



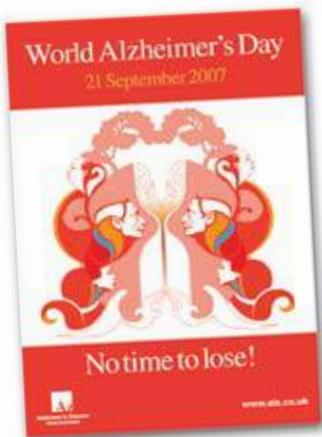
Alzheimer's Disease  
International

September 2007  
Volume 17 No.2

# Global Perspective

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

## People with dementia speak out



For World Alzheimer's Day 2007 ADI is encouraging its member associations to focus on the realities of life with dementia. Around the world, Alzheimer associations are growing in size and number as the issue of dementia makes headlines and our voice is recognised in policy agendas.

With so much activity and emphasis on organisational development we can sometimes

lose sight of the true meaning of our campaigns. 24 million people around the world and millions more families have to live with the daily challenges and persistent stigma of dementia. It is time for them to have their voice heard on a global stage.

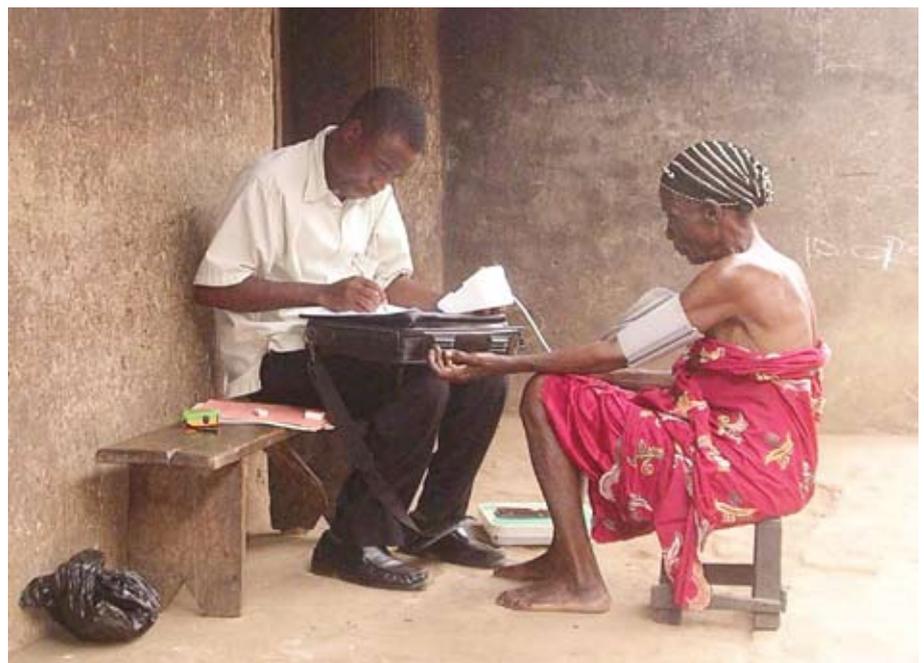
Join our World Alzheimer's Day campaign and show the world what dementia is really like. Only when we truly understand the challenges can we fight for a better future.

In recent months an African network of Alzheimer associations has started to emerge. This has been the source of much excitement in the ADI office. For years Africa's struggle with dementia has been neglected, with communicable diseases, such as HIV and AIDS, absorbing the world's interest in the region and dominating health agendas.

ADI is proud to be assisting the development of Alzheimer associations in Kenya, Tanzania, Nigeria and Ethiopia. Working alongside 10/66, ADI's dementia research arm, we have great hopes for the future of an East Africa network. With help and direction from ADI and its members – including the more established associations in South Africa and Zimbabwe – we hope to see more African communities coming together to support people with dementia and their families.

*Turn to page 5 to read about recent developments in Kenya.*

## Alzheimer's disease and dementia in Africa



Interviewer in Ibadan, Nigeria, conducts home assessments on elderly members of the community



## 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 November 2007**.

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## Editorial



**Orien Reid**  
Chairman, ADI

This edition of Global Perspective is packed with exciting news and events from the around the globe. Alzheimer's disease and other forms of dementia are currently high profile news items in many countries. Just browsing the pages of this newsletter you'll see the incredible progress being made by member associations in all continents.

