

Global & Alzheimer's Disease Perspective International

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IN THIS ISSUE

Announcements	2
Chairperson's message	3
From the Heart	4
Members' Forum	6
Research theories	8
Alzheimer's in Colombia	10
Spotlight on Luxembourg	11

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

A busy summer for conferences!



Nori Graham, chairperson-elect of ADI (front centre) with Brian Roycroft, chairperson of the UK's Alzheimer's Disease Society (front right) at the House of Commons reception



Nick Fox, one of the UK Alzheimer's Disease Society's research fellows, explaining his new brain imaging techniques

UK ALZHEIMER'S RESEARCH CONFERENCE

The Brain Event

Alzheimer's Disease International has been involved in a number of important events in the past three months. In the United Kingdom the Alzheimer's Disease Society held a very successful Alzheimer's Awareness Week under the theme *Opening the Mind*, which saw unprecedented media interest, prompted a record number of calls to the national office helpline and attracted all-party parliamentary support for the Society's campaign for more government funds for research.

The week was launched by *The Brain Event* conference which was attended by over five hundred carers, researchers and health and social service professionals. The conference looked at the latest developments in Alzheimer's research including a new 3-D brain-

imaging technique for identifying Alzheimer's disease and other forms of dementia, developed by the ADS research fellow Dr Nick Fox. Dr Fox hopes that his work will enable earlier diagnosis of dementia and enable clinicians to monitor the effectiveness of drug treatments. Among a number of distinguished speakers was Mr Michael Ignatieff, an old friend of ADI, who gave a very moving talk about what he had learned from people he had known with dementia. Another old friend of ADI present was Dr Zaven Khachaturian, who spoke about the newly formed Ronald and Nancy Reagan Research Institute, which is hoping to stimulate greater research funding world-wide.

During the Alzheimer's Awareness week in which the Society's branches organised a myriad of fund raising and informative events, a delegation from ADS were joined by an all-party group of Members of Parliament led by Sir John Hannam MP and Alf Morris MP, and by Robert Gomez, Secretary General of ADI, to deliver

CONTINUED ON PAGE 2

International Conference in Osaka, Japan

ADI was also present in Osaka, Japan on the occasion of the 5th International Conference on Alzheimer's Disease and Related Disorders, which was attended by over 1300 delegates from all over the world. Prof Henry Brodaty, Chairman of the ADI Medical and Scientific Advisory Committee, reports on the meeting on page 8.

Visit to the Japanese Association

Robert Gomez was also able to be present in Osaka, thanks to the generosity of Japan Airlines and JNTO, which sponsored his trip. During his visit to Japan he was able to meet with members of the Association of Families Caring for the Demented Elderly (AFCDE), the local Japanese Alzheimer's Association, which is based in Kyoto. 'It was a great honour and pleasure for me to be

CONTINUED ON PAGE 2



Robert Gomez with Dr Kunio Takami and Dr Yoshio Miyaki of AFCDE, and Ed Truschke of Alzheimer's Association, USA



Delegation to number 10 Downing Street, home of the UK's Prime Minister

THE BRAIN EVENT CONTINUED FROM PAGE 1...

an open letter to the Prime Minister calling for more government support for research into all forms of dementia. This was followed by a House of Commons reception sponsored by Alf Morris MP which was addressed by the health minister, John Bowis MP, and which was attended by almost 40 MP's and Peers together with ADS branch representatives and individual donors. ADI was represented by Dr Nori Graham, its Chair-elect, and Robert Gomez.

VISIT TO JAPAN CONTINUED FROM PAGE 1...

able to meet Mr Kunio Takami, the President of the association and other key members of his staff, and to find out more about the splendid work being carried out by them throughout Japan.' Robert stated.

Accompanying Robert on his visit to Kyoto was Ed Truschke, President of the Alzheimer's Association in the United States. They both addressed a gathering of members of the local association, including some who had travelled to Kyoto from outlying districts for the occasion. Robert went on to visit a day care centre for the demented elderly and also spent a day in Kobe looking at facilities there. AFCDE was founded in 1980 and as such predates ADI, which was started in 1984. There are currently estimated to be over one million people in Japan suffering from dementia and this is likely to increase in line with the rapid growth in the aged population in Japan.

Global Perspective

The views stated in Global Perspective are personal and not necessarily reflect the views of ADI

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ANNOUNCEMENTS

CONFERENCES

ADI 12th International Conference

October 8-11 1996
Jerusalem, Israel
Conference Secretariat
Tel +9723 514 0000/0014
Fax + 9723 517 5674/
5140077

Alzheimer's Association US Annual Meeting

October 31- November 2
Chicago
Tel +1 312 335 1676

World Alzheimer Day Conference on Dementia and the Law

September 9 1996
Edinburgh
Alzheimer Scotland
Tel + 44 131 225 1453

European Conference Alzheimer's Disease and Related Disorders

November 21-22 1996,
Limerick, Ireland
Practical Management of Alzheimer's disease – an evidence based approach
Tel +353 1 679 3406
Fax + 353 1 679 3458

American Society on Aging Conference

December 4 -7 1996
San Diego, California
Bridging the many worlds of case management
Tel +1 415 974 9600
Fax +1 415 974 0300

International Institute on Aging Conference

December 12-14 1996
Malta
Eliminating poverty in Old Age – a developing country perspective
Tel + 356 243044/5
Fax + 356 230248

Alzheimer's Disease International 13th International Conference

29 September – 1 October 1997
Finlandia Hall, Helsinki, Finland
Main themes: advances in the care of dementia, new perspectives on services

development, innovative approaches to support family carers, human and legal rights of those with dementia
Contact Alzheimer Society of Finland. Tel 358 06 226 2013. Fax 358 06 226 2020

