ADI conference relocates to the Dominican Republic

15–18 October 2003

ADI's 2003 conference has been relocated from Caracas, Venezuela to Santo Domingo, Dominican Republic due to the current economic and political situation in Venezuela. Dates for the relocated conference will be 15–18 October, as originally announced. Details on submitting abstracts and the venue are being finalised and will available on ADI’s website www.alz.co.uk/conference soon.

As Elizabeth Rimmer, executive director of ADI, explained, 'This has been a very difficult decision and is a bitter blow to our Venezuelan hosts. But the current economic and political climate in Venezuela makes it unrealistic to organise a conference in these circumstances. These are circumstances beyond everyone’s control.'

The Asociacion Dominicana de Alzheimer, new hosts of the conference, are very excited and committed to their challenge of organising ADI's 19th annual conference.

Although a relatively young association (established in 1995), the group is no stranger to ADI, having participated in the first Alzheimer University training programme back in 1998. Since then, the association has gone from strength to strength. They have established a branch in another part of the country, set up a telephone helpline and organise monthly carer meetings.

Each year the association also co-ordinates an extensive awareness programme for World Alzheimer’s Day (21 September). During the 2001 campaign ‘Diagnosing dementia; the first step to help’, the association trained 30 medical students to administer Mini Mental State Examinations. The medical students went out to locations throughout Santo Domingo and examined 1018 people. Those with a low score were contacted and referred to a specialist for follow-up examinations.

The campaign received wide media coverage and not only raised awareness about dementia but also the association’s profile.

ADI invites you to come and learn more about the Dominican Republic and its neighbouring Alzheimer associations at our first conference in the Caribbean. For those of who have never experienced the buzz of an ADI conference, you should! If you have been to an ADI conference before, come again! Say hello to some old friends and make some new ones too. The conference is an opportunity for people with dementia, their families, staff and volunteers from Alzheimer associations, clinicians, interested professionals and scientists to get together to share and learn from one another. We hope you will be able to join us.

For up-to-date information about the conference, please visit www.alz.co.uk/conference

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Send us your comments
If you have any comments about or items for the newsletter please contact the Secretariat. Articles and letters for the next issue of Global Perspective to arrive by 15 June 2003.

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Visit www.alz.co.uk/events for more conference announcements

Editorial

Making the decision to relocate the conference from Caracas, Venezuela to Santo Domingo, Dominican Republic was very difficult, especially for the Fundacion Alzheimer Venezuela. A lot of work and energy had gone into preparing for the conference in Caracas this year. This is the first time in ADI’s history that we have relocated the conference. We have always strived to hold the conference in diverse parts of the world and not be put off by political or logistical obstacles. However, this year, circumstances really were beyond our control.

It was an important factor in the decision making process that we did not cancel the conference and that we stay in the Latin American region. Although it is a big challenge to organise an international conference in eight months, we know we can do it. The Asociacion Dominicana de Alzheimer has seized this opportunity with great enthusiasm and the Fundacion Alzheimer Venezuela has offered to help in every way they can. Many members have contacted me with offers of help, so between us all it’s going to work. This opportunity provides us with the chance to reflect on our conference and its purpose. It will allow us to go back to basics and address fundamental issues. I have no doubt that with your help and support the conference will be a great success.

Nos vemos en Santo Domingo!
It started almost 12 years ago, here and there a few unusual symptoms, a lost computer programme, a sentence that did not end ... a silence between words ... nothing grand or concerning ... so I thought.

Two years later the world ended as I was looking at the film coming out of the MRI equipment. No one had to confirm the diagnosis, I knew it ... this COULD NOT be happening to this man, a brilliant scientist, accomplished researcher, dedicated teacher and the most wonderful husband any woman could dream of.

I, once a licensed psychiatrist, needed help and fast. I had to put our entire world in a new perspective. Understanding my fallibility and realising that my own career had to take another perspective was the hardest.

