



Global Perspective

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

22nd ADI International Conference, Berlin

The city of Berlin played host to the 22nd Conference of Alzheimer's Disease International. From all over the world delegates arrived to be part of a fantastic multi-disciplinary event covering all aspects of dementia care and treatment.

Whether it was large plenary sessions or intimate workshop discussions, medical professionals, Alzheimer association representatives, people with dementia and carers were all catered for in the varied conference programme.

Germany was a very appropriate place to commemorate a century of Alzheimer's disease, where 100 years earlier Dr Alois Alzheimer first described the disease that now affects over 24 million people worldwide. In Berlin, a city with such a turbulent



Heike von Lützu-Hohlbein welcomes delegates at the conference opening session

past, there emerges a great sense of regeneration and responsibility for a better future. As the dementia community looks forward to a better future it was very powerful to hear of latest developments in medicine, treatment and care in so historically apt an environment.

Over the three days the Berliner Congress Centre was home to discussions on early diagnosis, quality of life, drug treatments and research findings whilst Alzheimer associations had the chance to present their work and network in *continued page 8...*

Ascent for Alzheimer's: World Team reached the summit of Mount Kilimanjaro on World Alzheimer's Day Full story page 7





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 **1 February 2007**.

Secretariat

Alzheimer's Disease International
64 Great Suffolk Street
London
SE1 0BL
Tel: +44 (0)20 7981 0880
Fax: +44 (0)20 7928 2357
Email: info@alz.co.uk
Web: www.alz.co.uk

Editorial



Marc Wortmann
Executive Director

Exciting months

Autumn is a busy time of year when you are involved in an Alzheimer association. For me it meant taking part in World Alzheimer's Day activities in September, attending the premiere of the Alzheimer Opera in Amsterdam on the 21st and travelling to Berlin for ADI's international conference in October. It was also the time to finish work in the Netherlands and prepare for my new job as Executive Director of ADI. It takes a lot of energy but it certainly is an exciting time!

At this time of year I always feel part of the worldwide dementia movement. Around World Alzheimer's Day I feel linked to everyone in the world doing this work. We all share the same responsibility: to fight for people who suffer from the disease, both people with dementia and their carers and relatives; to raise awareness among the public and professionals; and to take up all opportunities to improve care, promote research and advocate where we can.

I very much look forward to working together with all the members of ADI and its associated organisations. I thank everyone for their kind words of support and to all those who have wished me success. I will need your support and will work to support you and your organisations, together with the fine and dedicated staff at the ADI office. Enjoy this edition of Global Perspective as it shows what we are all working for and can give you new ideas. As always it is encouraging to see what is happening worldwide in the dementia movement.

Events

29 November – 1 December 2006

1st Pan American Conference on Family Caregiving

National Alliance for Caregiving
Miami, USA
Email: aileen@caregiving.org
Web: www.caregiving.org

14 – 18 March 2007

8th International Conference on Alzheimer's and Parkinson's Diseases: Progress and New Perspectives

Salzburg, Austria
Tel: +41 22 908 0488
Fax: +41 22 732 2850
Email: adpd@kenes.com
Web: www.kenes.com/adpd

17 – 21 March 2007

15th European Congress of Psychiatry

Madrid, Spain
Tel: +41 22 908 0488
Fax: +41 22 732 2850
Email: aep2007@kenes.com
Web: www.kenes.com/aep2007

18 – 20 March 2007

Alzheimer's Association 19th Annual Public Policy Forum

Washington, USA
Tel: +1 866 575 4149
Fax: +1 404 832 3611
Email: alzreg@ambassadors.com
Web: www.alz.org/publicpolicyforum

27 – 28 April 2007

Alzheimer's New Zealand National Conference

Dementia Across the Ages
Wellington, New Zealand
Tel: +64 4 381 2361
Fax: +64 4 381 2365
Email: nationaloffice@alzheimers.org.nz
Web: www.alzheimers.org.nz