Alzheimer's Disease International 14th International Conference

September/October 1998
Cochin, India
First announcement shortly, for further details please contact ADI secretariat

PUBLICATIONS

Is it Alzheimer's? Warning signs you should know

Now available in Spanish. For copies contact Alzheimer's Association US, Office Services
Tel +1 312 335 5796

Alzheimer's Disease – Help for Caregivers

has been translated into Japanese. Contact Association of Family Caring for the Demented Elderly (AFCDE)
Tel+81 75 811 8195
Fax +81 75 811 8188

Clinical Diagnosis and Management of Alzheimer's Disease

edited by Serge Gauthier
Copies available from Martin Dunitz Ltd, The Livery House, 7-9 Pratt Street, London NW1 OAE

Help for those caring for Alzheimer Patients in the community

In Hebrew. Copies available from Malebev PO Box 3235 Jerusalem 90131 Israel \$12 inc p&p

World Alzheimer's Day September 21

Many member countries are organising events to mark World Alzheimer's Day this year. We would love to hear about your activities so please send photos and newspaper clippings to the Secretariat.

Chairperson's message

Recently when informing some colleagues of my retirement (effective 30 September 1996) I was reminded of the saying 'life is full of new beginnings'. That is indeed true – it is for me personally, and it is also the case for Alzheimer's Disease International.

At the Annual General Meeting of ADI scheduled to be held in Jerusalem in October, I will complete my four year term as Chairperson, and will be handing over to Dr Nori Graham from the UK. At the same time ADI will be contemplating a discussion paper *The Way Forward* and embarking on a new beginning. This is a very appropriate and proper process and one which will strengthen the 'family' of Alzheimer's Disease International. From time to time it is important that we stand back and objectively review our processes and directions. In this way we will ensure that ADI grows and prospers and improves its services for people with dementia and their carers.

As I look back on the development and growth of Alzheimer's Disease International, I do so with great admiration for the many people involved, people who have given of their time and talents to assist each other or assist others in a time of need.

It was a privilege for me to

attend the inaugural meeting of Alzheimer's Disease International held in Washington in October 1984, representing Australia, which at that time was at the threshold of establishing a national organisation. The meeting was attended by a number of people from the United States, with representatives also from Canada, the United Kingdom, Belgium and an observer from Germany. The United States played a leading role in establishing ADI, and the US association has been extremely generous in its support of the fledgling organisation. Although I was unable to attend the meeting held in Belgium in 1985, I have not missed an ADI meeting since, and as I reflect on the growth of the organisation I am warmed and encouraged by the camaraderie and support given across all boundaries by people bonded together through a common concern.

As we move into the next millennium, ADI must remain focused and not forget its primary responsibility, that is, to assist people with Alzheimer's disease or a related disorder (we must be continually reminded that there are a number of forms of dementia, not just Alzheimer's disease) and that we exist to support carers.

I am confident that Alzheimer's Disease International will rise to the challenge, it will continue to grow



as more and more countries form associations of their own and join its ranks. It will continue to disseminate information to assist national organisations and help them become more effective advocates. Hopefully one day we will be able to announce that research had led to a solution, and people around the world will no longer be devastated by such an insidious affliction.

I hope to see many of you in Jerusalem, where I will be chairing the ADI annual conference and meetings for the last time. I thank all those who have supported me during my time with ADI, I wish Dr Graham every success as she assumes responsibility for the Chairmanship, and encourage you all to continue your support for those with Alzheimer's disease or a related disorder, and their carers.

Brian Moss
Chairperson

ADI Chair-elect honoured by Open University



Our congratulations to Dr Nori Graham for being awarded an Honorary Doctorate in Public Services from the Open University, UK, in May of this year. The award was in recognition of her many years of devoted service to Alzheimer's sufferers in the United Kingdom. Dr Graham, or Nori, as she is best known to her many friends and colleagues, has worked as consultant

in Old Age Psychiatry to the Royal Free Hospital in London since 1980. Between 1987 and 1994 she was National Chairman of the Alzheimer's Disease Society in the UK, which grew significantly under her chairmanship and which helped to increase awareness of the disease and the problems faced by carers. Key achievements included the establishment of the Society's

Research Fellowships and the launch of the Open Learning Programme for carers.

Nori has been a keen supporter of ADI for many years and has been an active participant in its executive management. She will take up the Chairmanship of ADI from Mr Brian Moss AM at the end of ADI's annual conference, taking place in Jerusalem, Israel in early October.



With my husband suffering from Alzheimer's disease

Yuko Iwakiri, Fukuoka Branch, Association of Families Caring for the Demented Elderly, AFCDE, Japan

'I don't have any melody, chords or resonance. My heart, beautiful throbbing mind, Please come back to me again!'

I want to tell you a little bit about the past ten years in which confusion and depression has attacked my family.

My husband was a preacher and president of a nursery school attached to a large church. In 1984 he started to complain of headaches and consulted several doctors in vain.

My husband loved music, played the piano and taught choirs. At the onset of his problems he wrote a poem, 'I don't have any melody, chords or resonance. My heart, beautiful throbbing mind, please come back to me again!'

We moved to Oita, Kyushu, the southern large island. On arrival the congregation had prepared a special collection of hymns, knowing that the new preacher was musical. My husband had difficulty accompanying the singers on the piano. He must have been struggling in dread, noticing that he was changing. I now deeply regret that I was irritated by my husband's behaviour instead of being considerate – I did not understand what was wrong.

