

## World Alzheimer's Day™ 2004

### No time to lose



Boniface Kisi and Sister Sheila Devane from Tanzania support 'No time to lose'

Plans for this year's World Alzheimer's Day campaign 'No time to lose' are well under way. So far, 40 associations have signed up to organise a range of events around the world, including marches to parliament, parades and Memory Walks through city centres, and picnics with traditional dancing.

ADI is encouraging Alzheimer associations to call stakeholders in the dementia field to action by stressing that none of us has any time to lose.

If you are interested in participating in World Alzheimer's Day, please contact your local Alzheimer association to find out what they are planning on 21 September 2004 or visit [www.alz.co.uk](http://www.alz.co.uk)

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## Twenty years of ADI

By Jerome Stone, founder of ADI

- London 1984. The year in which Orwell predicted that machines would take the place of man.
- Washington 1984. A small band of pioneers with stars in their eyes were looking forward to a 'world without Alzheimer's disease'. This couldn't come about with machines. It took vision and daring, a feeling for humanity and most of all a blessed heart and compassion not only for their loved ones – but for future generations.

Thus, October 21, 1984. A small group met in Washington DC. The pioneers of the meeting consisted of Alzheimer associations from just four countries, USA, UK, Canada and Australia. Observers came from Belgium, France and Germany, as well as Presidents of Alzheimer's boards, heads of medical advisory boards, scientists from the National Institute of Health, representatives of the World Health Organization, adjunct scientists and neurologists.

As hosting organiser and president of the US Alzheimer's Association, it was my privilege to chair the meeting. I stated that although some of us had latched onto the statement 'world without Alzheimer's', there was no world organisation to fulfil the promise.

We met again in January 1985, in Chicago, to formally adopt by-laws, vote for official officers and formalise a budget and dues structure. While this meeting took five hours to consummate our business, it achieved giant leaps in success in forming a dynamic and vibrant



Jerome Stone, ADI's founder, with Henry Brodaty, ADI's current chairman, in Chicago, July 1984

organisation. Just think of it, four countries to begin with and 66 now.

With dynamic leadership we have accomplished such momentous achievements as collaboration with WHO, publication of thousands of educational booklets, surveys in member countries, World Alzheimer's Day, the Alzheimer University, the 10/66 Dementia Research Group and co-hosting the World Alzheimer Congress in 2000.

Now it is no longer the handiwork of a devoted and selfless few but the magnificent spirit of an entire association, indomitable, joining hands and linking itself together in a dynamic, vital movement of monumental achievement.

As we look back to 1984 Orwell was not 'all well' in his prediction. The progress we made was not a mechanistic movement, it was a result of scores of people working together to dream of a better world for our loved ones, our children and their children. It was Tennyson who wrote 'Dreams are true while they last, but do we not live in dreams?'



## Alzheimer's Disease International

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### Send us your comments

If you have any comments about or items for the newsletter please contact the Secretariat. Articles and letters for the next issue of Global Perspective to arrive by **15 June 2004**.

### Secretariat

Alzheimer's Disease International  
45/46 Lower Marsh  
London SE1 7RG  
United Kingdom  
Tel: +44 (0) 20 7620 3011  
Fax: +44 (0) 20 7401 7351  
Email: [info@alz.co.uk](mailto:info@alz.co.uk)  
Web: [www.alz.co.uk](http://www.alz.co.uk)

### Corrections

There was an error on page 6 of the November 2003 issue of Global Perspective. The gentleman in the photo with Christine Bryden was Dr Mathew Abraham and not Dr Prasad Punnoose.

On page 7 of that issue, in 'Montessori meets dementia care', we incorrectly stated that the activities included sorting fishing hooks. One of the activities in the program is sorting fishing lures (small artificial creatures which are attached to a fishing line to attract the fish) – all hooks are removed before the activity to avoid injuries.

Apologies for any confusion caused.

