



# Global Perspective

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

## First leadership training a great success

*'This has been a wonderful learning experience for me ... the workshops, meeting colleagues from the other countries, finding out how they do things, making friends'* Silvia Olza, CEAFA, Spain

In April, ADI brought together members from Germany, Belgium, Denmark, Greece, Russia, Poland, Romania, Switzerland, Spain, South Africa, Israel and Luxembourg for an Alzheimer University training programme focused on leadership.

Effective leadership is crucial. ADI created a programme to equip participants with skills to get the best out of people and to develop a learning organisational culture. Workshop topics included developing the board, strategic planning, team building and internal communications. The sessions were facilitated by specialist trainers who had been fully briefed on each participant's role in their Alzheimer association.

At the end of the training, participants identified three action points they would implement on their return home. Within a week, several participants were giving ADI feedback on how they were doing.



The workshops gave participants an opportunity to exchange their experiences with other participants (left to right) Eugen Stefanut (Romania), Ruth Goldberg (Israel) and Karin Rosenquist (Denmark) discuss the internal communications of their respective Alzheimer associations

The programme was particularly timely for Birgitta Martensson, executive director of the Association Alzheimer Suisse, who together with her board was looking at the issue of restructuring the board. Birgitta was able to put her learning straight into practice and said, 'I really got a lot out of the course and we have already met to discuss our future structure. I used the diagrams showing the stages in the life of a board and those describing governance and management. It allowed a very positive and future orientated discussion. We also decided on a nominations committee to find new members.'

This training programme was the first one in which ADI's staff participated – all four staff found it an intense, thought provoking, fun and rich learning experience! Elizabeth Rimmer, executive director, said 'we

decided to go through the same process as members and use the training to tackle some of the challenges facing ADI. Each member of staff took one key aspect of the programme and identified and summarised the issues raised for ADI. Some actions we can take immediately and others will require further discussion with the executive committee. We will meet again in six months, to evaluate the steps we have taken and what difference we think they have made.'

It is clear from feedback that this training programme really met a need. In addition, members really appreciated the ADI staff participating with them and demonstrating that we face the same sort of challenges that they do. There was a very strong sense that we are all in this together. We are looking into replicating this training programme in our other regions.

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## 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 October 2003.

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## ANNOUNCEMENTS & CONFERENCES

### 2003

17-22 August  
**IPA 11th International Congress**  
Chicago, USA  
Tel: +1 847 663 0574  
Fax: +1 847 663 0591  
Email: [ipa@ipa-online.org](mailto:ipa@ipa-online.org)  
Web: [www.ipa-online.org](http://www.ipa-online.org)

12-14 September  
**Alzheimer's Society AGM and conference**  
York, UK  
Tel: +44 20 7306 0606  
Fax: +44 20 7306 0808  
Email: [enquiries@alzheimers.org.uk](mailto:enquiries@alzheimers.org.uk)  
Web: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

18-20 September  
**1st Croatian conference on dementia**  
Zagreb, Croatia  
Email: [iivankovic@inet.hr](mailto:iivankovic@inet.hr)

19-20 September  
**4th Leonard Berg Symposium**  
*Early Detection of Alzheimer's Disease: Structural, Functional & Molecular Neuroimaging*  
St. Louis, USA  
Email: [adrcedu@abraxas.wustl.edu](mailto:adrcedu@abraxas.wustl.edu)  
Web: [www.alzheimer.wustl.edu/adrc2/BergSymp/2003](http://www.alzheimer.wustl.edu/adrc2/BergSymp/2003)

15-18 October  
**19th International Conference of Alzheimer's Disease International**  
*Discovering dementia*  
Santo Domingo, Dominican Republic  
Tel: +1 809 532 2528/2521  
Fax: +1 809 508 0581  
Email: [info@alzheimer.com.do](mailto:info@alzheimer.com.do)  
Web: [www.alzheimer.com.do](http://www.alzheimer.com.do)

1-2 November  
**IX National Conference ARDSI**  
*Memory – its many faces*  
Calcutta, India  
Tel: +91 33 2475 5827  
Email: [ardsikolkata@vsnl.net](mailto:ardsikolkata@vsnl.net) or [ardsikolkata@yahoo.co.in](mailto:ardsikolkata@yahoo.co.in)

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



**Mirka Wojciechowska**  
Chairman Polish Alzheimer's Association and executive committee member of ADI

## Editorial

The Polish Alzheimer's Association celebrated its 10th anniversary last year. We are developing and getting stronger but there are times when I question my skills, especially when I feel that the

people I work with do not share the same enthusiasm and passion and do not get involved as much as they could or simply when things do not go well or not as fast as we plan. Am I a good leader? What can we do to be more effective?