I got tired of a life of keeping up appearances. No one could tell us what the problem was. Eventually, when my husband was 55, Dr K Hasegawa of St Marianne Hospital, diagnosed Alzheimer's disease.

'Let's lead a quiet life after retirement' – this was the most I could say to my husband, who sat in the corner of the room shedding tears. I recall a sad moment when a young physician asked me how his dementia was, in the presence of my husband, who at the time still had the ability to understand.

For the first few years of the disease, my husband spent rather

calm days looking after his grandchildren. Three years after the onset there came a period of sitting still and quiet. I bought a very special chair and his life on it lasted for a year. The following four years were a period of violence and restless walking inside the house.

In May 1990, I found an article about the National Meeting of AFCDE (Association of Families Caring for the Demented Elderly) in Fukuoka, Kyushu. I became a member on the day of our 33rd wedding anniversary. Although my husband was only in his late 50s, he could get day service twice a week, organised by AFCDE. Their bulletin was a textbook for me and I was much encouraged by the articles written by family caregivers on their experiences.

Saying to myself, 'Don't be angry', I tried to converse with my husband gently; however, in my sadness, no smile was ever on my face. I treasured his ability to appreciate music, which remained with him the longest. He could enjoy musical television programmes, listen to CDs and even attend concerts. Sadly that ended when he became unable to keep quiet in the concert halls.

I attended the caregiving study class at the public health centre with my husband. On a nurse's recommendation, my neighbours kindly attended at the centre to increase their knowledge of the disease. I was helped by them enormously after his wandering started.

Convulsions followed wandering. They attacked early in the morning bringing about a furious look with groans. They escalated from twice to six times a year.

We joined a tour to Hokkaido, the most northern island, which my husband had longed to visit when he was well. It was the last opportunity for a journey before inconti-

nence started. There were some who blamed me for bringing such a disabled person, though the tour guide and other tourists understood.

Another thing which annoyed me was his relatives' lack of understanding. His brother and his wife were shocked to see him after five blank years.

Finally, my doctor advised me that caring for my husband was too much of a strain. I made the decision to admit my husband to an accredited nursing home where he has been since March 1994. At first I took him back home every Saturday for the weekend, returning to the nursing home on Monday. No sooner had I thought this arrangement would be the best for my husband than I realised that I had to abandon the idea of us attending a church service together. I found it difficult to look after him at weekends and soon stopped having him at home, but I made a point of visiting him as often as possible.

Although I feel I will never be able to accept my husband's disease, I would like to thank him for giving me the opportunity for mental development. I also thank the members of AFCDE who have been so supportive. I open my house to nearby family caregivers for small meetings which they have begun to look forward to. Talking at these meetings, without reserve, is helpful not only in clearing away our stress but in teaching us what can not be learned even from doctors.

Partly due to ex-president Reagan's announcement of his suffering from Alzheimer's disease, people's awareness has increased and social conditions have been changing. Making the most of my experiences privately and socially – this is the least I can do to show my heartfelt gratitude to persons who have been encouraging and supporting me warmly.

Over the last eighteen months we have established contact in over twenty 'new' countries where there are moves afoot for the creation of Alzheimer's disease societies. Some of these will take a long time to materialise but everywhere there is a sense of urgency, a sense of 'we must do something now before it is too late'. Everywhere there is a thirst for knowledge; about Alzheimer's disease; about how to develop a society; about how best to deal with the thousand and one problems that confront all those involved in the care of Alzheimer's sufferers. Knowledge that is readily available through our member country associations and which is slowly but surely being disseminated throughout the world.

A lot of this knowledge and experience will be shared at our 12th ADI conference being held from 8th to 11th October in Jerusalem. The full programme, which is shown on the back page, will include a wide variety of interesting topics. We are expecting around forty countries to be represented in Jerusalem.

Pre-conference workshops being held on the 6th and 7th of October include topics such as 'Memory and Language for Alzheimer's Patients'

Reflections from the Secretary General

and 'Training for Caregivers'. Over ten round tables will discuss behavioural and psychiatric manifestations, long term care, ethical rights of AD patients, sexuality and dementia, caring for AD patients in developing societies and minorities, and many other issues.

Symposia will examine modern management of AD, economic considerations and development of services for AD patients in Israel, and dementia from the point of view of social work. In addition there will be the all-important updates on the development of drugs for dementia. Topics such as molecular biology approaches to AD research, genetics of AD, genetic testing and genetic counselling in AD are but a small sample of everything that is being offered at the ADI conference this year.

Our conference is fairly unique in that it brings together world leading scientists and researchers who are trying to find a cure for the disease, clinicians who are in the front line of



providing treatment, and family members and other carers who are having to experience the '36 Hour Day' in learning to cope with the disease now. This union is what makes us strong and gives us added hope for the future. One carer wrote to me recently and among other things she said, '...There is something special about being linked up in an international way for a common cause. In the early days of caring for someone with AD, it is impossible to think of such things, international or otherwise, but as the years pass and you accept (more) the adversities which beset you, there is strength to be found in a united front...' Nothing will demonstrate this better than our 12th ADI Conference. I look forward to seeing you there.

