



**Alzheimer's Disease
International**

The global voice on dementia

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Global Perspective

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



Alzheimer University participants
with ADI staff and Tarun Dua at
the World Health Organization
headquarters

Geneva hosts Alzheimer University

As home to the World Health Organization (WHO) headquarters and the second largest office of the United Nations, Geneva in Switzerland was a natural location for ADI to host this year's Alzheimer University programme centred on advocacy.

Under the title *Campaigning for Change*, the programme took place from 23 to 26 June and was attended by 30 participants from 19 Alzheimer associations. Topics up for discussion at the event included

developing strategy, the role of patient organisations in research and treatment, and working ethically with the corporate sector.

A lively panel discussion on clinical trials, organised in collaboration with PhRMA, took place, and participants were given the opportunity to visit the WHO headquarters with a tour from Tarun Dua from the Neurological Disorders and Public Health department. Along with the programme participants, Annette Dumas from Alzheimer Europe and Johanna

Ralston from the World Heart Federation attended the event and presented their expertise in building relationships with policy makers and the work of the NCD Alliance.

Isabel Rochat, a former Swiss politician and now Chairman of Association Alzheimer Suisse Geneve, was present to welcome the group to the city.

To find out more about the Alzheimer University visit
www.alz.co.uk/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 31 October 2014.

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Editorial

Marc Wortmann, Executive Director



International attention on Alzheimer's disease and other dementias is now bigger than ever before. We had to work simultaneously on two major events in June and July. The first G7 Legacy Event on financial and social innovation for dementia took place in London on 19 June, and many representatives from Alzheimer associations were present and actively took part in the programme and discussions.

The day before the meeting we came together for a catch up on what has been happening. A week earlier, Scotland hosted a G7 related event, focusing on dementia care and this will help to put the issue into the spotlight. The next two G7 events will be on collaboration between academia and industry in Canada in September, and on care and prevention in Japan in November.

In parallel with these events we worked with the NCD Alliance to present our views at the UN Non Communicable Disease Review Summit in New York. This started with a civil society hearing on 19 June in New York, and Jason Hatke from the USA addressed the United Nations as a family carer. At the age of just 18, he is the youngest dementia advocate ever to speak at such an important forum and we are very proud of him!

The Review Summit itself took place on 10 and 11 July, also in New York, and the importance of including dementia was reconfirmed with the outcome declaration and several member state speeches. This work is mainly aimed at reducing risk factors. We also used this event to come together with the Global Alzheimer's and Dementia Action Alliance Steering Group for the first time. More news on this Alliance will be available soon.

As you can see, these are all positive developments towards our aim of making dementia a global public health priority!

Events

20 – 22 October 2014

Alzheimer Europe Conference Glasgow, Scotland

Web: www.alzheimer-europe.org/Conferences

23 – 25 October 2014

The 9th International Conference on Frontotemporal Dementias

Vancouver, Canada
Web: www.ftdvancouver2014.com

7 – 9 November 2014

17th Asia Pacific Regional Conference of Alzheimer's Disease International

New Delhi, India
Web: www.aprc2014-india.com

10 – 12 February 2015

2015 Ageing Summit

London, UK
Web: www.regonline.co.uk/Ageing2015

18 – 22 March 2015

The 12th International Conference on Alzheimer's and Parkinson's Diseases

Nice, France
Web: www2.kenes.com/adpd

15 – 18 April 2015

30th Annual International Conference of Alzheimer's Disease International

Perth, Australia
Web: www.alzint.org/2015

23 – 25 June 2015

2015 Alzheimer's Disease Congress

London, UK
Web: www.regonline.co.uk/Alz2015

15 – 17 October 2015

8th Iberoamerican Congress on Alzheimer's Disease

Rio de Janeiro, Brazil
Web: www.aibbrasil2015.com.br/ingles/

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

■ News

World Dementia Council grows



Daisy Acosta and Harry Johns

In July it was announced that membership of the World Dementia Council would increase to incorporate additional areas and fields.

