New partnerships in New Zealand

ADI's 17th annual international conference hosted by Alzheimers New Zealand brought people from 44 countries together in Christchurch during October. Delegates were welcomed with a Maori haka and then went onto to hear about recent advances in neuropsychiatry, research and treatments in dementia.

The theme ‘Partnerships in Dementia Care' was drawn upon throughout the three days and looked at from many perspectives including Maori, Chinese and Australian. Workshops on cross-cultural partnerships and service delivery focused on how Alzheimer associations are meeting the needs of people from diverse communities in their own countries (see page 6).

This ADI conference was the first to include the voice of people with dementia. Delegates heard first hand from a person with dementia about diagnosis, drugs and determination. Full report pages 8-9.

The world on Alzheimer’s day

World Alzheimer's Day continues to go from strength to strength and over 45 countries commemorated the day on 21 September 2001. For the Alzheimer associations of China and Hungary, this was the first year that World Alzheimer's Day was observed in their country.

This year, ADI issued a press release on World Alzheimer's Day supported by television celebrity Anne Robinson, presenter of The Weakest Link. Although ADI did not organise an event, we participated in member activities. Nori Graham, ADI chairman, attended Alzheimer Scotland – Action on Dementia's inaugural annual lecture delivered by Susan Deacon MSP in Edinburgh. Susan Frade, membership and information officer, participated in Berlin's first Memory Walk organised by the Deutsche Alzheimer Gesellschaft.
ANNOUNCEMENTS AND CONFERENCES

2001

14-15 December
International College of Geriatric Psychoneuropharmacology
Hawaii, USA
Tel: +1 615 322 4247
Fax: +1 615 322 4246
Email: oray@icgp.org

2002

24-27 January
2nd International Congress on Vascular Dementia
Salzburg, Austria
Email: vascular@kenes.com
Web: www.kenes.com/vascular

15-16 February
3rd Leonaard Berg Symposium
Neurobiology of the Aging Nervous System: Models, Manipulations & Alzheimer's Disease
St Louis, Missouri, USA
Email: meuselt@adrc-map.wustl.edu
Web: www.adrc.wustl.edu

17-20 April
IPA European and Mediterranean Regional Meeting
The Qualities of Aging
Rome, Italy
Tel: +1 847 784 1701
Fax: +1 847 784 1705
Email: ipa@ipa-online.org
Web: www.ipa-online.org

27-30 April
Alzheimer's Association 14th Annual Public Policy Forum
Washington DC, USA
Tel: +1 202 393 7737
Fax: +1 202 393 2109
Email: info@alz.org

1-4 June
XIIth Alzheimer Europe Conference
Commitment to Care
Maastricht, The Netherlands
Tel: +31 43 361 9192
Fax: +31 43 361 9020
Email: cal.conferenceagency@wxs.nl

20-25 July
8th International Conference on Alzheimer's Disease and Related Disorders
Stockholm, Sweden
Tel: +1 312 335 5813
Fax: +1 312 335 5781
Email: internationalconference@alz.org
Web: www.alz.org/internationalconference

5-8 September
5th Asian Pacific ADI Regional Meeting
Kowloon, Hong Kong
Fax: +852 2338 0772
Email: gemma@hkuspace.hku.hk
Web: www.hkada.org.uk

23-26 October
18th Alzheimer's Disease International Conference
Dementia: meeting the challenge together
Barcelona, Spain
Tel: +34 93 201 7571
Fax: +34 93 201 9789
Email: support@supportserveis.com
Web: www.supportserveis.com

PUBLICATIONS

Early Stage Dementia
By Lorraine West
Available from Hodder Headline Australia (Tel: +61 2 9357 1688; fax: +61 2 9380 8207; email brettowrittenperspectives.com.au)

Supporting ADI

After distributing Global Perspective free of charge for 11 years, Alzheimer’s Disease International (ADI) will be introducing an annual subscription charge for individuals receiving the newsletter in the new year. This decision comes after reviewing the organisation’s growing costs. The newsletter will remain available free of charge to Alzheimer Associations and individuals on ADI’s committees.

