



**Alzheimer's Disease
International**

The global voice on dementia

December 2013
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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 2013

World Alzheimer's Month launched on 1 September with the theme *Dementia: a journey of caring*. From Memory Walks to memory screening, exhibitions to laughter therapy, and Alzheimer Cafés to meetings with government, never has there been such a variety of events taking place across the world to raise awareness of dementia. Feedback from members so far has shown that their creativity is paying off with an increase in enquiries and interest since September. Turn to our *Members' forum* World Alzheimer's Month special on pages 6 and 7 to find out more about just some of the activities this year.



World Alzheimer Report 2013

On 19 September, ADI published the fifth in the *World Alzheimer Report* series with roundtable events taking place following the launch in Washington DC, London and Beijing. The *World Alzheimer Report 2013* features a comprehensive analysis of current long-term care for people with dementia, revealing that greater support for informal care is vital in preparation for the world's ageing population as needs for care increase. The report sets out seven recommendations for improving long-term care worldwide.

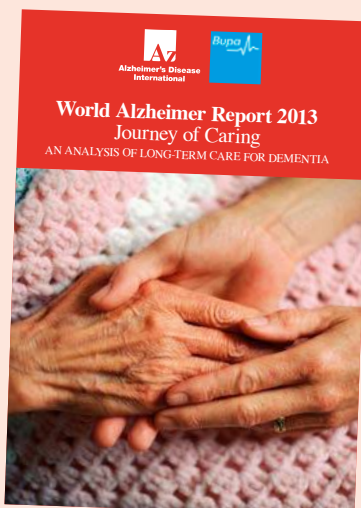


Roger Baumgart of Home Instead Senior Living and Norm McNamara, who is living with dementia, with ADI Director of Development Johan Vos and Executive Director Marc Wortmann at the London roundtable

In partnership with Home Instead Senior Care, ADI hosted the three roundtable discussions about the issues raised in the report and to gather opinion on what is and isn't working worldwide.

ADI wishes to thank Bupa for funding the report and Home Instead Senior Care for their support with the roundtable events.

To download the *World Alzheimer Report 2013* visit www.alz.co.uk/worldreport2013



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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 2014.

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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 2014

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Editorial

Jacob Roy, Chairman

Warm greetings!



Looking back, there was never a dull moment during 2013. ADI now has a regional office for the Asia Pacific region in Singapore, with a full time regional director. Indeed a major step forward in strengthening the region. Similarly the African regional meeting, the Middle East and North African conference, and the English-speaking Caribbean meeting have all reemphasised our commitment to developing regions. We have signed a new memorandum of understanding with Alzheimer Europe which we hope will strengthen our relationship with the members in the region. It was indeed a great experience to participate in the Alzheimer Iberoamerica congress in Uruguay in October and realise how valuable ADI's work is to our members in the region.

Developing dementia friendly communities is the buzz word in several countries around the world. This is an idea we would like to see happening in all our member countries. It will not only be more inclusive, but also economical and sustainable in the long run.

We are anxiously waiting to see the outcome of the G8 health ministers meeting on dementia in December in the UK. Obviously a positive outcome will certainly give more impetus to dementia research.

In the coming years we would like to see a member association in each of the WHO member countries. Similarly we would like all countries to make dementia a health and social care priority. Thus we have a long way to go in this journey; with those affected and their family members. To reach our goal, we certainly need to take an extra step.

I would like to welcome the new regional director for Asia Pacific, Francis Wong. I also want to express our deep appreciation to the ADI staff for their excellent team work. Let me wish you all of a very successful, productive and peaceful new year.

Events

2013

11 – 14 December 2013
16th Asia Pacific Regional Conference of Alzheimer's Disease International
Hong Kong SAR and Macau SAR
Web: www.aprc2013-hongkong.com and www.aprc2013-macau.com

2014

1 – 4 March 2014
22nd European Congress of Psychiatry
Munich, Germany
Web: www.epa-congress.org

26 – 29 March 2014
13th International Geneva/Springfield Symposium on Advances in Alzheimer Therapy
Geneva, Switzerland
Web: www.siumed.edu/cme/alzheimer

1 – 4 May 2014
29th International Conference of Alzheimer's Disease International
San Juan, Puerto Rico
Web: www.adi2014.org