9 – 12 May 2007

17th Alzheimer Europe Conference Estoril, Portugal

The Sound of Silence
Tel: +351 21 361 04 60
Fax: +351 21 361 04 69
Email: alzheimers@netcabo.pt
Web: www.alzheimerportugal.org

29 May – 1 June 2007

Alzheimer's Australia 2007 National Conference

A Journey of Passion and Purpose. The next 100 years

Perth, Australia

Tel: +61 89 389 1488
Fax: +61 89 389 1499
Email: info@eventedge.com.au
Web: www.alzheimers2007conference.com.au

9 – 12 June 2007

2nd Alzheimer's Association Prevention Conference

Washington, USA
Tel: +1 312 335 5790
Email: prevention@alz.org
Web: www.alz.org/preventionconference

16 – 19 June 2007

Festival of International Conferences on Caregiving, Disability, Aging and Technology (FICCDAT)

Toronto, Canada
Tel: +1 416 425 34 63 Ext. 7720
Fax: +1 416 425 18 02
Email: info@ficcdat.ca
Web: www.ficcdat.ca

10 – 13 October 2007

23rd International Conference of Alzheimer's Disease International

New Perspectives New Hope
Caracas, Venezuela
Tel: +58 212 263 9733
Fax: +58 212 263 3672
Email: info@congreg.com.ve
Web: www.adi2007.org



Carer's story

Sir Cliff Richard ADI Centenary patron

To mark World Alzheimer's Day Sir Cliff spoke to the BBC Radio 4 programme 'You and Yours' about his experiences with his 86-year-old mother, Dorothy

At the beginning none of us took our mother's memory lapses seriously. She would say, 'I'm getting so stupid, I can't remember', and I would reply, 'oh, come on, I can't remember what I'm doing tomorrow – I'm not stupid, I've just got a bad memory.' If only we had known.

My sister Joan looked after my mother, and there came a point when she would complain about mother being difficult, and get into arguments with her. Now my sister says to me, 'If only I had known early on that this was what it was. I would have said, 'Yes, mum. No, mum,' and just made her happy, because that's all we can do.'

It got to the point when my sister would phone me up and say, 'I can't do this any more. We have just found mum walking about lost in the village. I have a family, I can't be chasing after her all the time.' Eventually we found a fabulous home for mum, but even there, at the end of a family visit, she would beg not to be left alone. Hearing her say that really hurt and made us feel terribly guilty. It was as if we were doing her a terrible disservice, but what else could we do? She needed care 24 hours a day.

Only a few months later we realised that if we distracted her as we were about to leave, she would forget and we could slip away. Her carers said she never complained, because the minute she looked away her mind went elsewhere and all the things she had talked to us about were gone.

In that respect it is a gentle disease. My mother knows nothing about the world's problems, about political uproars and the terrorist threat. She does not know what time or month it is or how bad the weather is outside. She is living, but dementia has taken away her life and



her problems. I personally feel as though I have already mourned my mum because the person we have with us is not the vibrant woman that we all knew.

Whenever I used to go out with my mother people often thought she was my new girlfriend. She looked fantastic right until the time dementia took a hold. She always looked great, very much younger than her age. Now, of course, dementia has taken all that away. She doesn't care what she looks like or care about what she is wearing. Now she just stays in bed dressed in a night gown.

I'm not able to visit my mum as much as I would like, and very often when we do go she is asleep. I think mum quite enjoys the fact that when I visit with my sister or my niece, we take it in turns to feed her and she can look from one to the other, and we become a little community again.

I don't think she recognises me any more. It is hard to tell because she no longer speaks. We have lost our mother, but we still have the woman who gave us life, and we appreciate that, and do the best we can for her.

There is nothing we could have done to prevent this from happening to our mother. We have come to terms with this terrible illness. It is bearable, but only just.

Members' forum

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

ADI welcomes new members



Representatives from Alzheimer associations in Iran, Malta and Lebanon gathered for the Alzheimer University for emerging associations in May. Iran and Malta have now been accepted as full ADI members.

