

21st International conference of ADI in Turkey

Communities unite in Istanbul

September 28 –
October 1 2005

Over a thousand delegates from 64 countries were present at this year's international conference in Istanbul, hosted by the Turkish Alzheimer Society (TAS). 'Bridge at the Crossroads' brought together medical and care professionals, people with dementia, carers and Alzheimer association representatives to contemplate how far we have come in our fight against dementia and to unite efforts in planning for the future.

The interdisciplinary programme featured international experts in science and care, such as Peter George St Hyslop from Canada and Jiska Cohen Mansfield of the USA. A great diversity of subjects were addressed and many topics were up for discussion. Is the term 'dementia' obsolete? How does the 'memory preservation diet' work? What is the role of neuro-imaging in the diagnosis of dementia?



Orien Reid, new chairman of ADI, thanks her predecessor, Henry Brodaty for all his hard work and dedication at Henry's farewell party

Delegates were also presented with the emotional side of dementia as those with the condition were given the chance to express their views and share their experience.

The Turkish hosts treated delegates to great hospitality with non-stop provision of elegant cultural performances, delicious local fare and sparkling social events.

Educational days were followed by splendid Turkish nights, opening with a beautiful ceremony that combined traditional Greek and Turkish dance and set the scene for the cultural unity present at the conference. The week culminated in a haze of farewells and dancing at the elegant gala dinner at the Çırağan Palace on the banks of the Bosphorous.

Delegates left the conference better able to face the challenges that lie ahead with a renewed sense of global solidarity. TAS hope that the media exposure from the conference will increase dementia awareness and help their organisation to grow to support people with dementia and carers all across Turkey.

World Alzheimer's Day 2005

In Chinese Taipei dragons and cymbals lead the way against dementia. Full report page 6-7



CONTINUED ON PAGE 11



Alzheimer's Disease International

The views stated in Global Perspective are personal and do not necessarily reflect the views of ADI. Published by Alzheimer's Disease International, London, United Kingdom. Editor: Melanie Legg. Design: Julian Howell. Printed by Maygray Graphics Ltd. Copyright © Alzheimer's Disease International. All rights reserved. ADI is a not for profit organisation registered in the State of Illinois, USA.

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 **1 February 2006**.

Secretariat

Alzheimer's Disease International
64 Great Suffolk Street
London
SE1 0BL
Tel: +44 (0)20 79810880
Fax: +44 (0)20 79282357
Email: info@alz.co.uk
Web: www.alz.co.uk

■ Editorial



Orien Reid
Chairman, ADI

Assuming my new role as chairman of ADI fills me with excitement and anticipation. Excitement because our 21st International Conference in Istanbul was informative, inspiring and exceptional in every way. The conference had momentum and I'm eager to continue it.

Anticipation because I am thrilled about taking our great organisation to the next level. As the number of people with dementia grows each year, we have an urgent need to provide better care and support for them and the families who love them. There is an urgent need to educate, raise awareness and attack the stigma of dementia. We must raise our collective voices to government leaders about the social and economic impact of dementia. We are now 75 members strong, but we must build a presence and support the growth of associations in many under-served countries where there are limited or no services for those living with dementia and their carers.

It's a huge challenge to follow the stellar leadership of Professor Henry Brodaty but I look forward to building upon his wonderful legacy. Emboldened by the voices of people with dementia, we must all work together to strive for better conditions and services for those living with the disease. We have no time to lose.

■ Announcements and conferences

15–16 December 2005
Iranian Alzheimer Association (IAA) 1st International Conference

Tehran, Iran
Tel: +98 21 4651122
Fax: +98 21 4651122
Email: info@alzheimer.ir
Web: www.alzheimer.ir

22–26 February 2006
World Parkinson Congress

Washington D.C., USA
Tel: +1 800 457 6676
Email: info@worldpdcongress.org
Web: www.worldpdcongress.org

15–19 March 2006
1st Middle East Congress on Ageing

Istanbul, Turkey
Tel: +90 312 231 70 50
Fax: +90 312 231 70 54
Email: info@meca2006.org
Web: www.meca2006.org/english

30 May – 2 June 2006
Global Ageing: the North-South Challenge
8th Global Conference of the International Federation on Ageing (IFA)
Copenhagen, Denmark
Tel: +45 70 23 5056
Fax: +45 70 23 5057
Email: ifa2006@ics.dk
Web: www.global-ageing.dk

29 June – 1 July 2006
Alzheimer's 100 Years On
16th Alzheimer Europe Conference
Paris, France
Tel: +33 1 42 97 52 41
Fax: +33 1 42 96 04 70
Email: conferenceparis@francealzheimer.org
Web: www.francealzheimer.org

15 – 20 July 2006
Alzheimer's Association
10th International Conference on Alzheimer's Disease and Related Disorders
Madrid, Spain
Tel: +1 312 335 5790
Email: researchconference@alz.org
Web: www.alz.org/icad

12–14 October 2006
22nd International conference of ADI
Berlin, Germany
Tel: +49 30 85 99 62 0
Fax: +49 30 85 7 98 26
Email: alzheimer@ctw-congress.de
Web: www.alzheimer2006.de

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

Quotes from the annual conference

It was an amazing experience for me and I benefited greatly from meeting such diverse people, listening to state-of-the art lectures, presentations and personal testimonies and from being immersed in such a world of scholarship, clinical reality and deep care for a few days.