Fifth International Conference on Alzheimer's Disease and Related Disorders

Osaka 23-29 July 1996

Extract from report by Michael Woodward

Henry Brodaty eloquently presented a review of depression in dementia, noting that the two interact in several ways, and depression on top of dementia increases carer stress. Around 5-15% of those with AD and 20% of those with vascular dementia have major depression, more if subsyndromal depression is included. He also noted the difficulty in diagnosing depression in a person with dementia – dementia alone can cause a score of 36 on the Hamilton rating scale. He has

assessed 288 people with dementia, attending an academic memory clinic or whose carer was attending a support program and found a prevalence of major depression of 6-8% using 3 widely accepted diagnostic criteria – yet each set identified different people! One third of those with depression had psychotic symptoms. In a subgroup of 68 with depression only one in eight continued for more than 12 months, suggesting people with dementia move in and out of depression.

NEWS FLASH – 8 September

We have recently heard that our dear friend Dr Carlos Mangone, one of the leading members of ALMA, the Argentinian Alzheimer's Society, has been involved in a very serious car accident in the city of Rosario, Argentina. As I write this, Carlos is in intensive care at the Clemente Alvarez Hospital in Rosario. His family and friends, and I include myself, ask you to pray for his recovery. Carlos, who was Chairman of the 11th ADI conference held in Buenos Aires last year, is a member of the ADI Executive Committee. We all wish him a speedy recovery. Anyone who would like an update on his condition is asked to contact the ADI Secretariat, which is being kept fully informed of his progress.

Robert Gomez

Members' Forum

News from prospective members around the world

The ADI secretariat has been busy forging links with Alzheimer's disease societies around the world. This special edition of Members' Forum highlights progress in some of those societies.



DOMINICAN REPUBLIC

A country with a population of just over 7 million; it is estimated that there are about 38,000 Alzheimer's disease sufferers in the Dominican Republic. The Asociacion Dominicana De Alzheimer y Trastornos Relacionados, was formally established in July 1995 and has just applied for provisional membership of ADI. The Association has five chapters and runs 12 support groups. A 24 hour helpline providing information and advice is in operation. The Board of Directors are all family members of persons with Alzheimer's disease. The goals of the organisation are to raise public awareness about AD, to promote respect for those suffering with dementia, to create support groups for families of those with AD, and to train carers of AD sufferers.

GREECE

The Greek Society of Alzheimer's Disease and Related Disorders was registered as a charitable organisation on 23 March 1996 and has now applied for provisional membership of ADI. Greece has an estimated population of 10 million of which about 1.4 million are aged over 65. Current figures indicate 46,300 Alzheimer's sufferers. The new society currently runs a telephone helpline during the week, which is manned by volunteers who have all been trained by doctors. The three chapters and two support groups are staffed by 30 volunteers. It is hoped to expand the number of support groups and promote understanding of AD by a series of educational programmes.

PERU

The Comité de Investigación y Ayuda al Paciente con Enfermedad de Alzheimer was formed in January 1995 and has recently applied for provisional membership of ADI. Trained volunteers provide a telephone helpline service Monday – Friday during office hours. So far there are two chapters with a total volunteer staff of four. The main aims of the association are to promote research and understanding of AD in Peru, support the formation of family support groups, and organise meetings for both scientists and the public. It is not known how many Alzheimer sufferers there are in Peru out of a total population of 22 million.

THE CZECH REPUBLIC

For some time now ADI has been encouraging the formation of an Alzheimer's Society in the Czech Republic. In this connection we are pleased to report that ADI participated in a seminar on *Alzheimer's Disease – Caring for the Carers*, which was organised by Dr Hana Janeckova in Prague on 27th May 1996. Among the principal speakers was Noreen Siba, who covered the work being done by ADI throughout the world and spoke about how to go about setting up an Alzheimer's Society. Noreen is a former executive director of the Alzheimer's Disease Society in the UK and is a keen ADI volunteer. Forty people attended the meeting, including two carers, many care workers from residential homes and hospitals, and doctors working with dementia patients. It is expected that a model of residential short term care will be set up at the Centre of Gerontology

in Prague and Noreen Siba was able to offer practical advice on day care provision. There was a very lively question time and many requests were received for information, education and training materials. Any country willing to assist further in supporting the formation and development of an AD society in the Czech Republic please contact the ADI Secretariat.

HONG KONG

Earlier this year the local AD association, the Alzheimer's Disease and Brain Failure Association, received visits from Evelyn McPake (Alzheimer Scotland - Action on dementia) and Elayne Brill (Alzheimer's Association, USA), both of whom were in Hong Kong on private visits. Both Evelyn and Elayne met with Dr Edwin Yu, Chairman, and other members of the Hong Kong Association during their stay.

The Hong Kong Association, which has applied for membership of ADI, is slowly helping to increase awareness of Alzheimer's disease in Hong Kong. The award winning Alzheimer's disease film 'Summer Snow' by Anne Hui, produced in Hong Kong, has also helped in this respect. The Association has been



running workshops which have been extremely well attended. The biggest need is to educate the trainers as there are only very few who are qualified to do this, at the present time. With 1997 and the hand over to China fast approaching, contact has been made by ADI with doctors in Beijing and hopefully there will be a growing interchange of information with them. ADI has been able to obtain sponsorship for a doctor from China, working in the field of AD, to attend the ADI conference in Israel next month.

We are very grateful to Evelyn McPake and Elayne Brill for their assistance in Hong Kong. If any of our members are travelling and would like to link up with Alzheimer's disease societies in other countries, please let us know. We will be delighted to put you in touch with the relevant parties.

BAHAMAS

We have been in correspondence with the Pilot Club of Nassau, which has expressed an interest in establishing an operational Alzheimer's association in order to assist people suffering from the disease and to provide support for caregivers. Member countries in the region

who may wish to assist in this endeavour please contact the ADI Secretariat in London.

