



**Alzheimer's Disease
International**

25 YEARS 1984-2009

December 2009
Volume 19 No.3

Global Perspective

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

World Alzheimer's Day 2009

A young advocate helps to raise awareness of dementia in Goa, India



World Alzheimer's Day is the only day on the calendar that unites members of the global dementia movement across all regions and countries of the world, and 2009 was no exception. ADI member associations marked the day with a broad range of activities from colourful and creative to informative and campaign-driven.

Conferences, public forums, exhibitions, memory walks and training sessions were just some of the events organised by members to raise awareness of dementia and to encourage members of the public, medical professionals, and governments to work together to improve recognition and diagnosis. ADI provided posters, bulletins,

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25th International Conference of ADI

Less than three months remain until ADI's 25th International Conference in Thessaloniki, Greece from 10-13 March 2010! The event promises to be a dynamic and enlightening meeting with representatives from across the world joining to discuss a variety of topics under the theme of 'Dementia: Making a difference'.

The conference will feature informative sessions on recent developments in the care and treatment of dementia, while offering lively discussion on the global Alzheimer's movement. The event

is designed to be both enjoyable and informative for all, offering participants the chance to share their experiences of the disease, gather more knowledge and make new connections with others from across the world.

The ancient city of Thessaloniki, the second largest city in Greece, is filled with historic monuments, archaeological sites dating back to prehistoric times and museums celebrating a variety of aspects of the city's rich history. We are sure this interesting and beautiful location

will complement your experience of what promises to be an equally impressive event.

You can register for the conference at www.adi2010.org. Early bird registration ends on 31 December 2009 and online registration closes on 3 March 2010.

ADI and the Greek Association of Alzheimer's Disease and Related Disorders hope you will join us in continuing to make this conference an inspiring and successful event. We look forward to seeing you there!



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 for the next issue of Global Perspective to arrive by 31 January 2010.

Secretariat

Alzheimer's Disease International
64 Great Suffolk Street
London
SE1 0BL
Tel: +44 (0)20 7981 0880
Fax: +44 (0)20 7928 2357
Email: info@alz.co.uk
Web: www.alz.co.uk

Seasons greetings from ADI

ADI would like to wish all of our members, associates and friends in the dementia movement all the best for the season and the New Year, whatever and whenever you are celebrating. Thank you all for making 2009 such a successful and enjoyable year and we look forward to continuing our hard work together in 2010.

Editorial



Marc Wortmann
Executive Director

It has been a busy and successful year for ADI. It was our first year with three Alzheimer University programmes; we had an excellent conference in Singapore; the launch of the World Alzheimer Report 2009 made World Alzheimer's Day even more exciting than in previous years; many new Board members were elected and are already very much engaged; and finally we had a stable financial year, which made life a lot easier.

In this issue of Global Perspective you will see reports on these activities and from the regional conferences in the Latin America and Asia-Pacific regions. It continues to show how many people from different backgrounds and perspectives are working towards the same goal. It also shows how we can support and encourage each other by exchanging information and knowledge.

We also conclude our look back into the history of Alzheimer's Disease International. Early next year we will launch a publication, which will look at the first 25 years of ADI.

I would like to thank everyone who supported ADI this year for their efforts, warm contact and friendship. We all share a passion for improving the lives of people with dementia and their families worldwide. I hope to meet you all in Thessaloniki in March 2010. Let's keep moving towards our vision of an improved quality of life for people with dementia and their carers!