Every year ADI continues to grow and extend its reach and we are happy to announce that at the Council meeting in Berlin new full and provisional members were welcomed into the ADI international family. Bulgaria, Croatia, El Salvador, Iran, Malta and Portugal were accepted as full ADI members, and new associations in Honduras, Hungary and Syria were invited to become provisional members. Congratulations to all our new members and we look forward to actively working with you in the future!

Canada brings people with dementia on board

Canada is leading the way in the current international trend of including people with early stage dementia in volunteer and advocacy opportunities. Individuals with dementia are active on boards and

committees, act as spokespeople, raise funds, and volunteer to support Alzheimer organisations across Canada. Their valued contribution led the Alzheimer Society of Canada to commission a study to identify strategies to promote the active participation of people with early stage dementia in their organisation, particularly in policy, research and service delivery.

The study team gathered information from people with dementia and Alzheimer Society staff and volunteers through interviews and surveys, and drew widely from related literature, research and representatives of other ADI member organisations.

The study affirmed that there are benefits from the inclusion of people with dementia and found that these benefits are widely recognised among staff and volunteers. Alzheimer Society staff are willing to overcome existing challenges, such as transportation costs and health factors, to increase the involvement of people with dementia in their work.

For people with dementia, volunteering offers social interaction and meaningful outlets for skills and experiences. Involvement enhances self-esteem by offering individuals 'active' outlets for self-advocacy as an alternative or complement to the 'passive' role of a service recipient. Engagement also provides opportunities to influence policies and programs that are aimed at improving their quality of life and that of others.

For the Alzheimer Society, increased involvement of people with dementia will lead to a better understanding of how to meet their needs and will strengthen the delivery of services to all users. Additionally, the inclusion of their



Brenda Hounam and Elaine Smith, both living with dementia, are seen here speaking to a group of delegates at the recent 'A Changing Melody' forum in Toronto, Canada. Brenda and Elaine are active volunteers with the Alzheimer Society of Brant, in Ontario, Canada.

voices and views will enhance the advocacy and lobbying efforts of Alzheimer organisations.

Engaging people with dementia in the work of Alzheimer associations represents a significant shift for organisations that have historically been focused on carers. Giving those with dementia a stronger voice will require some changes in attitudes, systems and structures and will also require additional sources of funding.

Although challenges will accompany this new path, the Alzheimer Society of Canada is dedicated to creating opportunities for people with dementia to become full, active participants in the organisation. It is hoped that the findings will be of interest to other ADI members and other charitable and non-profit organisations concerned with advocacy, inclusion and empowerment.

The full report is available from the Alzheimer Society of Canada's Web site at www.alzheimer.ca

NICE decision disappoints

The UK's National Institute for Clinical Excellence (NICE) has failed to change its recommendation



Crowds gathered in Westminster, London to protest against the NICE recommendations in June

that Alzheimer drugs should only be prescribed to people in the 'moderate' stages of the disease, and not in the early or later stages. The decision will mean that patients must wait until their condition deteriorates before receiving adequate treatment.

The Alzheimer's Society has expressed its outrage at the NICE appeal panel's rejection of the appeal on access to Alzheimer's drugs. Neil Hunt, Chief Executive, said, 'What sort of society have we become when the health of

hundreds of thousands are sold to save just £2.50 a day? This blatant cost cutting will rob people of priceless time early in the disease. This is victimisation of the most vulnerable in society.'

The British actress Dame Judy Dench also made her voice heard against the NICE decision. 'I was terribly shocked to hear about the proposed withdrawal of the Alzheimer's drugs. Alzheimer's is such an appalling disease that it is wicked to remove any kind of drug that gives the patient some comfort or relief.'

The Alzheimer's Society is currently organising a campaign to rally against the decision with a series of protest walks, letter campaigns and targeting of government ministers.

Third Dementia Congress takes place in Croatia



Dr Ninoslav Mimica, Scientific Director & Vice-President of ADSC addresses the 3rd Croatian Congress on Alzheimer's Disease

The third Croatian Congress on Alzheimer's disease took place in September as a result of the collaboration between Alzheimer Disease Societies Croatia (ADSC), the Croatian Society for Clinical Psychiatry and the Croatian Society for Neuroscience. People from all

over the world attended the event held on the Brijuni islands, Croatia from 7 –10 September. The main objective of the conference was to highlight the tremendous growth in the number of people affected by Alzheimer's disease and dementia in modern societies.