## Announcements and conferences

### 2004

14-17 April  
**8th International Springfield Symposium on Advances in Alzheimer Therapy**  
Montreal, Canada  
Tel: +1 217 545 7711  
Fax: +1 217 545 4413  
Email: [ahamilton@siumedu.edu](mailto:ahamilton@siumedu.edu)

22-24 April  
**Alzheimer Society of Canada 26th National Conference Montreal, Canada**  
Tel: +1 416 488 8772  
Toll-free: 1 800 616 8816 (valid only in Canada)  
Fax: +1 416 488 3778  
Email: [conference2004@alzheimer.ca](mailto:conference2004@alzheimer.ca)  
Web: [www.alzheimer.ca/english/newsevents/conference-intro.htm](http://www.alzheimer.ca/english/newsevents/conference-intro.htm)

20-23 May  
**14th Conference of Alzheimer Europe**  
Prague, Czech Republic  
Tel: +420 239 041 661  
Fax: +420 239 041 663  
Email: [info@alzheimer-europe.org](mailto:info@alzheimer-europe.org)  
Web: [www.alzheimer-conference.org](http://www.alzheimer-conference.org)

26-29 May  
**IPA Latin American regional meeting**  
Santiago, Chile  
Tel: +1 847 663 0574  
Fax: +1 847 663 0591  
Email: [info@ipa-online.org](mailto:info@ipa-online.org)  
Web: [www.ipa-online.org](http://www.ipa-online.org)

14-19 June  
**12th World Congress International Association for the Scientific Study of Intellectual Disabilities**  
Towards mutual understanding: person, environment, community  
Montpellier, France  
Email: [corum@enjoy-montpellier.com](mailto:corum@enjoy-montpellier.com)  
Web: [www.iassid.org](http://www.iassid.org)

17-22 July  
**9th International Research Conference on Alzheimer's disease & Related Disorders**  
Alzheimer's Association  
Philadelphia, USA  
Email: [internationalconference@alz.org](mailto:internationalconference@alz.org)  
Web: [www.alz.org/internationalconference](http://www.alz.org/internationalconference)

17-19 September  
**Alzheimer's Society Annual Conference and AGM**  
Warwick, UK  
Email: [info@alzheimers.org.uk](mailto:info@alzheimers.org.uk)  
Web: [www.alzheimers.org.uk/About\\_our\\_work/AGM](http://www.alzheimers.org.uk/About_our_work/AGM)

15-17 October  
**20th International Conference of Alzheimer's Disease International Dementia Care in an Aging Society**  
Kyoto, Japan  
Tel: +81 75 823 6544  
Fax: +81 75 823 6545  
Email: [adiconference@alzheimer.or.jp](mailto:adiconference@alzheimer.or.jp)  
Web: [adi2004.jtbcom.co.jp/english/](http://adi2004.jtbcom.co.jp/english/)

Visit [www.alz.co.uk/events](http://www.alz.co.uk/events) for more conference announcements

## Editorial

We will be celebrating ADI's 20th anniversary in style at our ADI conference this year in Kyoto. There will be a big party for members and close friends of ADI, a special 20th anniversary lecture and an exhibition outlining our history with photos and memories from the many people and organisations who have contributed to the development of our global family. This important milestone is an opportunity for celebration and reflection.

We will be celebrating the fact that we have come a long way from our early days, when a small group of people gathered in Chicago in 1984 'with stars in their eyes' (as Jerry Stone the founder of ADI put it), to the global federation of 66 countries we are today. We really are well on our way to building a movement. Our membership now spreads across all regions of the world and has grown to reflect the global impact of dementia. This is a significant achievement and gives us a strong platform from which to raise awareness about dementia and what it means to millions of people with dementia and their families around the world. We have much to do. We have ambitious plans for our 'No time to lose' campaign for World Alzheimer's Day this year and really hope this will raise the profile of our cause and ADI.

We must also reflect on the rapid growth of ADI and the challenges this presents for the future. This is a time to revisit the purpose of ADI to ensure that we stay on track to deliver our mission of improving the lives of people with dementia and their families worldwide, by strengthening the work of our members.

I would like to invite all of you to come to Kyoto and join us in celebrating ADI's 20th anniversary. The more the merrier!



