



# Global Perspective

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

## The world commemorates 100 years of Alzheimer's disease

Around the globe people with dementia, carers and Alzheimer associations are rallying together to meet the challenge of dementia, one hundred years after the first description of Alzheimer's disease in 1906.

When he first described the illness affecting Auguste D, Dr Alois Alzheimer could not have thought that a century later the world would be working together as it is today – providing care and support for people with dementia and their families and urging governments to make dementia a health priority. ADI is proud to report on its centenary activities and on those of its members. See pages 6-7 for more details.



Centenary year campaign is inaugurated in El Salvador with a Memory Walk



## Protests in UK for fair access to dementia drugs

Crowds of angry protesters gathered in Westminster, London at the end of June to challenge the unfair recommendation by the National Institute for Clinical Excellence (NICE) to limit access to dementia drugs. NICE have recommended that three widely used dementia drugs be limited to the treatment of moderate stages of Alzheimer's disease only, thus effectively excluding their use by people in the mild and severe stages.



Angry protesters gather outside the Houses of Parliament to rally against the NICE recommendation

The Alzheimer's Society provided protesters with banners and signs which were carried through Parliament Square to the Department of Health to cheers of 'Free access to dementia drugs!' A red double-decker bus, decorated with banners, took another crowd of protesters through the streets of London to spread the message even further. Many participants arranged to see their Members of Parliament to explain face to face the importance of these drugs to people living with dementia and carers.

The protest came just before Alzheimer's Awareness week, 2-8 July, a focus point for all the Society's awareness activities.



## Alzheimer's Disease International

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### Send us your comments

If you have any comments about or items for the newsletter please contact the Secretariat. Articles for the next issue of Global Perspective to arrive by **15 October 2006**.

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## Editorial



**Elizabeth Rimmer**  
Executive Director

I am reflecting on my ten years at ADI against a background of the 100 years that have passed since Alois Alzheimer first described the condition that was later to bear his name. 1906 is a distant place to all of us, an era when the world felt large and unknown. Even ten years ago the world felt a larger place; in 1996 the internet was just emerging but was mainly confined to universities and few people had email or mobile phones.

The dementia world has come a long way since 1906. I doubt Dr Alzheimer ever envisaged that future generations of people with dementia would speak out about their experiences, or that organisations would develop to meet their needs and support their carers, or indeed that organisations and people worldwide would come together to share common ground.

In my time at ADI we have experienced a rapid growth in membership, a positive reflection of increased awareness of dementia and accessibility of information. I think the dementia movement is poised for huge expansion. We are gathering momentum to put dementia in its rightful place as a health and social care priority. This is of course an important goal, but it is even more important that as our movement grows we do not ever lose sight of the ground on which we stand. The ground where people with dementia and their families struggle every day to cope with the demands of dementia.

Although the world may feel a smaller place to us now, the reality is different; the gap between rich and poor widens every day. We each have an obligation to ensure that scientific discovery and greater knowledge about dementia translates into tangible benefits for people with dementia and their families.

## Events

30 August – 1 September 2006

### 3rd Annual International Mental Health Conference at the IOP

*People on the Move*  
London, UK  
Tel: +44 20 7848 0537  
Email: [imh@iop.kcl.ac.uk](mailto:imh@iop.kcl.ac.uk)  
Web: [www.iop.kcl.ac.uk/iopweb/events/?event=274](http://www.iop.kcl.ac.uk/iopweb/events/?event=274)

10 – 14 September 2006

### 6th International Neuropsychiatry Congress

Sydney, Australia  
Tel: +61 2 92 41 14 78  
Fax: +61 2 92 51 35 52  
Email: [info@inacongress2006.com](mailto:info@inacongress2006.com)  
Web: [www.inacongress2006.com](http://www.inacongress2006.com)

11 – 14 September 2006

### 14th Annual Alzheimer's Association Dementia Care Conference

Atlanta, Georgia  
Tel: +1 312 335 5790  
Email: [careconference@alz.org](mailto:careconference@alz.org)  
Web: [www.alz.org/careconference](http://www.alz.org/careconference)

16 – 20 September 2006

### 5th European Congress of Biogerontology

Presented by International Association of Gerontology  
Istanbul, Turkey  
Tel: +90 312 304 3306  
Fax: +90 312 304 3300  
Email: [sakman@gata.edu.tr](mailto:sakman@gata.edu.tr)  
Web: [www.biogerontology2006.org](http://www.biogerontology2006.org)