8 – 11 May 2014
The 8th World Congress on Controversies in Neurology
Berlin, Germany
Web: www.comtecmed.com/cony/2014

10 – 13 June 2014
IFA 12th Global Conference on Ageing
Hyderabad, India
Web: <http://ifa2014.in>

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

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

■ Meetings round-up

Alzheimer Iberoamerica

Uruguay 16–19 October



Representatives from Latin America at a social event at Dr Roberto Ventura's house

ADI hosted a lively one-day Alzheimer University programme on advocacy for members before the start of this year's Alzheimer Iberoamerica conference. There was discussion about promoting the cause to political figures and participants were asked to develop action plans for their associations.

The conference featured further discussion on national plans, in response to the recent developments towards plans within the region. The voices of people with dementia were heard through four poignant speeches, a real sign of development and standing up against the stigma within Latin America.

Alzheimer associations gave presentations on their successful activities while speakers from outside of the region, including Prof Martin Prince from the 10/66 Dementia Research Group and Dr Graham Stokes from Bupa, shared knowledge on the cost and prevalence of dementia and person centred care.



Jacob visited Alzheimer's Association Korea staff at their headquarters during his visit

1st National Dementia Management Workshop

South Korea 31 October to 3 November

ADI Chairman Jacob Roy was invited to attend and speak at the National Institute of Dementia's 1st National Dementia Management Workshop, held in Seoul. The event, which was attended by almost 400 participants working in the dementia field, included much discussion on national dementia plans, including the French and South Korean plans as well as Jacob's international perspective.

The following day saw the 2nd International Conference on Ageing Cohort Studies take place at the city's national hospital where Jacob joined a number of doctors and researchers. During his visit, Jacob was also able to spend time at some care facilities and said of these visits, 'All these facilities are well run with very dedicated staff. I feel most of us are not so aware of the huge progress made in Korea in the last 20 years.'

Alzheimer Europe

Valletta, Malta 10–12 October

Positive messages and calls to action marked the opening of another successful Alzheimer Europe conference in October, with Dr George Abela, President of Malta, declaring of people with dementia: 'We have a lot to learn from them. Their voice should be our voice and their aspirations should be our goals.' A commitment was made by the Maltese government that a national plan would be developed focussed on increasing awareness, training and provision of services.

This followed Alzheimer Europe's AGM in which the organisation's members reached an agreement on an appeal to be presented ahead of the G8 summit on dementia. As part of the diverse programme, the European Working Group of People with Dementia continued to building upon the success and awareness of their group with a session organised by and featuring members of the group.

ADI to attend G8 dementia summit

At the time of going to press we are just days from the start of the G8 summit on dementia in London. ADI Executive Director Marc Wortmann received an invitation to attend the event, hosted by the UK Department of Health on 11 December. Health Ministers from the G8 countries (Canada, France,

Germany, Italy, Japan, Russia, UK and USA) will meet alongside professionals in the dementia field to discuss ways in which their governments can build cooperation networks for dementia research among governments, regulators, the private sector and non-profits. Prevention as well as investment

in solutions and treatment will be under discussion. In connection with the G8 summit, ADI will host an event for Alzheimer associations based in the G8 member countries as well as other associations that fund research, including Alzheimer Europe. More information about the events will feature in the next issue of *Global Perspective*.