Asia Pacific is a very dynamic region forging ahead in policy and advocacy; the UK is continuing its battle to ensure dementia drugs are subsidised by the government and the USA continues to raise its voice to ensure that dementia is high on the national health agenda.

However, it is not just the larger associations that are making progress. The news that countries in the African continent are recognising the challenge posed by dementia is of great importance. ADI's 10/66 dementia research group are conducting some fantastic work in ensuring that the developing world is equipped with the statistics and information to run awareness campaigns of their own, within their own individual contexts.

As Alzheimer associations, medical professionals and researchers make advances in their work, and more people with dementia are given the opportunity to speak out, it is easy to see the reaction this activity has generated in the world's media and by policy makers.

The most important thing for us to do now is work together and share our knowledge and experience so that this progress can continue. Those fighting for recognition and funding for dementia are a global family. We must come together – through events like World Alzheimer's Day – to show solidarity and commitment to a cause that affects over 24 million around the world. We have no time to lose.

## Events

28 – 30 September  
**13th National Conference of Alzheimer's & Related Disorders Society of India (ARDSI) and 1st Congress of the Asian Society Against Dementia (ASAD)**  
*The Frontiers of Dementia Care and Research*  
Madras, India  
Tel: +91 2435 3079  
Email: [marundeshwara\\_tours@vsnl.com](mailto:marundeshwara_tours@vsnl.com)  
Web: [www.nsig.org](http://www.nsig.org)

10 – 13 October  
**23rd International Conference of Alzheimer's Disease International**  
*New Perspectives, New Hope*  
Caracas, Venezuela  
Tel: +58 212 263 9733  
Email: [info@congrex.com.ve](mailto:info@congrex.com.ve)  
Web: [www.adi2007.org](http://www.adi2007.org)

14 – 18 October  
**International Psychogeriatric Association (IPA) Osaka Silver Congress**  
*Active Aging: Wisdom for Body, Mind and Spirit*  
Osaka, Japan  
Tel: +81 6 6229 2555  
Email: [ipa2007@congre.co.jp](mailto:ipa2007@congre.co.jp)  
Web: [www.congre.co.jp/ipa2007](http://www.congre.co.jp/ipa2007)

26 – 28 October  
**4th International Symposium on Alzheimer's Disease and Related Disorders in the Middle East**  
Athens, Greece  
Tel: +1 773 784 8134  
Fax: +1 208 575 5453  
Email: [meetings@worldeventsforum.com](mailto:meetings@worldeventsforum.com)  
Web: [www.worldeventsforum.com/alz](http://www.worldeventsforum.com/alz)

5 – 7 November  
**UK Dementia Congress**  
Harrogate, UK  
Tel: +44 20 7720 2108  
Email: [suec@hawkerpublications.com](mailto:suec@hawkerpublications.com)  
Web: [www.ukdementiacongress.co.uk](http://www.ukdementiacongress.co.uk)

7 – 9 November  
**2nd Iberoamerican Congress of Psychiatric Gerontology and 1st Uruguayan Congress of Psychiatric Gerontology**  
*Ageing, Collective Memory and the Building of the Future*  
Montevideo, Uruguay  
Tel: +598 2 400 8555  
Email: [psicog07@psico.edu.uy](mailto:psicog07@psico.edu.uy)  
Web: [www.psicogerontologia07.blogspot.com](http://www.psicogerontologia07.blogspot.com)

8 – 11 November  
**5th International Congress on Vascular Dementia**  
Budapest, Hungary  
Tel: +41 22 90 80 488  
Fax: +41 22 73 22 850  
Email: [neuro13@post.tau.ac.il](mailto:neuro13@post.tau.ac.il)  
Web: [www.kenes.com/vascular](http://www.kenes.com/vascular)