The recent Alzheimer University training in London helped me realise that there is nothing wrong with my association or my thinking about the future. All organisations undergo crises from time to time. The fact that there is a theory behind all this and there are ways of getting out of crises was very comforting.

In the association's 10 year history we have hardly had time in the board to sit down and review our vision, mission and strategy. I learned how important it was to do that regularly. After the training,

which was very exciting, valuable and useful, I identified some important questions to ask ourselves – what is the role of our association? What is the role of our board? How do we plan (from general to strategic and operational level)? How effective is our association? Are we communicating with our networks in the best possible way?

I distributed these questions to the other board members and we set a date to discuss them, stressing that it would better if we could spend a day out together to talk only about these questions and review our strategy and policy. They all agreed. We are meeting in June and in September. I hope members of the board understand that regular review meetings are necessary.

I am also very pleased that ADI staff participated in the training together with us. I realised that all the problems we were discussing concerned not only our national organisations but also ADI. I feel more empowered and wiser. I understand how important it is to be a learning organisation if we want to be more effective. Thank you for a very useful workshop, for the opportunity to meet friends and share our problems.



# My Grandma

By Miss Mai Izumi (aged 12) from Japan

Do you know about Alzheimer's disease? It is an illness of the brain in your head. The brain has many rooms. Each room is important for thinking, talking or moving your hands and feet. Mother told me that this illness is as if someone slowly puts off the light of these rooms, one by one.

My Grandma has this Alzheimer's disease. When I was little and my friends came to play with me, Grandma said 'It's late and dark so you must go home,' although it was still daylight. She insisted on not saying again what she had said, or forgot she had already had meals. Her condition got worse, and she could not return home when she went out.

Now she does not talk much and cannot walk by herself, but if I hold her hands she can still walk. Others may think she cannot do anything and does not understand anything, but when she hears a song from the television or when we say a few words to her, she laughs merrily. Then I laugh with her. When I was practicing my multiplication table aloud and made a mistake, she

would correct me although at that time she could not find her way home.

I want everyone to know about this illness. It is called dementia. The reason I want you to know about it is because the people who have this illness are not helpless or do not understand everything, but remember the old days, and can understand other people's feelings. When I am angry and say unkind words to Grandma, her face becomes angry. Then I ask her if she is angry, she has forgotten all about it. She immediately forgets what has happened. But the light in her heart has not died out. That is why she knows me and she understands our kindness.

I was told that there are more and more people with this illness. When Mother and I were driving through town, there was an old lady sitting on the road. We stopped the car and talked to her. She had walked a long way from her house in the heat. She was suffering from the same illness as my Grandma. While Mother telephoned someone, I was told to



go and buy tea. When I handed it to the old lady, she said 'Thank you, thank you' and started to cry.

My Mother is in a group of people who care for people with dementia at home. She often says: 'I hope everyone will be kinder to the people who have this illness, so the light in their hearts will not be extinguished. If everyone knew more about this illness, it would be easier for Grandma and others to live in peace.'

There were times when I did not want to but now I help in taking care of Grandma.

There are many people who take care of Grandma, which makes me happy. I hope there will be more to do so. I admire my Mother who looks after Grandma. She has a job, she does the housework and she looks after us. She must be very tired as caring for Grandma is very hard work. I am a member of the family. I hope to do what I can and be kind to Grandma.

## Global Perspective – what you *really* think!

Thank you to those of you that completed our questionnaire. We were pleased to see that every section of the newsletter was of interest to some.

The research update that we introduced last year seems to be very popular, with 80% of the responses rating it 'very interesting'. People liked it because it offered 'a synopsis of all types of research' and was 'reliable' and 'accessible'. The medical articles also scored well. The carer stories received a more mixed reception – they were

popular with carers and Alzheimer association staff and volunteers but less so with professionals and researchers.