All my business travelling had to stop. He missed me way more than before. I had to learn to accept that we were a couple of one. I had to learn and learn and learn. I had to be totally responsible for our lives. Finally I gave up my job as a pharmaceutical physician. Two years have since passed and waking up to his soft smile and kisses make it all worthwhile. I am at peace now. Although every now and then I cry and ask ‘why him?’

The disease has advanced, but his quality of life is still excellent. Our love for each other is stronger than ever. He can still tell me that he loves me and does so every day. He still puts on his devilish smile. And when I ask him something, he acts as if he is thinking but his answer is always ‘yes dear’. I thank God each day because we are still together.

A carer story from Argentina

Susana Dennis

Research update

By Richard Bonwick
Consultant Psychiatrist, Austin and Repatriation Medical Centre, Melbourne, Australia

In the process of keeping up with the latest research, I thought it worth looking at some of the reputable websites with reliable information about dementia research. And where better to start than at the website of the Alzheimer’s Association (US) www.alz.org This includes an interesting section entitled ‘Research News’. Currently this section examines the chemical transmission between nerve cells in the brain which produces the molecular changes that form the basis of learning and memory. A failure in this may be related to the development of Alzheimer’s disease (AD). The research also explores the turnover of specialised brain proteins tagged for disposal with a molecule called ubiquitin, that has been implicated in AD and other neurodegenerative diseases. Whilst highly technical, this sort of neuroscience research is the key to early detection and treatment of dementia. Other reported research includes advance notice of a US National Institute of Ageing trial on simvastatin (Zocor) as a treatment for Alzheimer’s disease. Simvastatin is a very widely prescribed drug for lowering serum cholesterol. The links between high cholesterol, consequent cerebrovascular disease and dementia are becoming increasingly interesting. To me it reinforces the need for a broad approach to health maintenance in ageing populations as part of the fight against dementia.

A couple of other resources to recommend to you. For those seeking a sophisticated overview of the current state of dementia knowledge and research, there is The British Journal of Psychiatry. The February 2002 edition was devoted to old age psychiatry, and included review articles on the genetics and treatment of Alzheimer’s disease with overviews of each of the other causes of dementia. The journal can be accessed at http://bjp.rcpsych.org and then follow the menu prompts through ‘Select an issue from archive’.

As deputy editor of the International Psychogeriatric Association (IPA) Bulletin, I must also recommend the ‘Recent Advances’ column in our quarterly bulletin. The column provides a global view of ‘what’s hot’ in dementia research. The bulletin is accessible at www.ipa-online.org (and then follow the menu to ‘IPA Bulletin’, ‘Current Issue’ and then ‘Recent Advances’).

Happy surfing!
EMERGING ALZHEIMER ASSOCIATIONS

AUSTRALIA

Evaluation of Dementia Awareness Week (16-21 September) has revealed many positive outcomes for Alzheimer's Australia. This year’s campaign – ‘Because understanding dementia makes a world of difference’ – was used to increase community understanding of dementia as a major health issue and to increase community awareness of the vital role of the association.

Dementia Awareness Week was officially launched in Canberra by the Minister for Ageing, with support from the Prime Minister’s wife and a celebrity basketball player. In total, 27 events were organised throughout Australia.

The campaign received extensive print and radio media coverage – a 56% increase in the number of media spots delivered from last year’s Awareness Week. Media highlights included an interview with a gentleman with dementia and his daughter on a popular TV show and a three-page feature in a woman’s magazine.

Dementia Awareness Week was also used to raise funds. The association established a new partnership with the Photo Imaging Council of Australia to deliver the campaign ‘Thanks for the memories – frame a memory for Alzheimer’s on World Alzheimer’s Day’. This initiative provided the public with the opportunity to purchase photo frames from participating retailers, with proceeds going to Alzheimer’s Australia. A total of 22,500 photo frames were sold.

ARmenia

ADI has recently been contacted by Professor Aghajanov, who was inspired to set up an Alzheimer association after attending ADI’s annual conference in Barcelona last year.

Armenia is located between Turkey (to the west) and Georgia (to the north). About three and a half million people live there – half of whom are based in the capital Yerevan City.