20 – 22 September 2006

### 3rd International Congress on interdisciplinary gerontology and Alzheimer academy

Bad Ischl, Austria  
Tel: +43 61 32 21 410  
Email: [verein@mas.or.at](mailto:verein@mas.or.at)  
Web: [www.mas.or.at](http://www.mas.or.at)

21 – 23 September 2006

### 1st National Congress of the Alzheimer's Disease Association of the Philippines

Quezon City, Philippines  
Tel: +632 72 31 039  
Email: [secretariat@alzphilippines.com](mailto:secretariat@alzphilippines.com)  
Web: [www.alzphilippines.com](http://www.alzphilippines.com)

3 – 6 October 2006

### ICGP 6th Annual Scientific Meeting

Hiroshima, Japan  
Email: [icgp2006@umin.ac.jp](mailto:icgp2006@umin.ac.jp)  
Web: [www.icgp2006.umin.jp](http://www.icgp2006.umin.jp)

11 – 13 October 2006

### 16th Neuropharmacology Conference

*Long Term Potentiation (LTP), Forty Unforgettable Years*  
Atlanta, USA  
Tel: +44 12 95 25 33 34  
Email: [np-conference@elsevier.com](mailto:np-conference@elsevier.com)  
Web: [www.neuropharmacology-conference.elsevier.com](http://www.neuropharmacology-conference.elsevier.com)

12 – 14 October 2006

### 22nd International Conference of ADI

*Dementia – a Challenge for the 21st Century. 100 Years Of Alzheimer's Disease*  
Berlin, Germany  
Tel: +49 30 85 99 620  
Fax: +49 30 85 79 826  
Email: [alzheimertctw-congress.de](mailto:alzheimertctw-congress.de)  
Web: [www.alzheimer2006.de](http://www.alzheimer2006.de)

2 – 5 November 2006

### Alzheimer: 100 years and beyond

Centenary Meeting  
Tübingen, Germany  
Tel: +49 7071 29 81947  
Fax: +49 7071 21 4521  
Email: [info@alz100.de](mailto:info@alz100.de)  
Web: [www.alz100.de](http://www.alz100.de)

6 – 7 November 2006

### Reflecting on 100 Years of Alzheimer's

*The Global Impact on Quality of Lives*  
University Center on Aging and Health  
Cleveland, Ohio, USA  
Tel: +1 216 368 4945  
Fax: +1 216 368 6389  
Email: [sandra.hanson@case.edu](mailto:sandra.hanson@case.edu)  
Web: [fpb.case.edu/CFA](http://fpb.case.edu/CFA)

6 – 8 November 2006

### 28th National Conference of Alzheimer Society of Canada

*Alzheimer Research and Innovation: Yesterday, Today, Tomorrow*  
Toronto, Canada  
Tel: +1 416 488 8772  
Fax: +1 416 488 3778  
Email: [conference2006@alzheimer.ca](mailto:conference2006@alzheimer.ca)  
Web: [www.alzheimer.ca/english/newsevents/conference-intro.htm](http://www.alzheimer.ca/english/newsevents/conference-intro.htm)

9 – 11 November 2006

### 12th National Conference of ARDSI

New Delhi, India  
Tel: +91 4885 223 801  
Fax: +91 4885 223 801  
Email: [ardsi@sancharnet.in](mailto:ardsi@sancharnet.in)  
Web: [www.alzheimerindia.org](http://www.alzheimerindia.org)



# Until the clouds came...

By Frank Bentley, Randburg, Alzheimer's South Africa

**My wife, Jill, was diagnosed with Alzheimer's disease in April 1999 and died in May 2006, one day before her 73rd birthday.**

At first Jill's failing memory was manageable. She would say, 'It's just part of old age, dear', and I developed the phrase 'Don't worry, I'll think and do for two.'

Later on when her memory lapses were becoming noticeable, we told friends of the diagnosis. Having run a Brownie pack in the Girl Guides movement for 32 years, Jill had to retire as she could not remember the girls' names. Her life had revolved around her work with the Brownies – she would teach them arts and crafts and was known as the 'garbage lady' always making something from nothing – yet she now could not sew a button on a shirt.

In 2002 we moved to a retirement home with a frail care facility. It was here that Jill's faculties began to fail – writing, reading, bathing, dressing, eating and she began to wander. My caring for her took on a new dimension, including choosing her clothes, dressing her, watching over her whenever she moved and taking over the household chores.

It was distressing to see her holding her toothbrush and not knowing what to do with it, turning on a water tap and not knowing how to turn it off again, not knowing the difference between a knife, spoon or fork. Caring for Jill became an increasing strain, particularly not knowing what would happen next. I became impatient at times, not appreciating that something she could do yesterday she could no longer do today.