28 November – 2 December  
**World Psychiatry Association (WPA) International Congress Working Together for Mental Health. Partnerships for Policy and Practice**  
Melbourne, Australia  
Tel: +61 3 9417 0888  
Fax: +61 3 9417 0899  
Email: [wpa2007melbourne@meetingplanners.com.au](mailto:wpa2007melbourne@meetingplanners.com.au)  
Web: [www.wpa2007melbourne.com](http://www.wpa2007melbourne.com)

29 November – 2 December  
**3rd International Congress on Brain and Behaviour (ICBB)**  
Thessaloniki, Greece  
Tel: +30 23 10 99 46 22  
Fax: +30 23 10 26 65 70  
Email: [kfount@med.auth.gr](mailto:kfount@med.auth.gr)  
Web: [www.psychiatry.gr/congress](http://www.psychiatry.gr/congress)



# Caring for those who cared for us

**Ms Nayantara Mascarenhas de Lima Leitao**

**M**y mother-in-law, Mrs Urminda Mascarenhas de Lime Leitao, was the first lady member of the Legislative Assembly in Goa and the founder member of the United Goans Party. She was very much a woman in a man's world.

Graduating with a Bachelor of Science in Mathematics & Chemistry and a Bachelor in teaching, Urminda held the post of principal in a number of schools in Goa before she married entrepreneur Jose Xavier Marcelino da Piedade Lima Leitao in 1952. Over the years she raised a family of six children. It was her husband who encouraged her to move into politics. On his death in 1972, Urminda was thrown into the world of business, and she calmly and efficiently set to work on managing the family enterprise.

In 2002, we received a terrible shock. Mama was becoming increasingly forgetful and somewhat aggressive. She was eventually diagnosed with Alzheimer's disease.

Our mother has been battling bravely with the disease since then. It was only a year ago that she stopped going to the office as

she had done so consistently for all those years. Now she spends her time wandering about the house, a shadow of her former self, often confused and sometimes aggressive. She can no longer read the newspaper or continue to sew – her favourite hobby – and only recognises me, her son and our five children.

Mama's doctors are pleased with her progress but have noticed a steady decline in her mental condition in the last six months. However, she is still extremely agile and physically fit.

It is poignant to remember the time Mama told me how fortunate she considered herself to have us to look after her in her old age. I remember her talking about the large number of elders in India who had no one to care for them. She hoped that the government would one day understand the specific needs of elders in society.

Although her lucid periods are becoming fewer and farther between, Mama can still maintain a telephone conversation with her usual flair and style. Her grace



**Ms Urminda Mascarenhas de Lima Leitao has been living with Alzheimer's disease since 2002**

## **Message of hope**

*'I know that there are a lot of people in India with the same condition as me. I have my loving family to care for me but I know that the others might not be as fortunate. I hope the Government will support these people and help them live a respectable life.'*

and impeccable manners serve to remind us of the elegant lady she has always been. She has been a source of strength for our family for all these years and we will be her strength in the days to come.

# Members' forum

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



**Marc Wortmann and US advocates lobby on Capitol Hill**

## USA

### Public Policy Forum, Washington

Hundreds of advocates raised their collective voices on Capitol Hill, Washington as part of the US Alzheimer Association's 19th Annual Public Policy Forum. The event from 18-20 March attracted people from around the United States and around the world to meet with legislators and participate in a Senate hearing on Alzheimer's disease.

The event was timed to coincide with the release of the 2007 *Alzheimer's Disease Facts and Figures* report. The report, which illustrates the impact of Alzheimer's on individuals, society and the economy, generated national headlines.

The event was well attended by the global dementia movement and testimonies were provided for a subcommittee hearing on Alzheimer's disease and the introduction of the Alzheimer's Breakthrough Act of 2007 and the Family Assistance Act of 2007. Dr Sam Gandy, chair of the Association's Medical and Scientific Advisory Council, provided testimony (see page 11).



**A volunteer in Sri Lanka spreads the word on World Alzheimer's Day**

## Sri Lanka

### Lanka Alzheimer's Foundation gears up for World Alzheimer's Day

The struggle against dementia in Sri Lanka has made great progress in recent months thanks to the hard work of the Lanka Alzheimer's Foundation. The team are currently working on an awareness and fundraising campaign. At the end of July the Foundation conducted an all day awareness workshop on dementia for Senior Girl Guides islandwide. In addition, World Alzheimer's Day will be commemorated with a Memory Walk and a musical concert performed by two leading choirs.