Several people commented that there was 'too much about a conference that hasn't happened yet', and 'yet more pictures from conferences'. We will bear in mind the feedback and rethink our reporting of the conference.

We asked about some new features, and more than half of the responses were positive for every feature we suggested! A 'Hot Topics' section with debate

on an organisational or research issue generated most interest and we will be introducing these new features next March, when we re-launch the newsletter to coincide with our 20th anniversary.

In response to the numerous suggestions to include more features about people with dementia, we have introduced a new section 'Living with dementia' in this issue.

We were delighted to read that so many of you felt that the best thing about the Global Perspective was 'Just that, it is a global perspective ... the only one of its kind'.

# Members' Forum

## ASIA PACIFIC



**Edwin Yu (Hong Kong), Amit Dias (India) and Li Ling Ng (Singapore) at the Asia Pacific meeting**

ADI's members in the Asia Pacific region met in Melbourne, Australia earlier in the year to share their achievements and challenges over the previous year.

The day's programme included informal workshops in which members heard about:

- The coalition that Alzheimers New Zealand formed for the subsidisation of dementia drugs, and the advantages of working in such a coalition.
- How in Goa, India, they are setting up a day care centre not only to act as a model of service provision for the government but also as a prompt for people to start demanding such services – as Amit Dias pointed out 'people can't demand services they do not know about.'
- How the Alzheimer's Disease Association in Singapore managed to attract 2,000 walkers and raise SG\$200,000 from their first Memory Walk.

## SCOTLAND

### **Dementia helpline launches campaign to target Scottish GPs**

Last month, Alzheimer Scotland – Action on Dementia launched a new initiative targetting GPs.

Every GP practice in Scotland was sent a specially designed display stand with leaflets promoting Alzheimer Scotland's free 24 hour telephone dementia helpline.

The helpline has, to date, helped over 32,000 callers, but Alzheimer Scotland has found that there are many people who still do not find out about the service until far into the illness. Maruska Greenwood, the helpline manager said 'Often callers say how much they wish they had known about the helpline earlier on, and how much help it could have been to them when they first found out about the diagnosis. GPs are ideally placed to put their patients in touch with the helpline, as they are the first port of call for those worried about their memory.'

## AUSTRALIA

### **National Cross-Cultural Dementia Network**

Alzheimer's Australia, with funding from the Commonwealth Government, has set up the National Cross-Cultural Dementia Network to ensure that dementia services are available to the 200 or so ethnic communities in Australia. The network was launched in March 2003 at Alzheimer's Australia's national conference.

The network aims to advise, direct and identify gaps in information, resource and service provision with respect to dementia and the culturally and linguistically diverse communities. It will also act as a nurturing ground for innovative ideas and models, and ensure that national policy is advanced. The network comprises members of the health, government and community sectors from all states and territories of Australia.

A number of priorities were identified for the network at its inaugural meeting – the most important being the lack of community awareness of dementia.

Many ethnic groups have very little knowledge of dementia and how to manage challenging behaviours. Other action areas identified included:

- developing appropriate assessment and diagnostic tools
- identifying ways to improve staff training
- developing best practice guidelines for various professional groups

For further information on the Australian Cross-Cultural Dementia Network, contact Helena Kyriazopoulos at [helena@alzheimerssa.asn.au](mailto:helena@alzheimerssa.asn.au)

## INDIA

### **Chennai hosts workshop on dementia and cognition**

Southern India was the location of this international workshop organised by the TS Srinivasan Institute of Neurological Sciences and Research & the Neurosciences India Group ([www.nsig.org](http://www.nsig.org)). The meeting had both an educational theme 'From Science to Patient' and a research development theme 'Transcultural Perspectives'.

A range of patient care and research development issues in dementia were discussed and debated over the three days, including symposia on epidemiology by ADI's 10/66 Dementia Research Group and caregiving by the Alzheimer's Disease and Related Disorders Society of India.

Highlights of the workshop included a public forum 'Understanding Dementia' which was attended by over 250 people. Another unique feature was the programme 'Dementia through Art' which attempted to communicate the experience of a person with dementia and their carer using a fusion of Indian and western music and dance which left many members of the audience deeply moved.

**UK****Harry Cayton leaves the Alzheimer's Society**

A fond farewell to Harry Cayton, chief executive, who will be leaving the Society in September to become director for

patients and the public at the UK Department of Health. Harry has been with the Society for 12 years and throughout this time has always been a great supporter of ADI.