Eventually I had to concede that professional care was needed. I explained to her why I could not care for



Jill and Frank Bentley

her any more, then I took her to the caring unit of our retirement home and settled her in her room. I went back to my flat and sat at the dining room table, head in hands. What had I just done to my wife after almost 50 years of marriage? Guilt. I felt that I could have done more for her but, in reality, what else could I do?

In the early hours of May 20th, the nursing sister telephoned to say that she had passed away. Here was my gentle lady who, throughout her illness, remained the same and just as quietly moved on.

I have had to make substantial adjustments in my life without Jill. There's a hole in my life that I must fill but I hope that, in memory of Jill, I can help champion the Alzheimer's cause. I now have no regrets. We had a wonderful life together, were proud parents and grandparents and everything set fair until the clouds came. I now live to remember those happy years I spent with Jill.



**Craig Hill, a Scottish comedian, launched Alzheimer Scotland's handbook for carers. The handbook is available online at [www.alzscot.org](http://www.alzscot.org)**

## New carers handbook launched in Scotland

Alzheimer Scotland and NHS Health Scotland have launched a valuable resource for carers of people with moderate to late stage dementia in the form of the booklet *Coping with Dementia: a practical handbook for carers*.

Scottish comedian Craig Hill, who launched the booklet, said, 'Caring for someone with dementia can be very challenging. My mother had Alzheimer's disease. However, with the appropriate information and support, it can also be rewarding.'

*Coping with Dementia* is a revised edition of a highly regarded handbook. It gives practical advice on coping, provides guidance on how to find caring more rewarding and directs readers to further help and information.

Kate Fearnley, Policy Director for Alzheimer Scotland, one of the authors, said, 'The handbook looks at all the different effects dementia may have, and explains to carers how to deal with them, as well as negotiating the maze of money and legal matters that are thrust upon them.'

# Members' forum

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

## Anniversaries in Mexico and Uruguay

Twenty years ago very little was known about dementia in Mexico. Today the country has 18 Alzheimer regional associations and 25 support groups distributed through various cities, and is making a difference by empowering families through education about dementia.

Since 1986, dementia groups, along with the Mexican federal government, have been training geriatricians, nurses and other health professionals in the field of dementia. Mexico was the first developing country to join Alzheimer's Disease International in 1988 and in 2002 the Mexican Federation of Alzheimer's Disease (FEDMA) was established to unite the efforts of all the country's dementia groups.

2006 also marks the 15th anniversary of the Asociación Uruguaya de Alzheimer y Similares (AUDAS). In 1990, with the support of the Alzheimer's Society in the UK, a group of family carers for people with dementia decided to start a support group in Uruguay. The group was such a success that AUDAS was founded on May 10th 1991 and became a member of ADI at the ADI conference in Edinburgh in 1994.

AUDAS, which runs a Day Centre and support groups in Montevideo and in the country's interior, now has a membership of around 350 people.

### A lunch party at the AUDAS Day Centre



## Advocates for dementia meet in Washington DC



Gerald Michalak and Hilary Clinton at the US public policy forum

High profile figures such as Hilary Clinton were present at the 18th Annual US public policy forum which took place in Washington DC at the beginning of June. The annual forum brings advocates from across the USA to meet their legislators.

Hilary Clinton launched a report on early onset Alzheimer's disease which highlighted that the under-65, early onset population has unique needs which are not addressed by current public policies. The report also addresses the difficulty of getting an accurate diagnosis due to dementia being perceived as a disease exclusively of the elderly. 330 participants lobbied their congressmen to increase funding for dementia research and the Alzheimer's Association's programmes. As a result the \$1 million funding for the safe return programme was maintained despite proposed budget cuts.

Stephen McConnell, Senior Vice President for Advocacy and Public Policy, of the Alzheimer's Association was pleased with the outcome of the meeting. 'This year's forum included a large number of people with dementia who contributed in so many ways to the meeting's success. There was real passion shown for the cause.'

Gerald Michalak, a person with Alzheimer's disease from Buffalo, New York, added, 'I wish that there were greater awareness and standard procedures in place to identify early-onset Alzheimer's disease. Proper diagnosis leads to early intervention and appropriate planning. We need more funding for research and we must maintain our commitment to supporting affected families by restoring the budget cuts to Alzheimer care programs. We have to make Alzheimer's an urgent national priority today.'

## Introducing children into the care environment

Children in Western Australia (WA) are cheering the lives of people with dementia through an innovative project combining a children's playgroup with day-centre respite care.