**Elizabeth Rimmer**  
Executive Director



## Carer's story

# Finding harmony

There is one fact that all humans face – life is followed by death. While birth is the celebration of life, death is seen as the villain who takes from us someone who was always by our side.

The experience of having a relative with Alzheimer's disease is really challenging. It sometimes gives us the sensation that we have lost the person that was always with us. It's upsetting and enigmatic to see our grandmother, Nelba, behaving like a child at the age of 86.

Since the first signs of Alzheimer's disease appeared in 1999, it has been a fight for us to find harmony with our grandmother. We had to fight intensely against all that society tells us because we are the children of a generation that makes us individualist and immediatist. This fight is easier when you have information, support and learn to accept this disease. And although

the initial stage of the disease was less physically demanding than the later stages, it was far more mentally exhausting.

To begin with we had no idea what had happened to our grandmother. We only noticed her strange behaviour for which we had no patience. It was incomprehensible for us to see someone so close to us not knowing how to take a shower or come back home after a short walk with the dog. When our grandmother was diagnosed with Alzheimer's disease we changed the way we looked at her. What was stress became lighter, with humorous touches which is very important to fight against this disease. As we all know, it was very difficult to put a humorous approach into practice in the beginning, but when we did we soon noticed what a difference it made. The relationship with our grandmother



Thiago (19 years old) and Bernardo (17 years old) with their grandmother in Brazil

became much more harmonious and each chore became less tiresome. It is not good to grow angry with the person who has Alzheimer's disease when they do something unusual. They can pick up on bad feelings that will make them more stressed which makes it harder for them to socialise.

Then as life has a beginning, middle and an end, it is necessary to deal with the things that each stage presents us with, regardless of the difficulties. Because even experiencing sad circumstances can enrich your life.

## Holland to the Himalayas in a 45-year-old Land Rover!

**Good luck to Louisa Elliott and Stephen Carless who set off on 1 March for a nine-month overland expedition to the Himalayas in aid of ADI.**

**The 15,000km trip for Louisa and Stephen is a once-in-a-lifetime challenge. Furthermore, the British couple living in Holland wanted to combine their dream with raising money for Alzheimer's disease as Stephen's aunt was diagnosed with the disease in 1998. Their trip through mainland Europe, Turkey, Iran, Pakistan, India and Nepal naturally led them to ADI!**

**Just before heading off, Louisa told us 'our choice of charity lies very close to our hearts. Our journey will take us through**



Louisa Elliott

**many countries and Alzheimer's disease affects people in all of them. We are proud that our expedition is associated with ADI and hope that we can raise funds and awareness – both of which are essential.'**

### No time to lose!

**Louisa continued 'in this 20th anniversary year of ADI, our Holland2Himalayas trip fits in well with the spirit of ADI. ADI's goal is to link up Alzheimer groups all over the world and by meeting members along our route from Europe to Asia, we too hope to spread that spirit. We have already been in touch with Dr Jacob Roy from India and plan to be in Cochin to observe World Alzheimer's Day. We also have no time to lose if we are going to make it to southern India in time – as our top speed in the Land Rover is only 80km per hour!'**

**You can follow Louisa and Stephen's progress and make a donation at [www.holland2himalayas.co.uk](http://www.holland2himalayas.co.uk)**

# Members' forum

## ● Scotland

### Scottish Medicines Consortium does not recommend memantine

Alzheimer Scotland is bitterly disappointed at the Scottish Medicines Consortium (SMC) decision not to recommend memantine for the treatment of people with moderate to severe Alzheimer's disease.

The association has written to the SMC asking for an independent review, emphasising the tangible benefits of the drug to carers of people with late stage Alzheimer's disease as well as those with the illness. They are encouraging people in Scotland who disagree with the decision to write to the SMC and explain why.

Jim Jackson, Alzheimer Scotland's chief executive, said 'we are particularly disappointed because we know that this treatment will benefit some people in this stage of the illness. The reported benefits add up to helping people with Alzheimer's disease maintain a little more dignity and self respect at a particularly difficult stage of the illness.'

## ● USA

### Americans unaware of research progress

A national survey released by the Alzheimer's Association found that only 44% of Americans knew that treatments are now available which can ease symptoms of Alzheimer's disease and improve quality of life.