Events

2010

10 – 13 March 2010
25th Annual International Conference of Alzheimer's Disease International
Dementia: Making A Difference
Thessaloniki, Greece
Tel: +44 870 458 4171
Fax: +44 870 442 9940
Email: adi2010@mci-group.com
Web: www.adi2010.org

24 – 27 March 2010
11th International Geneva/Springfield Symposium on Advances in Alzheimer Therapy
Geneva, Switzerland
Tel: +1 217 545 7711
Fax: +1 217 545 4413
Email: ahamilton@siumed.edu
Web: www.ad-springfield.com

10 – 15 July 2010
Alzheimer's Association International Conference on Alzheimer's Disease
Honolulu, Hawaii
Tel: +1 312 335 5790
Fax: +1 312 604 7837
Email: icad@alz.org
Web: www.alz.org/icad

22 – 25 September 2010
5th Croatian Congress on Alzheimer's Disease
Zadar, Croatia
Tel: +385 1 6110 449
Fax: +385 1 6110 452
Email: congress@studiohrg.hr
Web: www.alzheimer2010.com

30 September – 2 October 2010
20th Alzheimer Europe Conference
Luxembourg
Email: info@alzheimer-europe.org
Web: www.alzheimer-europe.org/conferences

21 – 23 October 2010
IV Congreso Iberoamericano sobre la enfermedad de Alzheimer y IV Congreso Nacional de Alzheimer
Seville, Spain
Web: www.congresonacionaldealzheimer.org

22 – 24 October 2010
13th Asia-Pacific Regional Meeting of Alzheimer's Disease International
Kuala Lumpur, Malaysia
Tel: +603 7956 2008
Fax: +603 7960 8482
Email: adfmsec@streamyx.com
Web: www.alz2010.org

2011

26 – 29 March 2011
26th Annual International Conference of Alzheimer's Disease International
Toronto, Canada
Tel: +44 870 458 4171
Fax: +44 870 442 9940
Email: adi2011@mci-group.com
Web: www.adi2011.org



Alzheimer's, the disease of love

Virginia García de Avilés
President of the Honduran Alzheimer Association, Honduras

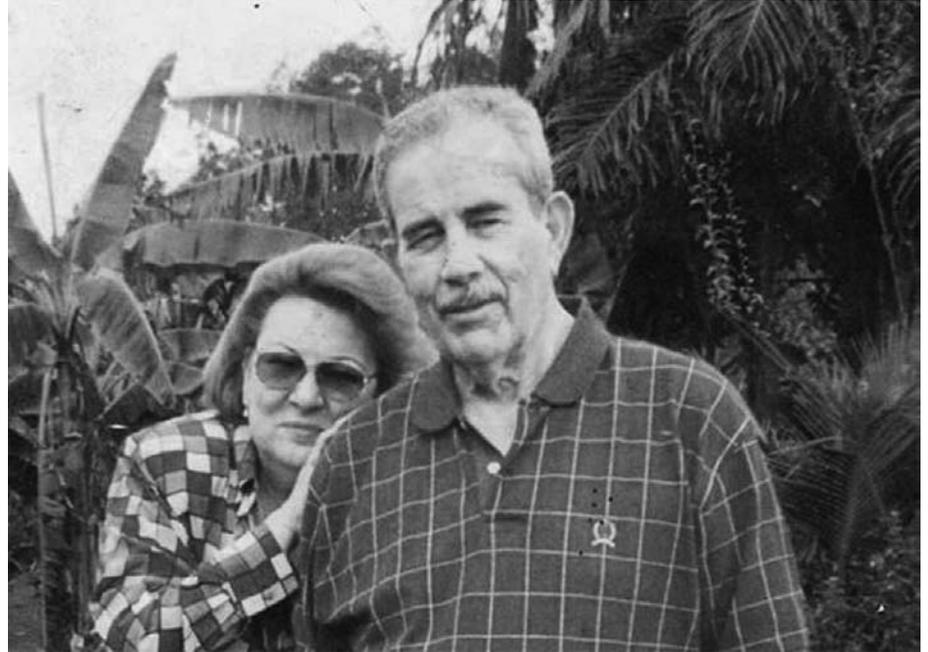
My husband Roberto died two years ago after ten years with Alzheimer's. Ten years lived as a sad, but very beautiful love story.