While some faces such as Prof Ronald Peterson and George Vradenburg are familiar to the global dementia community, there was a lack of representation from within the Alzheimer association and ADI network.

The announcement of ADI's Honorary Vice President and former Chair, Daisy Acosta, and the Alzheimer's Association CEO Harry Johns being added to the Council membership came as welcome news.

The World Dementia Council was brought together by World Dementia Envoy Dr Dennis Gillings to support him in his leadership of global collaboration against dementia. In May the Council released their Statement of Purpose, highlighting the key areas of focus for the group.

This statement details the vital changes and actions required in finance, research collaboration, regulation and trials, sharing knowledge, health and care, and awareness.

The World Dementia Council have distributed their first newsletter online at <http://dementiachallenge.dh.gov.uk/2014/05/30/newsletter1/>

G7 legacy events begin

The UK government played host to the first in a series of legacy events in June following the 2013 G8 Dementia Summit. The focus of the event, at which World Dementia Envoy Dennis Gillings and UK Prime Minister David Cameron spoke, was on finance and social impact investment.

Calling for the finance and dementia experts present to work together on a global solution, David Cameron committed to contacting his fellow G7 country leaders to encourage them to take notice of and back, where possible, the models that will be proposed by those who will work on a solution.

Other speakers at the event included Shekhar Saxena, Director of the Department of Mental Health and Substance Abuse at World Health Organization and DY Suharya from Alzheimer's Indonesia, who shared details of the association's awareness raising and carer support activities. ADI Executive Director Marc Wortmann also spoke at the event as part of a panel discussion.

Collaboration between the governments in Canada and France will see the next of the G7 legacy events taking place in Ottawa, Canada on 11 and 12 September. This event will mark the second of the four legacy events with the focus of this meeting on greater collaboration between academia and industry. The Canadian Institutes of Health Research hosted a session on the Legacy Events and to continue international dialogue at the recent Alzheimer's Association International Conference in Copenhagen, Denmark.

Following the event in Canada, the Japanese government will host the third Legacy Event on prevention and care on 5 to 7 November. The final event is due to take place in the USA in February 2015.



ADI Executive Director Marc Wortmann being interviewed at the London event

ADI involved in UN hearing

Following the original meeting of the United Nations (UN) in September 2011 at which the issue of addressing non-communicable diseases (NCDs) was raised, this year the UN General Assembly requested an informal interactive hearing on 19 June in New York, USA. This meeting was organised to allow non-governmental organisations, among others, to provide input into a comprehensive review and assessment of the progress made in the prevention and control of NCDs since 2011. (continued on page 4)



Jason Hatke speaking at the informal hearing

Kicking off World Alzheimer's Month 2014



Look after your heart



Be physically active



Follow a healthy diet



Challenge your brain

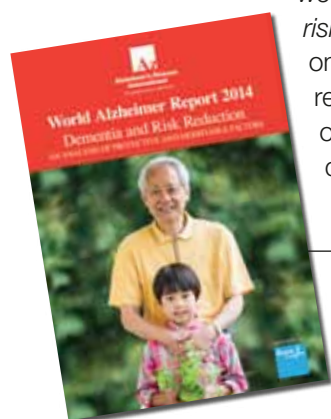


Enjoy social activity

This month Alzheimer associations worldwide are raising awareness and promoting activities while the ADI team make final preparations for the launch of the *World Alzheimer Report 2014*.

The theme for World Alzheimer's Month this year is *Dementia: Can*

we reduce the risk? focusing on helping to reduce the risk of developing dementia by looking after



your heart, leading a healthy lifestyle, and maintaining and challenging your brain.

For details of activities taking place around the world throughout World Alzheimer's Month visit our website at www.alz.co.uk/associations to find your national Alzheimer association.