The Association also launched a national campaign designed to change the way Americans think about Alzheimer's disease. The campaign will target the 77 million individuals born between 1946 and 1964. By 2030, when this generation is over 65, the number of

Americans with Alzheimer's disease is projected to increase by 70%.

The campaign urges all Americans to 'Maintain Your Brain' as increasing evidence suggests that changes in lifestyle and health habits such as those that help the heart – exercising, eating properly, and controlling weight, cholesterol and blood pressure – may also benefit the brain.

Sheldon Goldberg, the Association's CEO commented 'we have tremendous work to do in educating Americans about the disease, the resources available, and what they can do to fight it'.



The Association's campaign also includes a new brand identity and their first-ever paid advertising campaign.

A full survey report is available at [www.alz.org](http://www.alz.org)

## ● India

### World Health Organization Asia office supports Home Care Project in India

The Goa chapter of the Alzheimer's and Related Disorders Society of India is busy implementing the state's first community-based care programme for people with dementia through the Home Care Project. This is a modified version of a community based intervention developed in collaboration with ADI's 10/66 Dementia Research Group. The project uses doctors, priests and newspaper advertisements to identify probable cases of dementia in two densely populated areas of Goa. All cases are then confirmed by a trained clinician and randomised to either receive care immediately or in 6-months time. The intervention is delivered by a community team

led by a Home Care Advisor and supported by mental health professionals. The principal outcomes being evaluated are carer burden and mental health, behavioural disturbances in the person with dementia, and costs of the illness.

The project is also the first randomised controlled trial measuring the effectiveness of any community based intervention for dementia in India.

For more information contact Amit Dias at [apdias@sancharnet.in](mailto:apdias@sancharnet.in)

## ● UK

### Memory Walk

With many associations adopting the Alzheimer's Association's (US) Memory Walk fundraising initiative, there is a growing interest to find out how to organise successful walks. Last year, the Alzheimer's Society (UK) piloted Memory Walk nationally for World Alzheimer's Day and raised around £70,000. This year, they sent fundraiser Marietta Richardson to the Memory Walk training in Atlanta to learn more. Marietta said 'It was a great experience. I was a bit daunted but have come back inspired by the sheer potential of what can be achieved through this event. And, now I have a few friends from around the US that I can email from time to time for advice.'

## ● Philippines

### Philippines launch first compendium for Alzheimer's disease

The Alzheimer's Disease Association of the Philippines (ADAP) has just launched its first compendium for dementia entitled 'ADAP's recommendations for diagnosis, prevention and treatment of Alzheimer's disease'. The document was presented to stakeholders at a public forum in Manila. The compendium is now being submitted for copywriting and then publication.

## Hot topic

# Should Alzheimer associations receive funding from pharmaceutical companies?

## **YES but conditionally!** **Murat Emre, Turkish Alzheimer Society**

Here are the conditions we impose on companies when we accept funding:

- Transparency
- Unrestricted grants or funding of well-defined projects
- No mention of drugs, no logos, just an acknowledgement stating 'this publication was made possible by financial support from Company X'
- Co-operation for raising awareness of the disease and no co-operation beyond this (for example, promotion of treatment).

## **YES Ricardo López Contreras, Asociación de Familiares Alzheimer de El Salvador**

We think you should accept funding from the pharmaceuticals, especially in a developing country like ours with no other source of funding. Money from the industry pays our basic costs including a secretary and utility bills. However, it is important that in accepting such funds, we do not compromise ourselves in any way.

## **YES Jacob Roy, Alzheimer's and Related Disorders Society of India**

The pharmaceutical industry and Alzheimer associations are inseparable partners in the pursuit for finding a cure for this mind crippling illness. The question is how can two groups coexist ethically, with mutual respect and without compromising their good. While one is a non-profit agency, the other one is for profit. So obviously their outlooks are different.

The ideal situation would be to work together and create clear guidelines to safeguard the interest of people with dementia and their families. One way is to establish a body, drawing people from both Alzheimer association and the pharmaceutical industry. In my view Alzheimer associations can accept funding from pharmaceuticals companies under these guidelines.