The project, run by Alzheimer's Australia WA, aims to encourage greater interaction between the young and elderly and is part of the Mary Chester Centre's Eden Alternative™ care philosophy that aims to combat loneliness, helplessness and boredom among the elderly.

Playgroups are for children aged under five years of age, who go along with their parents for a couple of hours every week.

'The project gets all three generations – older people, parents and children – interacting and playing together and establishing very natural bonds,' said Frank Schaper, Chief Executive of Alzheimer's Australia WA. 'The elderly people in our care take on the role of grandparents. They interact positively with the children who by nature are spontaneous and non-judgemental. Playgroup day makes Thursdays a very special day.'



Different generations interact at the playgroup in Western Australia

## Alzheimer's Australia connects people and cultures

In 2003 Alzheimer's Australia set up the National Cross Cultural Dementia Network.

With financial support from the Australian Government, the network works to provide culturally appropriate services to the different ethnic populations in Australia. The network aims to overcome some of the barriers which inhibit effective service provision to marginalised populations – barriers such

as language, prejudice, and accessibility – and seeks to ensure that people from culturally and linguistically diverse backgrounds remain recognised as an important group when improving the quality of care offered to people with dementia, their families and carers.

In June the network issued its first newsletter with news from the different chapters and information on access to publications

in different languages. The newsletter is introduced by the Australian Minister for Ageing, Senator Santo Santoro. He says, 'I congratulate the members of the network on their work to ensure that people living with dementia who come from different cultural backgrounds are cared for appropriately and their particular needs are recognised and met.'

For more information visit [www.alzheimers.org.au](http://www.alzheimers.org.au).

## Centenary updates

### Kolkata Marathon

The Kolkata branch of ARDSI, the Alzheimer association in India, got their centenary campaign up and running as carers, supporters and people with dementia took to the streets for the 2006 Kolkata Marathon.

The marathon saw over 20,000 participants flow through the streets of the city on a Sunday morning in February. ARDSI supporters used the event to fundraise and raise awareness, distributing thousands of leaflets with the 'No time to lose' centenary message.

Another big step forward for the Indian society is their success in being chosen by the International Federation of Ageing as one of the three NGOs in India to work on the 'Building Capacity in Health Care' project. As a result,



**ARDSI supporters launch their centenary campaign at the Kolkata Marathon**

the 'Quality Dementia Care: A Western Australia – West Bengal Collaboration' has combined the efforts of ARDSI Calcutta and Southern Cross Care, Western Australia to support and enhance the quality of life of people with

dementia and their families in West Bengal. The centenary year will see the society providing in-depth training for carers, as well as information and counselling in rural areas. A day and respite centre is also planned for the local area.

### Centenary Memory Walk in El Salvador

Colourful centenary commemorations took place in El Salvador in May when the old and young took to the streets for a Memory Walk. Amongst banners and balloons, a troupe of traditional dancers helped to attract the attention of passers by and the media. As a

result of the activities, two articles were published in national papers and Ricardo López Contreras, of the Asociación de Familiares Alzheimer de El Salvador, was interviewed on national television.

He told the press, 'Dementia is a big public health issue and we must

be prepared to face the approaching epidemic that the new statistics suggest'. The day's events had the support of the Ministry of Health and the Institute of Social Security in El Salvador.

**Ricardo López of AFAES talks to the media in El Salvador**



## Ascent for Alzheimer's

The countdown to World Alzheimer's Day is set and the Ascent for Alzheimer's team are stepping up their training as Kilimanjaro beckons.

On 21 September the team will reach the summit of Africa's highest mountain, Mount Kilimanjaro in Tanzania, in a display of international unity against dementia. Eight different countries are represented on the team: USA, Canada, Dominican Republic, UK, Hungary, Denmark, Turkey and Hong Kong. Apart from nationalities, there is also a great mix of ages and backgrounds of the participants and each climber has their own special motivation for taking the challenge.

'I see this climb as an opportunity to raise awareness and funds for a great cause while fulfilling and sharing a personal goal. This is a way to honour millions around the world living with Alzheimer's, their families, and friends. Personally, I am dedicating my hike to the memory of

**The team members: Aniko, Claudia, Dave, Hanne, Jean, Melanie, Nasuh, Paul, Todd, Ruben – and the majestic Mawenzi peak**



FACE OF EARTH PICTURES, HUNGARY

my wife's grandmother who had the disease,' says Paul Inboriboon, a Thai-American member of the team from Chicago, USA.