National dementia plans update

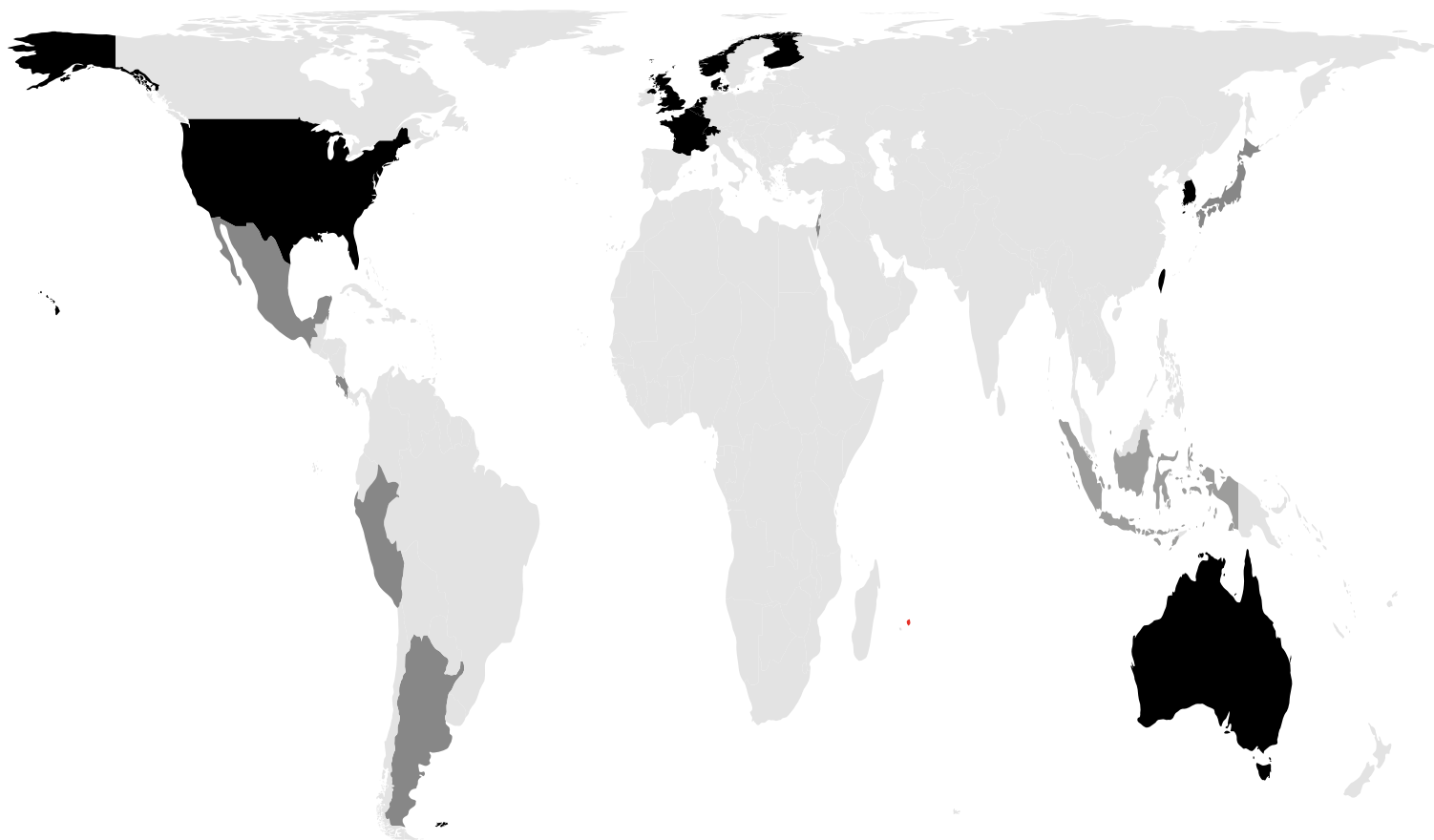
With TADA Chinese Taipei welcoming a new dementia plan in August and a number of others in progress, there is growing evidence that governments worldwide are recognising the need for greater support and services for people with dementia. The map below shows how far government commitment has come since the first national plan was launched in Australia in 2006.

Countries with national dementia plans

Australia	Finland	Netherlands	Switzerland	USA
Belgium	France	Norway	Taiwan	
Denmark	Luxembourg	South Korea	UK	

Countries with plans in development

Argentina	Israel	Mexico
Costa Rica	Japan	Peru
Indonesia	Malta	



Call for focus on disability

In September, a new collaborative report was released titled *We can also make change*, highlighting the issues faced by older people and people with disabilities living in Bangladesh. The report was developed by Sightsavers in partnership with HelpAge International, ADD International and ADI and launched at an event in the Houses of Parliament in London in November.

Key findings from the study conducted for the report show that up to half of all people aged over 60 in Bangladesh are living with a disability with the figure rising to an estimated 14.6 million people by 2025. The report makes a number of key recommendations for policymakers around the involvement and inclusion of people with disabilities in the post-2015 development agenda, which will take effect when the Millennium Development Goals expire.