At the Honduran Alzheimer Association we call this disorder 'the Disease of Love'. Why? Every person needs love, and a bunch of it, but particularly the person with Alzheimer's disease. He or she needs to be loved and accepted in spite of his or her limitations and the gradual loss of intellectual capacity. This is a very dramatic process for the person, and as carers we should support them, make them happy, give quality to their life. To achieve this we need to surround them with LOVE.

Anybody could argue that he does not feel love. I believe this not to be true, even though I cannot prove it scientifically. I experienced that the last type of memory Roberto lost was his emotional memory, and he felt my love until the moment of his death.

Only with the help of God and with the goal of making our loved one happy can we find the strength to smile in spite of the pain in our hearts, as we see the person losing himself and going away like a lighted candle.

When the diagnosis of Alzheimer's disease was confirmed, I knew that not only Roberto's life was going to change, but mine and that of my children too. I asked God to illuminate our path as to what to do and I felt it was necessary to quit my full time job. I wanted to be a full time caregiver. In my prayers I also asked God to help me love Roberto more than before (if that could be possible), since my love had to be



Virginia with Don Roberto in 2000, after his diagnosis

endless, strong enough for anything to come.

Another important decision I took was to know more about this disease. I searched for information. We arranged family meetings with our neurologist to know more about what to expect and be prepared. We never tried to look away from this reality. We told all of our friends and relatives what was going on, and it turned out we had them near at every moment, especially in the most difficult.

Roberto participated in our family and social life as long as he could. We shared many beautiful moments during his illness: we listened to music, we danced, I read to him, I sang poetry, I chatted about events happening in our lives, we saw family pictures and videos.

We always treated him with respect and consideration, as is the right of any human being, and we filled him with tenderness and love, since he was so special to us, because we loved him and still do.

Something that helped me very much during that time in my life was the Honduran Alzheimer Association, where I learned more about the disease, where I could exchange experiences with other carers and we could mutually support each other, but above all to feel the company of others living through the same experience. As we say: we are not alone.

My husband does not suffer from Alzheimer's disease any more, and is enjoying the glory of God. I am still very much involved with the association as there are many families that are suffering as we did and need our support, especially in my country where resources are scarce. I consider it a way to serve my husband during his absence, and I honour him every time I help a family affected by Alzheimer's.

Finally, I would like to share with you the belief that everything I experienced with Roberto has made me a better human being, more aware of the pain in other people's lives. I thank God for this every day.

Members' forum

ADI members: do you have any news you would like to share with the global dementia community? Please contact us

CZECH REPUBLIC

Children's book teaches about memory loss

A story book that offers children an accessible way into understanding the symptoms and development of dementia was launched on 1 October 2009 by the Czech Alzheimer Society and the American Embassy.

'The Magic Tape Recorder' was first published in the US in 2007 and was translated in Czech by the Society at the beginning of 2009. The original publication was written by American author Joyce Simard and illustrated by Inka Delevová, a Czech artist.

The translation of the book is part of a programme aimed at educating elementary school children in the Czech Republic about disabilities relating to ageing. The book uses toys and stories to help children understand why memory loss occurs.

Iva Holmerova, president of the Czech Alzheimer Society, commented: 'The Magic Tape Recorder helps children not to be frightened of someone with a memory problem but explains how they can be "helpers". It explains how they can continue to have a happy relationship with grandparents in spite of their memory loss.'

This programme, which has already proven effective in the US, was presented to an international group of children at the Prague British School Vlastina on 6 October. The Czech translation of the book can be purchased from the Czech Alzheimer Society, www.alzheimer.cz.



NEW ZEALAND

Dementia exposed in rural New Zealand

What started as a chance comment made at a support group became a project that energized a rural community in the heartland of New Zealand. The 2010 Forget-me-not calendar, produced in the 'Calendar Girls' style and intended as a fundraiser, has captured the imagination of people across New Zealand and will be displayed in various homes and locations around the world including the House of Lords and the Globe Theatre in London.