Professor Aghajanov, a researcher in the field of neurochemistry, and his colleagues aim to set up an association focused on helping people with dementia and their carers by providing training, counselling and setting up a day care centre. They also hope to provide training for physicians and social workers.

The fledgling association has already translated the booklet ‘I have dementia’ and are looking to observe their first World Alzheimer’s Day this September by targeting various media and organising lectures for carers and professionals as well as a concert.

KENYA

Earlier this year, ADI was contacted by Alan Rubia with news that the Alzheimer Society of Kenya had just been set up and had been officially registered in January 2003. Although the Society currently meet at Alan’s home in Nairobi, they are already on the lookout for an office and are hoping to set up a membership database and recruit paid members.

The Society was set up as a result of Alan’s father developing dementia two years ago. Alan says that at first the cause of his father’s illness was not clear. His symptoms included memory loss, losing things and getting lost, and the family thought it was old age. However, various tests and scans showed shrinkage of the brain which suggested a diagnosis of dementia, possibly Alzheimer’s disease. The family then decided to look for treatment but found that there were no organisations who could help with care or information. Alan’s mother stopped working in order to take full-time care of his father.

In Alan’s quest for information, help and support, it became apparent that there were no care organisations in Kenya dealing with dementia. Alan said ‘During my search, it also became apparent that there were many people with this disease. Even more importantly there were many carers looking after the people with the disease – but most have no idea that they are dealing with Alzheimer’s disease. Carers just tend to ‘get on with it’. Further enquiries showed that many people would like more information about the disease and would be interested in an organisation that helps in the care and support of the disease.’ Hence the foundation of the Society.

Kenya has a population of about 30 million. Whilst the Mental Health Act covers a wide range of mental health issues, there is now a concerted effort by the government to draw distinctions between the various forms of mental illness by changing the attitude of mental health workers and encouraging associations like the Alzheimer Society of Kenya. The Society has arranged a meeting with the Ministry of Health and an association that was recently set up for people with schizophrenia.
This year the Alzheimer Society of Canada is celebrating its 25th anniversary. As the Society commemorates a quarter century of helping people with dementia – through support and education programs and by funding Canadian researchers – they also recognise a significant change has recently taken place, influencing how services for people with dementia and their families are provided.

Today, people with dementia are playing an increasing role in their own care and are collaborating with the Alzheimer Society to develop programs and educational materials. This has happened as more and more people are receiving an early diagnosis of dementia. Steve Rudin, executive director of the Society, says the opportunity for early diagnosis is a significant advance in the history of the disease and one that the Alzheimer Society of Canada fully encourages people to seek. He also says that the Society has benefited from having the insight of people living with the disease and that the Society will continue to partner with them to maintain and create new programs to serve them.

While this ‘partnering’ philosophy guides how the Society will operate in the future, below is a short list of some of the Society’s milestones.

1977 The Alzheimer Society is established when researchers at the University of Toronto and Surrey Place Centre who are investigating Alzheimer’s disease become deeply concerned about the lack of support available to families affected by the disease.

1978 The organisation is incorporated federally under the name Société Alzheimer Society, the first organisation of its kind in the world.

1984 The Alzheimer Society of Canada joins the Alzheimer’s Association (US) and representatives from three other countries to form Alzheimer’s Disease International (ADI).

1986 The Society’s executive director, Vince Gillis, begins a two-year term as acting Secretary-General of ADI. The general membership approves the establishment of a three-tier system with:
- a national office to co-ordinate Canadian and international activities
- provincial organisations to liaise with local chapters and support groups
- chapters and support groups to offer direct services to people with dementia and their families.

1987 The Society adopts a new mission statement; “To alleviate the personal and social consequences of Alzheimer’s disease and to promote the search for a cause and cure.”

1993 The Society goes nationwide with the signing of formal affiliation agreements with Quebec and Ontario – the remaining two provinces.

1998 All provincial Alzheimer organisations now begin using the name Alzheimer Society and all accept the Society’s brand to create ‘one look’ for the organisation nationwide. A task force addresses the issues around roles and responsibilities at the various levels of the organisation and develops a sound financial framework for raising and distributing revenues.

