

Global Perspective

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

14th annual international conference

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NHS TRUST, MIDDLESEX, UK

ADI's 14th International Conference was held in Kochi, India September 24 – 27 1998. The setting was the beautiful coastal city of Kochi in the unique and picturesque Indian state of Kerala. This ADI conference was the first to be held in a developing country and was hosted by the Alzheimer's and Related Disorders Society of India (ARDSI) under the chairmanship of Dr K Jacob Roy.

Truly international

The conference was attended by 650 delegates from almost 50 countries. Delegates came from a range of disciplines including carers. The conference was a great opportunity to share and exchange information between disciplines and across countries making the meeting truly international and multidisciplinary.

Emphasis on demography

The scientific programme consisted of plenary sessions, free oral presentations, poster presentations, debates and interactive



Opening ceremony: Governor of Kerala, Justice Sukhdev Singh Kang inaugurating the conference. Others from left to right: Dr Jacob Roy, Chairman ARDSI; Dr Jose Bertolote, Mental Health Division, WHO; Dr Nori Graham, Chairman ADI; Mr D K Manavalan, Secretary Ministry of Social Justice and Empowerment; Dr B M Pulimood, Chairman organising committee

The conference was a great opportunity to share and exchange information

workshops. The scientific component of the meeting appropriately commenced with an excellent presentation paying homage to the great Alois Alzheimer. Speaker after speaker reinforced the anticipated and predicted demographic changes with an ageing population leading to an increase in the number of individuals with dementia all over the world. Eminent speakers, representing several disciplines and countries, gave very comprehensive accounts on the diagnosis, epidemiology, pathology, aetiology, treatment and carer issues with regard to dementia. These plenary sessions were very popular and were extremely well attended.

Widespread discussion

Several workshops were run concurrently and included a range of topics from assessment methodology to World Alzheimer's Day. One special workshop I attended, chaired by Mrs Leela George of India, was entitled *Development of a programme for training workers for skilled care at home: Indian experience*. Excellent Indian initiatives from Kerala and Delhi for training community workers and full-time live-in carers were described. These served as examples of innovation and we were all able to learn from their experience. All the workshops were well

CONTINUED PAGE 6

IN THIS ISSUE

Announcements	2
From the heart	3
Member's Forum	4-5
Conference report	6
Reagan Institute	7
World Alzheimer's Day	8

ANNOUNCEMENTS

CONFERENCES

1998

December 10-13

4th International Conference on Long Term Care*Case Management: Which Way to Quality?*

San Diego, USA

Tel: +1 415 974 9600

Fax: +1 415 974 0300

Email: info@asa.asaging.org

Web: www.asaging.org

1999

25-26 January

Skills enhancement and quality improvement in the care of Alzheimer patients

Groningen, The Netherlands

Tel: +31 594 55 50 57

Fax: +31 594 55 50 59

Email: alzheimer.conference@gmx.net

20-23 March

11th Annual Alzheimer's Association Public Policy Forum

Washington D.C., USA

Tel: +1 202 393 7737

Email: diane.blake@alz.org

6-7 May

Multidisciplinary Conference on Pick's Disease and Frontotemporal Dementias

Philadelphia, USA

Fax/tel: +1 609 374 8774

Email: lradin@bellatlantic.net

12-14 May

Dementia, Depression in old age Psychopharmacology in elderly, community care

Beijing, China

Tel: +1 847 784 1701

Fax: +1 847 784 1705

Email: ipa@ipa-online.org

Web: www.ipa-online.org

27-30 June

Ageing Societies in a New Millennium*Global Trends in Care and Services*

Island of Oahu, Hawaii

Tel: +1 202 508 9410

Fax: +1 202 783 2255

Email: iahsa@aahsa.org

Web: www.aahsa.org/iahsa

June 30-2 July

9th Alzheimer Europe Meeting and Alzheimer's Disease Society 20th Anniversary Conference*A Meeting of Minds*