The content of the *World Alzheimer Report 2014* this year places the spotlight on dementia risk reduction and how risk factors can be addressed at a population level. The launch event, which will take place

in London on 17 September, will be chaired by television journalist Angela Ribbon and will feature presentations from, among others, the report's authors from the Global Observatory for Ageing and Dementia Care at King's College London and a representative from the NCD Alliance. These will be followed by an open discussion on the topic. The report and launch event are supported by international healthcare provider Bupa. The report will be available from www.alz.co.uk/worldreport2014

Dementia newsflash

■ Costa Rica

On 4 June, Asociación Costarricense de Alzheimer y Otras Demencias Asociadas (ASCADA) welcomed the launch of their new chapter in the province of Alajuela. The new group will work closely with ASCADA's Board to develop the chapter.

ADI involved in UN hearing (continued from page 3)

As part of the NCD Alliance, ADI was invited to attend the meeting and put forward a speaker recommendation to the UN. ADI's recommendation of Jason Hatke who is 18-years-old and cares for his father, Michael, at their home in Indiana, USA, was accepted by the UN and Jason was supported on the day by his parents as he delivered his statement.

In his speech, Jason shared his support for the inclusion of dementia in NCD planning: 'Action plans on NCDs often leave off dementia. It's unfinished business and a missed opportunity. On a personal level I know that my dad's thinking problems make him a more difficult patient because he has trouble managing his own care. Now, imagine tens of millions with similar problems and other chronic diseases, and the cumulative burden on health systems and countries. Just because my dad has Alzheimer's does not mean he is immune from other health issues.'

ADI representatives were also present at the review meetings that took place in July.

ADI is grateful to Jason and his parents for their involvement in the event, which has been a great help towards ADI's aim for dementia to be considered alongside currently recognised NCDs.

To find out more about The NCD Alliance visit www.ncdalliance.org

■ Member profile

Alzheimer's Association Lebanon



The association launched the World Alzheimer's Day Remembrance Tree in partnership with the Lions Club International in September 2013

Alzheimer's Association Lebanon (AAL) was established in 2004 by Diane Mansour and a group of dementia rights advocates including Dr Nabil Naja, Cesar Nammour, Randa El Achkar, Dr Selim Atrouni, Michelle Zoghzoghi and Randa Sarraf. It was formed as a national non-governmental not-for-profit organisation that aims to improve the living standards of individuals with dementia and their carers. In this issue's Member profile we take a look at their work and developments.

Mission

1. Reaching out to families to help provide a better quality of life to people with dementia and their carers.
2. Helping to build a professional infrastructure for the support and care through ensuring better knowledge about the disease and breaking the taboo around it.

Objectives

- Raise awareness of dementia and its management
- Respect the rights of people with dementia
- Highlight the important role of family caregivers in alleviating the disease
- Provide ways to reach the best social and health care
- Support the person throughout their dementia journey
- Enhance public health standards for people with dementia to avoid complications

Programmes

- AAL's Alzheimer's Disease Early Diagnosis Programme was launched in 2013 and carried out in partnership with the Ministry of Social Affairs and the Lions Club International – district 351. In 2013, 420 people over the age

of 64 from various regions were screened for Alzheimer's disease resulting in 89 cases of dementia being diagnosed.

- The Youth Awareness Programme is run in schools and universities.
- AAL raises awareness of pharmacological and non-pharmacological interventions.

Services

- Support group meetings are held at the AAL offices in collaboration with an occupational therapist every two weeks. These groups allow carers to share experiences. Twenty-four meetings took place in 2013, reaching more than 60 beneficiaries and their families.
- AAL offers personalised counselling, directly supporting family members of people with dementia.
- The AAL helpline provides counselling, reassurance and professional information and advice.
- The Wandering Task Force is a collaboration with the Ministry of Interior and Municipalities. Using social media and media connections, AAL advertises and assists in the search for people with dementia who go missing.
- AAL offers professional training for ministry staff and nurses in nursing homes.
- AAL provides equipment and medication when available. In January 2013, the association successfully distributed medication to 25 care homes across Lebanon.