Harry has been at the forefront of the Society's award-winning work to raise public awareness and has been influential in changing public policy in the field. In 2001 he was awarded an OBE for services to people with dementia.

We are delighted that Harry will still remain a friend of ADI as he indicated: 'I will be leaving the

Society but not leaving the world-wide Alzheimer's movement. I will continue to be an active supporter of ADI and to do what I can to support its work and promote the well-being of people with dementia and their carers.'

**GREECE****Science and care**

Alzheimer associations from throughout Europe recently met in Thessaloniki, Greece for Alzheimer Europe's conference, hosted by the Greek Society for Alzheimer's Disease and Related Disorders.

The conference gave ADI staff the opportunity to meet ADI's members in Europe and find out how participants of the Alzheimer University training programme had progressed with the three targets they set themselves.

It was also an opportunity for ADI to discuss its plans for the 20th anniversary in 2004.

**NETHERLANDS**

Congratulations to Karla Peijs, chairman of Alzheimer Nederland and a member of ADI's executive committee, who was recently appointed as Minister of Transport in the Netherlands. Since taking up this government position, Karla has had to give up all her voluntary commitments.

In addition to wishing Karla all the best in her new and challenging role, ADI would like to thank Karla for her commitment and contribution to ADI over the past five years.

**EMERGING ALZHEIMER ASSOCIATIONS****GUYANA**

The Alzheimer Disease Association of Guyana was founded by Mrs Bacchus after she met Norma Inniss (founder of the association in Trinidad and Tobago) at a conference in Grenada in August 1998. On her return home, Mrs Bacchus placed an advertisement in the national newspapers for volunteers interested in setting up an association.

Beverley Stuart, treasurer of the association says, 'The association's main focus was raising awareness on Alzheimer's disease because this disease was not well known our country.

'We held our first major seminar on World Health Day in April 2001 and we were fortunate to have a neurologist from Trinidad who came specially to Guyana, a psychiatrist and a carer who spoke about her own experiences of caring for a person with dementia.'



**Beverley Stuart (centre) at last year's Alzheimer University training programme**

In March 2002, representatives from Guyana were invited to attend ADI's Alzheimer University training programme. Beverley was able to attend and returned home saying, 'The workshops were very informative and really helped us identify our aims. My organisation will benefit tremendously. This is a great help to weaker organisations.' The association is currently focusing on recruiting more volunteers and expanding their membership.

The association has set up some

support groups but is still faced with the challenge of family members being reluctant to be a part of a support group and come forward for help. As yet, there are no people with dementia actively involved with the association. The association recognises that it still has a long way to go before reducing the stigma associated with Alzheimer's disease and changing people's attitudes about the disease.

The association celebrated World Alzheimer's Day in 2002 by holding a panel discussion and visiting several homes and facilities. The Minister of Health supported the campaign with a message and the association distributed flyers and information about the disease to people's homes, doctors' offices, and in other public places.

The association is delighted that one of Guyana's leading psychiatrists has agreed to be part of the association.

# Living with dementia

**A new section about the involvement of people with dementia in Alzheimer associations around the world**



**Marilyn Truscott (second from left) with some other 'dementia directors' Lynn Jackson, Christine Bryden, Peter Ashley and Jeanne Lee at ADI's conference in Barcelona**

## Canada

The Alzheimer Society of Canada (ASC) has recently appointed someone with dementia onto their national board of directors. Marilyn Truscott, who has Alzheimer's disease, is the first person with dementia to have this position on this board, having previously been appointed to the provincial board of directors in British Columbia in 2002. ASC is the second country (after the UK) to appoint a person with dementia to their national board of directors.

Marilyn said 'It is an exciting time

in Canada, as the ASC moves forward with its drive to include people with dementia in working partnerships. I am in a small group of directors with dementia, but we are bound to be a growing group, as other countries recognize the advantage of including us! Marilyn has written about her experiences of being on the board. You can read her report at [www.alz.co.uk](http://www.alz.co.uk).

## UK

For the last few years, the UK Alzheimer's Society, through its 'Living with Dementia' programme,

has been working not just *for* people with dementia but *with* them. This work was celebrated at a special event at the Café Royal in London in March, called 'Living and Learning Together'. About 60 people with dementia came together to direct the Society's work.