In March 2007, the deed for a crown lease property in Maradana was signed by the President and

granted to the Foundation. On the land the Foundation plan to build a Dementia Services and Information Centre. This Centre will be the focus of a groundbreaking ceremony on World Alzheimer's Day. Once the centre is complete, the Foundation will be able to expand its current activities and programmes and aims to provide extra day care, library services and training for professional carers. The Foundation also intends to establish an Alzheimer café, charity shop and a memory clinic to further support people with dementia and their carers in the community.

## Suriname

### Stichting Alzheimer Suriname

On July 18th 2007, a group of volunteers in Suriname officially registered 'Stichting Alzheimer Suriname' to support people with dementia and carers in this Latin American former Dutch colony.

The group are currently forming a board and establishing the foundations of governance with the help and support of Alzheimer Nederland. Marc Wortmann, Executive Director of ADI, is also meeting with the group to further their development.

The association will begin their media awareness campaign around World Alzheimer's Day and are to hold a conference on dementia and home care in Paramaribo, the country's capital city.

## Scotland

### Is the dementia epidemic inevitable?

Alzheimer Scotland is to hold its 7th Annual World Alzheimer's Day Lecture in Glasgow on 19 September.

In Scotland, as in many parts of the world, there is growing concern about the impact of demographic change on the number of people with dementia.

Phil Hanlon, Professor of Public Health at the University of Glasgow, will focus on this subject in his lecture, 'The Dementia Epidemic: is it inevitable?' Professor Hanlon will speak about the prospects for prevention of dementia and the evidence for risk reduction. He will look at its potential both for individuals and for the population as a whole as a strategy to avoid the impending dementia epidemic.

For more information contact Dorothy Keith on 0131 243 1455 or [dkeith@alzscot.org](mailto:dkeith@alzscot.org)



Oriën Reid and Maurice O'Connell sign the ADI / Alzheimer Europe partnership agreement

## Alzheimer Europe

### Annual conference

The 17th Conference of Alzheimer Europe (AE) was held in May in Estoril, Portugal. The meeting was well attended and fantastically organised by APFADA, the Portuguese Alzheimer association. Representatives from associations from all over Europe were present at the event, contributing to sessions and workshops on dementia policy and care. The event culminated with an elegant gala dinner where the entertainment was provided by gymnasts and dancers from the Cirque de Soleil.

Government officials were present at the conference closing ceremony where they formally signed the Paris Declaration. The Declaration, drawn up at the 2006 AE conference in France, is a document in which Alzheimer Europe outlines the political priorities of the European Alzheimer movement and issues a call for action to improve the situation of the 5.8 million people living with dementia and their carers in Europe.

ADI used the opportunity to meet with the Executive Committee to brainstorm about future activities. Also in Estoril, Oriën Reid, chair of ADI and Maurice O'Connell, chair of Alzheimer Europe, signed a partnership agreement between the two organisations to formalise all future collaboration.



ADI staff relax after a hard day at the Alzheimer Europe Conference, Estoril

## Iran Making progress



The IAA hold a counselling meeting in Tehran

Iran Alzheimer Association (IAA) have been making great progress in its provision of care services nationwide. The hardworking individuals within the Iranian association have secured support and an allocated budget from the government's Welfare Organisation.

After two years of negotiations, the IAA now have facilities in Tehran to offer counselling to a growing number of attendants. They have introduced a new awareness programme 'Maintaining Good Health in Seniors' which has received a very positive reception from the community.

Meetings with the municipality and persistent lobbying has resulted in the IAA being offered a range of venues and options for the expansion of services and programmes. During one particular meeting, the municipality offered the IAA two Health Centres in the north-east and north-west of Tehran, the logistics of which are being considered.