We will be writing to individuals towards the end of January asking them to support ADI through an annual subscription. However, if you wish to subscribe before then you can do so by completing the slip on page 9 of the newsletter.

Thank you for your support.

On-line donations

You can now make a donation to ADI through our website www.alz.co.uk Donations can be made in US dollars or sterling.

Your donation will help us with our work, strengthening Alzheimer associations and raising awareness about the global impact of dementia. Making a minimum donation of $US15/£10 will ensure your annual subscription to the newsletter.

US donations are tax deductible.
Whispering hope
By Osmond Moses, Trinidad and Tobago

Christiana Jurima Moses died in April 2001 at the age of 78, leaving behind four adult children – Alpheus, Osmond [Ossie], Hamlyn and Charmaine.

My mother’s life had been a hard one: constantly fighting poverty, later divorce, and finally, in the last 12 years of her life, Alzheimer’s disease.

The movie ‘Love Story’ describes terminal illness as ‘falling slowly off a cliff’. For me, Alzheimer’s means watching someone you love slowly fall off a precipice and disintegrate, piece by piece, even before they hit bottom.

It began with little forgettings, and graduated into the mysterious loss of large sums of money. She also forgot the names of relatives or merged certain identities. My younger brother Hamlyn, for instance, became ‘Clayton, an uncle he somewhat resembled.

Ossie and his wife, Beth were her caregivers at first. Then Hamlyn, Charmaine and Alpheus took over, with Beth and Ossie as relief caregivers and therapists for the whole family, giving massages and stress reduction to all the players.

In the end though, painful as it was to surrender, we were forced to move her to a home for the round the clock professional care that we could not provide.

But all of it has not been gloomy. To the very end, my mother maintained her love of prayer, music and massage, and these three communication lines reached her when all other lines of communication were closed – since she had become an emaciated stranger, quarrelsome, combative and extremely confused.

I cherish the hope that one day soon Alzheimer’s will be curable. Until then, I will continue to give up a little of my privacy on occasions like this to help educate and console others who must walk through the same long, dark tunnel that the Moses family walked through.

The Alzheimer's Association of Trinidad and Tobago has been for us, a shining light at the end of that tunnel. I give God thanks to this group. I recommend that family caregivers learn how to mobilize family, church, community, corporate and government resources to the fullest. No isolated individual can win this guerrilla war.

But all of us can help spread the light of hope, understanding, compassion, commitment, cooperation and generosity. Most of all, whatever your religious faith – hold on to your sanity and the knowledge that God exists, to solve the problems that we cannot fully solve ourselves. Learn how to ‘Let go and let God’.

Campaign news
ADI’s conference in Christchurch succeeded in lifting the awareness of dementia in New Zealand’s media and the importance of subsidising medications for Alzheimer’s disease. Currently only those who can afford to pay have access to these medications. Alzheimer’s New Zealand have acted quickly on the momentum generated by the conference by meeting with Grey Power, Aged Concern, the Parkinson Association and clinicians with a view to mounting a campaign to subsidise these medications.

To assist this process, the National Executive Director of the Australian Alzheimer’s Association, Glenn Rees, travelled to Wellington to explain how in Australia they successfully lobbied their government on this issue. The two associations were able to share many media materials and letters that had been used in the Australian campaign together with the detailed briefings provided to journalists and all members of the Australian Federal Parliament and Senators.

The organisations in New Zealand will meet in the new year to plan a lobbying campaign with the hope of securing a decision from the Minister for Health and Pharmac (the pharmaceutical management agency for the government which lists approved pharmaceuticals, decides on subsidisation and advises the government).
Welcome to our three new members in China, the Philippines and Sri Lanka whose associations were formally approved as members of ADI at the council meeting held in Christchurch, New Zealand.

**China**

The Preparatory Committee of the Chinese Association of Alzheimer’s Disease and Related Disorders (ADC) was set up a year ago. Up until now, the association has mainly worked through publishing papers and giving lectures about dementia on TV and the radio. The main focus of the association is to support people with dementia and their carers in China and to alert government leaders to the fact that dementia is an urgent and rapidly increasing health issue. The association was officially launched on 19 November 2001 with the support of Eisai Japan and Eisai China. The chairman of ADI, Nori Graham, was present.

