness of dementia, giving people with dementia a new, more accurate image of a person with dementia. ADI is thrilled that Helga's ongoing work has been recognised in this way and congratulates her on this well-earned award.



In the next issue of *Global Perspective*

- All the news from our 30th Annual International Conference
- A report on the First WHO Ministerial Conference on Global Action Against Dementia
- The winner of the Family Carer of the Year Award