The calendar, produced by Alzheimers New Zealand's member association in Otago, features men and women of different ages, backgrounds, and stages of life who have all, in some way, been touched by dementia. Photos were taken in snow, rain and very cold temperatures in significant places across the region and include climbing from a World War 1 tank, riding a Harley Davidson and laughing amongst the flowers.

'One of the most exciting things to come from this is that people are talking about dementia and in such a positive way', says carer Sue

One of the pictures used in the calendar produced by Alzheimers New Zealand Otago

Noble-Adams, calendar photographer and Mrs May. 'Referrals to the Alzheimers Society have surged as families are more comfortable coming forward. This is of special relevance as this is a small community where notoriety can be hard to live down'.

The interest of local and national media in various forms has given Alzheimer's disease a huge boost in terms of raising the profile and awareness of both the disease and the support that Alzheimer's societies across New Zealand can give to families.

SINGAPORE

ADA open new day care centre in shopping mall

On 25 July the Alzheimer's Disease Association in Singapore opened their fourth New Horizon Centre for people with early stage and younger onset dementia. The centre was officially opened by Mr Lim Boon Heng, Singapore's minister-in-charge of Ageing Issues, and is the first day care facility in Singapore to be located in a shopping mall.

The centre features an activity hall, library and computer room, arts and games room and a multi-sensory

room. Staff at the centre adopt a person-centred care approach and offer face-to-face counselling, training and support. At the centre people with dementia are encouraged to partake in a range of activities including daily exercises,

reminiscence sessions, group games and use of a computer. The location of the centre also allows for therapeutic activities such as grocery shopping, going to the cinema, window-shopping and visiting food and beverage outlets.

ADA opened the first of their New Horizon Centres in 1990 with the aim of providing continued care in a 'home-like' setting. More information about the centres can be found at www.alzheimers.org.sg/facilities_nhc.htm

REGIONAL MEETINGS

ASIA PACIFIC



Yasmin Raashid of Alzheimer's Pakistan welcomed attendants to the Asia Pacific regional conference in Lahore

The 12th Asia Pacific regional meeting took place in November in Lahore, the city often referred to as 'the cultural heart of Pakistan'. Among the topics under discussion were the regional rotation of future Asia Pacific meetings and the region's newsletter. A representative from each association was given time to inform their peers of the progress made in their country over the previous year.

Attendance at the regional conference was higher than anticipated and two training sessions were held in the lead-up

to the conference. Anne Deck and Sheila Hayward from Alzheimer's Australia WA coordinated the first of these aimed at carers while the second, a well-attended workshop for GPs, offered information on various aspects of dementia.

Following the meeting, ADI's Executive Director Marc Wortmann joined representatives from Alzheimer's Pakistan at a meeting with the governor of the province of Punjab. The meeting was arranged to discuss future government funding objectives for Alzheimer's Pakistan.

LATIN AMERICA

A well-attended 3rd Alzheimer Iberoamerica conference and ADI regional meeting took place in San Juan, Puerto Rico's capital, in October.

Some lively and interactive sessions took place during the conference featuring a combination of scientific, non-pharmacological and care sessions. During the opening ceremony a presentation was given on the current prevalence of dementia as detailed in the World Alzheimer Report 2009.

At the regional meeting Alzheimer Iberoamerica (AIB) welcomed Fundación Alzheimer Aruba as a new member. A representative from the association said 'As part of this family we promise to do our utmost to contribute to a healthy cooperation in the AIB family for the well-being of all who have Alzheimer's disease, and their carers'.

The event was well received by all in attendance and praise was given for the welcoming attitude within the region and the organisation of the conference and meeting.

Changes in the pharmaceutical world

Earlier this year a takeover of Wyeth Pharmaceuticals by Pfizer was announced and in October we heard that this complicated process was complete. This means that Pfizer will own 50% of the development of bapineuzimab, the Alzheimer vaccine that is currently undergoing a phase 3 trial. ADI has worked with both of these companies in the past and we would like to thank Wyeth International and Wyeth UK for their support in

previous years. We will continue collaborating with the new organisation.