SHEILA DEVANE, TANZANIA

The conference was fantastic, my only complaint – having to choose between so many interesting topics!

LINDA HENDERSON, SINGAPORE



Carer's story by Maribel Mallens, San Juan, Puerto Rico

Dealing with the reality of dementia

The words 'dementia', 'Alzheimer's' and 'loss of memory' are three terms that are frequently used. However, they are certainly not provided with due attention. Having studied gerontology, I thought I knew all about dementia until the moment when it knocked on my door – with the diagnosis of my mother – and I felt my world collapse.

I now see what was a dominant, independent, successful woman and mother await instructions from her daughter to be able to function in daily life. Her condition no longer allows her to drive, cook, handle her finances or, at times, even convey her own desires. She is often anxious and perplexed, but becomes excited when surrounded by friends and family. It is hard to see how people do not notice her lost look and how her children do not know how to react to this harsh reality.

After three years of dealing with this illness I have dedicated myself to reading, learning and participating in educational seminars. I try to find as much information as possible and all the necessary tools to offer her a 'dignified dementia' and a certain quality of life in her ageing years.

I know that there is no cure for the moment, but this motivates me to keep my mother active as long as possible. I always try to make her feel involved and important and I encourage her to participate in all she can. She needs to keep her mind active by continuing to laugh, love and feel and through the knowledge that she still has a lot to give. Above all, I make sure she knows that she is still a loving human being. My mother is



Maribel and her mother show that dementia need not get in the way of love, friendship and quality of life

I try to offer her a 'dignified dementia' in her ageing years

in the primary stages of dementia and I am confident that I can ward off the later stages through continuous loving care, a healthy diet and an affectionate pet dog which has proved to be the best thing that has happened to keep her mentally and physically active. All this, along with my strong faith, will keep her active for as long as possible.

Since the diagnosis I must admit that my life has changed drastically. This cruel illness many times challenges you and makes you ask yourself such difficult questions as 'what is best for them, their own

home or a substitute one?' There are many delicate issues which one does not plan for: the cost, the time, the dedication but, above all and most importantly, the patience to love. Many times I ask myself, 'what else must I put up with?'

I will struggle in my lifetime to make people aware and conscious of this sad illness. Better care is a matter of wanting to learn and diagnose in time. Carers should be taught how best to look after a patient and should have easy access to support and tools to ease the difficulties of living with dementia.

Members' forum

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

REGIONAL ROUND-UP

Latin American networking

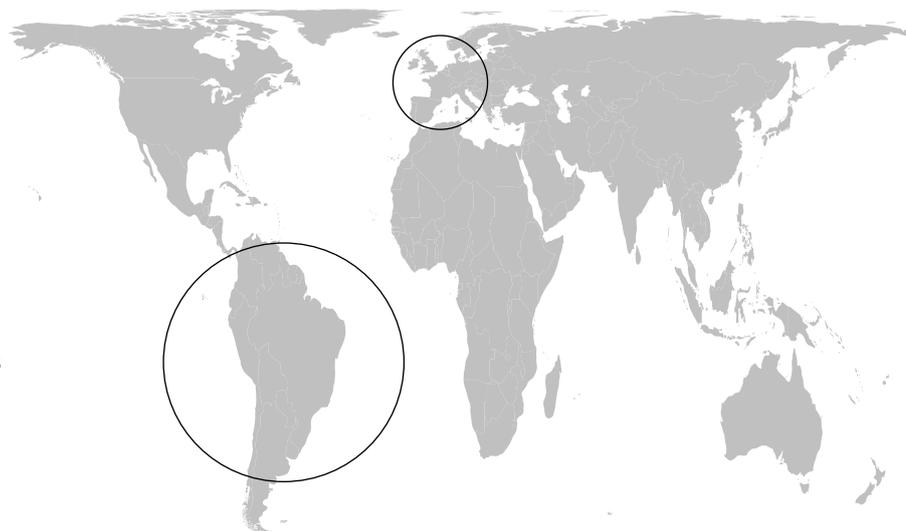
First Uruguayan congress on dementia

On the weekend of 7th October 2005 Uruguay's first congress on dementia took place. Present were doctors and specialists from around the region as well as carers and those with a personal interest in dementia.