To read the report visit www.sightsavers.org/in_depth/advocacy/20038.html



■ Member profile

The Malta Dementia Society

Charles Scerri, Secretary



The Malta Dementia Society was launched in September of 2004 while commemorating World Alzheimer's Day. It's the sole non-governmental, non-profit organisation in the Maltese islands representing the ideas and needs of individuals with dementia, their caregivers and family members.

At the time, stigma and discrimination against individuals with dementia and their families were still prevalent in the Maltese society. Thus, the newly founded management board agreed that our main mission was to inform the Maltese public about dementia and how it will affect their families and society in general. Other aims included those of encouraging and promoting the best methods of care, to provide and furnish support, help and assistance to families of individuals with dementia, instruct and train personnel in patient-centred dementia care and to foster international relationships in this field so as to keep abreast with recent advancements in this particular area.

Achieving these aims is not easy considering that the Malta Dementia Society was run solely by volunteers who would offer some of their free time out of their busy schedule towards the Society. Notwithstanding the lack of financial resources and thus the inability to provide services directly, the society was instrumental in the launch of governmental services aimed at individuals with dementia and their caregivers.

The Malta Dementia Society works on various fronts. Awareness of dementia remains at the top of our agenda. Over the years, we've built a strong relationship with the media and members of the Society are frequent contributors to the printed press and regularly appear on TV and radio programmes to discuss the various aspects of dementia management and care. With the advent and popularisation of electronic media, the Society launched its official webpage in 2005 and its Facebook page last year. These information portals are essential in keeping direct contact with our members and informing of events that are organised. These are various and include talks and seminars on a range of dementia topics intended for individuals with dementia and their caregivers as well as for

healthcare professionals. In collaboration with the central health authorities we also managed to release a number of publications aimed at various strata of Maltese society in order to continue in our awareness campaign of making dementia a comprehensible topic among the general public.

Another facet of our awareness campaign takes us closer to our members. We frequently organise talks on topics related to dementia management at home and better ways to interact with individuals with dementia in general. The Society is regularly invited by other non-governmental organisations as well as professional bodies to meetings and discussions on issues pertaining to dementia. These events are important in continuing our efforts to develop a network through which we can get our message across. An event that clearly brings us all together is the Memory

Walk, organised at the end of September of each year to celebrate World Alzheimer's Day. Members of the general public, those of the Malta Dementia Society together

with policy makers and healthcare professionals join in a commemorative walk to increase awareness of this condition and offer direct advice to the public. Recently we also launched the first issue of our newsletter *Reachout* in addition to a support group, the latter being an important step towards offering the best assistance to dementia caregivers as well as organising activities that bring them together and share their experiences. We are also involved in regular consultations with the central health authorities in introducing services aimed at individuals with dementia, their caregivers and family members.

Notwithstanding the lack of funding opportunities, members of the Malta Dementia Society are involved in research as part of their professional development. As a result, a number of contributions in the medical and social fields of dementia relating to the local setting were published. By way of its membership of Alzheimer Europe and ADI, the Society participates in international conferences and shares its experiences with foreign associations.

Over the past years, the Malta Dementia Society has been instrumental in raising awareness on dementia locally. Thanks to the support of our members, we look forward in continuing our effort in making dementia a top health priority in Maltese islands.



Members' forum

World Alzheimer's Month Special

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



Venezuela – Memory Walk



Turkey – Fingerprint campaign



Iran – Just one of the pictures drawn by children and exhibited under the theme 'Grandma, Grandpa, I love you'



South Korea – healing camp workshop for people with dementia and carers



South Africa - Olympic Gold Medallist Swimmer Cameron van der Burgh cuts the tape for Memorial Challenge



Bermuda – Julie Kay with the Minister of Health



Lebanon – Remembrance Tree campaign



Costa Rica – Fundraising



Barbados – Church service



India – Memory Walk

ADI would like to thank all members, organisations and individuals who took part in World Alzheimer's Month this year. Particular thanks go to MetLife Foundation for their continuing support.

MetLife Foundation



Belgium – Alzheimer Café Day

Dementia newsflash

■ Bulgaria

Compassion Alzheimer Bulgaria have been awarded a grant to support a project which provides innovative social services to people with dementia and their families. The funding from the Ministry of Labour and Social Policy will allow the project, *Mission Possible*, to be carried out over four months.