2001 A Memorandum of Understanding (MOU), developed over the previous three years, is signed by the Alzheimer Society of Canada and the provincial Alzheimer Societies. The MOU establishes a common understanding and direction for future activities of the Society. A Planning Assembly builds on the momentum of the signing of the MOU to agree on strategic priorities and launch the Society’s Strategic Planning Process.

To learn more about the Alzheimer Society’s history, please visit www.alzheimer.ca/english/society/history-intro.htm
Concepts of Alzheimer’s disease

Professor Paul G Ince, Neuropathology, Division of Genomic Medicine, Sheffield University, UK

A large UK research study, the ‘Cognitive Function and Ageing Study’ (CFAS), of more than 17,500 people raises some interesting questions about our concepts of dementia as it relates to the elderly – especially those in their 80s and 90s.

The basis of the study

This is a longitudinal, prospective study of six groups of elderly people in different localities in England and Wales. The respondents in the study were recruited by selection from National Health Service registers to give a random, population-based sample for epidemiology. Those who volunteered to participate have been screened several times over the years, using a test battery which is sensitive to cognitive decline. People who appeared to show dementia or significant cognitive decline went into a more intensive, detailed, assessment arm of the study and were matched with a respondent of the same age and sex and from the same locality, who was ageing with intact mental function. The respondents were also invited to join a brain donation programme after their death and many have chosen to do so. We now have donations from 400 people and the sample is sufficiently large to be representative of the spectrum of brain pathology present in the brains of older people in the UK. More than three quarters of these brain donors were older than 80 years when they died. The CFAS pathology study is therefore very different compared to those from which the concept of Alzheimer’s disease emerged, which tended to be composed of ‘younger’ old people selected from patients referred to hospital.

‘Mixed dementia’?

Two findings from this population-based autopsy study, spanning across people with normal healthy ageing through to those with profound dementia, are relevant to this article.

Firstly, in contrast to most hospital-based autopsy series, dementia associated purely with the pathology of Alzheimer’s disease is not the most common finding. The study shows that, in these older people, Alzheimer’s pathology is frequently accompanied by changes due to blood vessel disease in the brain. These cases would correspond to the concept of ‘mixed dementia’ in clinical practice. This blood vessel disease is not mainly related to ‘stroke’, but rather affects very small arteries giving more diffuse changes.

The second, and equally intriguing, finding is that a substantial proportion of these old people have cognitive function which is not easily accounted for by the brain pathology present. Thus there are about one in five of the sample who have, inappropriately, either loss or preservation of cognitive function compared with the burden of brain pathology demonstrated.

Indistinct boundaries

It is important to emphasise that the pathology of Alzheimer’s disease (plaques and tangles) is a major factor in cognitive decline in this study. However the medical model of dementia which seeks to allocate people to distinct ‘diseases’ becomes increasingly untenable in the face of this type of data. One of the ways in which we are trying to take this forward is to look for other pathologies, ones that are not routinely included in our evaluation of the brain, to see if they help explain the anomalies between pathology and mental function in some people. However it is unlikely that we will get much better at predicting whether a person in their 80s and 90s has dementia or not from the pathology in their brain, than the current five out of six correct calls.

What protects intellect?

For the moment we don’t know what it is that, for a given amount of brain disease, protects the intellect of some people but is absent or fails to protect in others. The solution may well not lie in pathology. Perhaps lifestyle, environmental influences, previous and continuing mental stimulation, and genetic influences are the truly important factors. The group of people for whom the concept of Alzheimer’s disease has its truest validity are those who have genetically driven early onset disease. Compared with the older people with dementia in the CFAS study those with dementia in these families usually have a much more severe pathology, against which no amount of beneficent background factors can improve the impact on mental function.
World Alzheimer’s Day™ 2003

As many of you know, ADI co-ordinates World Alzheimer’s Day™ on 21 September each year. The day is an opportunity for our member Alzheimer associations, as well as other organisations and individuals, to raise awareness about dementia in their communities. ADI produces a variety of promotional materials which are distributed by our members to a cross section of audiences including health professionals, the media and the general public.