To commemorate the 100th year since the disease was first described, an exhibition of sculptures named 'In Honor of Alois Alzheimer' by Assistant Professor Dr Eduard Pavlovi accompanied the Congress.

Each of the topics was presented by distinguished invited speakers. During the opening ceremony, and prior to her introductory lecture on Alzheimer's Disease International, Christine McGregor, ADI elected board member, read a warm greeting letter from Orien Reid, ADI Chairman.

The Congress was focused on three main aspects: basic sciences, clinical science and self-support groups. After each session of lectures there was time for questions and discussions from which the participants seemed to benefit the most. A large number of submitted papers were presented in poster form, and they remained on display throughout the Congress.

Two hundred participants attended from ten different countries, making this the biggest event on Alzheimer's disease and dementia ever to have been held in Croatia. In future ADSC plan to hold this conference biannually to foster a comprehensive and holistic approach to dementia, bringing together Croatian and international experts and all people involved in dementia and related fields.

World Alzheimer's Day 2006: **No time to lose!**

All around the world Alzheimer associations, individuals, people with dementia and carers came together on 21 September to commemorate World Alzheimer's Day 2006. As the Ascent for Alzheimer's World Team made it to the summit of Mount Kilimanjaro, people around the world took to the streets on Memory Walks, attended public lectures, concerts and dances to raise awareness of a disease that is set to affect more than 80 million people by 2040.

In Los Angeles, USA, organisers drew a crowd of over 2,000 enthusiastic walkers for their Memory Walk and raised nearly a half-million dollars to fight Alzheimer's disease. In Bangalore, India, a life-size dinosaur was carried in procession down the street to draw attention to the size of the approaching dementia epidemic, a helpline was launched and a report presented to the Minister of Health.



Celebrities in Los Angeles join the Alzheimer's Association Memory Walk

In Bermuda, a film showing of *The Notebook* raised money for the association and in Malta a car wash raised funds for the Malta Dementia Society.

Motivated by his personal experience of dementia, ADI's Centenary Patron, Sir Cliff Richard, gave a passionate interview on BBC Radio about the need for

more recognition of a condition that currently affects his mother (see page 3). The media picked up the story all over the world and ADI received clippings and photos from associations worldwide united under the 'No Time to Lose!' theme, demanding more attention and

Malta's Memory Walk





The view from the summit



The team at Kibo Hut 4750m, the evening before the summit attempt

Ascent for Alzheimer's: World Team

Ten people from eight different countries met for an unforgettable adventure on the slopes of Mount Kilimanjaro, Tanzania for World Alzheimer's Day 2006. Climbers from countries as different as Turkey, Hungary and the Dominican Republic met on common ground with one common purpose: to reach the summit of Mount Kilimanjaro in honour of the 24 million people around the world with dementia. In total the team managed to raise over US \$250,000 for their national Alzheimer associations. The event was a great success and a fantastic way to mark World Alzheimer's Day.

Melanie Legg, ADI staff member and a member of the

Ascent team, wrote:

'Summit night was possibly one of the longest nights of our lives. We were woken at 11pm after only a few hours rest, put on every layer of clothing we had and started the long and slow ascent to the summit. We walked through the night in a line, in zig zags over the loose scree. For hours we just walked uphill through the darkness, eyes fixed on the boots of the person in front, listening to the guides warning us to go 'pole-pole', slowly, slowly.

'Finally after what seemed like an eternity, with aching legs, numb fingers and toes stiff from the cold, we arrived at the crater edge, Gillman's Point at sunrise.

'Never has the sight and warmth of the sun been a more heartening

and welcome sensation than it was that morning. As day dawned on World Alzheimer's Day 2006 and the team made that final effort to make it to the summit, the feeling of awe, pride in our achievement and solidarity against dementia was overwhelming. Suddenly the exhaustion and aching limbs were forgotten as we jumped around, cried, laughed and embraced with full realisation of what we had achieved. Standing there together on the summit we paid tribute to the millions of families living with dementia who had inspired our adventure and who climb their own mountains everyday.'