■ Iran

Iran Alzheimer Association has signed a 2-year Memorandum of Understanding with the country's Ministry of Health and Medical Education. This document confirms the

government's commitment to raising awareness about dementia among those most at risk.

■ Netherlands

At the start of their collection week fundraising campaign in early November, Alzheimer Nederland launched a Facebook campaign which saw people inserting a picture of a friend into an event that they had not attended, giving the person an idea of how it might feel to lose their memory.

■ Spain

CEAFA has teamed up with Clubdelchocolate.com to raise funds, with €2 being donated to CEAFA for every Chocolate para la memoria (*Chocolate for memory*) solidarity gift selection purchased.

■ UK

Alongside Alzheimer's Society, the UK's Lloyds Banking Group have launched a new Dementia-Friendly Financial Services Charter, a guide for banks and insurers to help improve the banking experience of people with dementia who bank with them. The new guidance outlined in the Charter will enable people with dementia to continue to run their own finances for as long as possible.

■ USA

In partnership with the CDC Healthy Aging Program, the Alzheimer's Association have developed an updated *Road Map* aimed at the public health community, offering guidance on how to address cognitive health, dementia, and the needs of caregivers through 35 actions.

■ Living with dementia

Emphasis on Living

Kate Swaffer, Australia

When first diagnosed with younger onset dementia aged 49, I 'came out' about the diagnosis, and it was like being gay 30 years ago. Many people quietly disappeared from my life, and I have had some say they'd rather not engage in my dementia journey. I know many others who have had this experience, although am glad to see this changing for people more recently diagnosed as the global awareness campaigns start to positively impact on the stigma and discrimination we face.

My willingness to advocate by speaking out and writing is fuelled



Kate Swaffer is a published author and poet, and now works as a writer and speaker, and she is an advocate and campaigner for dementia and aged care. Kate is the first Chair of the Alzheimer's Australia Dementia Advisory Group, which met for the first time during Australia's Dementia Awareness Week this year. She worked as a nurse in aged and dementia care and in operating theatres in her first career for over 20 years. She was diagnosed with younger onset dementia aged 49. Her blog, *Creating Life with Words*, can be found at kateswaffer.com

by the fact that much of our care still feels symptom based, and I believe nothing will change until we recognise the importance of everyone understanding the human cost of dementia. Another reason for speaking out is the only way you can understand me is to walk in my shoes and if I don't invite you into them, how can I reasonably expect you to. There is also a gross under representation of people with dementia involved in self advocacy, and in deciding on our care and futures.

Since being diagnosed with dementia, I have been told I can't possibly have it, or that I must be lying about the diagnosis. I've been told no matter what I do, it will get me in the end, and have even been told, 'but you sound and look so intelligent!' I hope by speaking out I can break down some of the myths, stereotypes and stigma about a diagnosis of dementia. I also firmly believe there should be 'nothing about us without us'. I have seen this motto being used regularly, but rarely see true inclusion. I attend conferences, forums and workshops where the 'experts' tell me, the real expert, what it is like living with dementia, and what is best for me. I believe it is the power of personal stories that will bring about the greatest change.

For me, the first major key to living well has been to treat the symptoms of dementia as disabilities, and I work hard to find ways to accommodate them, in the same way as a person who is physically or intellectually disabled.

When I started blogging and writing, it was initially to share my world with family and friends, and as a way to discipline myself to write about my life and this journey for my children, but blogging has opened up a vibrant channel of communication, and a

memory bank. I blog or write, and it is always there. Writing is also very therapeutic, and I believe has kept depression and chronic sadness away from me. It has helped greatly with the complicated grief and loss of dementia.

I engage in non pharmacological and positive psychosocial interventions every day, many more than once a day, as if it is the Olympics training of my life. These include studying, phenomenology, autoethnography, neuroplasticity brain and body training, exercise 6 days per week, authentic brain injury rehabilitation, poetry (in particular haikus), blogging, creative writing, nutrition, supplements, music therapy, hydrotherapy, Transcendental Meditation, self hypnosis (for pain relief instead of drugs, which can worsen the symptoms of dementia), and mind mapping. The positive psychosocial interventions I use include advocacy, volunteering, laughter, spiritual health, love, reading, belief, family time, friendships, and creative writing.