London, UK

Tel: +44 171 306 0606

Fax: +44 171 306 0808

Email: info@alzheimer.co.uk

July 5-7

International Conference with a Special Focus on Older Women in Asia*Women's Health: The Nation's Gain*

Singapore

Tel: +65 336 8855

Fax: +65 336 3613

Email: dmc@kenair.com.sg

August 15-20

9th Congress of the International Psychogeriatric Association*Challenges for the New**Millennium: Professional, Cultural and Regional Diversity*

Vancouver, Canada

Tel: +1 604 681 5226

Fax: +1 604 681 2503

Email: congress@venuewest.com

September 7-11

4th Congress of the European Federation of Neurological Societies

Lisbon, Portugal

Tel: +351 1 847 25 77

Fax: +351 1 847 37 46

Email: efnscongress99@mail.telepac.pt

September 16-18

Alzheimer's Disease International 15th International Conference*Dementia, Challenge of our Time, Creating Hope for the New Millennium*

Johannesburg, South Africa

Tel: +27 21 762 8600

Fax: +27 21 762 8606

International directions

ELIZABETH RIMMER, EXECUTIVE DIRECTOR



We were all so warmly welcomed by Dr Jacob Roy and his team at our conference in Kochi, India in September. 650 delegates from nearly 50 countries were given a true taste of India from the elephant at the opening ceremony to the exceptional food and culture of Kerala. The programme had a distinctive Indian flavour, there were many stimulating presentations from carers and researchers from developing countries. Representatives from emerging Alzheimer associations in Thailand, Turkey, Trinidad and Tobago, Ghana, Egypt, Sri Lanka and Nigeria all attended. The conference was a melting pot of cultural perspectives and experiences of dementia and a real opportunity to share and learn. I think all who were there were inspired by the motivation and energy of our friends in India to make the conference a success and we have all come away with renewed enthusiasm for our work at home and a feeling of truly belonging to a global family.

In this issue of the newsletter you will read about new links we are making in Africa – in Nigeria and Uganda. Encouraging new Alzheimer associations is one of our core aims and in the build up to our meeting in Johannesburg next year it is important that we extend our network in Africa. We are hoping to encourage as many participants from African countries as possible.

This is the last newsletter of 1998 – I think it has been a great and exciting year for us and I am really looking forward to the challenges ahead next year. I wish you all a very happy festive season and best wishes for stronger, louder Alzheimer associations in 1999.

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Web: www.globalconf.co.za/adi99

Email: angellproductions@

bigpond.com.au

PUBLICATIONS

Alzheimer's: The Answers You Need

by Helen D. Davies and Michael P. Jensen. First guidebook written for people in the early stages of Alzheimer's disease and their caregivers. \$13.90 postpaid from Elder Books, PO Box 490 Forest Knolls CA 94933 (tel +1 800 909 COPE). Can also be ordered at bookstores.

Poppy's Head – infodrama video for schools

Australian video for families coping with dementia. aimed primarily at teenagers between the ages of 12 and 16. Written, Produced and Directed by Barb Angell. Prices vary internationally. Angell Productions Pty Ltd, Australia.

Tel: +61 2 9985 7207

Fax: +9985 7175

Interventions for Alzheimer's Disease

By Ruth M. Tappen. New reference that brings together the best practices that can reduce stresses on caregivers and improve quality of life for the person with Alzheimer's disease. £29.00 Jessica Kingsley Publishers (for UK and European distribution)

Tel: +44 171 833 2307

Fax: +44 171 837 2917

Rest of world: Paul H. Brooks

Publishing, USA

Tel: +1 410 337 9580

Fax: +1 410 337 8539

Developing Support Groups for Individuals with Early-Stage Alzheimer's Disease

by Robyn Yale

Practical step-by-step guidelines for developing and administering effective support groups.

£23.00, publishers same as

above.

Global Perspective

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Mailing list

If you would like to receive this newsletter, please give the Secretariat your details. There is no charge, but donations are always welcome.

Send us your comments

If you have any comments about or items for the newsletter (we are particularly keen to hear from carers) please contact the Secretariat.