At the end of the World Alzheimer's Day campaign in 2006, the IAA received another vote of confidence. A letter, sent to the Interior Ministry requesting that dementia be placed as a priority on the provincial health group's agenda, was granted. Since then the IAA have had a series of meetings and invitations from other provinces and they hope that this will be rolled out on a national level.



## Kenya

### Emerging association

The Alzheimer's Association of Kenya was launched in April 2007 in Nairobi. At a meeting on Brain Ageing and Dementia in Developing Countries a team of carers and medical professionals committed themselves to the dementia movement. The group is led by Professor David Ndeti, Professor of Psychiatry at the University of Nairobi and director of the Africa Mental Health Foundation (AMHF). The Foundation have agreed to provide office space and administrative support until the association

is strong enough to provide this infrastructure itself.

Together the team has put together a comprehensive and realistic plan of action. Education of carers and professionals is the group's main objective. With the help of AMHF, ADI, 10/66 and colleagues in Tanzania, the group will work on research, advocacy and dissemination. The group is also supported by care professionals in the USA. Together we hope to create a sustainable and effective project which uses the experience and knowledge of the network around it to confront the reality of dementia in its African context.

## Pakistan

### Raising awareness in the community



Memory Walk, the association's usual way of commemorating the day. A weekend Iftar party will be a better opportunity to attract people and attention to the event. An awareness seminar in Karachi is also planned.

Alzheimer's Pakistan will be organising an Iftar Party in Lahore to celebrate World Alzheimer's Day 2007. 'Iftar' means 'sunset', the time at which Muslims break their fast in the month of Ramadan. 21 September falls in the fasting month of Ramadan and organisers believe that less people would be able to join together for a



**Marc Wortmann contributes to the discussion at the Alzheimer Australia conference**



**Jodie Cross at the ADI stand**

## Australia

### 12th National Conference

Perth in Western Australia is the fastest growing major city in Australia. With a growth rate of 2% yet situated over 1,000 miles away from the nearest city, Adelaide, it reflects the pioneer spirit of the Australian people.

A perfect setting, therefore, to hold Alzheimer's Australia's 12th National Conference. Hosted by the Western Australia chapter, the meeting was brilliantly organised and attracted a record 950 delegates. Keynote speakers included past ADI chairman, Henry Brodaty, ADI Executive Director, Marc Wortmann, Mary Marshall, Murna Downs and Alexander Kurz. Andrew Watt, a young man affected by his father's journey through Alzheimer's disease, contributed a very moving testimony to the conference opening session and effectively communicated that dementia is not just an issue for the elderly. His story reminded those present that dementia affects both the young and the old as families try to cope with the effects. Alzheimer's Australia has a wealth of experience to offer other ADI members and the conference was well attended by the ADI community.

### 10th Asia Pacific Regional meeting

ADI held its 10th Asia Pacific Regional meeting before the conference. The meeting was the best attended regional meeting so far. We were pleased to welcome ADI friends from Thailand, Malaysia and the Philippines along with more established ADI members from Japan, Chinese Taipei, India, China, Hong Kong, Singapore, Pakistan, Sri Lanka and New Zealand.

Asia Pacific is a very dynamic area of the world and this is reflected in the great work being undertaken by Alzheimer associations in the region. ADI members discussed plans and alliances and brainstormed new ideas to work towards a bright future.

The 11th ADI Asia Pacific Regional meeting will be held from 13-15 June 2008 in Taipei.



**Delegates, health care professionals and volunteers at the conference opening reception**

## ■ Living with dementia

# People with dementia speak out

Some of this text appears in the 2007 World Alzheimer's Day bulletin



*'I want to support others with dementia and their families by sharing my experience. I do not know for how much longer I will be able to communicate with people, so I try to do my best to inform the world about the difficulties of life with dementia whilst I still can. We need places where we can casually drop in at anytime to chat, paint and relax. What's more, it would be nice to have doctors and nurses there who understand and with whom we can consult about our health.'*

**Tamiji Yoshida, Japan**

*'Before diagnosis I was a dentist. Now I still live at home but with the help of two carers. I would like to participate more fully within my Alzheimer association, even if only by telephone, so as to be better able to help people like me, who have an illness of the memory. I wasn't told about my condition at first. The doctors weren't prepared to attend to people like me and they need to be taught so that we are treated with the respect we deserve.'*