There is a body of clinical evidence slowly growing to support non pharmacological and positive psychosocial interventions, by respected medical doctors, neuro physiotherapists and scientists. What is missing from research is how to help people with a diagnosis of dementia to achieve well-being, and how to maintain this for as long as possible. As health professionals generally refuse to believe anecdotal evidence of patients who have healed themselves using alternative interventions, it is the evidence based research needed to get them to support options that do work for some people, and might work for many people if doctors offered and supported them as main stream interventions.

CONTINUED ON BACK PAGE

■ Carer's story

Understanding the Caregiver

Lyndon James, Trinidad and Tobago

My Mother

When my family and I first suspected that my mother had contracted the disease we had had some experience in dealing with its effects. This was because my grandmother also had the disease, though we didn't know it at that time. What I had no real knowledge of was the "stigma" within the local Trinidad and Tobago society with dealing with the disease, and how much having to deal with my mother would affect my entire life.

Experiencing Alzheimer's Disease

During her lifetime my mother was always quite an active person. She cherished her independence. The changes started slowly at first. I guess we were like most persons, in denial. My mother would start to do "strange" things. For example, move money around to different parts of the house at different times of the day and then accuse someone else of taking it. She would also forget where she would put important items like her house and car keys and call us frantically to come and assist her in finding them, no matter what part of the world we were in. She always complained about not wanting to become like her own mother, who had had the disease as well, so she tried to pursue many things "to keep her brain active". She played Scrabble with friends, loved to watch trivia game shows and even got hooked on taking tablets to help "boost memory retention". Sadly, none of these worked in the end.

Caring for a person with Alzheimer's involves quite a lot of patience. However, if that person is as strong willed and accustomed to having their way as my mother was, it can

also take quite a lot of getting used to. Almost two years in, I belatedly came to realise that it never makes sense arguing with someone who has the disease – never. I started to feel my own health deteriorate and the family history of suffering with hypertension was catching up with me even though I considered myself a normal healthy individual.

Physical, Social and Economic Aspects

Normal hygienic health practices and routines like taking a bath, combing one's hair and brushing one's teeth are serious dilemmas for the person with Alzheimer's. They always seem to think that it was either not necessary or that they had done it very recently. Doctor visits were never an issue though, as they were always seen as social outings to highlight various ailments that she felt and were never evident to our normal layman's eye.

Generally, regular social outings and gatherings are a must for persons living with the disease to give them that sense of being important and still considered relevant in today's society. Sadly however, most relatives feel the need to mask their loved one's illness to the society at large and fall prey to not making others aware of its existence. In fact, we were encouraged to keep our Mom at home, not wanting to expose her to "strange environments". Such were the confines of a society riddled with fear and stigma about the disease. I must add, however, that there were a few embarrassing moments. Learning to cherish these very moments proved to be quite therapeutic to us, as caregivers.

The costs and other economic aspects of coping with the disease



Lyndon's mother Gloria with his sister Lindi

were very traumatic. Medicines are quite costly, approx. \$1,200 - \$1,500 a month depending on the particular brand. Although some supplies of these are available at the local hospitals and health centres, these are always in short supply because of the demand. Memory clinics at the local health centres were always on a stop and go basis. Many times the after hour, or supplemental geriatric care, is sporadic in existence and in cost levels, depending on who you approach. We often agonised about the fact of putting our mother into a specialised home because of what it represented to us. In the end, however, we had to succumb to this notion as we were unable to provide the required support 24 hours a day.

Caregiver Support

Having the support of friends and family at times like these is vital to a caregiver. I was happy to learn from a good family friend of the existence of the Alzheimer's Association of Trinidad and Tobago. This group was formed out of a project of the Soroptomist International, Port of Spain Club. Here persons who care for, and deal with, persons living with the disease can share their experiences and get some information about it. It has proven to be a great help to me, as the meetings provide a great soundboard for discovering that I was not alone in dealing with the issues of my mother.

■ How associations help – Twinning special

In the first of a two-part series of *How associations help*, we look at how Alzheimer associations worldwide have provided help to each other through ADI's Twinning Programme.