## **NO and YES Bengt Winblad, Karolinska Institutet, Sweden**

Alzheimer associations should be independent organisations that defend the quality of care and life of people with dementia and their relatives. This also means playing an important role in lobbying authorities, making them improve quality of care, education for carers and staff, and reimbursing dementia drugs. In putting pressure on authorities it would be easy for them to turn around and say that associations have been bought by the industry. This is certainly the case for us clinical researchers who certainly collaborate a lot with the pharmaceutical drug industry.

## **YES Lilian Aliche, FEBRAZ and ABRAZ, Brazil**

In our country, funding for patient associations is seldom received from social responsibility programmes, multi-nationals or even personal fortunes. Projects submitted to foundations, banks, etc. are successful only when dealing with children and adolescents – Brazil's biggest social challenge.

Likewise, wealthy families or individuals never give organisations such as ours donations or leave any assets in their will. Personal donations, even small ones, are not considered. To illustrate my point, only

2% of our 6,500 associates make an annual donation of approximately US\$10. Only 4% pay the full associate contribution.

Pharmaceutical companies, for obvious reasons, are the only ones that study our projects and are prepared to contribute with part of the amount needed. What associations need is to negotiate the terms of the funding. This is the crucial point. Never be under the demands of the donor.

## **YES Daisy Acosta, Asociacion Dominicana de Alzheimer**

Of course we can receive funding from the pharmaceuticals. They earn lots of money from patients. It is just fair that we use some of that money to help them and their caregivers.

## **YES under suitable circumstances. Peter Whitehouse, University Memory and Aging Center, USA**

Under appropriate circumstances it is acceptable for Alzheimer associations to receive unrestricted grants from pharmaceutical companies but companies must expect such lay groups to advocate broad social approaches to care, challenge dominant medical models promising technological fixes, raise questions about the cost of drugs and address ethical issues head on including individual and organisational conflicts of interest. The power of multinational pharmaceutical companies to influence not only our medical and social priorities but our very conceptions of health and disease should not be underestimated. While encouraging entrepreneurial behaviour, the for-profit model of health care distorts values underlying health such as care of the poor and disadvantaged.

## Living with dementia

# The Scottish Dementia Working Group

By Chris McGregor, ADI executive committee member with responsibility for involvement of people with dementia and vice convener of Alzheimer Scotland, and James McKillop, chairman Scottish Dementia Working Group

The Scottish Dementia Working Group is the first national forum for people with dementia in Scotland. Like many good things, it had a simple beginning – a conversation between two people with dementia, a support worker and a researcher leading onto fortuitous wider discussions.

The researcher, Heather Wilkinson of Edinburgh University, happened to encounter Alzheimer Scotland's public policy director, Jan Killeen, who mentioned that Alzheimer Scotland had been having a series of discussions along similar lines. Alzheimer Scotland's 'Having Our Say', an initiative for people with dementia in Glasgow, along with other converging ideas about how to reach out to people with dementia – including the work of ADI – had pushed forward the thinking about involvement. A group within Alzheimer Scotland was looking at the subject on a number of fronts – the involvement of members, volunteers, and external bodies as well as people with dementia.

All of this gave impetus to the growing Glasgow group and a steering committee was set up. Through the network of support workers, people were invited to an initial meeting to test viability. The outcome was positive – people with dementia were frustrated by not having a sufficient voice and by the general lack of understanding they encountered among 'officials'.

It was recognised from the start that the needs of people with dementia had to be built into the format of meetings and the programme. Timing of meetings and duration with adequate breaks,



Members of the Scottish Dementia Working Group

support and confidentiality, facilitating contributions and travelling were issues discussed as well as those affecting any fledgling organisation – finance, governance, aims and objectives.

The first formal meeting was in April 2003 and such was the support that the Scottish Dementia Working Group was set up straightaway. June 2003 saw the aims and objectives and a constitution or set of guidance rules being addressed. For example, it was decided that although supporters were welcome, all voting members had to have some form of dementia.