NIGERIA

Contact has been made with Dr R Uwakwe, Department of Mental Health, University of Benin Teaching Hospital, who is keen to set up an Alzheimer's disease society in Nigeria. Dr Uwakwe writes, '*... as I explained in my earlier communication ... old age mental disorders have not engaged any reasonable attention from any quarters in my country. However, a study has recently been completed on the prevalence of dementia at Ibadan in collaboration with a centre in Indianapolis. Although lack of funds has prevented any major studies, our preliminary impression is that psychogeriatric disorders here are basically the same as in the developed nations.*

'... we have unfortunately neither social security provisions nor any form of specialist services for the elderly. Our recent survey indicated that our hitherto enviable extended family system that has been at the forefront in the care of the elderly is gradually been eroded without alternative ... The presence of an Alzheimer's society in Nigeria will go a long way in raising awareness of the disease in both the government and the public, apart from the benefits to dementia patients and their caregivers ...'

Any member country wishing to offer assistance to Dr Uwakwe please contact the ADI Secretariat.

CUBA

For some time now Cuba has been interested in the possibility of forming an Alzheimer's disease society, and has been encouraged to do so by the Alzheimer's Disease Society of Puerto Rico. Recently, Cuba has established contact with the Alzheimer's society of Uruguay, who have been most helpful in providing AD material in Spanish. Any other Spanish speaking countries wishing to assist please contact the ADI Secretariat.

Member's news

ISRAEL

Two junior researchers in AD, Dr Joab Chapman and Dr Liat Lomnitski, are to receive support from the Rubinowicz Fund. This legacy was established by Mariel Rubinowicz (1911-1992) for research in AD, in memory of her late husband Efraim, who was born in Grodno, Poland and survived the Holocaust.

Dr Joab Chapman studied medicine at Tel Aviv University (TAU) Sackler Faculty and received his MD degree in 1986. His MD thesis, supervised by TAU Professors Daniel Michaelson and Amos Korczyn, won a special prize from the dean of the faculty. His PhD thesis was on the prevalence and role of antibodies to cholinergic neurons in Alzheimer's disease. Dr Chapman will continue his Alzheimer's research at TAU Sackler Faculty of Medicine under the supervision of Professor Korczyn, incumbent of the Heinrich (Yehexkel) Sieratzki Chair in Neurology. Professor Korczyn is a prominent member of the Alzheimer Society of Israel and co-chairman of the 12th ADI conference being held this year in Jerusalem.

Dr Liat Lomnitski completed her doctoral studies in the study of cellular oxidative mechanisms at TAU's George S Wise Faculty of Life Sciences. She is presently undergoing postdoctoral training in neurobiochemistry under the supervision of Prof Daniel Michaelson of the Faculty. Dr Lomnitski's research focuses on the role of oxidative stress in neurodegeneration and Alzheimer's disease and on the interaction between oxidative damage and other molecular risk factors of the disease.

Research themes at the Osaka conference

Professor Henry Brodaty, Chairman of the ADI Medical and Scientific Advisory Committee

The fifth international conference on Alzheimer's Disease and Related Disorders was held in Osaka, Japan from 24-29th July 1996. The conference was attended by well over 1000 delegates from many countries. It featured over 800 papers and posters, abstracts of which have been published in Neurobiology of Aging 1996, Supplement Volume 17, No 4S. The diet was rich, the fare mainly neurobiological and the choice often difficult as there were up to four simultaneous sessions. What follows is a personal smorgasbord selection.

IS THERE A LINK BETWEEN VASCULAR DEMENTIA AND ALZHEIMER'S DISEASE?

Vascular risk factors

N M B Breteler from Rotterdam, The Netherlands, reported epidemiological evidence that vascular risk factors are not only associated with vascular dementia (VaD) but also with Alzheimer's disease (AD). In population-based Rotterdam Epidemiological Follow-up Study of 7983 subjects aged 55 years or more, the relative risk (RR) for dementia was significantly increased by the presence of plaques in the carotid arteries (RR=2.0; 95% Confidence Interval, 1.4-2.9), thick carotid intima-media walls (1.3, 1.1-1.7) and generalised atherosclerosis (1.5, 1.1-2.1). Atrial fibrillation and severe diabetes mellitus were significantly also associated with a greater risk for dementia. All of these associations existed for both AD and VaD.

Difficult to distinguish

K Rockwood from Halifax, Canada, re-analysed data from 1132 subjects who had participated in the Canadian Study of Health and Aging. Rockwood pointed out that it was often difficult to distinguish clinically between AD and VaD and that mixed cases were commonly assigned to either AD (53/137; 38%) or VaD (33/137; 24%)

Vascular lesions

From Lund, Sweden, A Brun, reported that vascular lesions were

common in AD with the majority having small vessel disease, either meningocortical or intracerebral atherosclerosis. This study, which prospectively followed 150 consecutive cases to post-mortem examination, found that an important factor in the cause of AD seemed to be episodes of low blood pressure in conjunction with narrowing (stenosis) and inefficient autoregulatory adaptation of the small blood vessels (arterioli). He concluded that this indicated a link between AD and vascular disease.

Blood pressure changes

These presentations accord with a Swedish prospective study report by Igmar Skoos and colleagues in the Lancet (1996:347;141-145). They found that high blood pressure increased the risk of both VaD and AD some 5-15 years later. At the time dementia was diagnosed, blood pressure had dropped to normal or low levels. To what extent the decline in blood pressure before dementia onset is a consequence or cause of the brain disease remains to be elucidated. It may be that high blood pressure induces small blood vessel disease and white matter lesions.