Put your requests for help in Members' Forum

Member countries requiring help or information are asked to put their requests in writing for inclusion in Global Perspective.



A CARER'S STORY FROM IRELAND

Dementia affects younger people too

Many people are under the impression that Alzheimer's disease is a disease that only affects the elderly. My dear husband Billy died of the disease in February 1997 at the age of 58 years. In hindsight I think he developed the disease about ten years before he died. It was such a gradual and unusual process that diagnosis was very difficult. He had to retire from work in 1993 when it became obvious that he could no longer cope. By then he had withdrawn from conversation as his ability to express himself was deteriorating.

We led a busy life after his retire-

ment. We did a lot of hill walking in Wicklow and walked the dog in the local park, the dog being one of Billy's best pals. We visited family and friends and had them visit us. We babysat our grandson twice a week. Billy did all the chores with me in the garden and house (even if I had to repeat some of them, which were only half done!) We regularly attended an alternative practitioner/healer, whose help with relaxation techniques and various supplements and advice to me on coping was invaluable. All of these activities kept Billy very fit and he was very happy and relaxed in himself.

So his very sudden deterioration in November 1996 came as a great shock to the family and to me. He developed much agitation, wandering, and failed to recognise us much of the time. Within two months we had to part with him and he was admitted to a nursing home. He went rapidly through the final stages and Billy died on 26 February 1997.

On our visits to the nursing home we met a man aged 52 in the late stages of Alzheimer's disease and a lovely woman in her mid sixties. My point is : don't forget about the younger people with dementia.

Alzheimer Scotland - Action on Dementia

Glasgow younger persons project

What do you do when a carer of a person with dementia who is 55 years of age asks about getting a break for a week? Do you suggest a residential or nursing home, where the average age of residents is about 80? Would you suggest a home respite package, which means the carer has to go elsewhere and perhaps impose on family members or incur hotel costs?

This was the problem facing us at the Younger Persons Project where we had five carers in this position. Luckily, we had the option of using Alzheimer Scotland and Order of St. John Holiday Home in Crammond on the outskirts of Edinburgh.

The challenge was set for September: to take five clients and four helpers for a respite break. Costing was calculated on a half-board basis, together with the hire of a mini-bus to allow us to explore as a group, giving us an estimated figure of £2,500 to raise for the venture!

Clients and carers were enthusiastic about the idea, agreeing to pay a sum towards the cost, leaving us with the decision of how to raise the difference required. Our first goal was the annual sponsored walk at the beginning of Dementia Awareness Week. Several people volunteered to walk the Old Kilpatrick Hills, whilst carers and

friends of the project collected sponsors on their behalf. By the end of the day, we were halfway to reaching our target. We also launched our 'Forget Me Not' lapel badges, placing boxes of badges in several locations across the city. This proved to be a popular way of raising funds and awareness of the needs of people with dementia. Our funds were further enhanced by a Glasgow High School, who nominated our project as their named charity for the year. Remaining funds were raised by the Glasgow half-marathon runners.

By 11.30am on 7 September, all clients and workers were on board the bus which was to be our chariot for the week. We stopped off at the Scottish Agriculture Museum at Ingleston, and by the end of our visit, everyone had settled into a relaxed mood which, for some, lasted beyond the time we spent together. We arrived at St John's to a very warm welcome from Ann, the housekeeper, who was responsible for producing a menu which delighted everyone throughout the week. Daytimes were spent visiting places like Edinburgh Castle, The Royal Mile, St Andrews, with its ancient cathedral and castle and Deep Sea World. Evenings were spent leisurely about the house or enjoying the local hospitality in Crammond.

Everyone has shown an interest in repeating the event, especially now that they each have their photograph album of memories to reflect on and show their family. The carers all said they enjoyed the break and did not feel guilty that they had taken advantage of it or that they had to use an inappropriate resource to get it.