During 2013 AAL services reached 700 people with dementia and their families. *continued on page 7*

Members' forum

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

BANGLADESH

Students debate support issues

In July the Dhaka University Debating Club hosted an inter-hall parliamentary debate on the topic Who is more responsible for people with dementia – family or government? The debate, which was attended by around 200 students, received sponsorship from the Bangladesh Dementia Action Alliance (BDAA) and HelpAge International Bangladesh. Ahead of the debate, the students were encouraged to research dementia in Bangladesh and were directed to the websites of both the Alzheimer Society of Bangladesh (ASB) and Sir William Beveridge Foundation. The general consensus at the end of the debate was that government should take responsibility for the care and support of people with dementia and that awareness raising should be a key area of focus for the government.

As previously reported in Global Perspective, the BDAA was formed to create a Dementia Friendly Bangladesh and is a collaborative effort between ASB, HelpAge International Bangladesh, ADI and the Sir William Beveridge Foundation.

To find out more about the work of ASB visit <http://alzheimersbd.com>

SLOVENIA

Sudden passing of founder

At the age of just 52, the founder of Spominčica (the Slovenian association for people with dementia and their carers), Aleš Kogoj, tragically lost his life in a climbing accident in July.

Dr Kogoj was Associate Professor of Psychiatry at the University in Ljubljana and, early in his professional career, he became aware that carers of people with dementia were receiving very little support. It was this knowledge that inspired him to form the association in Slovenia in 1997 and he worked closely with the association as president, working with people with dementia and their carers and building the association's membership. In 2013, due to other professional commitments, Dr Kogoj stepped down as president of the association, but retained the post of honorary president. ADI sends deepest condolences to all at the association and Dr Kogoj's family and friends on the loss of Aleš, a true campaigner in the dementia field, who will be greatly missed..



USA

AAIC 2014 success



Marc Wortmann and Puzzle with me at the ADI stand

The Alzheimer's Association hosted yet another successful international conference in July. AAIC 2014 took place in Copenhagen, Denmark, bringing together the biggest names in dementia research worldwide to share their latest findings. During the six-day conference new findings were revealed on topics such as early detection of dementia, risk factors and prevention and the results of the first-ever long-term clinical trial of a multifaceted lifestyle change in older adults. More than 80 information stands filled the conference exhibition hall and Her Royal Highness Princess Benedikte of Denmark joined delegates and was presented with a gift by Gerry Sampson, Chair of the Alzheimer's Association Board and a member of ADI's Elected Board.

ADI Executive Director Marc Wortmann was present at the event, sharing the latest news on global dementia care and advocacy efforts. Martin Prince from the 10/66 Dementia Research Group also shared latest findings on the global prevalence of dementia. The conference provided an opportunity for G7 country representatives to come together for an update on the progress made following the G8 dementia summit in 2013.

AAIC 2015 will take place from 18 to 23 July 2015 in Washington, D.C., USA. For more information about AAIC visit www.alz.org/aaic

Members' forum

NAMIBIA



Progress for emerging association

In 2013, through the Africa regional conference in South Africa, ADI came into contact with a developing association in Namibia, Alzheimer Dementia Namibia, who were attempting to challenge some of the greatest stigma imaginable (as reported in the June 2013 issue of Global Perspective). This contact has

been maintained and the association has now begun to see some of the rewards for their efforts.

Inspired by the idea of dementia friendly communities, the association's founder Berrie Holtzhausen visited six towns with their outreach programme. The last of these towns was Henties Bay, a small coastal town with a large population of older people. While in the town Berrie was approached by a local shop owner with experience of dementia in her own family. In July, Berrie returned to Henties Bay to provide dementia training to all 35 of the shop's staff, a great step forward for both the local community and the association. Berrie's training was supported by materials available from the UK's Dementia Friends campaign.

Alzheimer Dementia Namibia are in talks with the University of Namibia to set up education and training programmes.