To read more about the Ascent for Alzheimer's and Melanie's adventure on Mount Kilimanjaro go to www.alz.co.uk/ascent.

better care for people with dementia in their communities.

The report 'Dementia in the Asia Pacific Region: The Epidemic Is Here' was launched on World Alzheimer's Day, warning of the potential impact dementia could have on the health systems and quality of life of people in the Asia Pacific region. The Access Economics report, commissioned by Alzheimer's Australia on behalf of the 15 Asia Pacific ADI member countries, predicts that by 2050 there will be nearly 65 million people living with dementia in the region.

The report called for greater awareness and de-stigmatisation of dementia, the building of effective partnerships between policy makers, clinicians, researchers, carers and people with dementia and the development of care services that are responsive to the needs of people with dementia and their family carers. Throughout the region member associations held official launches of the report, including public lectures and attending meetings with government ministers.

Keona Belmonta celebrates World Alzheimer's Day in Trinidad and Tobago



Conference report continued from page 1

the showcase area. Fifteen people with dementia from ten different countries attended the people with dementia forum, a chance to get together, make introductions and discuss topics of interest. The 7th Stroud interactive workshop was an opportunity for carers and people with dementia to share their experience and views on the pros and cons of early diagnosis.

The conference also provided ADI members from similar world regions the opportunity to get together and hear about latest developments in the region. Meetings were held between members in the Asia Pacific and the Middle East regions. ADI's medical and scientific panel came together for a meeting as did members of ADI's 10/66 dementia research group currently conducting population based research in many

centres throughout the developing world.

The international audience and setting of the conference was the perfect opportunity to unveil ADI's Centenary competition winners. Winners and runners-up of the International Photography Competition were exhibited at the conference and winners were formally announced and presented with prizes at the elegant Gala dinner on the Friday night at the Parochialkirche. The Journalist of the Year Award was presented to the Iran Alzheimer Association for Mina Sabbaghi's article 'Give me your hand.'

Once again the ADI conference was a powerful testament to the growing power of the global dementia movement. 1,550 people from 70 different countries gathered



Orien Reid and Mladen Pikulic, professional winner of the International Photography Competition

to learn from each other and make connections. We look forward to expanding ADI's reach even further as we venture to Caracas next year, to be the guests of the Fundación Alzheimer de Venezuela for the 23rd International Conference, 10–13 October 2007.

Federazione Alzheimer Italia takes over Theatre La Scala

To commemorate the centenary year of Alzheimer's disease and to celebrate World Alzheimer's Day, Federazione Alzheimer Italia organised a prestigious concert that took place in Milan's famous Theatre La Scala. The Filarmonica della Scala orchestra, directed by the young Daniel Harding, inaugurated the new theatre season with Mozart's 'Idomeneo'.

Filarmonica della Scala is the most prestigious and internationally acclaimed orchestra in Italy. Over 1,850 people attended the concert and the event enjoyed the patronage of the minister of the province and the municipality of Milan along with a host of journalists, neurologists, geriatricians and board members of Federazione Alzheimer Italia.

This year Federazione Alzheimer Italia is working to raise the profile of dementia and to call the government to action. The concert was a great opportunity to raise awareness of the disease, and to make the government and the public sit up and realise the devastating effect of dementia on people and families throughout the country.

Daniel Harding conducts for the World Alzheimer's Day concert in the Theatre La Scala



ADI's Centenary competitions

Throughout 2006, ADI ran two competitions to commemorate the centenary year of Alzheimer's disease.

The **International Photography Competition** was open to all ADI member countries and we accepted entries from both amateur and professional photographers. Our professional panel of judges selected the winners from over 100 entries and the results were announced at ADI's International Conference in Berlin. The focus of the competition was to present a more positive, human image of dementia. Photographs reflected the reality of living with dementia, respecting the dignity of people with dementia and

focussing on the person instead of the illness itself.