As the team make their way up to the 5,800m summit, we will be following their progress and publishing their updates on the ADI website. We hope to speak to

them directly from the top on World Alzheimer's Day!

Each climber is raising money for the Alzheimer association in their country, while Melanie Legg is raising money for ADI.

To read more about the Ascent and how you can support the team, visit [www.alz.co.uk/ascent](http://www.alz.co.uk/ascent).

## Centenary competitions

### International Photography Competition

As we reach the midway point of this centenary year, ADI's centenary activities are gaining momentum. There has been a lot of interest from members in the ADI International Photography Competition and we hope that you are sourcing your entries and deciding on which images to submit.

The focus of the competition is to present a positive, human image of dementia. ADI member associations are asked to submit photographs to ADI by Friday 1 September 2006 after which our professional panel of judges will choose the winners in time for the exhibition at the ADI conference in Berlin.

Visit [www.alz.co.uk/centenary](http://www.alz.co.uk/centenary) for more information and instructions on submitting your entries.

### Journalist of the Year Award

We have already started to receive entries for the Journalist of the Year award. So far the standard of writing is very high and we look forward to receiving further nominations for the award. We ask that member associations shortlist journalists who have written interesting and informative news stories on an aspect of dementia. The articles should be selected on account of the quality of the information and research as well as any impact the article might have had in spreading awareness of the disease. Submit one article to ADI by 1 September



and we shall put it before our judging panel of experts from the ADI medical and scientific panel.

### ADI centenary postcard

ADI's centenary postcard is available from the ADI intranet for associations who would like to adapt it so that their members can send it to the health minister in their country. We have come up with an eye-catching design and a clear message that we hope will bring dementia to the attention of health ministers worldwide. Let's make dementia a global health priority!

## ■ Living with dementia

### Japan

#### New publications for people with dementia

Since the groundbreaking 2004 ADI conference in Kyoto, Alzheimer's Association Japan (AAJ) continues to empower people with dementia by giving them a voice and clear channels of self-expression. In the last few months, three books have been published with the support of AAJ which address the needs of people with dementia, carers and care professionals.

'What people with dementia think', was written in collaboration with people with the dementia and was edited by AAJ. In addition, 'For you, who have dementia,' was written by a psychiatrist and a clinical psychologist and was published in January. Finally 'Alzheimer's Early Stages' by Daniel Kuhn of the USA, was translated by Yoshio Miyake and was published last month.

Furthermore, AAJ's monthly newsletter has a page dedicated to people with dementia. In the newsletter a column written by a Japanese person with Alzheimer's disease has recently been introduced.

### Netherlands

#### Consulting people with dementia

Utrecht, Netherlands, is the scene for a new initiative by Alzheimer Nederland to combine consultation with people with dementia with a support group. The group consists of about 8 people with dementia who gather every two weeks. The focus is primarily on providing support for participants who attend to talk about their experiences of how they are coping with life with dementia. However, a couple of times each year Alzheimer Nederland attend the group to question participants on issues to do with the policies, services and

activities of the organisation. The safety and intimacy of the support group means that participants have the confidence to answer questions honestly.

'What we want to achieve is a better insight into the wishes, questions and problems of people with dementia. We use feedback from the group to improve our own services and adjust them to the needs and wishes of those in our care,' said Maaïke Appels, of Alzheimer Nederland, who coordinates the initiative. 'The group has so far been a real success and we have plans to start a second group because of its increasing popularity. Our goal is to gather the opinions of about 40 people with dementia each year,' she added.

### USA

#### Initiative to include people with early stage dementia

Since January 2006 the Alzheimer's Association (USA) has been pioneering a brand new approach to its dementia services with its Early Stage initiative. The initiative comes as a result of increased numbers of people with dementia seeking to be involved in the work of the Alzheimer's Association.

A petition signed by thousands of people with dementia last September stated, 'We want to help. We want to become a part of the decision making process at all levels which determines the policies, actions, and programme you will deliver to us and to our caregivers.'

As a result the Association has created the first ever national reference group of people with dementia in the early stages to provide input, and to share experience and insight about goals and priorities. A parallel body of professionals with long experience

of working with people in the early stages of dementia has also been formed to help shape the initiative.

To date the initiative has succeeded in completing a nationwide survey to catalogue what services and activities people with dementia want to be involved in. The survey revealed that participating in support groups and advocacy were the top two. The Association has also released a report on the unique problems of people with early onset dementia which was released at the Public Policy forum in Washington by Hilary Clinton (see page 4 for more details). In addition, a national office staff post has been created to develop the initiative and implement the nationwide work plan.