Alzheimer's Association Lebanon *(continued from page 5)*



Awareness raising

- Bi-monthly caregiver meetings provide support and information, on topics including nutrition and safety for people with dementia.
- Public lectures take place in Community Development Centres, universities, companies, etc. Twelve lectures took place in various regions and venues in 2013. AAL reached approximately 600 individuals, including caregivers, specialised doctors, nurses, social workers, students and members of the public.
- AAL coordinates World Alzheimer's Day awareness campaigns. In 2013, they launched the Remembrance Tree Campaign on 22 September in partnership with the Lions Clubs International – district 351. The campaign took place simultaneously in five different locations across Lebanon, reaching out to people with the aim of raising awareness of dementia.
- In September 2013, AAL distributed 10,000 brochures in one day.
- A press conference was held in Beirut Souks in September 2013 to highlight the importance of raising awareness of Alzheimer's disease. Most Lebanese media outlets covered the event to show the importance of World Alzheimer's Day. This coincided with a social media campaign to support people with dementia and their families through the use of #iRemember on all social media channels.
- AAL support people with dementia to speak out. Esper Ghantous was the first person with dementia to speak out about his disease in 2013. He was honoured by being appointed the first "Dementia Ambassador" in the Middle East by AAL. This gave people with dementia a voice to speak about their disease and encouraged others.

Through their awareness activities, AAL reached more than 11,500 individuals.

Diane Mansour has now moved to Dubai where she is helping ADI to establish other associations in the region.

For more information about Alzheimer's Association Lebanon visit www.alzlebanon.org

Living with dementia

I can develop strategies to live well

Selva Marasco, Argentina



Selva during the Alzheimer Iberoamerica conference in Uruguay in October 2013

I will start by adopting and recognising the value of mottos promoted, from a full and conscious acceptance of their disease, by Helga Rohra at the ADI conference in 2012: “Nothing about us without us”, and by Phil Murray in the March 2014 issue of Global Perspective, who stated - paraphrasing his friend Ronnie - “I may have dementia, but it doesn’t define me”. Both mottos are true from the deepest of our beings.

I dare add mine: “I have a disease, I am not the disease”. Somehow I relate this to the extremely valuable views stated above. How did I arrive at the conclusion that I have a disease but that I’m not the disease?

I am 61 years old and I was diagnosed with Lewy Body dementia (LBD) more than five years ago.

How did the process of my disease start? Gradually. At around 54 years of age, symptoms appeared that led to psychological and psychiatric consultations: permanent sorrow; irritability; aggressive negativity; lack of willingness; depression; vivid dreams that brought about, on the following day, a feeling of unease and exhaustion.

These emerging behaviour patterns, as I called them, began combining with others: walking backwards; stumbling frequently; falling at times; visual hallucinations; difficulty reading; disorientation in time and space; ongoing and changing muscle pain; periods of time when my mind just disconnected, and then I would come back to reality and find myself in unexpected and harmful situations. Many other strange behaviours started and situations occurred that I did not understand, which scared me.

My general practitioner and psychiatrist noticed a neurological problem so I was referred to a specialist. When the neurologist told me that my diagnosis was LBD, I had an indescribable feeling of despair, but, at the same time, a nearly incomprehensible peace, putting it all in God’s hands.

With the help of my husband, I understood that both the medication and trust in my doctor would be the initial steps for my wellbeing; the rest was up to me. Those around me (my family) would help me.

By doing what I had to, socialising, entertaining myself, and encouraging my spirituality, I started feeling strong inside. One example was that I took singing lessons and joined a choir.

Although I fully understand that I have a degenerative disease, I struggle and do everything that is possible to delay its progress. I look for strategies that help me overcome it; trying to be useful to others, to my peers with dementia.

I collaborate actively with ALMA (Association for the fight against Alzheimer’s disease), and I volunteer at ALBA (Argentine Lewy Body Association): institutions that make me feel both proud and grateful.

I shared my experience for the first time as part of a panel at the 2013 AIB Conference in Montevideo, and this year at the ADI Conference in Puerto Rico.

Like those who suffer but whom, in spite of their ailment, are optimistic and move on, I am no longer afraid, I am no longer ashamed. I look for solutions instead. I do not consider my disease to be a tie, but a constant life learning process.

Many symptoms have evidently alleviated, while some others appear sporadically, and others persist. I know that the ones which persist fluctuate and disappear, that is why they cannot get me down.

To me, past, present, and future mean giving myself confidently. It is possible to live well if we place dementia outside ourselves and develop, as in a game, the strategies to do so. I have a disease, I am not the disease.