Elan Pharmaceuticals, who owned the remaining 50% of bapineuzimab, was taken over recently by Johnson & Johnson to become part of Janssen-Cilag. Elan will continue to do research into developing new treatments for Alzheimer's disease and other dementias and we look forward to working with both companies in the future.

World Alzheimer's Day 2009

continued from front cover

bookmarks and balloons to members in order to assist in their activities.

Alzheimer's Australia launched a new report 'Dementia: Facing the Epidemic' as part of their Dementia Awareness Week. The report suggests ways to tackle dementia in the country and appeals to the government to invest in improved diagnosis, intervention, prevention and research. The strong media strategy prepared for the report and coverage of other activities resulted in over 1,700 items of media coverage across the country. Dr Constantine Lyketsos, a US-based expert in the care and treatment of dementia, visited the country, giving interviews in almost every state and territory in Australia.

The Gibraltar Alzheimer's and Dementia Support Group, who attended the Alzheimer University in July (see page 8), marked their first World Alzheimer's Day by coordinating twelve volunteers to take part in the Pillars of Hercules Marathon Challenge, which saw them sailing to Morocco and back before climbing to the peak of Jebel Tariq, Gibraltar's highest point.

Alzheimer Scotland released a manifesto on World Alzheimer's Day in response to the country's new National Dementia Strategy. The report, entitled 'Words into Action on Dementia', urges the government to invest in improving services for people with dementia in the country. It asks for a £15m 'Change Fund' to assist local authorities in improving early intervention and individualised care for people with dementia and their carers.

Fundacion Alzheimer Aruba marked the day by hosting their first Alzheimer Social Club and launching their website. They also introduced



Fundacion Alzheimer de Venezuela organised a laughter workshop, conference and numerous memory walks across the country

their pilot programme 'Safe Bed', which hopes to improve the levels of care and comfort experienced by those in care facilities in the country.

The Alzheimer's Disease Association in Singapore held a World Alzheimer's Day photo exhibition at the second-largest hospital in the country. As well as booths and poster panels, an exhibit of an apartment with warning signs of dementia, such as a watch in

the fridge, was also set up as an informative and fun way to improve recognition of the disease.

World Alzheimer's Day 2009 saw ADI members engaging not only people with dementia, their families and carers, but also younger generations. Children were able to benefit a great deal from the knowledge of national Alzheimer's associations, while offering new and innovative ideas for raising

A Muistibussi (memory bus) toured the north of Finland offering advice and information to members of the public





Around 300 people took part in the Lanka Alzheimer's Foundation's Memory Walk, which marked the end of their 12-week campaign

awareness. In Hungary, hundreds of children from Budapest were invited to join the 'Memory Bridge', holding hands in a 'Live Chain' on the city's famous Chain Bridge.

Promising collaborations with national and local governments took place in a number of countries. Iran received news that the government are to set up an Alzheimer's committee within the Health Ministry and a supportive

message from a Health Minister was read at the association's press conference. It is expected that this committee will result in training courses for doctors, free hospitalisation for people with dementia and the establishment of four new dementia centres in the country.

ADI's member association in Cyprus collaborated with local MPs and European Parliamentary

figures and welcomed the involvement of the Minister of Health in their press conference. In Poland, local government ministers joined people with dementia, their families and carers for a picnic in the garden of a care home in Warsaw. Alzheimer's Association Japan received a message of support from the Vice Chair of the Ministry of Welfare and Labour in Kyoto and Saitama while TADA Chinese Taipei's national press conference was supported by the Department of Health. TADA also reached their goal of having all counties joining together for the first time in a nationwide campaign.

ADI would like to congratulate all members on their successes on World Alzheimer's Day. We are very proud of all of our member's achievements and it is such a pleasure to see the progress being made by associations of all sizes around the world. We are grateful to MetLife Foundation for their support of World Alzheimer's Day 2009, which has helped ADI and our members to broaden the reach of both national and international campaigns.