**Sri Lanka**

After working overseas for 25 years, Tami Tamitegama returned to Sri Lanka with a pledge to make a difference to the care of his homeland’s elders. It was his participation in ADI’s 3rd Asia Pacific Regional meeting and the Alzheimer’s and Related Disorders Society of India annual conference in 2000 that provided Tami with the knowledge and encouragement to set up an Alzheimer association in Sri Lanka. Tami also met with individuals working in the not-for-profit sector in Sri Lanka before finally setting his mind to setting up Lanka Alzheimer’s Foundation.

Coming from a business background, Tami applied his commercial skills and started by inviting 14 other individuals from a range of backgrounds to join the board of trustees. These included carers, public relations and marketing professionals, executives of other NGOs, trainers and administrators.

At the first meeting, the board agreed upon a mission statement and developed a focused work plan. In keeping with their work plan, the Foundation published some articles in a leading business monthly publication. They received lots of phone calls and letters. Over the coming three months, they received extensive media coverage in Sri Lanka’s three principle languages. Lanka Alzheimer’s Foundation was formally launched on 3 October 2001.

**Philippines**

The Alzheimer’s Disease Association of the Philippines (ADAP) was established in March 2000 after the need to create an association to support the estimated 90,000 people with dementia in the Philippines was recognised.

Two representatives from ADAP attended ADI's Alzheimer University training programme last February gaining knowledge on how to develop their association.

Recent activities have centred on raising public awareness in an attempt to dispel the notion that dementia is part of normal ageing. The association held a public forum in March 2001 which was well attended. Government representatives were invited and the Under Secretary for Justice attended. During the same month, a pilot carers support group was launched in metro Manila.

ADAP celebrated World Alzheimer’s Day for the second year with a Memory Walk. Over 800 people participated in the walk which not only served to raise a sizeable amount of money but also increased public awareness.

The association plans to continue raising awareness at public and political level, create satellite support groups, set up and run carer education programmes and recruit more volunteers.

Find out more about the ADAP from their website www.alzphilippines.com
USA

President Bush issued a proclamation declaring November 2001, as National Alzheimer’s Disease Awareness Month and called upon the people of the United States to observe the month by participating in appropriate programmes and activities. You can read the full proclamation at www.whitehouse.gov/news/releases/2001/11/20011109-24.html

Many of you may have read that Maureen Reagan, daughter of former US president Ronald Reagan, passed away on 8 August at the age of 60 after a long battle with skin cancer. Ms Reagan was a member of the national board of directors of the Alzheimer’s Association (US) and one of its leading advocates in the fight against Alzheimer’s disease.

Ms Reagan testified several times before Congress to advocate for increased funding for Alzheimer research and caregiver support. Most recently, she called on Congress to help find a prevention or cure for the disease by doubling Alzheimer research funding at the National Institutes of Health to US$1 billion a year.

Venezuela

August saw the gathering of 90 nurses from Venezuela and Mexico for the first symposium for geronto-geriatric nurses in Caracas. The aim of this meeting was to discuss the challenges of caring for people with dementia in the 21st century. The symposium enabled nurses to exchange knowledge and experiences with each other. In addition Aquiles Salas was able to share results from the 10/66 Dementia Research Group’s work in Latin America, which looked at the care arrangements of people with dementia and the impact of these on caregivers.

EMERGING ALZHEIMER ASSOCIATIONS

Indonesia

The Alzheimer’s Association of Indonesia attended the International Association of Gerontology’s Congress where they gave an Indonesian perspective on dementia in developing countries. Tony Setiabudhi described how there is no data on the prevalence of people with dementia in Indonesia and how the association has set up small study surveys around Jakarta, the capital, to establish some preliminary figures. Dr Setiabudhi attributed lack of data partly to the fact that life expectancy in Indonesia is lower than in neighbouring countries (63 and 65 years for men and women respectively).

Scotland and Romania

Earlier this year, Jim Jackson (Chief Executive of Alzheimer’s Scotland – Action on Dementia) visited Societatae Romana Alzheimer with a view to developing an exchange programme.