PRIMARY PREVENTION OF ALZHEIMER'S - IS IT POSSIBLE?

The cost of a trial

The possibility of preventing AD has intrigued researchers for some time,

but the logistics of organising such a trial are overwhelming. In an elegant paper, Leon Thal from La Jolla, California, estimated sample sizes and costs of such a trial. An incidence of AD of 1-1.5% per annum in a population aged over 75 would result in a 5-7.5% cumulative incidence of AD over 5 years. Sample sizes of approximately 2000 subjects per group would result in 100-150 cases per group. If a drug reduced the incidence of AD by 50%, 50-75 cases would exist in the treated group. These findings would be statistically significant and clinically meaningful. However, allowing for deaths and attrition, a total of almost 5000 individuals would be needed to carry out such a trial, the cost of which would be in excess of US\$20m and the duration of follow-up would be five years.

A study of women

Sally Shumaker, from Winston-Salem, North Carolina, presented details of Women's Health Initiative (WHI) a study of over 120,000 post menopausal women aged between 50-79 years selected from over 40 clinical centres in the US. The primary outcomes to be monitored are cardiovascular disease, breast and colorectal cancers, and osteoporosis. There will be trials of low fat versus usual diet; hormone replacement therapy (HRT) versus placebo; and calcium/vitamin D versus placebo. An ancillary study will determine whether HRT delays the development or slows the progression of dementia.

Choosing trial subjects

One strategy to improve the likelihood of prevention trials demonstrating positive effects, is to *enrich* subject selection. That is, by choosing subjects more likely to develop AD, investigators can more easily test whether a treatment is effective. Examples of enriched subject populations include people who have a positive family history, are very old, have an apolipoprotein E4 allele, or are already known to have mild cognitive impairment.

VERY MILD AND PRE SYMPTOMATIC AD

Progression of dementia

Ron Petersen from the Mayo Clinic, Rochester, Minneapolis, reported on a longitudinal study of subjects found to have very mild or questionable dementia (Clinical Dementia Rating Scale = 0.5). About 15% of these subjects 'converted' to dementia each year compared to 1-2% of suitable control populations. Predictors of progression of dementia included the apolipoprotein E status of patients and certain features of their memory function at the time of initial assessment.

Clinicians' predictions

John Morris and colleagues from Massachusetts General Hospital in Boston followed subjects diagnosed at baseline assessment as having very mild, questionable or pre-symptomatic AD. On longitudinal follow-up, clinicians were generally proved correct when asked to predict which patients would go on to develop a clinical dementia. Of interest was the sub sample of

patients who came to autopsy. All the very mild cases who had progressed to obvious clinical dementia had the neuropathological features of AD at autopsy. Unexpectedly, however, the group of very mild/pre-symptomatic AD patients who had been predicted by clinicians not to dement and who largely had not shown evidence of dementia in life, were also found to have pathological changes of AD at autopsy.

ALPOPROTEIN E4

The usefulness of ApoE testing

Any self-respecting Alzheimer's conference these days must have several or several dozen papers on ApoE4. Osaka was no exception. Allan Roses from Duke University highlighted the usefulness of apolipoprotein E typing in patients attending Memory Clinics (this was contrasted against strong recommendation that ApoE4 testing should *not* be used as a diagnostic test in community populations). In a Memory Clinic sample of 134 patients clinically diagnosed as having AD or non-Alzheimer's dementia and followed up prospectively to autopsy, the presence of at least one apolipoprotein E4 allele as a diagnostic marker of AD had a sensitivity of between 50 and 75%, a specificity of between 95 and 100% and a positive predictive value of close to 100%. That is, a patient who is diagnosed as having dementia of the Alzheimer's type when seen in a Memory Clinic and who has at least one E4 allele, is almost certain to have AD confirmed at post-mortem. However, if

the same Memory Clinic patient with clinically diagnosed dementia of the Alzheimer's type does not have an E4 allele, he or she could still have AD confirmed at autopsy. A clinical diagnosis of non-Alzheimer's dementia in patients negative for E4, will almost certainly be proven correct at autopsy.

Sensory loss

Jim Mortimer from Minneapolis reported on an epidemiological survey from Quebec in which 1934 persons over the age of 70 were examined for sensory loss and dementia. Loss of smell was significantly related to the presence of dementia in general and Alzheimer's disease in particular. The presence of anosmia increased the odds ratio for AD in this sample three times, the presence of at least one E4 allele also resulted in an odds ratio of 3, but the presence of both anosmia and at least one E4 allele increased the odds ratio to 18 times. It will be interesting to follow-up the sub-sample of older people with anosmia and normal cognitive function – will they have a greater risk of developing AD?

ETHICS

Then and now selves

An interesting paper from Stephen Post of Cleveland, USA, discussed the morality of slowing the progression of AD. Is it advisable to slow the progression of the disease once the affected person had advanced dementia? Is there a threshold point beyond which it is no longer justifiable, moral or advantageous to slow progression of the disease? Post proposed that the only 'kind point' in the progression of dementia is when the person with dementia forgets that he forgets. At that point the *then self* overrides the *now self*. This prompted considerable debate with Paul Leiber from the Food and Drug Administration pointing out that a patient with Korsakoff's disease had a *now self* (with only the ability to discuss what is happening at the very moment) but little *then self*. The issue was not resolved but the debate was one of the most stimulating of the conference.

Global Perspective

If you are not on our mailing list and would like to receive this newsletter, please write or fax the Secretariat with your details and we will be pleased to send you future issues. There is no charge for this, but your donations are always welcome.