In the amateur category, first prize was awarded to Federico Estol of Uruguay for 'Neli Smiling'. Second prize went to Lynton Crabb of Australia for 'Dancing in the Kitchen' and third prize to Jan Fredriksson of Finland for 'Letting Go'. In the professional category, the overall winner was Mladen Pikulic for his image 'Nany'. You can see these images on the back page. Winners and representatives of winning associations were present at the conference dinner to collect the prizes and the images were exhibited throughout the conference.

The **Journalist of the Year Award** was a competition designed to encourage the media to portray a

more positive and accurate image of dementia. Member countries were asked to submit one article from their national or local press where it was felt that the journalist had helped to further knowledge and understanding of dementia through their writing. For ADI it was a way to disseminate reliable information and encourage journalists to write about dementia. The winner of the competition was Mina Sabagghi, from Iran for her article 'Give me your hand.' Dr Brian Draper, one of the judges said, 'This piece really shines. It is written in an informative manner, provides good basic information in an engaging and poignant manner and gives a positive message in the cultural context.'

Give Me Your Hand

Mina Sabbaghi

This is an extract from a translation of the winning article, which appeared in an Iranian publication. To read it in its entirety go to www.alz.co.uk/competitions.

Now she is sitting on the chair and swinging, like 30 years ago embracing and nursing her child. As the breeze caresses her face she tries to remember a past memory. Her gaze is glued so anxiously to her child that it is as if she has forgotten those nights that she harmonised her heartbeat to her dear child's crying. And how humbly she looks at the rest of us, as if she were from another planet.

After two hours she takes her veil and starts saying her prayers. 'Mum, how many times are you going to say your prayers?' I asked. 'It is the first time that I have said my afternoon prayers today,' she says. I try to get her to understand that she has already said her

prayers but she will not accept that she is wrong.

Alzheimer's is highly prevalent among the elderly especially in people over 65 years. This illness develops steadily for between 8 to 20 years and during this period the person will suffer from memory loss, perhaps even getting lost in their own house. In time this memory loss will become more serious and the person may not recognise family members. They may show child-like behaviour and eventually may not manage basic tasks like dressing and washing themselves.

Some call it the madness of old age and believe that we should ignore or treat patients forcefully, considering the life of someone with Alzheimer's as finished or futile. Research and experience have shown that affection, tolerance and companionship are highly effective in calming people with Alzheimer's, even if they cannot remember their family members.

But how should we consider a patient who has no complaint or

The winner of the Journalist of the Year award was Mina Sabagghi, from Iran



concept of their illness? In today's cruel world maybe Alzheimer's is a gift from God in your last years of life so that in your illness you forget ongoing difficulties and previous bitter memories. With Alzheimer's, a person goes out steadily like a waning candle but is unaware of the process. Perhaps it is like a reminder from God for children not to forget our old and powerless mothers and fathers who were young and lively in their day. And we should remember that when they took our tiny and powerless hands, it is now our obligation to lend our youth and power to their weak hands.

■ Living with dementia

Newsletter for people with dementia

'Perspectives, A Newsletter for Individuals with Alzheimer's or a Related Disorder' is a free 8-page quarterly newsletter written by Lisa Snyder and published by the University of California, San Diego Shiley-Marcos Alzheimer's Disease Research Centre. Now in its 12th year, the newsletter addresses the concerns, reflections and coping skills of individuals with Alzheimer's or a related memory disorder. It provides up-to-date information, explores relevant topics, provides a forum for discussion, and builds bridges between people with memory loss around the world. Individuals with Alzheimer's or a related disorder contribute their perspectives to this international newsletter in the form of articles, poetry, or letters.

To subscribe to Perspectives, email Lisa Snyder at lsnyder@ucsd.edu or read the newsletter at the Shiley-Marcos Alzheimer's Disease Research Centre website at adrc.ucsd.edu. Click to newsletters and then scroll down to Perspectives.