The Societatae Romana Alzheimer was founded in 1992 out of the Romanian League for Mental Health by a group of psychiatrists. Initially the Societatae participated in research carried out by HelpAge International to assess the needs of older people. In October 1992, the Societatae developed a meals-on-wheels programme for older people in need with assistance from a British organisation, Romania Project UK.

HelpAge International continued to support the Societatae with a ‘Community Care for Older People Project’. The Societatae now provides a range of services including: a memory centre, a day centre operating three days a week and attended by 20/30 people, home care, a telephone line, and training programmes teaching old age psychiatry to doctors and nurses.

However, the Societatae face a number of challenges:

• No social services available for older people with problems, especially those with dementia

• Limited medical services and poor conditions in psychiatric hospitals

CONTINUED OVER…
Lack of recognition of old age psychiatry
Lack of understanding/respect for older people, especially those with dementia
Lack of public understanding for NGOs

The scale of these problems makes the choices facing the organisation very different from those familiar to Alzheimer associations in Western Europe. In particular the limited development of civil society makes comparisons with traditional models for the development of Alzheimer associations problematic.

In addition, it is unlikely that dementia will become a specific priority for the foreseeable future and therefore the strategy of incorporating dementia into emerging programmes for the care of the elderly and old age psychiatry makes sense.

The workshop encouraged others to share their experiences and highlight the successes and difficulties encountered in working not only cross-culturally but also with underserved populations (including rural/isolated populations, people of different sexual orientation and refugees). There was much enthusiasm for the establishment of a Cross-Cultural Network – an informal group of people sharing their work and experiences through the ADI website.

The network initially aims to:
- Foster working links with other countries
- Exchange information and resources
- Explore possible research projects and future collaborations

The first step in developing this network is to gather details of established projects in these areas.

What do you get when you put three Americans and three Australians, all from different cultural backgrounds, together? A workshop entitled 'Partnerships among cultures: sharing international experiences' at the ADI conference in New Zealand.

Both Australia and the United States of America are very similar in their cultural make up; diversity is ingrained in the framework of both societies. With this in mind, services for the culturally and linguistically diverse need to be provided in a far more flexible way than mainstream services are accustomed to. This begs the question: ‘why provide different services for ethnic communities?’ The response to this is simple: there are barriers within our current service provision including language, cultural appropriateness, location, prejudice, accessibility, and organisational constraints.

Who would have thought that with over 13,000 kilometers distance between us, both our groups would be doing similar work and have the same passion about what we do?

The key elements of working in a culturally inclusive manner for both groups were the principles of community development, community empowerment, outreach, participation, capacity building and mutuality/reciprocity.

The workshop encouraged others to share their experiences and highlight the successes and difficulties encountered in working not only cross-culturally but also with underserved populations (including rural/isolated populations, people of different sexual orientation and refugees). There was much enthusiasm for the establishment of a Cross-Cultural Network – an informal group of people sharing their work and experiences through the ADI website.

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Reaching out to underserved populations
If you or your organisation/branch/chapter are working towards reaching underserved populations, please complete and return the form enclosed with this issue of the newsletter. Alternatively, you can send us your details through the ADI website www.alz.co.uk
Risk factors for dementia

Dr Rob Stewart, Institute of Psychiatry, London, UK

Approximately a quarter of people aged over 85 have dementia. Three quarters do not. Is this just a matter of chance, or do a person’s genes or past experiences affect their likelihood of developing this disease?

A major objective for dementia research is to answer these sorts of questions. Many different avenues are being explored. Some factors may increase the risk of dementia, others may be protective. Many have not been fully established and further research is needed to clarify their role. Some studies have investigated risk factors for dementia as a whole, while others have focused on particular ‘causes’ of dementia such as Alzheimer’s disease (the most common cause).

Age

Dementia becomes steadily more common with increasing age. It affects about one in a hundred people in their late sixties, but about one in four people aged over 85. Age is therefore an important risk factor. However we are still not sure whether dementia occurs simply because the brain is getting older, or whether it is caused by other diseases or events which become more common with increasing age.