On the medical agenda different types of dementia were discussed along with the difference between normal ageing and pathological cognitive decline. In addition, a talk was given on the importance of early diagnosis.

Carers needs were addressed in the various presentations about care for carers, alternative treatments for dementia, the need to lobby national governments and the role of the local government in social programmes. The rights of people with dementia were asserted as delegates heard reports on violence against people with the condition and the legislation that can protect them.

Victoria Rivas, from the Alzheimer association of Argentina was present at the congress and proclaimed it a great success, but just the start of a long process. 'In this part of the world things are different... But nothing is impossible with strength, determination and a will to change things for the better. Let's hope we see the change soon.'



2005 Latin American regional meeting in Brazil

The regional meeting in Belo Horizonte in August was an opportunity for members of ADI in Latin America and Alzheimer Ibero-América (AIB) to gather and discuss the needs that should be addressed in their region.

The achievements of 2005 were presented and objectives were set for 2006. Amongst other things, next year AIB intend to develop an online carer's course following the Brazilian model, and to lobby their governments to implement an incapacity law throughout the region to secure the rights of people with dementia. Portugal was also invited to join the AIB elected board.

Mira Josic de Hernandez of the Fundación Alzheimer de Venezuela said that it had been 'an honour to see how our associations have improved since 2003' and congratulated the Brazilian team on such a successful conference. Next year's regional meeting will be held in Monterrey, Mexico, the date of which is to be confirmed.

ADI Collaboration with Alzheimer Europe

ADI are set to work with Alzheimer Europe on the 'EuroCoDe – European Collaboration on Dementia' project. Alzheimer Europe has been successful in obtaining funding for the project from the European Commission and aims to develop a European network of active players in the dementia field. The network will jointly develop consensual European indicators such as prevalence rates, guidelines on diagnosis, treatment and non-pharmacological interventions, as well as current figures on the socio-economic cost of Alzheimer's disease. 'Through this project we aim to develop an ongoing dialogue and encourage closer collaboration on the European level,' said Jean Georges, Executive Director of Alzheimer Europe.

OUTREACH PROGRAMMES

Supporting the Maori community in New Zealand

'Kia aroha tonu ki to Kaumatua inga wa katoa'

'Always love and support your elders'

The Maori community has been the focus for a new outreach programme being conducted by the Alzheimer's Society of Northland, New Zealand. Since October 2004, Doris Pilcher has been working as the Society's Maori Focus Support Worker, supporting 78 Maori families in their homes from Te Hana to Cape Reinga. Communicating with families in Te Reo, their own language, Doris travels between isolated rural areas providing information and support to families affected by dementia.

According to current prevalence rates there are approximately 1500 people over 65 in Northland with dementia. In the Maori community the over-65 population is small but onset of the disease tends to be from 55 years, reflecting the Maori demographic trend. In such communities understanding of the disease (whakama) is limited. There is little information or awareness of dementia and so families often find it difficult to accept the condition.

Doris certainly has her work cut out for her. 'In Northland some people live in very isolated areas with poor housing and resources,' says Lesley Noonan, the manager of the Alzheimer's Society of Northland.

'This means that often Doris has to become involved in supporting the family in many other areas.'

Such commitment and determination has meant that the Northland Society have seen a large increase in Maori families referring to



