



Global Perspective

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

No time to lose

World Alzheimer's Day™ 2004

ADI launched its plans for World Alzheimer's Day 2004 during the annual general meeting in the Dominican Republic. The campaign 'No time to lose' is an urgent reminder to everyone in the dementia field that there is no time to lose as the numbers of people with dementia around the world rise dramatically.

The campaign aims to put dementia on everyone's agenda by calling people with dementia and their families, medical professionals, Alzheimer associations and governments into action.

Central to the campaign is the involvement of people with dementia. ADI is encouraging Alzheimer associations to organise an event on World Alzheimer's Day, in either their capital or a symbolic city in their country, at which there will be a significant gathering of people with dementia and their families.

Participating in the campaign will bring numerous benefits to associations – not least being part of a truly global celebration and demonstrating global solidarity as ADI celebrates its 20th anniversary. ADI will provide free materials to each participating member in their country's official language. 'No time to lose' has been designed so it can be implemented at global, national and local levels, ensuring that each association maximises its efforts by addressing the specific challenges it faces.

Visit www.alz.co.uk for more information and find out how you can get involved.

19th annual conference of Alzheimer's Disease International Discovering dementia



LEFT TO RIGHT: Henry Brodaty, ADI chairman, Milagros Ortiz Bosh, vice president of the Dominican Republic, Daisy Acosta, conference chairman and Magdalena Frias, Asociacion Dominicana Alzheimer president at the opening ceremony of ADI's 19th annual conference

Some 500 years after Christopher Columbus discovered the New World when he arrived in the Dominican Republic, ADI has been 'discovering dementia' at its 19th annual conference, hosted by the Asociacion Dominicana Alzheimer.

Participants were welcomed to the conference by Milagros Ortiz Bosh, vice president of the Dominican Republic. The opening ceremony explored the concept of journeys. Roberto Garcia from Mexico took us through a journey of discoveries, reminding each of us that the work we do 'deals with one of the most important health issues of our time and we have to discover the best way to address it together'. Richard Mayeux went on to describe the genetic study of

familial Alzheimer's disease amongst Caribbean Hispanic families in the Dominican Republic. The session ended with Nori Graham taking participants through the journey of some people whose lives have been touched by dementia, demonstrating the similarities in experiences across countries and cultures.

See page 8 for a full report.

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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 February 2004**.

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ANNOUNCEMENTS & CONFERENCES

2004

25-28 March
IV Latin American forum on dementia & Alzheimer's disease
International workshop on caregiver's health
Havana, Cuba
Email: eventos@capitolio.cu

14-17 April
8th International Springfield Symposium on Advances in Alzheimer Therapy
Montreal, Canada
Phone: +1 217 545 7711
Fax: +1 217 545 4413
Email: ahamilton@siumed.edu
Web: www.siuemed.edu/cme

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@alzheimers.ca
Web: www.alzheimer.ca

20-23 May
14th conference of Alzheimer Europe
Prague, Czech Republic
Tel.: +420 239 041 661
Fax: +420 239 041 663
Email: info@alzheimereurope.org
Web: 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
Web: www.ipa-online.org

17-22 July
9th International Conference on Alzheimer's Disease & Related Disorders
presented by the Alzheimer's Association
Philadelphia, USA
Email: internationalconference@alz.org
Web: www.alz.org/internationalconference/

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@alzheimers.or.jp
Web: adi2004.jtbcom.co.jp/english/

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



Elizabeth Rimmer
Executive Director

Editorial

'There are lots more smiles per minute in groups of people who are connected to their Alzheimer association' Paul Bryden, Australia, said this during the quality of life workshop held in Santo Domingo at our conference last month. Paul's wife, Christine, has dementia and has just been elected to the executive committee of ADI. Paul has got to the heart of what ADI and our movement is all about, improving the quality of life of people with dementia and their families. Sure, its not all smiles caring for someone with dementia or having dementia, but making links with others to share your experiences and having access to information about dementia are powerful tools for living with dementia.