Mike Splaine, Director of State Policy and Advocacy Programs, says, 'The initiative is a response to the shifting demographics of Alzheimer's disease. As the baby boomer generation ages we are seeing more early diagnoses. We are laying the groundwork for organisational change and creating approaches to acknowledge the individuals in the earliest stages of the disease. We are evolving from a carer-focussed Alzheimer's organisation to an organisation that works for and with people with dementia and their carers. That shift is here to stay and will intensify.'

Richard Taylor is a man with Alzheimer's disease who for the last six months has been a member of the Association's advisory committee. He said, 'I have lived with the diagnosis of dementia for the past four years. As a member of the advisory committee I meet with the others through a conference call once a month to discuss agenda issues selected by the Association. Things are moving in the right direction. Management, staff, caregivers and those of us living with the disease all now seem united in the belief that the time to involve people living with disease is now.'

# Alzheimer University for emerging associations

London, 25-28 May 2006



Keith Smith runs a workshop on governance



Elias Bou Nader, Lebanon and Charles Scerri, Malta

**Representatives from seven different countries arrived in London at the end of May to participate in ADI's ninth Alzheimer University. The course was aimed at emerging associations who are gradually building strength and expertise in supporting people with dementia and carers in their countries.**

In true ADI style, participants had travelled from all corners of the world to attend the two and a half day course. Associations from Bermuda, Barbados, Croatia, Bulgaria and Malta, as well as from Iran and Lebanon were all represented with one thing in common: a desire to support people with dementia and carers by developing their strength and capacity as organisations.

The course aims to inspire Alzheimer association staff and volunteers with new ideas and practical tips on the running of an association. ADI secured a number of professional speakers and trainers to share their thoughts and experiences on various aspects of running an association. Sessions on governance, support groups, fundraising, raising awareness, the recruitment of volunteers and the provision of information took participants step by step through the most important starting points for any organisation. At each step participants were asked to update their aims and objectives and were encouraged to keep in mind what practical changes they would implement on their return home.

Many of the sessions turned into group discussions about the challenges of establishing an association and of reaching the public with the dementia message. Participants were staying at the same London hotel and joined the planned ADI social events so there were many

opportunities to continue discussions outside the meeting room.

ADI continues to work with those who attended and is following up with each association on the objectives set in London. Stephen Abela of the Malta Dementia Society later told us, 'We have already started to work on the objectives that were identified at the Alzheimer University. Our first priority is to develop a programme for volunteers. Unless we ask for help, how can people know we need it?' His colleague Charles Scerri added, 'The Alzheimer University was a fascinating experience for us. ADI definitely managed to get our priorities right and set us into action. The course format, content and the speakers were excellent.'

Despite the differences in culture, politics and demographics of the countries represented at the Alzheimer University, participants could all relate to each other through their shared desire to help people with dementia and carers. 'Ultimately the needs of a person with dementia in Iran are no different from the needs of a person with dementia in Bulgaria, and we must share our skills and resources to raise the profile of the disease and improve the quality of life for those living with it, no matter where they live,' said Helen Regan of ADI.

The Alzheimer University aims to reflect ADI's philosophy of supporting associations whilst respecting their autonomy, their varied cultures and circumstances and their wish to determine their own development strategy. It seeks to promote change by enhancing the participants' sense of their own value and the significance of their work in supporting people with dementia and their carers.

## ■ ADI regional meetings

**Meetings between Alzheimer associations in the same world region can be of great benefit to those involved. Sometimes facilitated by similarities in language and culture, these meetings provide an opportunity to establish and strengthen**

**networks and channels of communication. Within a world region many of the problems and challenges facing Alzheimer associations will be similar: stretched resources; difficulties in getting government recognition for their work;**

**or the challenge of reaching marginalised populations within the country. Regional meetings give ADI members the chance to talk about their associations and learn from, and hopefully be inspired by, the work of their neighbours.**

### Latin American Regional Meeting, Monterrey, Mexico

Monterrey, Mexico's third largest city surrounded by the jagged Sierra Madre mountain range, was the setting for the 2006 Latin American regional meeting and the first conference of Alzheimer Ibero America (AIB), the Latin American regional network.

The distinctive Cerro de la Silla (Saddle Mountain) provided a dramatic backdrop for a meeting that brought together representatives from all over the region, from the southern cone of Argentina and Uruguay to the tropical



**Latin American members of ADI and AIB**

climes of Panama and Puerto Rico. Four days of meetings and presentations gave those present a chance to share their experiences, skills and motivations in supporting people with dementia and their carers throughout the continent. Each country was given the opportunity to outline their work in the fields of public policy, fundraising and raising awareness and then questions were posed and solutions worked out through open discussions. Venezuela shared its experience of lobbying for government sponsorship, Guatemala explained how they are reaching the indigenous Maya community and Brazil shared its fundraising know-how.