DY Suharya, Alzheimer Indonesia

The Twinning Programme between Alzheimer Nederland and Alzheimer Indonesia began at an event on 1 and 2 June 2013 in Bandung, West Java in Indonesia. The event was attended by 30 participants and provided great potential and a platform for sharing knowledge and skills between Alzheimer associations.

This pairing has helped to strengthen both organisations by tackling shared issues together. It was discovered that the challenges in the Netherlands (a population of 18 million) were similar to those in Indonesia (a population of 240 million), such as coping with the rising numbers of people with dementia, solving the problem of under diagnosis, and re-defining standards of good care (caregivers are often overburdened).

Key areas that have helped during the Twinning Programme were related to the three components of

Representatives from Alzheimer Nederland joined Alzheimer Indonesia at an event in June this year

advocacy: awareness raising and strengthening internal organisations; sharing strategies and steps on understanding what really matters for people with dementia and caregivers; and the wide range of information materials that help to raise awareness and leverage advocacy to policy makers.

In June, Alzheimer Nederland shared the 10 warning signs of dementia that was adapted and transformed by Alzheimer Indonesia in September 2013. This was done through a 10 warning signs accordion-style brochure with illustrations that helped people to better understand dementia, seek early diagnosis, and pursue a healthy lifestyle in their everyday life. During World Alzheimer's Month in September, Alzheimer Indonesia succeeded in reaching approximately 150 million people in Indonesia through extensive print, radio, online and TV media covering

stories from a variety of forums, the memory walk and a charity concert under the awareness raising campaign titled *Jangan maklum dengan pikun* (Don't underestimate memory loss).

A national dementia plan from Indonesia is underway and under discussion between the Ministry of Health and Ministry of Social Welfare with the support of the local government of DKI Jakarta, health workers, stakeholders and private sectors aiming to deliver an excellent public-private partnership in improving the quality life of people with dementia and their caregivers in Indonesia.

Andrew Ketteringham, former Director of External Affairs at Alzheimer's Society, UK

The prospect of Alzheimer's Society twinning with Alzheimer's and Related Disorders Society of India (ARDSI) offered the ability to pass on our expertise and experience to others, in support of the global dementia campaign and the opportunity of getting to know better the south Asian population, a group with which we had few links.

To be honest the second objective was not fulfilled. Although we gained more knowledge about that group of people, which helped us to make contacts when we had something to tell them about the Twinning Programme, it did not go far. The reality is that to achieve this objective properly we would have had to have sent more of our people to India than was ever possible.

But we were able to recognise some success in passing on our knowledge. Those of us in the developed world need to understand our duty to be involved beyond our immediate horizons. The need for a global campaign is very evident; we have to do something about it. If it is achieved it will benefit us all.

Narendhar Ramasamy, ARDSI, India

The Twinning Programme of ARDSI with Alzheimer's Society (UK) has been of great utility. Prior to twinning, ARDSI had the basic structure in place with chapters running requisite services to people living with dementia, in isolation. The Twinning Programme enabled ARDSI to integrate isolated actions to produce cohesive action, which showed the need for an evidence base to kindle policy change and thus emerged the idea of bringing out a *Dementia India* report, a great advocacy tool indeed.

Meticulous work, structured research and assimilating facts, concerns and ideas regionally and consolidating them nationally brought out the report which was very well guided by Prof Martin Prince through Alzheimer's Society. Thus Twinning between countries shared and mainstreamed expertise, perspectives and experiences. However, the time period was short to realise structural changes and streamlining actions cohesively.

This essential action of Twinning enables sharing of experiences which builds the capacities of emerging organisations faster than would be possible if they were learning from their own experiences. ARDSI benefitted from this arrangement in terms of experience, administration, and creating a powerful tool for advocating to governments for much needed attention, which should yield benefits for people with dementia in the long run.

Part two of this Twinning special will appear in the March 2014 issue of Global Perspective.