The quality of life workshop brought ADI alive for me. People with dementia

and carers from Aruba, Canada, Australia, India, Surinam, Lebanon, Scotland, Dominican Republic and Puerto Rico all shared their personal experiences of dementia. It was moving and inspirational. The gentleman from Aruba was motivated to set up an Alzheimer association through his experience of caring for his wife and expressed how his role as the 'macho man' had changed to carer. The daughter living in the Netherlands, sharing her frustration and guilt from trying to support her father who is caring for her mother in Surinam. A husband and wife from Scotland sharing their experience of his early diagnosis and what this has meant to them and their children living at home.

Listening to people speaking during this session was a powerful reminder that ADI really does bring the world of dementia together and what a privilege it is to be part of it.



Carer's story

By Sander van den Ende from the Netherlands

Everyone noticed that our grandmother was becoming more and more forgetful. It began with names and activities she had just done. Then she started to wander off, leaving the house where she was living with my grandfather and unable to find her way back. After finding her about to use plastic pans on the stove, the family decided my grandparents could not live on their own anymore, so they moved to a house for the elderly.

It was around this time that I moved to Valencia in Spain to study for six months. When I returned to the Netherlands, I was keen to catch up with all my family and friends and went to see my grandparents in their new home.

My grandmother had been transferred to a different part of the home from my grandfather, where she could not wander off or hurt herself. My grandfather and I went to visit her and as we arrived in her section, my grandfather had to discuss some issues with one of the nurses but showed me where I could find my grandmother. So I walked up and greeted her full of enthusiasm and happiness.

No one had prepared me for how much 'worse' she had become. She did not recognise me at all. She told me to please go away, because she did not know who I was and she was very afraid of me. I had not expected this reaction at



Sander van den Ende with his grandparents

all and it affected me dramatically. How could my grandmother not recognise me? Completely confused, I went to my grandfather and broke down in tears.

Now four years later, I still have trouble seeing my grandmother in the state she is in. I feel so angry, confused, powerless and upset. I wish I could do something, tell her something and discuss what happened that day and how that upset feeling is still there, but I cannot.

These experiences made me want to raise money for an organisation like Alzheimer Disease International to assist in further research and help those affected. I therefore decided to participate in a triathlon, which consisted of a consecutive

1.5km swim, a 40km bike ride and a 10km run. I asked my friends, work colleagues and company to sponsor me to complete in the triathlon. I received a lot of positive reactions and trained hard.

On the day of the triathlon I was very eager to succeed and felt supported by the many generous 'gifts' I had received. It was my first triathlon and it was hard at times, but I feel it was very successful. I finished in 2 hours and 59 minutes.

In total I have raised £900 for ADI, which makes me very proud. I would like to encourage other people that are affected by the disease to arrange similar sorts of events – and to be amazed how generously people will sponsor them.

Members' forum

Congratulations to the Indonesian Alzheimer Association and Demensforbundet I Nasjonalforeningen for Folkehelsen in Norway who were accepted as provisional members of ADI at the annual general meeting in October. This takes our membership to 66 countries – an achievement we are proud of as we approach our 20th anniversary.

ISRAEL

Alzheimer's guide dogs

An initiative using guide dogs for people with Alzheimer's disease has been pioneered by Yariv Ben-Yosef from the Service and Therapy Dogs centre in collaboration with the Alzheimer's Association of Israel. Yariv, a professional dog trainer, has successfully trained a collie to help Yehuda, a 62-year old man who has Alzheimer's disease, home if he gets disorientated. On command, the dog leads the man safely back to his house avoiding obstacles. The dog has also been trained to recognise breathing distress and falls, and responds to these by activating a distress button.

Yehuda says, 'the dog has given me a quality of life by releasing me from the prison wall of my own home. This is the best thing that has happened to me.'

Yariv plans to train about 30 dogs a year for people in the early stages of the disease and hopes the idea will be adopted around the world.