Since the 'Living with Dementia' programme began in April 2000, over 200 people with dementia have been involved. Contributions have been varied, including writing articles for the Society's monthly newsletter, speaking at conferences and workshops, identifying support and information needs, commenting on the accessibility of publications, designing websites and publicity materials and influencing public policy by sharing views.

Throughout this period a recurring request from people has been to have 'their own' event and an opportunity to come together with other people with dementia. The Café Royal was the perfect place. As one delegate said 'It makes us feel very special. I want to be seen, not hidden away.'

## New ADI factsheet

A new factsheet 'How to include people with dementia in the activities of Alzheimer associations' is now available from ADI. The factsheet has been developed by ADI in consultation with our members and people with dementia. The factsheet is available at [www.alz.co.uk/publications](http://www.alz.co.uk/publications).

## ADI celebrates 20 years in 2004

Next year marks ADI's 20th anniversary. To celebrate, we are encouraging all Alzheimer associations throughout the world to participate in one globally co-ordinated event in each country's capital city on World Alzheimer's Day™ (21 September 2004).

ADI's 20th anniversary is an excellent opportunity to take a step back from what is

happening on your own doorstep and see how you fit into the bigger picture. It is an occasion to capture the spirit of belonging to an international movement, of not being alone, and an opportunity to demonstrate unity, strength and solidarity. For 'older' members, it is a chance of renewing your vigour, enthusiasm and commitment to ADI. For 'newer' ones, an

opportunity of making you really feel a part of the global dementia family that ADI has become.

We have drawn upon the expertise within our membership and formed a focus group to help us plan and co-ordinate an exciting event that all members will want to participate in. The focus group will have met by the time you read this newsletter and we will be sharing our plans with you in the next issue.

# Research update

*We would like to thank Richard Bonwick for contributing to 'Research update'. Unfortunately Richard is unable to continue as editor due to other commitments. However, the research updates will remain a regular feature of our newsletter.*

## Hormone replacement therapy

The piece of research that attracted most attention recently was a study which linked hormone replacement therapy (HRT) with oestrogen and progesterin in women over the age of 65 with an increased risk of dementia. Previous studies had suggested that this treatment might have a preventative effect, particularly when given from the time of the menopause. The study was carried out in the USA as part of the Women's Health Initiative, and published in the 28th May issue of the *Journal of the American Medical Association*.

The Alzheimer's Association (USA) Medical and Scientific Advisory Council pointed out that the risk for each individual was very small. Age is the greatest risk factor for dementia. In the general population, an individual's risk of developing dementia doubles approximately every five years after age 65. The data from this study suggests that a 65-year-old woman taking the therapy has roughly the same risk profile for dementia as a 70-year-old woman not taking the drug.

The advice is that older, post-menopausal women should not take hormone replacement therapy involving a combination of oestrogen plus progesterin to prevent or reduce risk of dementia. Women with symptoms of menopause

should consider the relative benefits and risks of hormone replacement therapy in consultation with their doctors but might note that the study involved women 65 years and older. There has been no prospective trial to demonstrate whether HRT is a risk factor for dementia if given at menopause. A trial involving oestrogen only therapy is continuing, and more research is needed to help evaluate the long term effects of HRT.

[http://www.alzheimers.org.uk/Research/Research\\_in\\_the\\_news/030528HRT.htm](http://www.alzheimers.org.uk/Research/Research_in_the_news/030528HRT.htm)

<http://www.alz.org/whatsnew/hormonetherapy.htm>

## Nicotine

Researchers at the Scripps Research Institute in California, USA have discovered that a by-product of nicotine, called nornicotine, appears to prevent the abnormal build-up of amyloid protein plaques associated with Alzheimer's disease. Nornicotine is involved in a reaction between sugars and proteins called glycation. In tests, the presence of nornicotine and glucose alongside amyloid beta proteins appeared to prevent the formation of plaques.

But nornicotine-based glycation is believed to be harmful to the body. Experts stressed that people should not smoke in order to protect themselves against the disease, but said that this could be a starting point for future research. Researchers could now try to find related compounds that mimic the action of nornicotine, but which are not harmful.