Members' Forum

CZECH REPUBLIC

A five day education workshop for carers followed by visits to homes for the elderly was implemented last May and run by Jitka Zgola, a Canadian occupational therapist who has, over the past 15 years taken a particular interest in the care of people with dementia. The event was organised by Diakonie and funded by the Soros Foundation (Open Society Fund). The training course was based on Jitka's book *Care That Works; A Relationships Approach to Alzheimer's Disease* (Johns Hopkins University Press) and comprised lectures, exercises and group work. The site tours enabled the participants to examine and combine the principles of effective care with the reality of existing conditions and facilities.

USA

*Alzheimer's Association Annual Meeting: October 21-26 1998
Shared Values, Shared Vision
Chicago, Illinois*

The 1998 meeting was a watershed for the Alzheimer's Association. Over the last two years the association has been looking at its purpose and philosophy and how it can work best to achieve its mission of creating a world without Alzheimer's disease and optimising the quality of life of those touched by dementia.

A year ago the association adopted a three year strategic plan due to start next year. A committee has been specifically set up to oversee its implementation and gave its recommendations during the meeting on structure, fundraising, internal communications, leadership skills and quality.

Staff and volunteers of both chapters and the national office attended the meeting and were given the opportunity to question and comment on the recommenda-



Ram Ray and Cheryl Ritzi enjoying the conference

tions of the committee during the main sessions and breakout groups. These comments were then fed back to the entire meeting over a lunchtime session and will be taken into account in refining the implementation of the strategic plan.

The association will meet again in February 1999 to discuss the plan further. It is hoped that it will be formally actioned in May.

CANADA

End-to-End charity walk in the UK

Congratulations to Lindsay Callander, who set off from John O'Groats on 10 May and arrived in Land's End eight weeks and two days later, in aid of Alzheimer's Scotland – Action on Dementia and the Alzheimer's Disease Society. The walk not only raised £1500, but also awareness about dementia through local media coverage. Lindsay, who lives in Canada, was inspired to do the walk as her grandfather died of Alzheimer's last year and was keen to illustrate how dementia affected her grandmother.



Become an associate member of Alzheimer's Disease International

Individuals and organisations can become associate members and receive the newsletter and notice of events and publications

I wish to become an associate member of Alzheimer's Disease International

Name

Address

Much of ADI's funding is provided by our member countries. However, national associations have enormous demands on their limited resources, so ADI continues to rely on donations from individuals and organisations. There is no fixed subscription for the newsletter, all donations are welcome. (Member countries and officers of ADI receive the newsletter free.)

I enclose payment of £10/\$15 £25/\$40 £50/\$75 Other

Payment can be made by cheque or banker's draft in either US dollars or Sterling, to Alzheimer's Disease International, 45/46 Lower Marsh, London SE1 7RG

EMERGING ALZHEIMER ASSOCIATIONS

NIGERIA

Dr Uwakwe, a psychiatrist, has been instrumental in the formation of an association in Nigeria. The need for an association became apparent following clinical experiences and local investigations into dementia by Dr Uwakwe, who was then working at the University of Benin Teaching Hospital. ADI became aware of Dr Uwakwe's work through a mutual contact, and positively encouraged him to set something up.

Dr Uwakwe found getting people involved particularly difficult, with few people being interested initially. Four families caring for people with dementia came together and in 1996, a modest gathering of 'Friends of Dementia Patients' was started in Benin City. As the association started taking shape, Dr. Ikeji became Public Relations Officer. In 1997, Dr Uwakwe was transferred to Nnamdi Azikiwe University Teaching Hospital in Anambra State. As the distance made co-ordinating activities very difficult, the group agreed to relocate to Anambra State for logistic reasons.

The group continued to advertise locally, and the hospital was very co-operative, providing an office within their premises. The Alzheimer's Association of Nigeria was formally adopted and inaugurated in January 1998. Several meetings have been held with professionals and carers, and members have responded positively. A fax and email service is now available.

The Association's activities include:

- increasing awareness about Alzheimer's disease
- holding seminars on dementia in health institutions
- education of general practitioners about dementia
- setting up a weekly dementia clinic at the hospital
- creating a carers forum.