If you have any comments or suggestions about the newsletter, or would like to submit an article – we are particularly keen to hear from carers around the world – please contact the Secretariat.

The address for the Secretariat is on page 2.

ALZHEIMER'S DISEASE IN COLOMBIA

Emerging awareness

Martine Jacquier MD, Neurologist
Coordinator of the Medical and Scientific Advisory Committee, ACA

If 70% of people over the age of 65 will be living in developing countries in the next century, it is time for Colombia to face the multiple issues related to this important public health problem, and to adapt to a changing socio-familial pattern.

Colombia is a country of 11,000,000 square kilometres, with a population of 39,450,000. Most people live in the four capital towns, Bogota, Medellin, Cali and Barranquilla.

Population aging

In 1996⁽¹⁾ 6.7% of the population are aged over 60 (2,700,000 people). By the year 2025, the population will increase to 51,300,000, of which 14% will be over the age of 65. If we assume that 5% of the population over the age of 65 has Alzheimer's disease, we could calculate that there are 100,000 people with Alzheimer's disease in Colombia. Moreover, the number will triple by the year 2025, whilst the population will only increase by 20%.

An effort to improve health services

True dementia units related to University hospitals are very scarce (less than five in Colombia) and only very few day care centres are available, although a wide set of activities have been designed for healthy

elderly people. Government nursing homes are few and very basic, only a few private nursing homes are really adapted to demented patients and hardly any have been specifically designed for this purpose.

Origins of the Colombian Alzheimer's Association

In December 1994 CASDA⁽²⁾ was created, a medical and scientific group. Increasing consciousness of a tremendous need for family support led to the creation of the Asociacion Colombiana de Alzheimer in November 1995. The Association has to date over 120 members and is ruled by an Executive Committee composed of patient's relatives and its Scientific Committee derived from CASDA. Conferences, support groups in

Bogota, provision of information and an informal help line are available. We have even had spots on TV and Radio. Regional chapters are in development, as is the newsletter. We are now registered as a not for profit organisation. Activities such as training programs for professional and family carers, and the creation of day care centres will be stimulated thereafter.

Colombia participated in a meeting held on March 23 1996 in Puerto Rico during the 13th anniversary of the Asociacion Alzheimer of Puerto Rico, along with Guatemala and Santo Domingo delegates.

First official Alzheimer's Day in Colombia

On September 21, World Alzheimer's Day will be celebrated officially for the first time in Colombia and a set of activities will take place at the residence of Colombia's First Lady. The President of the Asociacion Colombiana de Alzheimer, Constanza Baquero de Hernandez, invites all Latin American Association leaders to join us on the phone to set up an interactive network which will be transmitted on a radio broadcast. The new Asociacion Colombiana de Alzheimer needs your experience and skills for efficient problem solving in the perspective of coming challenging situations.



Dr Martine Jacquier (second from right) with officers of the Asociación Colombiana de Alzheimer

(1) Censur Departamento Nacional de Estadística (DANE) 1993 revised)
(2) Comité Asesor Sobre Demencia de Alzheimer

ALZHEIMER LUXEMBOURG ALZHEIMER (ALA)

A dwelling group for dementia patients

Luxembourg lacks long term care facilities for people with dementia. ALA's plan is to open specially adapted sheltered accomodation

Association Luxembourg Alzheimer (ALA) is a non-profit national organisation, founded in 1987 by a group of concerned caregivers. Its initial mission was to inform the public about Alzheimer's disease and related disorders, to increase national awareness and thus develop and improve caregiving and national dementia services programmes. Since 1989, ALA itself has become the main initiator and implementer of concrete national dementia services and structures. It is now operating two day care centres for demented patients in Luxembourg City for which the association is allocated on an annual basis a budget from the Ministry of Health. It also offers numerous other services on a national basis that are mainly financially sustained through private donations. The goals of ALA and its day care centres are to provide a multidisciplinary service for individuals with a diagnosis of Alzheimer's disease or a related disorder, who live alone or with their families in the community.

Alternative care

Since adapted institutional long term care facilities for demented patients are still lacking in Luxembourg and because most of the existing institutional care shows obvious shortcomings in both the content of the care and the environment in which it is given, ALA has decided to implement a care alternative in Luxembourg City. We expect to open this sheltered accommodation with three group dwelling units in 1997.

Definition

The group is a small unit of collective housing for eight permanent

residents. One place will be available to short term residents.

Objective

To offer individuals with dementia high quality care, an alternative from the traditional and often impersonal institutional care.

Population

Persons admitted to the group dwelling have to be diagnosed as suffering from dementia of the Alzheimer's type, a multi-infarct dementia or other related disorder.

Personnel

Personnel of the unit will provide services and supervise the residents 24 hours a day. To prevent burnout, health care personnel need to be recruited carefully and at best have experience in working with demented persons. Continuous monitoring and training opportunities should be given to the staff. Additional care (medical, social etc) will be provided from outside by home help services, the family doctor and, eventually, the relatives.

Infrastructure

Each of the three group dwelling units will be integrated in a normal apartment building. Each resident will have a large room of his own with minimal sanitary facilities. Bathroom, kitchen and living room will be shared by the community. Residents are invited to bring personal belongings to furnish their room and eventually the shared premises, so that the new environment will reflect a home like atmosphere.

Special care will be taken to adapt the dwelling environment to the needs of the demented per-

sons, such as accessibility, wandering possibilities, orientation facilities, safety and security.

Organised care delivery

For residents, the delivery of care by third parties is necessary. To be in a position to provide 24 hour care, a small team of attendants will be assigned to each residence. The basic team will consist of five to six people; one will always be present during the day and one during the evening. During the night there will be one person on duty at the disposal of the three units.