For more information about the project, contact the Alzheimer's Association of Israel misrad@alz-il.net or visit www.dservicedogs.com

LATIN AMERICA

Alzheimer Ibero América

ADI is delighted to announce the founding of Alzheimer Ibero América (AIB) – a formal regional network of 17 Alzheimer associations in Latin America. The group was launched in Caracas, Venezuela in early October, declaring that 'we cannot do it alone, but together we will succeed'.

The region hope that the establishment of AIB will allow them to overcome some of the financial difficulties facing their individual association by being eligible for funds set aside for regional-based work. They also hope that the creation of this regional network will strengthen

their links with each other by opening up more channels of communication and facilitating the sharing of best practice.

ADI wishes AIB the very best of luck and looks forward to working together so as to improve the life of people with dementia and their carers in Latin America.

Representatives from the Latin American Alzheimer Ibero América group



Research update

Oily fish may help

A report in the July issue of *Archives of Neurology* stated that weekly consumption of fish may reduce the risk of developing Alzheimer's disease.

The researchers, from Rush-Presbyterian St. Luke's Medical Center, Chicago, collected information about diet, including intake of omega-3 fatty acids, from 815 people selected at random for the prospective study.

Docosahexaenoic acid (DHA), one of these fatty acids, is an important component of fat molecules in brain cell membranes. The body also uses two other n-3 fatty acids to produce DHA: eicosapentaenoic acid (EPA) and alpha-linolenic acid. Fish is a direct source of DHA, which was associated with a reduced risk of developing Alzheimer's disease.

Alpha-linolenic acid, which is found in vegetable oils and nuts, was associated with a moderately reduced risk in some people. The Alzheimer's Association (US) commented, 'These findings are consistent with a growing body of evidence that what is good for your heart is good for your head.'

<http://archneur.ama-assn.org/cgi/content/abstract/60/7/940>

http://www.alzheimers.org.uk/Research/Research_in_the_news/030722fishoil.htm

<http://www.alz.org/WhatsNew/072103fish.htm>

Alzheimer's and obesity

Being overweight is a risk factor for dementia – particularly Alzheimer's disease – in older women, according to research by Ingmar Skoog and Deborah Gustafson which was published in the 15th July issue of the *Archives of Internal Medicine*.

In a retrospective association study, the researchers studied a

representative sample of 70-year-old residents of Göteborg, Sweden, over periods of up to 18 years to assess the possible impact of weight as a risk factor for dementia. They found that women who developed Alzheimer's disease between the ages of 79 and 88 were more likely to have been significantly overweight at ages 70, 75, and 79 than those who did not develop dementia.

This study did not find a connection between obesity and dementia in men. The researchers noted that a possible explanation for this might be that fewer men survived for the entire span of the study, and since the likelihood of developing dementia increases with advancing age, fewer men developed dementia.

This new link fits in with other risk factors for dementia such as high blood pressure and high blood cholesterol, which are also associated with being overweight.

<http://archinte.ama-assn.org/cgi/content/abstract/163/13/1524>

<http://www.alz.org/WhatsNew/071403obesity.htm>

http://www.alzheimers.org.uk/Research/Research_in_the_news/030714obesity.htm

Caregiver-supervised exercise benefits people with Alzheimer's disease

Exercise training, combined with teaching caregivers behavioural management techniques, can improve physical health and depression in people with Alzheimer's disease, according to a study published in the October 15 issue of *The Journal of the American Medical Association*.

The study enrolled 153 individuals with Alzheimer's disease aged 55 to 93 years old along with their caregivers, whose age ranged



Diet appears to affect the risk of developing Alzheimer's disease

from 24 to 91. Half of the participants were randomly assigned to an integrated exercise and behaviour management program and the others received routine medical care.

Caregivers in the integrated program were taught aerobic activities as well as balance, strength, and flexibility exercises. They were also coached on handling distress, behaviour problems and conflicts. Individuals with Alzheimer's disease whose caregivers received this training increased their physical activity, experienced less depression, and improved their health and function compared with those in the routine care group.