Gender

Most research shows no difference between men and women in the overall risk of dementia. However dementia in men tends to be more often associated with strokes.

Genes

Some very rare forms of dementia appear to be clearly inherited.

However the role of genetic factors for most people who develop dementia is less clear. Like many other diseases, relatives of affected people have a higher than average chance of developing dementia. One gene called apolipoprotein E (APOE) has been found to affect people’s risk of developing Alzheimer’s disease in particular. However most people with affected relatives or the APOE ‘risk’ gene will still not develop the disorder.

Education

Many studies show that dementia is less common in people with higher levels of education. One possibility is that higher education may delay the onset of dementia. It may also be important to keep mentally active throughout life.

Strokes

Dementia occurs in about one in three people following a major stroke. Repeated smaller strokes may also cause dementia because of progressive damage to the brain. They may also bring forward the age when early symptoms of Alzheimer’s disease become noticeable. People who have diseases which affect the circulation (such as high blood pressure, diabetes and heart disease) also have a higher than average chance of developing dementia. However, treatment of these conditions may substantially reduce this risk.

Smoking

It was once believed that smoking might protect against Alzheimer’s disease. This is no longer thought to be the case. Larger, more recent studies have suggested that smoking may, if anything, increase the risk of dementia.

Head injury

People who take part in boxing are at risk of developing a particular cause of dementia. Some research has suggested that a severe head injury earlier in life may be a risk factor for Alzheimer’s disease.

Many other factors are being actively investigated to understand better why some people develop dementia while others do not. For example, large studies are now underway to investigate whether particular medicines are protective – such as anti-inflammatory and cholesterol-lowering drugs, treatments for high blood pressure, and hormone replacement therapy. It is hoped that, before long, these and other findings may lead to ways of preventing this disease in future generations.
Alzheimer's Disease International · Global Perspective November 2001

ADI conference

Christchurch, New Zealand

“I take home a head and heart (and notebook) full of inspiration!” PARTICIPANT

At ADI’s annual conference there is a dynamic mix of perspectives and experiences of dementia and this year was no exception. Nearly 1100 delegates from 44 countries came together at ADI’s 17th annual international conference hosted by Alzheimers New Zealand, in Christchurch. The increasing recognition of the need to listen to and include people with dementia was probably the lasting impression for many at this year’s conference. People with dementia participated in the conference and built into the programme were workshops specifically for and run by people with dementia. Christine Bryden, a person with dementia from Australia, shared her personal experience of diagnosis at a plenary talk.

“Very well worth travelling 13,000 miles to attend” PROJECT COORDINATOR FROM SCOTLAND

The buzz at break times was almost palpable as delegates mingled in the exhibition area continuing conversations started as they emerged from sessions. The international mix of presenters in nearly every session provided an opportunity for participants to recognise that those touched by dementia, be they a person with dementia, a family caregiver, a professional caregiver, a medical professional or a volunteer of an Alzheimer association have much more in common than difference and can learn from one another. The unique aspect of an ADI conference is that all those with an interest in dementia are brought together.

“Global perspective increased my identity within the world of dementia” PROFESSIONAL CARER FROM NEW ZEALAND

We were reminded throughout the conference of the inequalities there are in the access to resources people with dementia and their families have in the world and the pressing need to raise awareness in many countries where dementia is still regarded as a normal part of ageing and is surrounded by stigma and myth.

“Hearing other’s stories and realising how we are all on the same path but at different stages” VOLUNTEER FROM ALZHEIMERS NEW ZEALAND

The ADI showcase provided an opportunity to literally walk your way around the world of dementia by visiting...
ADI member booths to learn about the activities and progress of Alzheimer associations throughout the world. The ADI workshops on organisational issues such as fundraising and how to get your government to recognise dementia enabled staff and volunteers of Alzheimer associations to share solutions to common problems.

The social events are an important part of any conference and the dinner at the Antarctic centre was a spectacular event. Frankie Stevens singing in Spanish and the first hand account of crossing the Antarctic given by Sir Edmund Hillary were wonderful moments as was the late night dancing to the New Zealand army band. A chance for everyone to relax and enjoy the spirit of an ADI conference.