I have Alzheimer's disease, by Martina Peters

At the end of 2005 Martina Peters was diagnosed with Alzheimer's disease at the age of 40. At the conference in Berlin she spoke of the history of her family and her life with the disease. Her mother developed Alzheimer's whilst still very young and died at the age of 54. One of her sisters and her brother are also affected by Alzheimer's disease. Martina has had symptoms since 2003 and can no longer work. Through her sad family story and her active participation in the conference she brought public attention to



Images from the Trebus Project, London

the cause of people living with dementia. She asked us to take the fears of people with dementia seriously. 'I am forgetful, but I am not stupid...'

Trebus Project

The Trebus Project is an original and very touching homage to the hidden or forgotten lives of people with dementia. The brainchild of David Clegg, a former community arts project manager, the Trebus Project is an archive of life stories each documenting the history of people with dementia living in nursing homes.

Some of the projects eventually lead to films, exhibitions or audio recordings but they all start the same way and most stay as stories. Funded by the Arts Council of London, David has built up a huge quantity of material, some of which is to be published next year.

'I've been lucky enough to work with some fantastic characters; a lady bullfighter, two professional boxers, a gunner on a ship that chased the Bismarck, theatre directors, a possible spy and countless other amazing people. If their stories don't get passed on they disappear.'

Raising public awareness of dementia is another important aspect of David's work, as is improving the quality of life of the people he works with. His work has a tremendous therapeutic value for people with dementia. Sitting with



someone in a nursing home, using various techniques to recall the past, the person's life history gradually emerges and transforms the person back into an individual as opposed to a patient in an institution.

'It is vital that people with dementia use their time purposefully, and this may depend on our knowledge of their personal history. It might come from playing a favourite piece of music to a bed bound resident, providing targeted sensory stimulation, encouraging communication by going to the pub or encouraging them to regain a little independence by rediscovering how to make a cup of tea,' says David.

The projects also give us a new and in depth insight into the world of someone with dementia. In one story a man described it as 'a feeling that the world is withdrawing'. He was convinced that he hadn't changed at all but that the world had moved away from him, leaving him feeling 'disconnected', and 'like looking at the world through dirty glass'.

Some of the stories are beautiful and very poignant and play a necessary role in our understanding of life with dementia. 'Songs and Stories From The Centre' is the result of two years work where artists and nursing home residents have worked together to interpret the experience of dementia and mental illness in sound and music. For more information or to order a copy go to www.trebusprojects.org.

■ Research update

Neuroimaging studies expand across the globe

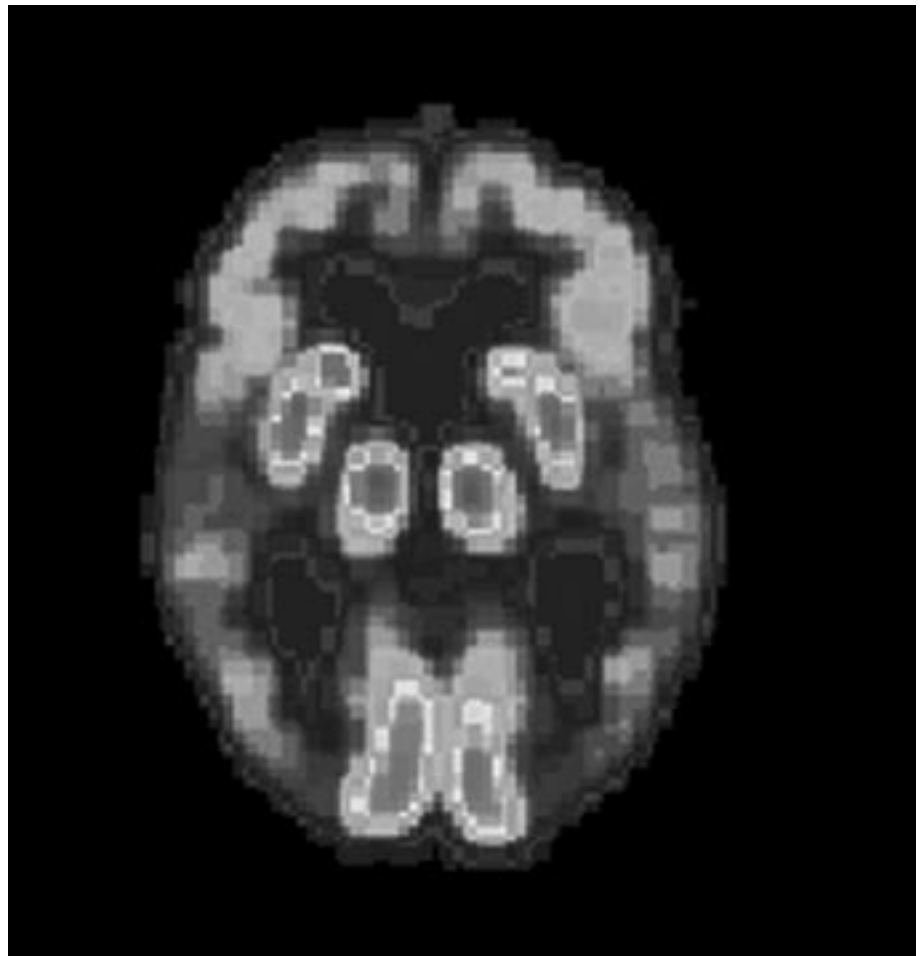
A study to identify brain and biological changes associated with memory decline is expanding across Europe, Australia and Japan to help speed up the search for treatments and cures for Alzheimer's disease. The study, the Alzheimer's Disease Neuroimaging Initiative (US-ADNI), started in October 2004 in the USA and Canada and an Australian study is planned.