From the past I take memories that make me feel good. In my present I have a positive attitude that gives me peace. My future is today: each day. I plan to continue developing myself, loving, giving and getting to continue living well.

■ Carer's story

Turn a negative situation into something positive

Rosabelle Toyer, South Africa



Rose with her husband

Rosabelle “Rose” Dorothy Toyer was awarded the 1st ADI-Home Instead Award for Family Carers of the Year in April after being nominated by Alzheimer’s South Africa. Here is her story, as told by Elena Hattingh, a social worker at Alzheimer’s South Africa.

Rose Toyer’s family consists of her husband (who is living with dementia), her two sons, a daughter in law and four grandchildren. The youngest grandchild has just turned 6-years-old. Although they do not stay together, she is fortunate to have their support as well as the support of her three sisters. Mr Toyer was intelligent, he read extensively, was fond of crosswords, Sudoku, and never missed the 7 o’clock news. He had a good command of English, Afrikaans, Swedish and Latin. He was the family’s “go to” man for general knowledge and maths.

Rose started to pick up some signs of Alzheimer’s disease in her husband in 2009 and on 12 January 2012 this was confirmed by a neurologist. It was very traumatic for everyone and, even though Rose (a retired professional nurse) suspected it, it was a difficult pill to swallow. She first had to tell their sons via telephone. She then had to tell the rest of the family and friends. People were very insensitive especially when they spoke about him both verbally and non-verbally in front of

him as if he were deaf and blind. Comments like “you will have to institutionalise him” and “your life has been cut short” were very hurtful. This, however, made her realise that there was a need to educate people about Alzheimer’s disease and that she had been given that task. She was adamant she would take care of him at home and decided to take him with her wherever she went. He was not an embarrassment; he was a person with Alzheimer’s disease.

She took early retirement to take care of her husband after 23 years as a medical representative and 33 years nursing experience. She started to read extensively on Alzheimer’s disease, became a member of Alzheimer’s South Africa and attended the local support group in Pinetown. In August 2013 she employed a carer so that she could take care of herself and not suffer burnout. She started to educate the carer at her home and sent her on a two-day Alzheimer’s Care Workshop run by Alzheimer’s South Africa. She has stayed hands-on and has a lovely relaxed approach towards her husband. He picks up on her calm approach, looking happy and content, smiling and singing throughout the day.

However, on 26 February 2014, Mr Toyer suffered a transient ischaemic attack (TIA) and was admitted to a private hospital. It turned into a nightmare. Mrs Toyer was alarmed to see the nursing staff’s ignorance in handling a patient with Alzheimer’s disease. She reported all the incidents to the doctor and unit manager as well as the nursing service manager. Rose was a professional nurse and knew how things had to be done. She spent

most of the time with her husband at the hospital, took care of him and reassured him. Her main concern was “What about the layman?” She decided to turn her negative experience into a positive one, offering to do talks on “spouse and carer perspective of the challenges on Alzheimer’s disease” at the hospital concerned. It was met with a positive reaction.

Already a member of Alzheimer’s South Africa’s KZN (KwaZulu-Natal) region, she contacted the social worker and together they have given two talks to the hospital staff on Alzheimer’s and dementia. It became evident that there was a huge need for awareness and training in this field and it was decided that it was important to get into the private nursing colleges as well as the other private hospitals. The coastal director of nursing education made contact with Mrs Toyer and set up a meeting for 3 April 2014 to discuss and plan for the inclusion of our two-day training on “Caring for the person with dementia” in the nursing staff’s syllabus.

Mrs Toyer decided to turn a negative situation into something positive which will benefit many people with dementia and their families in the future. Many people with dementia are admitted to hospitals and become frightened and bewildered in a strange environment. Through Mrs Toyer’s contacts and previous expertise, Alzheimer’s South Africa’s KZN region was able to get in contact with the relevant professionals in the nursing field, to discuss and plan the inclusion of our specialised dementia training into the nursing staff’s training material.