‘It has been a wonderful (and tiring) three days – learning, networking and knowing you’re not on your own’
FORMER CARER FROM NEW ZEALAND

Perhaps this is the essential experience of the conference. The voice of the person with dementia clearly emerged at this year’s conference and has been added to the voice of the family carer, the two together will send out an even louder message to policy makers worldwide of the need to tackle the impact of dementia in each country. The umbrella of ADI brings together such a wide range of perceptions and knowledge of dementia, each unique and each worth sharing. Come to Barcelona next year and experience it for yourself.

Please support ADI

I wish to support Alzheimer’s Disease International and subscribe to the newsletter.

I enclose my annual subscription for:

☐ £10/$15  ☐ £25/$38
☐ £50/$75  ☐ £/$ other __________

OVERSEAS PAYMENT

International bankers draft payable to Alzheimer’s Disease International. US donations to ADI are tax deductible.

UK PAYMENT

UK Cheque payable to Alzheimer’s Disease International. If you are a UK taxpayer, we can reclaim tax on your donation under the Gift Aid scheme provided you tick, sign and date the form on the right and make your cheque payable to Friends of ADI. Friends of ADI is the registered UK charity arm of ADI (Charity registration number 1076992).

☐ I am a UK taxpayer and would like Friends of ADI to reclaim tax on this and any future donations I may make. I understand that UK income tax, capital gains tax or the equivalent has been paid on these donations.

Signed Date

Name
Address

Send to: Alzheimer’s Disease International, 45/46 Lower Marsh, London SE1 7RG, UK

You can now donate online at www.alz.co.uk
Diagnostics dementia: the first step to help was the theme of this year’s campaign. It focused on the importance of having a diagnosis, the steps to making a diagnosis and who needs to know the diagnosis.

Many Alzheimer associations centred their activities around the theme. The Alzheimer’s Foundation of Malaysia launched the first diagnostic clinic in Kuala. The clinic was launched in response to people contacting the Foundation after they had seen their GPs with concerns about their memory but were told that was just a normal part of ageing. The Asociacion Dominicana de Alzheimer trained 30 medical students to administer Mini Mental State Examinations. The students were placed in locations throughout the city and tested 1018 people, referring anyone with a low score to a specialist. The Alzheimer Society of Ireland launched their GP training programme by sending out a bulletin to their GPs.

Several members used the theme as the basis of a national
Using the media to raise awareness is a key World Alzheimer's Day activity. Here Kheng Leng and Esther Gunaseli talk about the importance of receiving an early diagnosis and the work of the Alzheimer Foundation of Malaysia on national radio.

Alzheimer’s Day?

Over 1000 people came for free memory consultations at various hospitals in Beijing, China.

Members are encouraged to translate ADI materials into other languages making them accessible to a wider audience. In addition to English and Spanish materials provided by ADI, the bulletin and postcard were translated externally into Chinese and Hungarian. Other members (Brazil) used text from the official ADI bulletin but incorporated family testaments from their country.

Other Alzheimer associations (including Brazil, Pakistan, El Salvador, Cyprus, Indonesia, Scotland, Venezuela, Lithuania, Trinidad and Tobago, Korea, India, Costa Rica) held seminars and symposiums on World Alzheimer’s Day, informing carers, doctors and other professionals on the importance of receiving a diagnosis.

CONTINUED OVER...
How did you observe World Alzheimer’s Day?

Many members take World Alzheimer’s Day onto the street by co-ordinating leafleting campaigns and information stands such as in Poland, Japan, Argentina, Bangladesh, Czech Republic, Peru and Uruguay.

As well as Deutsche Alzheimer Gesellschaft, other members organised a Memory Walk to raise funds for their Alzheimer association including the Philippines, Puerto Rico and Kottayam in India. Fundraising tea and coffee mornings were hosted around Canada, Scotland and the UK, whilst South Africa hosted a fundraising business breakfast.

Preparations for World Alzheimer’s Day 2002 are now underway. Look out for details on our website in the new year www.alz.co.uk