Alzheimer's Society of Northland's Maori Focus Support Worker, Doris Pilcher

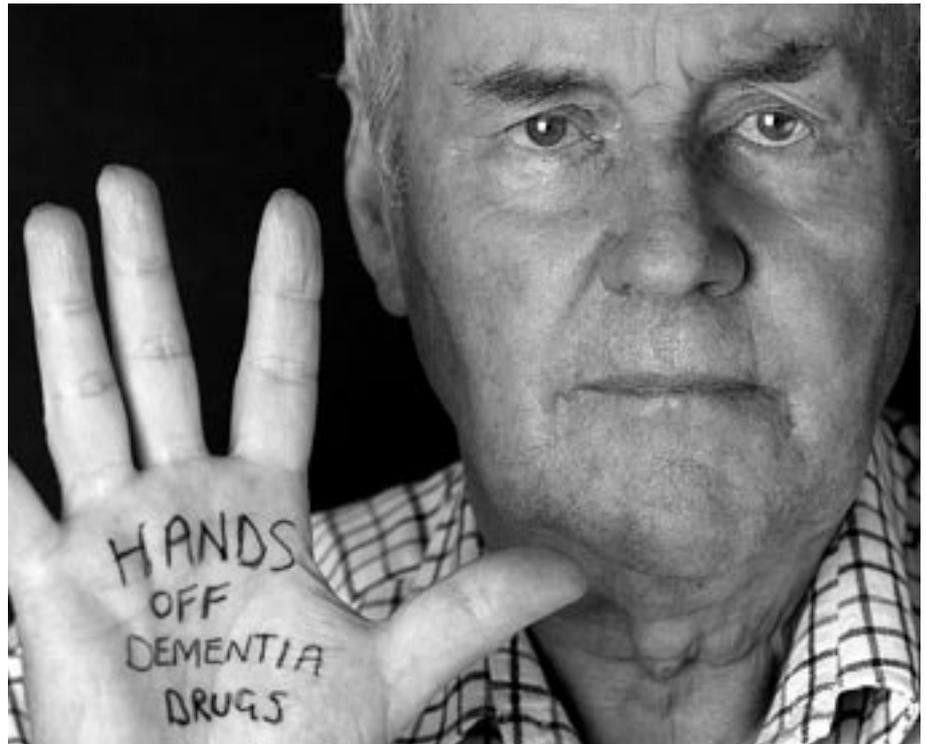


PHOTO: JAMIE HUGHES

Actor Richard Bryers puts up his hand in favour of the Alzheimer's Society's alliance on dementia drugs

Alzheimer's Society co-ordinates UK alliance to campaign for access to drugs

An Alzheimer's Drugs Alliance has been established to demand fair access to Alzheimer drugs on the National Health Service, UK. This comes in response to the National Institute for Health and Clinical Excellence's (NICE) recent review which might limit access to dementia drugs.

Other than the Alzheimer's Society, members of the alliance include the Royal College of Psychiatrists, Age Concern England and the Alzheimer's Research Trust. So far the alliance has held a successful press briefing which resulted in widespread national coverage and has run an active campaign informing MPs of NICE's decision.

The main focus of this campaign will be to get individuals to lobby their MPs. To co-ordinate this, the Society has produced 100,000 postcards on behalf of the alliance and is encouraging members to send them to their MPs.

'The alliance represents the collective views of people with dementia, carers and professionals in the media and in parliament,' said Julia Cream, head of public affairs of the Alzheimer's Society. 'We are planning a long running, sustained campaign over several months.' NICE's final decision is expected to be made by early 2006.

them for information and support since the outreach project began.

Doris is now developing an education package for school children in the area. She has developed a children's book called 'Koro and Hemi' in both Te Reo and English to help children understand the many changes that occur when

a grandparent develops dementia. Seeing as many children live with their grandparents in the Maori community, this is a particularly important angle to address in the struggle to raise awareness about the disease.

World Alzheimer's Day 2005

We can make a difference

On Wednesday September 21st 2005 a record 64 countries observed World Alzheimer's Day. As we rallied together, this year's message focussed on the positive role that we can all play in improving the quality of life for people with dementia: if we all work together, we can make a difference. There was a great show of diversity and imagination in the events that took place worldwide, with each Alzheimer association choosing their own way to raise the profile of dementia and the work of their association.

Building on the success of last year's 'No Time to Lose' campaign, we aimed to unite people on World Alzheimer's Day 2005 by illustrating how everyone is touched by dementia in some way. By demonstrating and speaking up about how we all can be affected by dementia, we can challenge myths and dissolve stigma.

There were dozens of associations this year who boldly stood up and raised their voices against the threat of dementia. Memory Walks took place in 17 different countries from Puerto Rico to India, and huge numbers of associations took advantage of the day to build public awareness, secure media coverage and to make a song and dance about a cause so often left in the shadows.

Many associations grabbed the attention of their media, making appearances on the television, radio and in newspapers. Alzheimer's Association Lebanon managed to get a 90 minute slot on the popular 'Zaven' talk show whilst Nori Graham in the UK conducted a half hour live interview on Live MediaCorp Radio in Singapore. The popular morning television show GMTV in the UK featured Alzheimer's as one of its health topics for the week. World Alzheimer's Day even made an appearance on 'Good Morning Barbados'!