■ How associations help

Iran Alzheimer Association breaks through the stigma



A person with dementia and carer during their recent television appearance. Picture from Monazereh

For twelve years Iran Alzheimer Association (IAA) has been working relentlessly to overcome stigma in Iran. In July 2014, this work bore fruit and two of our carers with their loved ones accepted the invitation to be interviewed live by one of the TV channels. It took them a lot of courage but it happened. This was only achieved because they were ready to share their issues with the public.

For years IAA had to fight the stigma. People with dementia and their carers would not consent to being filmed or having their photograph taken. They would not come forward or participate in a dialogue with the authorities. IAA requested them to fill the consent form for photography or filming but it was never done. The media suggested blurring their images while showing the event but IAA did not like the idea of their members being exhibited like criminals. For years IAA was unable to print posters, brochures etc. with Iranian images. It was restricted to showing people with dementia's hands or use of foreign images which usually was not as powerful. IAA also knew that many families

chose seclusion to avoid community judgements.

In recent years, IAA has been planning a huge awareness project to overcome the barrier of stigma.

- First, it held a photography competition with the themes of "aging" and "Alzheimer's". IAA received 2000 photos from all over Iran. Sixty photos were selected by the jury. IAA purchased the copyright and an exhibition was held to mark the end of the event. The project resulted in IAA raising awareness even in the remotest areas, acquiring many artistic and powerful photos. In the past 2 years, IAA has been able to produce brochures and World Alzheimer's Month posters with photos of local people.
- Next, IAA raised awareness about the disease and the importance of communicating with grandparents among 4,500 school children. Later an art competition was run in collaboration with the Intellectual Development of the Children and Young Adults which has an established network of 850 permanent, mobile stations in towns and villages across Iran. Eight hundred works of art were received and the selected 113 works were exhibited during the international child's week.
- During World Alzheimer's Month 2013, IAA trained 750 professional carers in a 2-day seminar on dealing sensitively with long-term residents.
- In 2013, IAA's staff raised their awareness sessions to reach 2,356 people.
- Now IAA has a bank of consents for various events which led to the recent television interview with the carers and people with dementia. IAA has had rewarding feedback.

IAA knows too well that stigma can rob a person of his or her right to receive support, care, diagnosis and treatment. Therefore we will continue our efforts to fight stigma across Iran so that all people with dementia receive the support and services they deserve.

To find out more about the work of IAA visit www.iranalz.ir



Some of the art that achieved distinction in the art competition on the theme of "Grandma, grandpa, I love you"



■ Research update

Dementia and tobacco link

A new factsheet, **Tobacco use and dementia**, examining current knowledge on the links between dementia and smoking was launched by the World Health Organization (WHO) and ADI in July. As well as smoking, the comprehensive literature review conducted for the factsheet also extended to smokeless tobacco use and risks from secondhand smoke.

Can smoking cause dementia?

Research has found that smoking affects the vascular system, causing cerebrovascular disease, stroke and coronary heart disease. This can occur in a number of ways:

- Smoking increases levels of the amino acid homocysteine, which itself is a risk factor for stroke, cognitive impairment and dementia.
- Smoking speeds up the clogging of arteries with fatty substances, which causes a narrowing of blood vessels in the heart and brain, and, as a result, deprives brain cells of oxygen.
- Smoking can lead to oxidative stress, upsetting the balance between the production of reactive oxygen and the body's ability to detoxify their harmful effects. This is associated with excitotoxicity, which sees nerve cells damaged and killed by over stimulation by neurotransmitters. It can also be linked to an inflammatory response that may be directly or indirectly related to the neuropathology of Alzheimer's disease.
- For those who carry the gene Apolipoprotein E (APOE) gene, smoking can increase the risk of dementia.

It is believed that while smoking may not be a direct cause of dementia, it can certainly be considered a risk



factor. Findings from the literature review suggest that around 14% of cases of dementia in the world could be attributed to tobacco use.

Some studies reviewed suggested that the use of tobacco could protect against dementia.