The studies will define the rate of progress of mild cognitive impairment and Alzheimer's disease. The aim is to develop a large database and improved methods for clinical trials. It will provide information and methods which will help lead to effective treatments for Alzheimer's disease, leading to effective prevention.

The nine month, European pilot study is now underway in Denmark, France, Germany, Italy, Netherlands and Sweden. It aims to act as a springboard to prepare a more extensive longitudinal study in the European Union as a companion, or to complement, the US-ADNI. A five year Japanese neuroimaging study, led by Prof Yasuo Ihara of the University of Tokyo, will start in 2007.

The Australian study, to be carried out in Melbourne and Perth, aims to recruit 200 people with early Alzheimer's disease, 200 with mild cognitive impairment and 600 healthy people over the age of 60. All will have a neuropsychological evaluation and blood tests, and will be questioned on lifestyle. They will be reassessed after 18 months. The study is supported by the CSIRO, a major government funded research organisation.

The USA group is still enrolling people for the study and in Europe



PET scan of brain with Alzheimer's disease

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organisers will be recruiting a small number of participants in the new year. Interested persons should contact Alzheimer's Australia on 1300-696463 or go to www.AIBL.nnf.com.au

For more information on the other studies go to:

European study: www.centroalzheimer.it/E-ADNI_project.htm

US study: www.adni-info.org or www.alzheimers.org/imagine

Dementia Risk Score system developed

In September's *Lancet Neurology*, Miia Kivipelto and colleagues describe the first attempt to develop a score to determine the risk of dementia in middle-aged people. The researchers identified

seven factors that predicted a high risk of dementia: older age, male sex, low educational level, hypertension, obesity, hypercholesterolaemia, and physical inactivity.

Many of these risk factors are modifiable through lifestyle changes, medical treatment, or both. Therefore, a risk score could identify high-risk individuals who can then be targeted with intensive lifestyle consultations and drug treatment.

Of course there exists the danger that a high score could be misused by some as a rationale for discrimination. However, this is a potential way to delay, or perhaps even prevent, the onset of dementia.

For more information see www.thelancet.com/journals/laneur/article/PIIS1474442206705294/fulltext



Photography competition winners

Winner in the amateur category:
'Neli Smiling' by Federico Estol,
Uruguay



Second in the amateur category: 'Dancing in the Kitchen' by Lynton Crabb,
Australia



The overall professional winner: 'Nany' by Mladen Pikulic



Third in the amateur category: 'Letting Go' by Jan Fredriksson,
Finland