**Marta Mariño de Martínez, Argentina**



*'We appreciate each day that we have together'* **Peter Hébert, USA**



*'I was diagnosed with vascular dementia in July 2005 at the age 54. Scary as a diagnosis like this is, I am glad that we have it. Early detection and acceptance allows me time to get my affairs in order but it also allows me time to enjoy all the blessings in my everyday life and make the most of each day. Yes, there are struggles; but there are also pleasures in life that I took for granted. Yes, life is really pretty good! I would like people to see me as the same guy I have always been who is continuing to work at having a good life. My family and I work at keeping a positive attitude which I believe is so important to my quality of life.'*

**Gord Grant, Canada**



*Seize the moment, though the moment will pass away.  
We will be known forever by the tracks we leave.  
Hang on!  
I will fight with my memory.  
I will face my illness positively,  
though I am so desperate to erase the fact of my illness.  
Face it, and it will be the biggest help to my family and me.  
Hang on there!  
I will seize today, though today will also pass away.  
Let my insistence today be my great assistance tomorrow.  
For my family and my own sake, I will keep trying and trying.  
I promise I will never give up.  
Seize the moment!*

**Dorothy, Chinese Taipei**

## ■ Alzheimer University

**April 2007**

### London, UK

Volunteers from emerging Alzheimer associations travelled from all corners of the world to attend the two and a half day Alzheimer University training programme in London, supported by the Helen Bader Foundation. Bahrain, Bangladesh, Bolivia, Honduras, Jamaica and Tunisia 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.

A management trainer, representatives from three established Alzheimer associations together with the ADI staff and Chairman equipped attendees with the skills to run a sustainable Alzheimer's association. Sessions on governance, support groups, fundraising, recruiting volunteers and providing information took participants step by step through the most important starting points for any organisation.

For the first time at an Alzheimer University, a person with dementia participated as a speaker. Keith Turner, UK, was diagnosed with dementia three years ago and is an active campaigner for the Alzheimer's Society. For many, this



**Helen Regan and Daryl White at the Alzheimer University, Milwaukee**

was the first time they had heard a person with dementia speak in this capacity. The representatives from Alzheimer Jamaica were so inspired by Keith's talk that they have obtained funding for him to visit Jamaica in August. His visit will help with raising awareness about dementia and building the association's profile.

**July 2007**

### Milwaukee, USA

The ADI community convened in Milwaukee, USA for its second

Alzheimer University on policy, 'Campaigning for Change'. Twenty one ADI member associations attended and were given three days of intensive training.

Practical help was given on working with the media and strategies worked out for campaigning and working with policy makers. The round table on making dementia a global health priority was a highlight, during which the group concluded that working together with the World Health Organization was a priority.

Speakers included Daryl White, a local person with dementia, Martin Prince from 10/66 and Mark Krueger of Mark Krueger & Associates. Representatives from the International Psychogeriatric Association and AARP were present along with sponsors GE Healthcare and Novartis.

Patricia Wilkinson from the Alzheimer Society of Canada said, 'thank you for this opportunity – I have learned a lot and will be taking so much back to Canada. We are part of a global movement and I am inspired to be a part of this.'

**AU participants, speakers and ADI staff at the AU in London**



## ■ 10/66 Dementia Research Group

# ADI's international research network

ADI's 10/66 Dementia Research Group is a network of researchers from Latin America, Russia, Africa, India, China and SE Asia ([www.alz.co.uk/1066](http://www.alz.co.uk/1066)). 10/66 studies have been underway since 1998. As a result we now understand much more about the problems experienced by the two-thirds of people with dementia living in the world's least developed regions.

The 10/66 pilot studies were a huge collaborative effort involving over 700 people with dementia in 26 centres worldwide. They highlighted difficulties in diagnosing dementia where many older people have had little education. Caregivers are as strained as those in developed countries, despite their big family support networks. Health care services do not meet families' long term needs for care and support. Financial strain arises when caregivers cut back on work to care, or need to hire paid help. Disability pensions and compensatory benefits were not forthcoming. Behavioural symptoms are a source of stigma, blame, and distress for caregivers.