Linda Teri, lead author of the study explained 'Earlier studies showed that for individuals in nursing homes, professionally led exercise programs may improve physical function even for some of the frailest residents. Our research is the first to extend those findings to community-residing individuals with Alzheimer's disease exercising under the supervision of their caregivers and to document an emotional as well as a physical benefit for this group.'

<http://jama.ama-assn.org/cgi/content/abstract/290/15/2015>

<http://www.alz.org/WhatsNew/101503exercise.htm>

Living with dementia

Congratulations to Christine Bryden, who has been elected onto ADI's executive committee. Christine is ADI's first board member with dementia. Her appointment comes at the end of a two-year consultative process co-ordinated by ADI to encourage Alzheimer associations to be more inclusive of people with dementia.

The factsheet *How to include people with dementia in the activities of Alzheimer associations* is available from ADI and can be downloaded at www.alz.co.uk/publications



Christine Bryden with Dr Prasad Punnoose in Cochin, India after her talk

Sharing my experience with Alzheimer associations around the world

On her way to ADI's conference in the Dominican Republic, Christine Bryden and her husband Paul visited Alzheimer associations in India, Israel, South Africa, France and Brazil. Below, Christine summarises her trip.

India

We were warmly welcomed to India. We visited the day care centre in Cochin and participated in a press conference in Goa – resulting in dementia making the headlines for the first time in Goa! Materials from ADI's World Alzheimer's Day campaign *In perfect partnership* were distributed along with specific information for Goa, and the result was great!

My overall impressions of India were of energy, commitment, person-centred care – yet huge challenges. People are cared for in their homes by family members. But changes in Indian society mean that the traditional values of close family support and caring for elders are breaking down. And the society is ageing as general health and nutrition are improving. India will need the support and encouragement of all of us involved in the world Alzheimer's movement to meet the challenges it faces.

Israel

Israel was a contrast. The population is older, yet for many families the needs of people with dementia can be met by home care (in particular from Phillipine maids). The challenge will be to train these workers in dementia care. Another major issue debated at the Association's conference was whether to tell people the diagnosis or not. For me it is important to tell us, so we can have that relief to know why we feel this way, and then make the decisions necessary to live a new life in the slow lane. But in Israel most people are not told the diagnosis.

South Africa

In South Africa we participated in the association's national conference, where I managed a few words in Afrikaans. Again, materials from ADI were used and formed a great resource as part of national activities. There were no people with dementia thought to be there but after the conference a

person spoke to the association's former chairman and told him he had recently been diagnosed. I do hope that this man will be encouraged to participate in South Africa's future activities. At the AGM, the decision was made to change the association's name to Alzheimer's South Africa, and to closely identify itself with ADI through changing its logo.

France

Over to France where I had the opportunity to share views with French health ministry officials and other Alzheimer groups. A key issue for France is the stigma surrounding dementia. In fact a person with dementia from Dementia Advocacy and Support Network (DASNI) had been invited to attend but his family would not allow him to identify himself this openly as a person with dementia! I was able to draw attention to the question about undiagnosed dementia. Health officials were very interested to learn about the Alzheimer's Australia study into the future economic impact of dementia. France has many similarities to Australia, including an ageing population, shrinking tax

base and the availability of day and residential care, but high costs of home care unless provided for by families.

Brazil

My visit to Brazil was organised with Judy Robbe, a friend I had met through DASNI who runs a day care centre and a monthly carers support group. Like Israel, middle class India, and white South Africa, home care is readily available at a reasonable cost.