[http://www.alzheimers.org.uk/Research/Research\\_in\\_the\\_news/030617nicotine.htm](http://www.alzheimers.org.uk/Research/Research_in_the_news/030617nicotine.htm)

## Alzheimer's vaccine

Preliminary data in an 'Alzheimer vaccine' trial in Switzerland suggests the possibility of a therapeutic vaccine for Alzheimer's disease. These results, published in *Neuron*, Vol 38, May 2003



([www.neuron.org](http://www.neuron.org)) are only from a small subset of volunteers in the study, which was conducted at multiple sites in Europe and North America. The study was stopped early after some participants developed a dangerous brain inflammation.

The researchers scored participants on the Mini Mental State Examination (MMSE), a 30-point test commonly used to assess cognitive function. Investigators also measured before-and-after levels of antibodies to beta-amyloid, which is associated with Alzheimer's disease, in blood or spinal fluid. They found that the decline in the MMSE scores of the individuals who developed anti-amyloid antibodies was significantly less than the decline in the individuals who did not develop the antibodies. Great caution is needed at this stage, but if these results were confirmed by the report on the entire study, it would be powerful evidence that the vaccine had a real effect on Alzheimer's disease in these people.

<http://www.alz.org/whatsnew/052203vaccine.htm>

[http://www.alzheimers.org.uk/Research/Research\\_in\\_the\\_news/030521vaccine.htm](http://www.alzheimers.org.uk/Research/Research_in_the_news/030521vaccine.htm)

**World Alzheimer's Day™ 2003**

# In perfect partnership

*In perfect partnership* is the slogan for World Alzheimer's Day™ 2003. The campaign encourages people with dementia and their carers to take an active role in their healthcare by developing a good relationship with their doctor, nurse or specialist – in other words the person they receive their healthcare from. Research has shown that people who prepare for their visit to the doctor and take an active role in their treatment receive a higher quality of healthcare than those who do not.

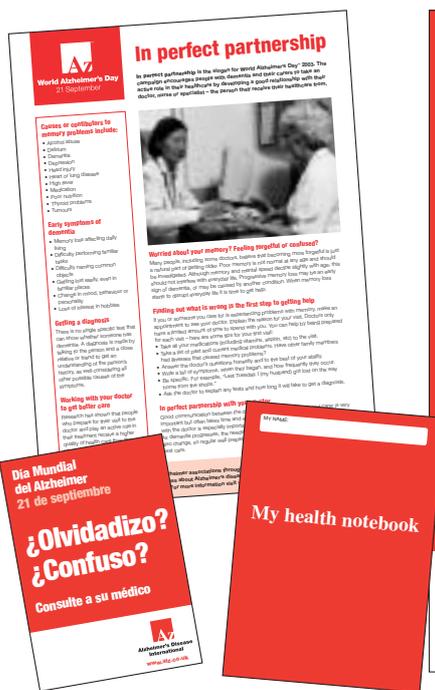
ADI has produced a leaflet to support the campaign which includes tips on:

- Preparing for your visit to the doctor if you are worried about memory problems and getting a diagnosis
- Getting the most from each follow-up visit to the doctor
- Questions to ask your doctor
- Getting further help

The leaflet also has a simple self-assessment quiz where you can evaluate how active a role you take in your own healthcare.

In addition, ADI has produced a pocket-sized notebook encouraging people with dementia and their carers to keep track of changes in their behaviour and/or medication since their previous visit, identify three top concerns to discuss with their doctor and to make notes during their clinic visit.

*Materials for World Alzheimer's Day™ are now available at [www.alz.co.uk/wad](http://www.alz.co.uk/wad) free of charge.*



**World Alzheimer's Day**  
**21 September**

# Forgetful? Confused?

**See your doctor or nurse**

Ask your local Alzheimer association for help—

**Alzheimer's Disease International**  
[www.alz.co.uk](http://www.alz.co.uk)

World Alzheimer's Day™ is observed by Alzheimer associations throughout the world on 21 September each year. The purpose of the day is to raise awareness about Alzheimer's disease and dementia, and promote the work of Alzheimer associations around the world.

If you are planning an event on World Alzheimer's Day™, why not register your details on our website [www.alz.co.uk/wad](http://www.alz.co.uk/wad)?

## 19th International Conference of Alzheimer's Disease International

# Discovering dementia

**15 – 18 October 2003**

**Hotel Coral Hamaca by Hilton  
Boca Chica  
Dominican Republic**

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