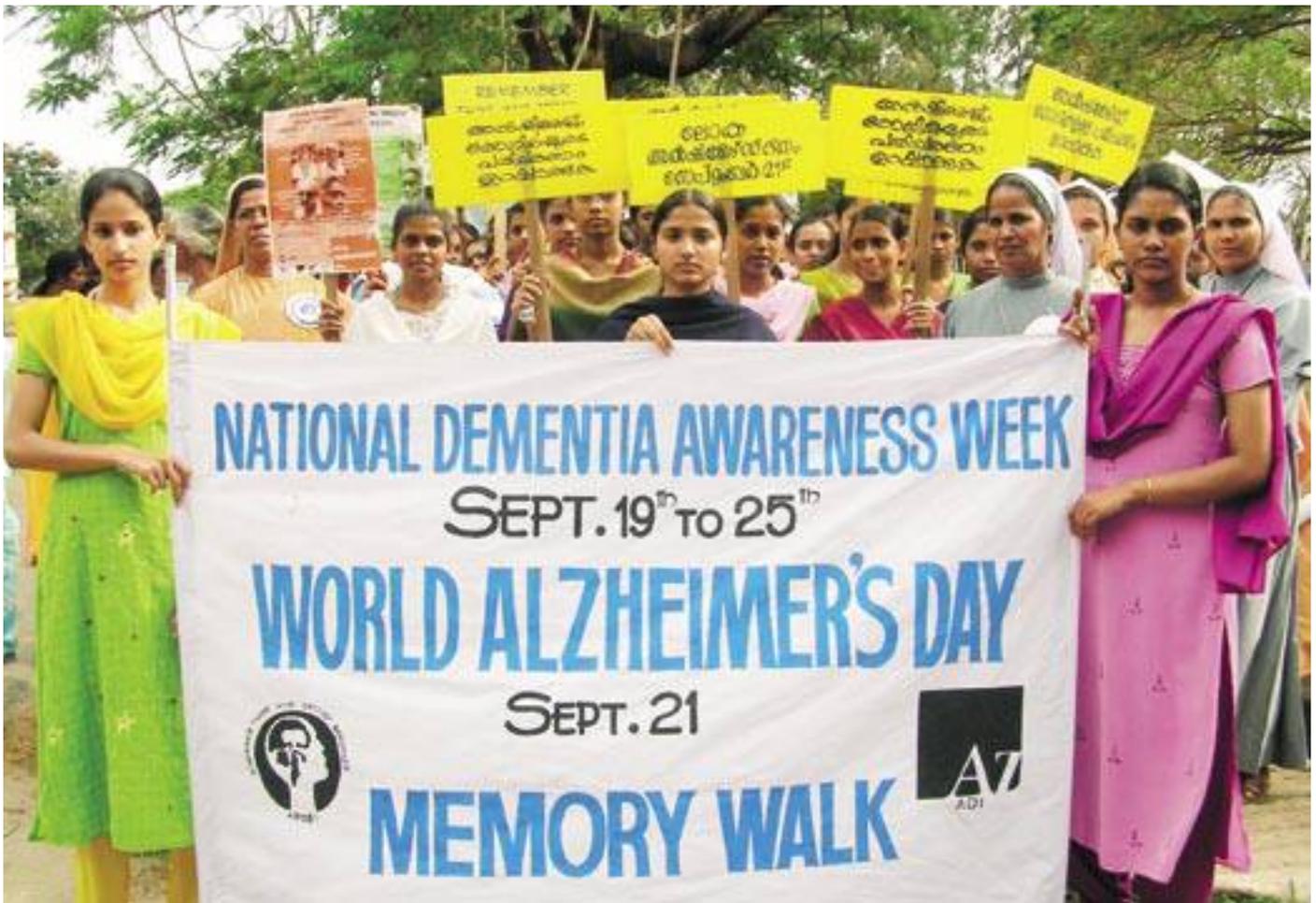
Artwork by Nylza de Souza Andrade (São Paulo, Brazil) who is 80 years old and has dementia

Other countries held competitions and themed events. In Brazil, an art exhibition displayed work by people with dementia. The association also held a special circus performance for people with dementia and their carers. In Switzerland, the Association Alzheimer Suisse hosted a series of 'Unforgettable Memories' themed Tea Dances and in Hungary, the Association of Hungarian Writers presented their collected works about memory loss. The day even captured the imagination of royalty – in Spain the Queen presided over a press conference and concert in Madrid.

World Alzheimer's Day is an opportunity to educate different sectors of the community on the impact of dementia. Alzheimer Scotland took the opportunity to launch a new publication, 'The Milk's in the Oven,' informing children about the illness and how it may affect their lives and those of their families. In India, the launch of 'Young Doctors for Dementia' saw medical undergraduates from Goa Medical College addressing people attending the out-patients department. In Guatemala, the Asociación Grupo ERMITA was celebrating its 10th anniversary with a conference and a training course while Syria was marking the first time

World Alzheimer's Day in Japan





Memory Walk, Cochin, India

it had observed World Alzheimer's Day, with a public lecture.

ADI supported these worldwide activities by sending letters to the health ministers of 191 countries. The message was clear: we urged governments to collaborate with

their Alzheimer associations to produce the policies and resources required to give people with dementia and their carers access to the services they need.

Throughout the world our members were joined in a moving

demonstration of international unity to honour the same cause. Each year we are managing to engage more people. We still have a long way to go but this year proved that together we can make a difference.