Further research into these studies suggested that the tobacco industry had influenced the findings of some studies and that, in other cases, the studies were designed in such a way as to be biased.

Second-hand smoke and dementia

There is currently little understanding of the link between second-hand smoke and dementia, although it is believed that it can have an indirect effect due to the associations between second-hand smoke exposure and the increased risk of cardiovascular disease and stroke. These risks, which operate in the same way as listed above, are almost as great as they are for smoking directly. The studies available also suggested that those with greater exposure to second-hand smoke were at greater risk.

Smokeless tobacco and dementia

Currently very little is known about whether smokeless tobacco use is a cause or risk factor for dementia. It has been suggested that it may be possible for smokeless tobacco to increase the risk of dementia through the known risks associated with its use and death from cardiovascular disease.

Can quitting smoking help reduce the risk?

There is less consistency in studies conducted on those who have a history of smoking and whether they are at an increased risk compared to

non-smokers. This may suggest that quitting smoking can still be beneficial with reduced risks of developing dementia.

A global view

Evidence has shown that current smoking is associated with an increased risk of developing dementia. While much of the literature reviewed came from high income countries, studies from low and middle income countries have reached the same conclusion. There is also evidence that suggests that the more a person smokes the greater their risk.

Recommendations

Recommendations made by the WHO in response to these findings include:

- Smoke-free public places and workplaces should be introduced
- Helplines should be available for those wishing to quit smoking as well as accessible advice and information on the risks associated with smoking
- Health warning labels on tobacco products should include the risk of dementia
- Mass-media campaigns about the risks
- The introduction of plain packaging on tobacco products
- The banning of advertising, promotion and sponsorship for tobacco products
- An increase in taxes on tobacco products

The WHO also suggested that, although there is strong evidence of a link between smoking and the risk of dementia, more well-designed long-term research is required as well as more studies into smokeless tobacco and second-hand smoke exposure.

To view the factsheet and full list of literature reviewed in its development visit www.alz.co.uk/tobacco

■ News

Join us in Australia

Do you have some news you'd like to share with the global dementia community? Or some research findings you would like to exchange? Perhaps you want to share the success a recent programme or activity? If so, then you could be a part of the 30th Annual International Conference of ADI in 2015.

Join us from 15 to 18 April in Perth, Australia to share in the experience of this landmark event. Abstract submission for the conference is now open and will close on Friday 31 October.

To find out more about the conference, to submit an abstract or to register visit www.alzint.org/2015



Best Friends is 30!



Nori Graham (left) with Best Friends founders David Troxel and Virginia Bell

ADI Honorary Vice President Nori Graham joined 250 people earlier this year at the Best Friends™ Approach 30th birthday celebration at the Best Friends Day Center in Kentucky, USA.

At the celebration Nori presented a history of the global dementia care movement to the Best Friends volunteers, both past and present.

The Best Friends Approach was developed in 1984 by Virginia Bell and David Troxel as a method of making people with dementia feel safe, secure and valued, enabling them to live a life with dignity.

The approach aims, through their books and training, to equip family

and professional carers with the tools to understand what it is like to have dementia, make plans for the future, offer the right activities in the right way, among many other recommendations.

The approach has grown in success over its 30 year history and is now used in 31 countries, including Argentina, Australia, China, France, Germany, India, Japan and Switzerland.



Best Friends' co-founder Virginia Bell speaking at ADI's 2009 conference in Singapore

In the next issue of *Global Perspective*

- **News from World Alzheimer's Month**
- **The launch of the World Alzheimer Report 2014**
- **An update on the G7 dementia meetings**

Sad loss of 10/66 researcher

Raul Lopez Mena, a valuable member of the global dementia movement, sadly passed away in June at the age of just 60.

Raul had been active in the field of neuropathology for a number of years and was one of the founding



members of the 10/66 Dementia Research Group.

In his home country of Mexico, Raul set up the first national brain bank for research on dementia and supported the creation of many others across the Latin American region. His passion for, and contribution to, dementia research will be greatly missed and ADI extends our deepest sympathies to Raul's family, friends and colleagues on this loss, which will be felt across the world.