As a result of the meeting, AIB formulated its first strategic plan and agreed on the importance of communication and maintaining up to date information on the activities of the associations. The potential for future twinning relationships for Latin America with USA and Spain was also established, as representatives from both countries were there to share their expertise.

Of course, no Latin American meeting would be complete without opportunities for song and dance. Evening social events gave the group the chance to relax and talk about their work over tequila and karaoke. As a special treat, Federico Ortiz of FEDMA arranged an elegant dinner for delegates at the Museum of Modern Art in Monterrey. The meeting was a great success and we look forward to meeting again in 2007.

### Asia Pacific Regional Meeting, Seoul, South Korea

ADI's 9th Asia Pacific regional meeting took place at the end of April in the bustling metropolis of Seoul, South Korea. Organised by Alzheimer's Association of Korea (AAK) with the theme 'Community based care for home-carers', the conference attracted over 800 people, with representatives from 10 different ADI member countries. Orien Reid, Chairman of ADI attended the meeting along with Elizabeth Rimmer and Jodie Cross from the ADI staff.

The event was sponsored by the Ministry of Health and Welfare, who have recently announced a five-year plan which aims to raise awareness of dementia. The plan will focus on prevention, and will invest in treatment and care for people with dementia and their families.

All ten Asia Pacific associations presented their year's progress and activities to their regional neighbours and updated the group on dementia care in their countries. ADI ran a very successful workshop on staff training which was attended by Thailand, Hong Kong, Korea, New Zealand and Singapore and led by Frank Schaper of Alzheimer's Australia.

Delegates were treated to the best of Korean hospitality and given an insight into local customs and culture at a dinner at the Korea House, within a traditional village. ADI staff and members were also given the chance to see AAK's care home facilities, an impressive combination of care, short stay and respite facilities.

The 2007 regional meeting will be held in Perth, Australia in early June.



**Enjoying an afternoon at Song-pa Skilled Nursing home, Seoul, Korea**

## ■ Research update

### 10/66 awarded Wellcome Trust Grant

ADI's 10/66 dementia research group, coordinated by Professor Martin Prince, has been awarded £1.5 million (US\$2.7 million) by the Wellcome Trust to further the population based studies currently under way in Latin America and China.

The research programme, entitled 'Cardiovascular risk, nutrition and dementia incidence in mixed populations undergoing rapid health transition in Latin America and China' will rely on the participation of 10/66 centres in China, Mexico, the Dominican Republic, Cuba, Peru, Argentina and Venezuela.

When completed, this study will provide the world's largest data set on dementia incidence.

'ADI is extremely proud of 10/66's achievement. It reflects the quality of the group's work and the importance of studying dementia within developing countries. The grant is a richly deserved award for the hard work and commitment of 10/66 researchers, many of whom undertook the pilot studies with no funding,' said Elizabeth Rimmer, Executive Director of ADI.

### Potential vaccine for Alzheimer's disease

Recent research by Dr Okura and colleagues at the Tokyo Metropolitan Institute for

Neuroscience suggests the potential for a future, workable vaccine for Alzheimer's disease.

Scientists have succeeded in producing a DNA vaccine that when tested on mice reduced the build up of the amyloid proteins in the brain, which are characteristic of Alzheimer's disease. A previous trial of a vaccine in humans had to be stopped because of serious side effects. These positive results mean that this vaccine may be able to be tested on humans in the future.

The findings support the idea that a vaccine is our best hope for fighting this devastating disease for which there is currently no cure.

<http://www.pnas.org/cgi/content/abstract/0600966103v1>

## ADI board members gather from around the world



ADI Board 2006

Seventeen members of the elected board, plus the ADI staff, gathered for the ADI board meeting in London on 5-6 May 2006.

Despite the unpredictable spring weather, the board came from around the world to discuss a very full agenda. Governance of an organisation with a large and diverse international membership is no easy task and board members immersed themselves in two days of talks.

The agenda covered topics such as ADI's strategic plan, its people with dementia consultation and the international conference. The meeting started with an orientation session, aimed primarily at the eight

new board members who were elected in Istanbul in October and had not previously met their colleagues. At the meeting, the board decided that the 2009 ADI international conference would be held in Singapore and Ang Peng Chye, President of the Singapore Alzheimer's association and member of the ADI board, was present to accept the honour on behalf of his association.