Emilio Marmaneu, President of CEFAA, addresses a press conference for World Alzheimer's Day in Madrid, Spain

Renewed vows

Romance was in the air this World Alzheimer's Day as Ken and Susan Eastaugh from London decided to use the opportunity to renew their wedding vows. Following a service for World Alzheimer's Day at St Martin's Parish Church in Epsom, London, the couple held a ceremony to commemorate the day they met, 34 years ago. Ken, who has dementia, was once a prominent Fleet Street journalist and met Susan on 21st September when they were both at the Press Club. After the ceremony, Ken said, 'It was a very moving service and I have this beautiful girl by my side.'



Ken and Sue Eastaugh renewing their wedding vows in London, UK

MEMBERS' FORUM CONTINUED FROM PREVIOUS PAGE

Guatemala involves the Mayan community in its fight against dementia

Doctors, medical students and social workers have been heading to the Guatemalan highlands to target the Mayan community in its latest research into dementia.

After an intensive three month training programme, volunteers put into practice a 'Basic Community Rehabilitation' scheme, targeting hundreds of homes to produce viable data about dementia in the indigenous community. Community leaders acted as mediators and translators for the researchers. 'People were questioned in their own language, Pocoman, by people from their own community,' said Haydeè Lopez, President of ERMITA, the Guatemalan Alzheimer association. 'This created more trust and gave us more positive results. At the beginning of the project the team intended to focus on 300 homes, but

with communication and relations facilitated by community leaders, this number increased to 800.'

The research highlighted that in the Mayan community the older generation continue to live in their own homes with their families and are generally well cared for. It was also found that there was no knowledge of dementia within the community and where symptoms of dementia were found, the person was oblivious to the fact that this could be caused by illness.

Since the end of the programme the benefits to the community are obvious. A special clinic has opened and operates twice a week at a regional hospital for elderly people with dementia. The team of researchers have also received further invitations to develop the same activity in other Mayan areas.

West Kent Alzheimer's Society hits the jackpot with its international online forum

In our March newsletter we featured the West Kent branch of the Alzheimer Society's online forum for people with dementia. Six months later we are happy to announce that the project has been awarded a £2,000 Innovation in the Community Award.

The awards scheme was set up by AOL UK and the national charity Citizens Online to encourage community groups and charities to make the most of the internet. Alzheimer's Forum has certainly done that since it started in 2000 by connecting people affected by dementia across the world through the medium of technology. The Forum is a unique website run



Communicating across the world: the West Kent website

by people with dementia for people with dementia. It offers a place to share experiences, advice, worries or humorous anecdotes.

'I am delighted that our work has been recognised by AOL and Citizens Online, and hope that this award will allow us to spread the word about the Alzheimer's Forum

ADI launches twinning programme

The Alzheimer Association Twinning Programme was launched at the ADI council meeting, 28 September 2005. It offers great potential for sharing knowledge and skills between Alzheimer associations. A developing ADI member will work with a more developed one to strengthen their organisations by tackling shared issues together. The relationship between Alzheimer's Pakistan and Alzheimer's Australia Western Australia (WA) shows what can be achieved through this kind of collaboration. Frank Schaper, Chief Executive of Alzheimer's Australia WA, visited Pakistan in July 2005. As a result of meetings with the World Health Organization (WHO), health ministers and the Australian High Commissioner, the partnership has both political and financial backing. Further to reciprocal exchange visits both parties drew up an achievable action plan. It is set to be a vibrant exchange of knowledge and skills.

ADI excitedly anticipates the many benefits in store for other ADI members that take part in the scheme.

so that more people with dementia can benefit from the site and from communicating with each other.' said John, Alzheimer's Society West Kent branch. The association will be invited to attend an awards ceremony in London in October.

www.alzheimers.org.uk/AlzheimersForum

■ Research update

Exercise to ward off dementia

Exercising for half an hour at least twice a week during midlife can significantly cut a person's risk of developing dementia later in life. These were the findings of a recent study conducted by a team of Swedish researchers. The results, which were published in *Lancet Neurology*, state that people in their late 40s and early 50s who take regular, leisurely exercise could reduce their risk of dementia by about 50%.

Approximately 1,500 men and women were involved in the study, almost 200 of whom went on to develop dementia between the ages of 65 and 79. The researchers looked at how physically active the study participants had been in their late 40s and early 50s.

Those who developed Alzheimer's disease or another form of dementia were far less likely to have been active when they were middle-aged than those who remained mentally fit.

www.thelancet.com/journals/lanneur/article/PIIS1474442205701988/abstract



New dye allows scientists to track the progression of Alzheimer's

Scientists have developed a glowing dye that in future may be used to detect early signs of Alzheimer's disease. The dye also offers the possibility of monitoring the progression of the disease as well as the efficacy of medicines used to treat patients. The dye, known as NIAD-4, works by attaching to and lighting up amyloid plaques in the brain and could allow direct imaging of Alzheimer's plaques through a patient's skull.