Pioneer members of the new Nigerian association

Dr Uwakwe found the materials received from ADI's secretariat invaluable. In setting up the Association, he has faced several difficulties including poor clinic attendance, as the majority of patients do not make use of western-type psychiatric services. Traditional medicine and spiritual healing continue to be the most popular method of care. There have also been logistic and practical problems in getting families together. However, Dr Uwakwe is trying to overcome these problems by working in collaboration with the church and native doctors, and calling professionals, clinicians and researchers to join forces with the Association.

UGANDA

Uganda are also in the process of starting an Alzheimer's association and have set up Alzheimer's And Dementia Awareness Project (ADAPT). The project – initiated by Grace Rwakeiru Robinson, a British resident whose mother lives in Uganda and has Alzheimer's disease – aims to provide support and training to carers, raise community awareness of

Alzheimer's disease and other forms of dementia, provide free advice and information, liaise with local community representatives, local authorities and other organisations, and provide an interpretation and translation service to enhance communication and ensure access to the help and services available.

Grace visited the ADI secretariat earlier in the year before her visit to Uganda. She took a supply of materials with her and set about trying to bring people together in the village where her mother lives. The first meeting of ADAPT attended by nearly 20 people was held in June.

Grace Robinson (right) with her mother in the temporary office of ADAPT



14th annual international conference

The many faces of our annual meeting

Dr Jacob Roy helping Dr and Mrs Henk ter Har celebrate their 50th wedding anniversary



The opening ceremony – a splendid affair



Awaiting the arrival of the Governor of Kerala for the opening ceremony



Henry Brodaty, vice chairman of ADI, participating in a workshop



The first Asia Pacific regional meeting



A boat trip on the river gave some people a chance to let their hair down!



CONTINUED FROM PAGE 1

attended and invoked widespread discussions which continued well into tea-time and the evening.

Many interesting issues

A very exciting debate on legal, ethical and quality of life issues raised a whole host of questions that all of us constantly struggle with. Poster presentations were wide and touched on many different areas of dementia, ranging from health economics to the biology of dementia.

Research collaboration

After the conference, a number of researchers from several countries met to discuss possible collaboration at clinical, information and research level. A database of interested individuals was gathered and there was discussion of future strategies on these themes. This

session was organised and chaired by Dr Martin Prince from London.

Careful organisation

Dr Jacob Roy and his team of organisers worked tirelessly to make this meeting a success for all participants. We were met by volunteers at Kochi airport who took us to our hotels. These volunteers were very patient and helpful to all the delegates throughout the conference. One example of their help: I am a Jain and with the patience and perseverance of one of the volunteers I was able to trace and visit two Jain temples (Jain temples are uncommon in Kerala). They made us feel at home.

A social life

The social programme was just fascinating with a range of cultural activities and fabulous

food. In the United Kingdom we often eat North Indian food. Local food in Kerala was incredible – hot, spicy and delicately flavoured. The tropical fruits added further mystic to Kochi. The tail end of the Indian monsoons essentially stayed away during the conference and allowed us to enjoy the meeting and Kochi without getting wet.

Raised awareness

The conference received widespread coverage from the Indian media both at a state and national level. This, no doubt, improved knowledge and awareness of dementia in India. The conference finished with a mood of optimism and delegates looked forward to the next conference in Johannesburg, South Africa in September 1999.

15th annual international conference

A warm welcome awaits you from The Alzheimer's Disease and Related Disorders Association of South Africa (ARDA) in Johannesburg next September. South Africa takes great pride in hosting the 15th annual ADI conference and looks forward to welcoming delegates to its unique multicultural rainbow nation. There will be opportunities to share your experiences of dementia and learn about what is being done in Africa.