■ Research update

A shift towards prevention

*Serge Gauthier, MD, FRCPC
Chairman of ADI's Medical and
Scientific Advisory Panel*

A large segment of the Alzheimer's disease (AD) research community is shifting its efforts towards prevention: multiple studies have been funded this year in the USA and Canada, testing strategies to prevent age-associated cognitive decline, mild cognitive impairment, and dementia in people with no symptoms. Most of these strategies aim at modifying risk-factors in mid-life, such as lack of physical exercise, obesity, high blood pressure, and adding cognitive training (such as the FINGER study). Some aim at reducing the inflammatory brain response in very early stages of Alzheimer's disease (Stop-AD project), others aim at reversing the accumulation of the protein β -amyloid in the brain of people who underwent a PET scan (A4 study). These interventions must be appropriate to the level of risk; hence the notion of "risk stratification" which will lead to prevention clinics against AD the same way as we have prevention clinics for heart attacks and strokes. Assessment of risk will take into account family history of AD, level of education, vascular risk factors, current symptoms, a cognitive test such as the MoCA, supplemented by a biological test using PET scan or spinal fluid examination to measure levels of β -amyloid and tau. The advice towards prevention will be evidence-based after all these studies are completed in a few years.

One very special group of people is invited to participate in preventive studies under DIAN-TU: children of patients who developed AD



before age 65, and where the family history is suggestive of a Dominant pattern of inheritance (50% risk for each child). Volunteers will be treated with medications that modify the β -amyloid build up in their brain. DIAN-TU sites are present in many parts of the world, and can be located through www.DianXR.org. A more geographically restricted project with the same strategy is taking place in Columbia (Alzheimer's Prevention Initiative).

These strategies are targeting inflammation, small vessel disease and β -amyloid. Another important component of AD is finally being tested: a derivative of methylene blue is to be compared to placebo in people with AD or with the behavioural variant of fronto-temporal dementia, as an attempt to lower the amount of hyperphosphorylated tau protein in their brain.

Important scientific meetings where all these issues will be discussed include the Geneva-Springfield Symposium in Geneva, March 2014 (www.siumed.edu/cme/alzheimer), and AAIC in Copenhagen, July 2014 (www.alz.org/aaic).

■ News

IPA Award for Nori Graham



Nori's award was presented at the IPA conference in South Korea in October

ADI Honorary Vice President Nori Graham has been awarded for her contribution to improving the mental health of older people by the International Psychogeriatric Association (IPA) at their recent conference in South Korea.

Nori's award, for Distinguished Service to the Field of Psychogeriatrics, was collected by Henry Brodaty, newly appointed President of IPA and fellow Honorary Vice President of ADI. ADI would like to congratulate Nori on her well-deserved award.



Agnes with her brother Brian at the awards ceremony

Award for Agnes

Many of those in the global dementia movement will know Agnes Houston, a lively and tireless campaigner for people with dementia, and dedicated member of the Scottish Dementia Working Group. On 19 September, Agnes's commitment was recognised when she was presented with Alzheimer Scotland's Lifetime Achievement Award. During her acceptance

speech Agnes explained how she'd struggled to keep her award win quiet after being informed by Henry Simmons, Chief Executive of Alzheimer Scotland, in advance of the ceremony. She also introduced her new best friend, her iPad, which is helping her to continue to live such a positive and active life with dementia. ADI send congratulations to Agnes on her on-going achievements.

New regional office for Asia Pacific



On 21 October, ADI, in partnership with members, launched the new Asia Pacific regional office in Singapore.

The office, which will share premises with Alzheimer's Disease Association Singapore, will help to build capacity in the region, promote information and resource sharing, and disseminate training and educational materials to members within the region.

A Regional Director, Francis Wong, has been appointed to lead the office and a work plan will be presented to members at the business meeting during the 16th Asia Pacific Regional Conference in Hong Kong in December.

ADI would like to welcome Francis to the team and look forward to working closely with him in the future.

LIVING WITH DEMENTIA CONT. FROM PAGE 8

Interestingly, most people will believe in a 'God miracle', even non Christians, but very few will believe in a cure or delayed prognosis brought on by positive psychosocial or non pharmacological interventions.

I am a person living with dementia, with the emphasis on living. Because the future is now defined by the possibilities of the dementia, I need to live more in the now. My husband and I are living our own lives, trying to be as normal as possible, in spite of the fact we have lost many of the dreams and aspirations we might have had.

Yes, I have a terminal illness, and am likely to die earlier than we would have expected, but why die now?

In the next issue of *Global Perspective*

- A report on the G8 dementia summit
- News from the Middle East & North Africa and Asia Pacific regional conferences