The dye has the potential to offer doctors a visual signal into a chemical process previously invisible to the eye. Prof Bengt Winblad, the new chairman of ADI's Medical and Scientific Advisory Panel (MSAP), said, 'this new dye will be an important tool in evaluating diagnoses and also in measuring the effects of new Alzheimer's drugs affecting the beta amyloid metabolism.'

www3.interscience.wiley.com/cgi-bin/abstract/110575590/ABSTRACT

Folates may lower risk of dementia

Research published in the inaugural issue of *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* suggests that older adults whose diets include a total folate intake at or above the recommended dietary allowance (RDA) are at a significantly reduced risk of developing Alzheimer's disease. Folates are vitamin B nutrients that are found in foods such as bananas and oranges, leafy green vegetables, asparagus, broccoli, liver, and many types of beans and peas. According to the researchers, study participants who consumed the recommended daily allowance of folates had a 55 percent reduction in risk of developing Alzheimer's disease. They also noted that most people in the study who reached that intake level did so by taking folic acid supplements, which suggests that many people do not get the recommended amount of folates in their diet.

Prof Bengt Winblad commented, 'It is important to maintain a balanced diet throughout one's life time. Folic acid and vitamin B12 are important for the nervous system and if there is not sufficient intake through diet, they should be supplemented.'

www.alzheimersanddementia.com/article/PIIS1552526005000026/

World Alzheimer's Day 2005

Warming up for Memory Walk in Venezuela



■ Living with dementia

Friendships blossom in Chicago

Buddy Programme: Northwestern University, Chicago, USA



Jenny Knauss with her buddy Sarah Cole

In Chicago, USA, people with dementia are forging new friendships through a Northwestern University community initiative. The 'Buddy Programme' matches people with early stage dementia in the community with first year medical students and researchers. Buddy pairs spend their time together in leisure, sharing interests and hobbies or simply sitting and

talking. 'It's a great way for students to learn about Alzheimer's outside of a clinical setting. By getting to know a person with the illness, students get to see how they are actually living with the changes on a daily basis,' says Darby Morhardt, the programme co-ordinator.

People with dementia involved in the project benefit from having

the chance to maintain interests and share their knowledge and experience with their new friends. By acting as a mentor to students, the buddy with dementia is given a sense of purpose. 'After just a few afternoons with my first medical school buddy, Sarah, I saw that Alzheimer's was not going to keep me from leading an active and happy life,' said Jenny Knauss, who participates in the programme.

Sarah Cole, a medical research student at the university, is Jenny's buddy and the pair frequently spend time together. 'Participating in the buddy programme has been a brilliant experience,' Sarah said. 'The wonderful relationship myself and Jenny have established has entirely overturned my misconceptions of Alzheimer's disease.' Sarah and Jenny never meet at home and are always out and about, at art galleries or going to concerts. 'Alzheimer's hasn't changed our interaction,' Sarah comments, 'our conversations are always non-stop, meaningful and fulfilling.'

Alzheimer's New Zealand establishes a people with dementia reference group

People with dementia in New Zealand are being given the chance to have their say in the running of their Alzheimer association. Since late 2004, Alzheimer's New Zealand has been giving people with dementia a voice and direct role in the association by establishing a reference group for those with the disease.

The group is consulted on a range of different topics, like standards of care and government policies as well as what the association's key priorities should be. They are also referred to on all topics that may affect people with dementia and therefore provide a valuable, direct service to the association.

'So far we have four members in our reference group. We have decided not to put a limit on the numbers in this group and it is hoped that as awareness of the group builds, so will the number of participants,' said Wendy Fleming, President of Alzheimer's New Zealand.

Romanian Alzheimer Club

In Romania a new pilot project is being set up to further address the needs of people with dementia and their carers. The 'Alzheimer Club' is a new project co-ordinated by the Romanian Alzheimer Society in Bucharest.

Apart from short discussions about the disease, participants are involved in a whole range of activities. 'We get them to bring in photo albums and talk about their lives. We dance and hold cookie days when they have to bring in cookies and talk about how they made them,' said Eugen Stefanut, Executive Director of the association.

Admittance to the club is conditional on members being in the early or moderate stages of the disease, without serious behavioural symptoms, and being aware of the diagnosis. Family members also attend the support groups every week so that they can comment on how the person with dementia is getting on at home and get support from those in a similar situation.

At the moment the project receives no funding and is based on the goodwill of volunteers and the family committee.