For a conference announcement please contact Global Conferences:
Tel: +27 21 762 8600
Fax: +27 21 762 8606
Email: adi99@globalconf.co.za
or the ADI secretariat

www.globalconf.co.za/adi99

Profile

The Ronald and Nancy Reagan Research Institute

The Ronald and Nancy Reagan Research Institute comprises the scientific program of the Alzheimer's Association. A number of work groups have been developed under the Institute, each group critically evaluating a specific scientific or policy issue relevant to advancing Alzheimer's disease research. The Institute aims to:

- promote research, both nationally and internationally
- foster communications between and among investigators
- facilitate the dissemination of scientific information
- accelerate the transfer of technology
- encourage international co-operation across disciplinary investigations

Several work groups have been co-sponsored by the National Institute on Aging. Completed work groups include Reform of Food and Drug Administration, Molecular and Biochemical Markers of Alzheimer's Disease and Diagnostic Criteria for the Neuropathologic Assessment of Alzheimer's Disease. Current Work Groups include Behaviour and Social Research Agenda Steering Committee and the Care of People with Alzheimer's Disease in the Next Millennium. Several Work Groups are being developed, namely treatment of Alzheimer's Disease, Neural Networks in Aging and Alzheimer's Disease and Resources and Infrastructure.

For more information about the institute please contact the Alzheimer's Association: fax +1 312 335 1110; email info@alz.org; web www.alz.org



Alzheimer's Disease International

Booklets

Available in English and Spanish

How to develop an Alzheimer's society and get results

Creating an Alzheimer's society is the most efficient way to achieve help for the largest number of people

How to develop an Alzheimer's society and get results



Starting a self-help group

Produced by carers with experience of self-help groups from around the world

Help for caregivers

Useful and concrete information on



how to care for someone with dementia. Also available in Arabic, Danish, Hebrew, Japanese, Russian and Spanish.

Influencing public policy

Aimed at helping organisations to plan and run successful campaigns aimed at influencing public policy

Factsheets

- Prevalence of dementia
- Organisation of a prevalence study
- Reasons for prevalence studies
- Demography of ageing around the world
- Alzheimer's disease and genetics
- Caring for people with dementia around the world

All publications are free of charge from the secretariat

World Alzheimer's Day

Some of the ways 21 September 1998 was celebrated around the world

Ireland

Encouraging news from our friends in The Alzheimer Society of Ireland. To celebrate World Alzheimer's Day this year, President Mary McAleese officially opened the Society's new day care centre in Dublin. It is the first purpose built centre opened by the Society and has been designed around the special needs of people with dementia. The day centre caters for 25 people per day and provides a much needed service. WAD has been given good media coverage this year. President of the Alzheimer Society of Ireland, Michael Coote, explained that the focus of WAD this year was to call for early and accurate diagnosis of dementia. Some 33,000 people in Ireland have been diagnosed with some form of dementia. Other events throughout the country were also a great success.



India

Delegates to the conference (including Harry Cayton, executive director of the Alzheimer's Disease Society, to the left in the photograph) joined in a fun run through the streets of Kochi.



New South Wales

An awareness campaign was launched for WAD this year, the association in New South Wales organised a free public seminar at the Parramatta Park Royal Hotel. About 180 people participated and the event was a great success. To help support groups hold WAD events, sponsorship was given and 23 support groups throughout the region received help with organising luncheons, seminars, displays and afternoon teas. Over 40 newspapers in the State ran articles and many radio interviews were given.

Germany

Several events were organised throughout Germany, including the second Memory Walk coordinated by Alzheimer Gesellschaft Hamburg, in which 300 people participated.



Czech Republic

The Czech Republic celebrated WAD for the first time by organising 'Concerts for a Dragonfly'. A short introduction was given before each concert to try to inform other generations about the problems associated with dementia. Concerts were given by music students at 30 locations throughout the country.

Taiwan

On 19 September this year, the Alzheimer Patients Family Association was established. Hundreds of people with Alzheimer's disease, their families, representatives from related institutions and professionals happily united to offer their best wishes and blessings. They wrote down their hopes for the future with a 'wish and blessing tree'. Members of the association can now expect to receive the latest information on Alzheimer's and carer support including on-going participation in carer training courses and lectures. The association gave their support to WAD by organising a hike in which over 100 participated.