The members of the basic team will not be selected exclusively on the basis of diplomas. The determining factor of their professional competence should in the first place be a vast experience in the care of demented persons gained in earlier positions. Furthermore, they should be creative and flexible and be able to work independently. The care needs of individual residents vary and it may be that some individuals will require more than one attendant. Therefore, in order to support the members of our team, we will call on the help of the relatives of the patients and established home helping services.

Neighbourly help

The three buildings comprise one group of dwelling units on the ground floor and fourteen apartments on the other floors. The concept of the project is to create a group of older people (healthy and demented) sharing these residences and functioning on the basis of neighbourly help. It is planned to rent the apartments to family members of the patients, if desired, or to older people, as their presence during the day is required. It is hoped that the residents will continue to help those with dementia by accompanying them on walks, visiting the doctor or hair-dresser, and shopping. The residents of the buildings will be able to call upon the help of the personnel of the dwelling group, if needed. Furthermore, ALA assures the presence of a nursing service available around the clock in case of sickness.

12th International Conference of Alzheimer's Disease International Jerusalem, Israel, 8–11 October 1996



PROVISIONAL TIMETABLE

SUNDAY OCTOBER 6 - TUESDAY OCTOBER 8

Alzheimer's Disease International committee meetings

MONDAY OCTOBER 7

- 09.00–13.00 **Pre-conference workshop 1: Memory and language for Alzheimer patients** S Arkin, USA
15.00–17.00 **Pre-conference workshop 2: Students as Alzheimer rehab partners: an effective low cost resource** S Arkin, USA

TUESDAY OCTOBER 8

- 08.30–18.00 **Pre-conference workshop 3: Training for caregivers** F Jordan, Australia
Scientific Session: Dementia update
Half-day professional tour in Jerusalem 08.00–13.00
21.00 **Get-together**

WEDNESDAY OCTOBER 9

- 08.00–08.30 **Opening ceremony**
08.30–10.15 **Alzheimer's Disease International: The way forward** N Graham, UK
Dementia: Who cares and who ought to care? T Arie, UK
10.45–12.00 **The voices of old age: The predicament of audibility in later life** H Hazan, Israel
Diagnosis of Alzheimer's disease and biological markers M Davidson, Israel
12.15–13.45 **Satellite symposium: Modern management of Alzheimer's disease** Sponsored by Bayer AG (Lunch will be served)
The challenge of measurement of Alzheimer's disease – the Bayer activities of daily living scale
Speakers: B Reisberg, USA; H Erzigkeit, Germany
14.00–15.45 **Risk and protective factors in Alzheimer's disease** A D Korczyn, Israel
The reversible dementias H Chertkow, Canada
Review of carer research H Brodaty, Australia
16.15–18.00 **Round Table 1: Longterm care and management facilities**
Round Table 2: Behavioral and psychiatric manifestations
Round Table 3: National Alzheimer's disease associations
Round Table 4: Education
Symposium: Dementia from the point of view of social work
20.30 Reception and **Sound and light** at the Tower of David

THURSDAY OCTOBER 10

- 08.15–10.15 **Molecular biology approaches to Alzheimer's disease research** D Michaelson, Israel
Public policy N E Lombardo, USA
The psychological responses of the carers G Livingstone, UK
Vascular factors and dementia T Erkinjuntti, Finland
10.45–12.00 **Industry considerations in the development of new anti-dementia drugs** R Van Der Mark
Novel M1 muscarinic agonists: from symptomatic treatment to delaying the progression of Alzheimer's disease A Fisher, Israel
Behavioural management of agitation in demented persons J Mintzer, USA
12.15–13.45 **Satellite symposium: Modern management of Alzheimer's disease** Sponsored by Bayer AG (Lunch will be served)
Towards the ideal pharmacological management strategy - needs and expectations Speakers: L Schneider, USA; Z Khachaturian, USA
14.00–15.45 **Interactions between cognitive and emotional factors in Alzheimer's disease** F Boiler, France
Denial of illness R Friedland, USA
Palliative care D Marin, USA
16.00–17.30 **Round Table 5: Legal and ethical rights of Alzheimer's patients**
Round Table 6: Early stage Alzheimer's disease
Round Table 7: Carer research for AD patients in Israel
Symposium: Economic considerations and development of services
18.30–20.00 **Mind the Gap 'Change of Mind' – theatre performance**
20.00 **Festive dinner (optional)**

FRIDAY, OCTOBER 11

- 08.15–10.15 **The challenge of care in residential care and the role of special care units** B Moss, Australia
Genetics of Alzheimer's disease I Lahad, Israel
Genetic testing and genetic counselling in Alzheimer's disease S Lovestone, UK
Dementias other than Alzheimer's disease M Emre, Turkey
10.45–12.00 **Legal and ethical rights of demented people** G Grunefeld, Israel
Ethical and legal issues in brain banking R Ravid, Spain
Financing models for care costs J Krecke, Luxembourg
Round Table 8: Caring for Alzheimer's disease patients in developing societies and minorities
Round Table 9: Care in the community
Round Table 10: Neuro-psychology
Workshop: Sexuality and dementia C Archibald, UK
E Baikie, UK
12.00–12.15 **Closing ceremony**
12.15–13.45 **Satellite symposium: modern management of Alzheimer's disease** Sponsored by Bayer AG (Lunch will be served)
Strategies in patient care-giving
Speakers: S Kenowskv, USA; A Nordberg, Sweden
14.00 **Alzheimer's Disease International General Meeting**