ADI conference

CONTINUED FROM PAGE 1

'Excellent quality of the speakers'

SESSION TASTERS

Dutch euthanasia law and dementia

Marc Wortmann, Netherlands



Marc Wortmann stirs up some controversy as he addresses a group on the Dutch euthanasia law

Marc Wortmann's presentation on this controversial topic sparked lively debate. In the Netherlands the practice of euthanasia is legal and in the last 10 years there have been four cases of people with Alzheimer's disease requesting that euthanasia relieve them of their suffering.

Many of these requests come in the form of advanced directives where a person, knowing they are facing a future of degeneration and incapacity, prefers to terminate their life rather than face the reality of dementia.

Audience members commented that it would be difficult for a person with dementia to coherently express a well-considered and voluntary request to die, or to express that they are suffering hopelessly and unbearably – the criteria that makes euthanasia lawful. They also remarked that this was a symptom of the stigma of Alzheimer's disease: that many were suffering from the terror at the prospect of the condition as opposed to the condition itself.

Building partnerships in multi-cultural communities

Peter Braun, USA

Peter Braun of the Los Angeles chapter of the Alzheimer's Association, USA gave a presentation about his chapter's outreach project to assess the needs of the Latino community in LA. Over 45% of LA's population is of Hispanic origin and Peter has identified a huge deficiency in services available for the community.

He stressed the importance of culture in our lives: 'It's like oxygen, it influences the way we think and act. Culture affects our perception of dementia and can influence the care given to someone with the disease.' Language, discrimination and low income are only some of the service barriers that prevent adequate care and services being delivered to minority groups. 'Terminology and materials need to be made language specific and appropriate to the particular culture,' said Peter.

'The best thing about the conference was meeting people from other countries, gaining carer advice and bridge building.'

CONFERENCE DELEGATE

6th Stroud interactive workshop: The role of spirituality in the quality of life of a person with dementia

Nori Graham, UK, Barry Gurland, USA, Sube Banerjee, UK

Nori, Barry and Sube presented this interactive and emotionally charged workshop looking into quality of life for people with dementia. They were joined by Stavros Baloyannis (Greece), and Christine Bryden (Australia) who each told the group of their own personal experiences of spirituality in caring, treatment and living with the disease. The group was given the chance to talk openly about their lives as carers and the discussion was a touching demonstration of compassion and understanding as the group shared its common experiences of dementia.

MAKING HEADWAY IN THE MIDDLE EAST

The conference was a unique opportunity to reach out to the Middle East region. Thanks to funding from the Helen Bader Foundation, it was an opportunity that ADI took. Within the twenty countries of the region, there

CONTINUED ON BACK PAGE

Delegates from the Middle East share challenges and solutions at the regional meeting





Helen and Melanie join Latin American members at the showcase



A Turkish dance troupe welcomes delegates to the conference as part of a spectacular opening ceremony

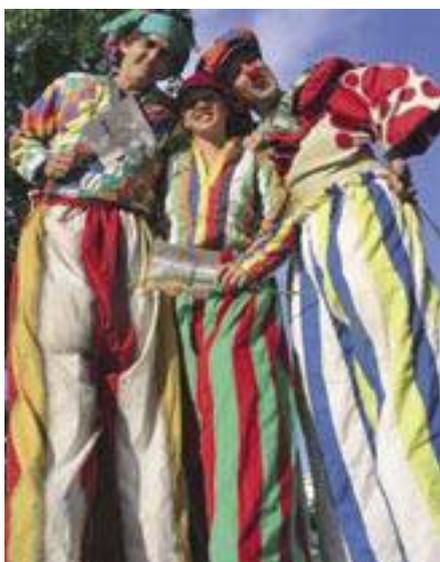
MAKING HEADWAY IN THE MIDDLE EAST CONTINUED FROM PAGE 11

are an estimated one million people with dementia but just five ADI member associations to support them. ADI wants to change this and Istanbul was the first step towards this goal. Eleven representatives from the region were sponsored to attend the meeting; including people from Bahrain, Jordan and Saudi Arabia where associations are in the early stages of development. The centrepiece of the week was a

regional meeting where Alzheimer association representatives met with other interested individuals from the region. They were able to share information and hopes for the future, whilst learning about ADI, prevalence studies and the importance of Alzheimer associations. Although there are clearly common challenges in the region, there is also great enthusiasm for supporting people with dementia and their carers. As

Mrs Basrawi from Saudi Arabia commented, 'It was a wonderful opportunity to meet distinguished figures and others from the region with the same aim as me. I came back so energetic to do so many things; it is overwhelming'. ADI will continue to support the development of the associations in the region by providing advice, sharing contacts and inviting representatives to the Alzheimer University in London next May.

World Alzheimer's Day 2005



Clowning around in Matanzas, Cuba



The Association of Chinese Taipei marks World Alzheimer's Day with a balloon release