The founding group was largely Glasgow based so it was essential to attract members from other parts of Scotland. To this end, the next meeting was held in Dundee where the work of identifying aims and objectives continued, including:

- ensuring that people with dementia and their carers have a say in the decisions that affect their lives
- campaigning on specific issues, eg respite care
- becoming involved in public awareness raising and professional training
- contributing to / developing information for people with dementia and others.

By September, the group was deciding about the status of the new organisation; whether to be an independent voice of people with dementia in Scotland or to accept the invitation to become part of Alzheimer Scotland. The preference of the majority was to take up the latter option and Alzheimer Scotland was delighted to welcome the group into the national association and to provide some funding. A committee of seven was elected with James McKillop as chairman and Doreen O'Sullivan and Doreen Cairns as joint secretaries.

Now the way ahead is to consolidate on a sound start particularly in regard to funding, to take forward the aims in a continuing way and to extend membership so as to be truly representative of all parts of Scotland – one idea is to travel round different areas with a road show. The enthusiasm and commitment to the task is evident as a visit to any meeting reveals and the words of members convey. James McKillop writing recently said 'We need to be seen as a viable group, acceptable in the great wild world. We need support from you, the person with dementia and you, a supporter of our dreams'. And another member said 'We want to do something to help others while we still can, before we fade away...'

## Research update

### Further evidence of stroke increasing risk

Research, by Dr Honig of the Taub Institute for Research on Alzheimer's Disease and the Aging Brain (USA) and colleagues, confirms the existence of associations between stroke and Alzheimer's disease. The study concluded that the relationship between the two is strongest in the presence of known vascular risk factors, such as hypertension, diabetes, and heart disease.

The Alzheimer's Society (UK) commented that the study 'underlines the potential for preventative approaches towards stroke and vascular disease, which could minimise the incidence of Alzheimer's disease. The approaches include limiting the amount of salt and saturated fat we eat.'

<http://archneur.ama-assn.org/cgi/content/abstract/60/12/1707>

### Clioquinol and beta amyloid

Researchers in Australia have reported that Clioquinol, an antibiotic used to treat skin infections and some severe forms of diarrhoea, appeared to slow cognitive decline for some participants in a clinical trial.

The results of the trial showed that in participants with more advanced Alzheimer's disease, those receiving clioquinol declined more slowly than those receiving the placebo during the first 24 weeks of treatment. No beneficial effect was observed in individuals with less severe Alzheimer's disease. Because there were only 36 subjects, no conclusion could be drawn about possible efficacy.

The Alzheimer's Association (USA) commented 'With the caveat that this study involved a very small number of participants, we

believe that the lack of toxicity and possible effectiveness warrant further investigation. The main importance of studies like this is to attempt to prove the principle that amyloid-lowering agents can stabilize or possibly even reverse cognitive decline in Alzheimer's.'

<http://archneur.ama-assn.org/cgi/content/abstract/60/12/1685>

### Combined vitamins may reduce risk

A study published in the January 2004 issue of Archives of Neurology suggests that taking a combination of vitamins may reduce the risk of developing Alzheimer's disease.

Lead researcher Dr Peter Zandi, of the Johns Hopkins University, said: 'These results are extremely exciting. Our study suggests that the regular use of vitamin E in nutritional supplement doses, especially in combination with vitamin C, may reduce the risk of developing Alzheimer's disease.'

The Alzheimer's Society UK pointed out that 'the doses of vitamins that made a difference in this study are quite extreme.' The amounts involved were 400 international units of vitamin E and 500 milligrams of vitamin C, amounts usually found only in individual supplements. Multivitamins typically contain the recommended daily allowance of vitamin E (22 IU) and vitamin C (75-90 mg). The study did suggest that people taking a higher dose of vitamin E combined with the amount of vitamin C usually found in a multivitamin might have reduced risk.

Because this was an observational study, based on data from several thousand older people in Cache County, Utah, USA, the data can suggest an association between the vitamins and reduced risk of dementia but cannot prove cause and effect.