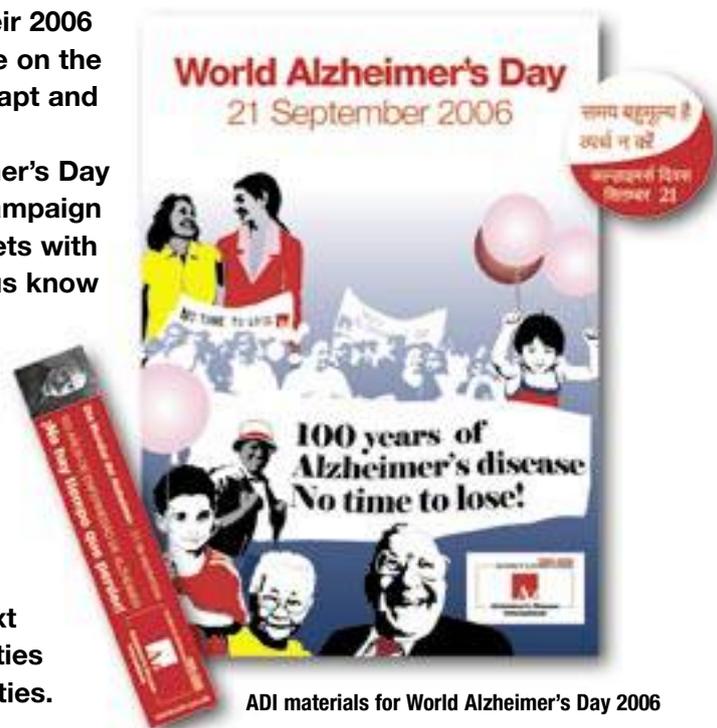
A lovely summer party at Honorary Vice President Nori Graham's house allowed the group to socialise in an informal setting and get to know their ADI colleagues. The next board meeting will be held in Berlin, before this year's international conference.

# Warming up for World Alzheimer's Day!

Member associations should by now have received their 2006 World Alzheimer's Day™ materials. The artwork files are on the ADI intranet in English and Spanish for members to adapt and print for themselves.

We look forward to a really successful World Alzheimer's Day this year. The day is the focus of our centenary year campaign so there has never been a better reason to hit the streets with a memory walk, or raise money with a tea dance! Let us know what you are doing and we will publicise your event on the ADI website. ADI will be providing a sample press release to help get media attention for the day's activities.

Don't forget to check the ADI website for updates on the Ascent for Alzheimer's team as they make their way up to the 5,800m summit of Mount Kilimanjaro in Tanzania, and look out for pictures and a report of the climb in the next edition of Global Perspective. The next edition will also report on World Alzheimer's Day activities around the world so be sure to inform us of your activities.



ADI materials for World Alzheimer's Day 2006

## ADI says farewell to Elizabeth Rimmer



Elizabeth and her son, Alfie Myers



After ten years with ADI, Elizabeth Rimmer is leaving her position as executive director. Elizabeth is looking forward to spending more time with her son, Alfie, who is now 10 months old.

Elizabeth has overseen the growth of ADI from an organisation with one member of staff to six, while membership has grown from 39 to the 75 members of today. During her time with ADI, Elizabeth has travelled the world and made

many friends. Elizabeth has championed the rights of people with dementia and carers and helped to support the development of Alzheimer associations around the world.

The search committee is now in the process of recruiting a new executive director to take ADI forward.

*'I shall always remember how my heart sank when Elizabeth told me about the building site in Cochin, India that was shortly to be the venue for the ADI conference. Her response was, 'It will be alright, Nori.' It was more than alright, it was highly successful. Elizabeth's capacity to make friends and her cheerful and ever-optimistic personality have been the fuel that have powered the growth of ADI.'*  
Nori Graham, Chairman of ADI 1996-2002

*'Elizabeth's leadership and generosity of time and effort have transformed this organisation from its early developing stage into an international federation that has become the global leader and global voice for people with dementia and their families. Thank you, Elizabeth for all your hard work and dedication.'* Orien Reid, present Chairman of ADI

*'It has been wonderful working with Elizabeth. Her humour, infectious laugh, keen intelligence, fearless readiness to confront adversity, integrity and daredevil approach to deadlines made our work together fun, challenging and enormously rewarding. Elizabeth has worked hard but also had a good time and ADI has been lucky to have her. I look forward to continuing our friendship for many more years.'* Henry Brodaty, Chairman of ADI 2002-2005