Dominican Republic

We then went to the ADI conference in Santo Domingo. There were several people with dementia there, from Puerto Rico, Scotland and Canada. We were encouraged to participate in sessions, and our views were listened to with great interest. We heard about ADI's plans to include people with dementia in next year's World Alzheimer's Day campaign *No time to lose*. I was greatly honoured to be elected to ADI's executive committee, and will do my best over the next three years to work with ADI and its members to achieve greater participation and influence by people with dementia on policy and programs in all member countries. DASNI has certainly achieved a great deal since its start as the *Coping With Personal Memory Loss* email group, and ADI deserves accolades for its recognition and acceptance of the value of listening to and including people with dementia.

Montessori meets dementia care

Most of us are well aware that maintaining a basic level of physical fitness can contribute to a better quality of life. Now, more and more studies are demonstrating that the mind also benefits from exercise and that repetition of tasks strengthens mental muscle.

Skills learned through repetitive muscle use are known as procedural memory. It is procedural memory that helps a person remember all their lives how to ride a bike or how to tie their shoes. This type of memory function has been studied extensively at the Myers Research Institute, USA, where a research team have completed a six-year longitudinal study which suggests that skills learned through muscle movement are accessible even when short term memory falters.

The study's program, which was designed to stimulate the brain, was based on principles first created by Dr Maria Montessori, an Italian physician and educator. Montessori-based activities, originally designed to teach children through procedural learning techniques, have now been adapted by the research team to help adults maintain skills that enhance their quality of life; reading, range of motion, care of self, care of environment. These Montessori-based activities are designed to be purposeful and well-ordered, and concentrate on one skill at a time. The activities cover different aspects of life from polishing silver to arranging flowers to sorting fishing hooks.

Perhaps the most valuable aspect of the Montessori-based activities is that they are designed to be shared by a person with dementia and their family members. Arranging flowers or sorting out a tackle box can open up conversations that lead to shared memories, allowing caregivers to interact with those they care for in a purposeful way. Montessori-based activities have certainly enhanced the lives of people with dementia and their caregivers at the Myers Research Institute.

For more information about this work contact Tom and Karen Brenner at Bren04@aol.com

Alzheimer's New Zealand virtual march

Frustrated by years of campaigning for the subsidisation of medication for Alzheimer's disease to no avail, Alzheimer's New Zealand have set up a website where interested parties can conduct a 'virtual march' that will be heard by the government and Pharmac (the pharmaceutical management agency which lists approved pharmaceuticals, decides on subsidisation and advises the government).

Visit www.rememberme.org.nz to submit your support.

Discovering dementia

CONTINUED FROM FRONT COVER

Every ADI conference is unique in that it brings researchers and medical professionals, people with dementia and their families, and staff and volunteers from Alzheimer associations from around the world together under one roof to learn from each other's perspectives. And our conference in the Dominican Republic was no exception.

Leading researchers including Ingmar Skoog, Deborah Gustafson and Peter Whitehouse shared the latest thinking about vascular dementia, the link between obesity and Alzheimer's disease (see *Research update* on page 5) and mild cognitive impairment. James McKillop from Scotland and Marilyn Truscott from Canada spoke about the work they are doing with their Alzheimer associations and the changes they have made to their lives since being diagnosed with dementia. Delegates also had the opportunity to learn about the work of Alzheimer associations around the world by visiting their exhibition stands during the ADI showcase. A range of projects were displayed – including information



Members of the Latin American region met the day before the conference and participated in a day of workshops which tackled a range of organisational issues



Wendy Fleming (right), chairman of Alzheimers New Zealand, tells a delegate about the association



Booy Escalona from Aruba and Anneke Matil and Gerda Havertong from Surinam, who are setting up Alzheimer associations in their respective countries

materials, models of best practice and World Alzheimer's Day™ activities. The session on quality of life – now a regular feature at ADI conferences –

explored the relationship between the person with dementia and their carer. Both people with dementia and carers participated in this



Left to right: Jacob Roy (India), Edwin Yu (Hong Kong SAR) and Yoshio Miyake and his wife (Japan) catch up at the welcome reception



James McKillop and his wife Maureen from Scotland talked about their involvement with Alzheimer Scotland since James' diagnosis of dementia



Daisy Acosta, conference chairman, and Helen Regan, ADI administrator, at the gala dinner

interactive session, giving moving accounts of their lives and feelings towards each other before and after a diagnosis of dementia.