There is increasing evidence of a link between diet and the intake

of vitamins with an antioxidant action and a lower incidence of dementia. However, it is still unclear whether very high doses of specific antioxidants are an effective anti-ageing remedy in humans. The authors of the study suggest that the results are strong enough to justify a controlled clinical trial, which has been proposed by the Alzheimer's Disease Co-operative Study in the US.

<http://archneur.ama-assn.org/cgi/content/abstract/61/1/82>



#### **Dementia Care in an Ageing Society**

Alzheimer's Disease International's 20th anniversary conference  
15-17 October 2004  
Kyoto, Japan

Daily conference themes include

- future strategy of dementia care
- people with dementia and family
- dementia and human rights

All sessions will have simultaneous translation into English and Japanese.

ADI and Alzheimer's Association Japan look forward to welcoming you to Kyoto.

For more information or to register contact the conference secretariat:

Alzheimer's Association Japan  
Tel: +81 75 823 6544  
Fax: +81 75 823 6545  
E-mail: [adiconference@alzheimer.or.jp](mailto:adiconference@alzheimer.or.jp)  
Web: <http://adi2004.jtbcom.co.jp/english/>

## Raising awareness

## Public figures speak out

There is no doubt that using public figures can add unique value to our cause as well as our organisations. Positive benefits of their endorsement include raising awareness and the association's profile, attracting new audiences, demystifying campaign issues, raising funds, and mobilising public opinion and involvement.



**Hazel Hawke (ex-wife of former prime minister Bob Hawke)**

In November 2003, Australia's 'first lady' Hazel Hawke (ex-wife of former prime minister Bob Hawke) disclosed on national television that she has Alzheimer's disease. Now in the mild to moderate stage, Hazel said 'I hope that by speaking out about this very private issue, I can help to promote openness, awareness and support for all people living with dementia. No illness should carry a negative label. None of us is immune.'

Hazel is hoping that her 'coming



**When well-know individuals like former president Ronald Reagan, who announced he had Alzheimer's disease in 1994, speak publicly about their diagnosis, they help people from all around the world recognise that dementia can affect anyone, regardless of their social, economic, ethnic or geographical background.**



**ADI's president Princess Yasmin Aga Khan, whose mother was Rita Hayworth, has been a great ambassador by sharing her experiences of caring for her mother, attending our conferences and endorsing World Alzheimer's Day. Princess Yasmin has also raised over US\$33 million since 1985 for the Alzheimer's Association (USA) through the Rita Hayworth Galas.**

out' will help raise funds for research. So far, over AU\$300,000 has been collected. Lewis Kaplan, Chief Executive of Alzheimer's Australia New South Wales said 'Hazel Hawke has achieved for Alzheimer's in a few short months what otherwise would have taken years.'

The Alzheimer's Association of Trinidad and Tobago have also worked closely with their now former President Arthur Robinson. Whilst still in office, the association

came to know that the President's wife had Alzheimer's disease. Whilst wanting to support the association, Mr Robinson said he wanted to wait until his term of office had ended before speaking publicly. True to his word, the former president made a public announcement about his wife's diagnosis and accepted the association's invitation to become their patron. Last year, Mr Robinson, accompanied by his wife and family gave the association a huge boost by participating in their Memory Walk.

## Coalition of Hope

The Alzheimer's Association (USA) has just launched the 'Coalition of Hope' – the largest coalition ever formed to promote Alzheimer's disease support and research. Over 150 local, state and national organisations representing more than 50 million Americans have committed to supporting research to find new treatments and preventions for Alzheimer's disease. The Coalition wants to make Alzheimer's disease a national priority by:

- Raising awareness of new Alzheimer's discoveries
- Improving the quality of life for individuals and their families
- Educating the public on how to 'Maintain Your Brain' with good health practices
- Calling on Congress to provide \$40 million in additional funding this year to support large-scale clinical trials.

The coalition comprises a range of organisations from all across the USA representing baby boomers and Americans over the age of 60 and includes religious, labour and ethnic groups, and rural organisations. The Coalition of Hope is a major component of the Alzheimer's Association's new national campaign to change the way Americans think about the disease (see article on page 4). Visit [www.alz.org](http://www.alz.org) for more information