From 2003, 10/66 started population-based surveys with grants from the Wellcome Trust, the US Alzheimer's Association and the WHO. The aim was to measure the prevalence of dementia, its impact, and the support and care available in regions where little research had been carried out. Studies in Cuba, Brazil, Dominican Republic, Peru, Argentina, Mexico, Venezuela, India, China and Nigeria each have the same design – a comprehensive survey of all residents aged 65 and over; comprising 20,000 older people living in 15 catchment areas in ten countries. Everyone is interviewed with a questionnaire



**A 10/66 researcher conducting a survey in Beijing**

covering health and lifestyles, use of health services, cognitive tests, and a clinical interview. Physical and neurological examinations follow. A family member is asked about intellectual decline, loss of independence and needs for care. Fasting blood samples are tested for diabetes, high cholesterol, dietary markers and anaemia. DNA is available to test for genetic factors.

### How will this research make a difference?

- In many world regions, there is uncertainty about the true prevalence of dementia, and hence the numbers affected. Research evidence raises awareness and informs policymaking and planning.
- Evidence on the contribution of dementia to disability, needs for care, caregiver strain and economic costs should encourage a debate in developing countries about the roles of state and families in providing and paying for care. Currently, this falls

disproportionately upon family caregivers.

- 10/66 is evaluating, in randomized controlled trials, the effectiveness of a five session primary care intervention designed to inform caregivers about dementia and train them in care techniques.
- In a three year follow up, 10/66 will be looking at the incidence of dementia, and examining the role of cardiovascular, dietary, lifestyle and genetic risk factors

The challenge now is to use these studies to raise public awareness, and promote the development of policies and services to support people with dementia in developing countries. These are key priorities for ADI. 10/66 findings will be made available in an easy to understand and accessible format through ADI conferences, the 10/66 website, newsletters, policy briefings and press releases. This is your research network – the research evidence, disseminated actively by committed NGOs can be a powerful argument for change.

## ■ Research update

# Alzheimer's at a crossroads

Alzheimer's research has reached a major crossroads. The genetic causes of rare forms of the disease have been identified and, in every case, these genes point to buildup of the substance called 'amyloid' as the initiating event. The genes have mistakes either in the amyloid itself or in one of the molecules that regulate amyloid breakdown. If these genes are inserted into a mouse, the mouse develops brain amyloid buildup and forgetfulness. This is now unequivocal scientific fact.

So, why all the controversy about amyloid? The reason is simple: these gene mistakes only occur in about 3 out of every 100 Alzheimer's patients. Where does the disease begin in the other 97 of every 100? This is not yet known with certainty.

There exist two possible scenarios. In scenario one, the final pathway to all Alzheimer's (genetic and common forms) leads to amyloid accumulation, and all nerve cell injury is caused by amyloid. In this case, if amyloid accumulation is reversed or prevented, no clinical disease will occur. This is the scenario that was encountered in heart disease, where cholesterol accumulation turned out to be the final pathway. Thus, as cholesterol accumulation has become controlled or abolished (for example with statins), heart disease prevalence has significantly decreased. Could this happen in Alzheimer's? Yes, but probably not at the same rapid rate of fall because Alzheimer's is a much slower disease.

In scenario two, an accident causes brain damage and then amyloid buildup comes later. In this scenario, if we prevent amyloid buildup, we might partially reverse or

prevent the disease, but the primary injury would persist.

It is conceivable, but highly unlikely, that amyloid is entirely innocuous, in which case ridding the brain of amyloid would have no effect. In living mice and in nerves in a dish, amyloid is a poison. This is probably true in the human brain.

How will we sort this out? The most promising strategy involves clinical trials with anti amyloid drugs. Now, with new amyloid-revealing brain scans, we can test the new anti amyloid medicines (Alzhemed, Flurizan, AN1792, IVIg, etc). We can follow subjects clinically to see whether cognitive function improves and follow them with plaque-load brain scans to prove that the medicines are doing their job. We must prove that we have purged the brain of amyloid before we can say that we have adequately tested the 'amyloid hypothesis', as it is called among researchers.