The ADI conference has been an opportunity for the 10/66 Dementia Research Group to meet since its foundation in 1998. This year the Group shared with conference delegates news about the next phase of its work – population-based studies of the prevalence and impact of dementia and its risk factors in rural and urban centres in Cuba, Brazil, Dominican Republic, India and China. Lead investigators from each project described their work and the contributions they hope their research will make, which include raising awareness, supporting family caregivers, encouraging and guiding service development, influencing policy and evaluating new interventions.

With about 400 attendees, this year's conference had an intimate feel to it. It was a real opportunity for participants to get to know each other, especially individuals from the Caribbean who are just setting up Alzheimer associations. As one participant said, 'For me the conference was most positive because of its inclusion of younger people with dementia. Very powerful indeed. I've already made use of what I've learned whilst with you – that worldwide perspective is so very helpful. And being in that location with great people from around the world – it's certainly a great way to learn!'

We hope you can join us between 15 and 17 October 2004 for our 20th anniversary conference in Kyoto, Japan. For more information visit <http://adi2004.jtbcom.co.jp/english/>



Sixty-four year old Granny Kay arrives at Parliament House on 21 September with her grandchildren after running 300km from Sydney to Canberra

World Alzheimer's Day™

21 September 2003

The success of World Alzheimer's Day™ continues to grow each year and 2003 was no exception. Forty-five countries around the world organised events which generated national, regional and local media coverage.

The theme 'In Perfect Partnership' drew attention to the importance of people with dementia and their carers forming a good relationship with their doctor and taking an active role in their healthcare. Many associations organised seminars, conferences and public consultations focused on the theme – and appeared on television, ensuring the message was taken to as wide an audience as possible.

A growing feature of World Alzheimer's Day is the participation of Alzheimer associations in a single event that unifies the Alzheimer movement on this international day. This year, 17 associations organised a walk (known as 'Memory Walk') in their country – including Panama, Trinidad and Tobago, Pakistan, Luxembourg, Hong Kong SAR, Turkey, Singapore, Brazil, UK, Belgium, Thailand, Argentina, Taiwan ROC, India, Puerto Rico, Austria and Sri Lanka.

Other events included film screenings, tea and coffee parties, leafleting campaigns, art exhibitions, parliamentary debates, balloon releases and information displays.

The sense of unity and being part of something bigger has been an important component in the successful growth of World Alzheimer's Day. This concept was taken one step further by the German speaking associations in Europe (Germany, Luxembourg, Switzerland, Belgium and Austria) who collaborated on a cross-

ADI participated in Alzheimer Scotland's tea day by having a tea party with work colleagues from Lower Marsh





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border campaign 'Alzheimer's has no frontiers'. Each association organised its own programme of events drawing attention to the impact of dementia in neighbouring German-speaking countries.

Church and religious ministers continue to play an important role in reaching communities with health care messages. In some countries, such as Nigeria, this is the only way of reaching local communities. Other countries including Aruba, Germany, Hungary, Guyana, the Bahamas and Austria worked

closely with the church to prepare special Sunday services.

This is the ninth year ADI has coordinated World Alzheimer's Day and most associations are now enjoying the longer-term benefits of participating in this global awareness-raising day. Impacts include an increase in recognition of Alzheimer's disease as a disease, growth in understanding of what the Alzheimer association is all about, and better recognition and respect from government and media.