In perfect partnership

This year’s campaign will focus on the importance of forming a good partnership between doctors, people with dementia and carers in order to get the best care possible for a person with dementia. Research has shown that people who prepare for their visit to the doctors receive a higher quality of health care than those who do not come prepared.

Doctors only have a limited amount of time to spend with each patient. The campaign will encourage patients to help themselves prepare for their visit by, for example, keeping a record of how they have been feeling between visits and what medication they have been taking.

ADI hopes that this topic will be helpful not only to people who have already been diagnosed with dementia but also to those who are worried about their memory. In addition, by educating people in how to make their visit to the doctor as effective as possible, we hope that doctors will become more informed about dementia and its symptoms.

To register your interest in receiving a World Alzheimer’s Day™ promotional pack, please visit www.alz.co.uk/wad or contact ADI at 45/46 Lower Marsh, London, SE1 7RG, UK. Tel: +44 (0)20 7620 3011; fax: +44 (0)20 7401 7351. Packs will be distributed in June.

10/66 Dementia Research Group news

Improving dementia diagnosis in developing countries

Congratulations to 10/66, who have had their first piece of research published in The Lancet medical journal (March 15 issue). The article describes the study to develop culturally and educationally sensitive instruments for diagnosing dementia.

10/66 was established to encourage good quality research into dementia in developing countries. One of the group’s aims is to work out the number of people with dementia in developing countries. However, difficulties arise as the standard two-stage method used for dementia diagnosis in developed countries identifies cognitively unimpaired people with low levels of education, literacy and numeracy as positive for dementia.

Thus the group have developed screening instruments which exclude items testing numeracy, writing or reading skills. These screening instruments have now been translated into most languages of the developing world.

For more information about the 10/66 Dementia Research Group visit www.alz.co.uk/1066

To read the article in full visit www.thelancet.com
Providing effective, basic and reliable information about dementia is a fundamental role for all Alzheimer associations. India is a country with a population of one billion people. Along with Hindi and English, 17 other languages are officially recognised. The average literacy rate is 56%. In a country where dementia is little recognised or understood, these statistics present quite a challenge. How can we alert people who cannot read that memory problems and other early symptoms of dementia are not a normal part of ageing?

Ravi Samuel, a member of ADI’s 10/66 Dementia Research Group, has developed a cartoon book to overcome this literacy barrier. The cartoon book is based on the true story of a lady who developed dementia. The lady was a well-respected member of her local community and a key figure in her family.

The artist working on this project was given literature on dementia, then introduced to families of the lady and other people with dementia. The artist was particularly interested in understanding behavioural patterns. Soon after, Ravi and the artist developed a story line depicting scenes showing common difficulties a person with dementia faces with everyday activities, making the diagnosis and challenging behaviour.

Ravi has been using the pictures in his clinic and says the response from family members has been overwhelming. He continues ‘Families seem to comprehend three things when they view the cartoon book: the progressive nature of the illness; the need for specific education when families encounter specific problems; and the focus on ‘care’ rather than ‘cure’. The cartoons have also had a positive impact among educated people, as the pictures communicate information about the illness, behavioural problems and the issues in caring in a very simple way. However, we have also noted one negative impact of using this cartoon book. The information can be a bit overwhelming for families, especially as the story represents a gradual deterioration. Families can feel that the existing symptoms are difficult enough to cope with and can become apprehensive at the thought of the progression of the illness.’

Diversity is also a key feature of South Africa. About 85% of the population (40 million) are literate in at least one of the 11 officially recognised languages. The Alzheimer’s and Related Dementias Association (ARDA) have also launched a poster and booklet campaign targeting people with low levels of education. The association has actively distributed these promotional materials in churches, clinics, hospitals and schools throughout the country. Volunteers in the Eastern Cape region report that the campaign has also successfully raised awareness amongst illiterate people in this community. Although the association has not formally evaluated the effectiveness of these materials, they have reported a steady rise in telephone calls.