When will we know? Drug trials in the United States pass through three phases, the last of which must be successful in order for the US Food and Drug Administration (FDA) to approve a medicine as effective. Ninety percent of test drugs that enter phase one fail, so phase three is the home stretch. Currently in the home stretch are Alzhemed, Flurizan, and some of the immune approaches (the Wyeth/Elan antibody infusion, IVIg). Patients, families, physicians, scientists, and policymakers are watching these trials very closely. Once a drug has succeeded in phase three, the approval process at the FDA can be completed within a few years more.

What can you do to accelerate the progress? Stay in touch with your chapters, physicians, researchers, and universities. Ask

about clinical trials in your area. Check [www.clinicaltrials.gov](http://www.clinicaltrials.gov) where all US trials are registered. You may find referral information there so that you can access the same trials in your own country. Enroll as subjects or as normal volunteers.

A century after Auguste D., Alois Alzheimer's first patient, we are on the verge of having major insight into how and why the brain fails and why our lives and those of our loved ones are increasingly threatened. In the US, half of those over age 85 years have dementia, and worldwide cost already exceeds \$300 billion. No government will be able to sustain itself against the economic devastation that Alzheimer's will wreak.

What else can you do to accelerate the progress? Contact your legislators. Let them know the importance of sustaining basic and clinical research on Alzheimer's disease and other dementias. Global warming is getting the spotlight this year, but global warming is still controversial. Alzheimer's is here. Now. Today. Take action!



*Sam Gandy MD PhD  
Chair, National Medical and Scientific Advisory Council, US Alzheimer's Association, and Sinai Professor of Alzheimer's Research, Professor of Neurology and Psychiatry, Mount Sinai School of Medicine, New York NY 10029*

## Youth For Dementia™

ADI is pleased to support a new charitable venture established by a group of young people in London. Youth For Dementia is the international network of young people working to raise money and awareness of Alzheimer's disease and other forms of dementia.

On Saturday 7th July, 2007 ADI attended the unofficial launch of this new network. The evening was held in a North London venue where the young and the young at heart gathered for a small photo exhibition and party. Organisers had gathered a selection of signed prints of well known musicians and rock stars. All proceeds from the sale of the prints went to Friends of ADI, the UK trust established to support the work of Alzheimer's Disease International.

Since the event more prints and artwork have been donated and will be on sale shortly. To find out more information go to [www.youthfordementia.org](http://www.youthfordementia.org) or contact Melanie Legg at the ADI office.

Artwork on display at the Youth for Dementia launch celebration



## My Life with Al

Andrew Watt

My life with Alzheimer's began when I was 18 years old, when my father Alan, a former head of



Andrew Watt at the opening ceremony of the 12th National Conference of Alzheimer's Australia

surgery, was diagnosed at the age of 55. In the first few months the diagnosis did not overly affect me. Dad had always been somewhat of a 'nutty professor' type and the disease just seemed to exaggerate these qualities in him. Over the next few months, however, little changes became noticeable; from his increased forgetfulness to the eventual realisation that he had lost the ability to both read and write.

His loss of abilities became a source of embarrassment for me and I would quickly become angry at him for not being able to do the simplest of tasks. I began to isolate myself from him, from my family and my friends, and got caught up in a spiral of guilt, anger, grief and self pity. I was put on anti-depressants to try and stabilise my emotions and I self-medicated with alcohol and marijuana. But none of this seemed to work.

After more than a year I confronted Dad and told him that I was scared and that I didn't want him to die. That day was a turning point: I stopped self-prescribing and feeling sorry for myself, and instead began spending more time with Dad.

A few years have since passed and the grieving continues. My father no longer remembers who I am. I am now simply waiting for the time that I may mourn him and remember him for the great man that he once was.

I am now working with Alzheimer's Vic (Australia) to try and increase awareness of dementia in both its effect on youth and the wider community. I am pleased to support ADI's efforts to bring a more youth oriented approach to dementia care and support. After all, dementia does not just affect the old. It is an issue for all the generations.