- 1 ALMA, Argentina's Alzheimer association, release hundreds of balloons in Buenos Aires
- 2 Over 1000 volunteers participated in leafletting campaigns in 60 cities throughout Japan
- 3 The Lambeth branch of the Alzheimer's Society walked along the River Thames for their first Memory Walk, stopping to admire the view of the Houses of Parliament
- 4 Members of the Alzheimer's Association of Guyana attended a church service in the country's largest Catholic church
- 5 People with dementia and their families, politicians and health workers all joined the picnic organised by the Polish Alzheimer's Association
- 6 Lanka Alzheimer's Foundation gained huge media coverage for their second Memory Walk by inviting Sri Lankan international cricketers Sanath Jayasuriya and Kumar Sangakkara



- 7 Some 500 people walked 3km through the streets in Bangkok attracting great media interest and raising the profile of the Alzheimer association
- 8 About 2500 people participated in Singapore's Memory Walk. Several fringe activities were provided making it a family day out
- 9 Volunteers at the maze in the Cape Town Flower Show, which was developed by the Western Cape region of Alzheimer's South Africa. Over 10,000 people walked through the maze, which creatively raised awareness about dementia and the association



Putting theory into practice

ADI follows progress of Alzheimer University participants

Earlier this year, ADI ran its first Alzheimer University training programme for established Alzheimer associations. Sixteen participants from 12 member associations (mainly from Europe) participated in the training. The focus was on leadership and covered topics such as strategic planning, internal communications, the board, how to be an effective leader and team building.

At the end of the training, each participant set three objectives for the coming year. As part of ADI's commitment to strengthening the work of our members, we have

followed participants' progress – finding out what challenges they have faced and what difference participating has made to their association.

Benefiting associations

Each person gained something positive out of attending and in many cases this has already made a tangible difference within their association. In particular, many participants felt that the 'group work was invaluable – especially learning about how other associations do things'.

One participant said, 'the training has given me energy, knowledge, skills and meaning. I hope other members of the board will become infected with my enthusiasm.' Another said, 'it has helped me identify the strengths and weaknesses in my association, enabling me to try and change certain situations.'

Facing challenges

Reflecting on the challenges they faced in implementing their objectives, there was one challenge common to a greater or lesser extent to most participants – the board not recognising the need for change. One participant described her experience of training as 'bittersweet' in that 'I thought I could change our *modus operandi* but it's going to be a slower process than I expected.'

Two participants' perspectives demonstrating the value of such training

Anne Ogg SOUTH AFRICA

Anne was determined to share her experiences with the board in Alzheimer's South Africa and the staff based in her region.

Attending the Alzheimer University was very helpful in orientating two new employees in the KwaZulu Natal region. All the workshops were useful, especially those on strategic planning and leadership.

I have also recently been appointed president of our association. Taking on this role is a huge personal challenge. To do so without having attended the Alzheimer University would have been well nigh impossible. I know that during my term of office I will be able to use the knowledge I gained. The literature we received and the further reading I have done is going to be a great source of support and assistance. I hope that Alzheimer's South Africa will equally gain by my greater knowledge and ability.

I gained a great deal from the training. Quite apart from the



Silvia Olza, Anne Ogg and Elizabeth Rimmer

workshops, spending quality time with people from so many different countries, all involved with dementia associations and all facing the same problems as us, was a new and very valuable experience for me. I hope that in the future, more people will be able to share such an experience.

Eugen Stefanut ROMANIA

Eugen's objectives were to revitalise the board, to clarify their responsibilities, and to evaluate and change the association's strategy, if necessary.

Since returning home, we have managed to replace three board members and worked towards

changing the statute of our organisation so as to meet legal changes in Romania. It was quite hard to convince the board members of the necessity of having clear and focused responsibilities. After eventually agreeing, each person was given a written list of their responsibilities – this immediately made our board meetings more fun!

Reviewing our strategy, the board came to the conclusion that it needed dramatic change. It is important and more efficient to run programs based on training and providing information. We have signed partnerships with local authorities to develop services such as day centres and counselling in collaboration with them. We have also signed a protocol with the police for a safe return program, which we are piloting in Bucharest.

This has been the most important event of the year for me. Not only has it crystallised the importance of good leadership, it allowed me the opportunity of meeting and sharing knowledge with other Alzheimer associations.