The Hungarian Alzheimer Society's live chain symbolised their wish to connect people with dementia with their families and friends both locally and around the world



■ Alzheimer University

July 2009

London, UK

Six emerging associations attended the Alzheimer University in July to learn how to set up an effective Alzheimer's association. Representatives from Albania, Curaçao, Gibraltar, Jordan, Macedonia and the Slovak Republic met in London to share experiences and gain knowledge and support in areas including raising profile and awareness, governance, and recruiting volunteers.

Speakers at the three-day event included Shona Blakely, Head of Fundraising and Development at Alzheimer Scotland, Reza Motazed from UK accountancy firm Vantis, Peter Braun, former CEO of the Alzheimer's Association Los Angeles/California Southlands chapter in the USA and Julie Pejnovic and Christine Cribb from the Alzheimer's Society in the UK. Graham Browne offered advice from the perspective of a person with dementia during a discussion on the benefits of support groups.

Participants exchanged ideas based on their own association's activities, including conferences, lectures, newsletters and Alzheimer cafés. Workshops offered them a chance to consider their current practices in developing community information provision, partnerships and their volunteer needs.

At the end of the three-day event participants were asked to consider their association's primary objectives based on what they had learnt. These included preparing fundraising strategies, setting up helplines and websites and organising conferences. Eman Al-Khateeb from the Jordanian Alzheimer's Association commented 'This training course was an eye opening experience to me and I will start my first steps in establishing the JAA with confidence and on solid bases.'

Participants at the Alzheimer University in Puerto Rico



October 2009

San Juan, Puerto Rico

A highly interactive and popular Alzheimer University took place in San Juan, Puerto Rico before the Latin American regional meeting in October. More than thirty representatives from 16 Spanish-speaking countries around the world joined the programme to develop their knowledge of how to fundraise successfully.

Victor Naranjo, a professional fundraiser based in Costa Rica, offered attendants practical advice on all aspects of fundraising, including developing good techniques and the best places to seek funding. Discussion was encouraged throughout the day and a creative session at the end of the programme meant attendees left feeling positive about their fundraising plans for the future.

The event allowed representatives from associations of all sizes to exchange ideas and knowledge of fundraising, which was particularly beneficial to those from smaller associations with less experience of raising money for their activities and services. The response from those who took part in the programme was extremely positive, with many commenting on how motivating they had found the experience. An attendant from Spain remarked 'It was magnificent and I learnt a great deal'.

November 2009

Lahore, Pakistan

ADI members from across the Asia Pacific region gathered in Pakistan to learn more about strengthening their associations. Representatives from ten countries in the region attended the insightful and constructive Alzheimer University programme, which took place during the Asia Pacific regional meeting.

Topics such as working with volunteers, successfully advocating for people with dementia and improving service provision were covered during the three-day event, with lively sessions being run by ADI's Marc Wortmann, Yasmin Raashid from Alzheimer's Pakistan and Frank Schaper and his team from Alzheimer's Australia WA. Daishiro Sugitani and Ryu Yoshino from Alzheimer's Association Japan, Tami Tamitegama from the Lanka Alzheimer's Foundation and Nirmala Narula from ARDSI in India shared their knowledge and experiences of working effectively with volunteers.

Feedback from participants at the event confirmed that they had found the programme extremely useful in strengthening their associations. Frank Schaper commented 'In every sense of the word, the regional meeting and the ADI Alzheimer University were a great success'.

25 Years of ADI

We conclude our series of articles marking 25 years of Alzheimer's Disease International by looking at advocacy and ADI's collaboration with the World Health Organization

Advocacy and public policy

Supporting associations and bringing them together to promote the urgency required to tackle dementia has always been at the heart of ADI's work.

A Public Policy Committee was formed by ADI in 1991 and later became known as the Public Policy Work Group in 1996.

The aim of the Committee was to 'encourage governments to recognise the needs of people with dementia and their families, and to develop policies to meet these needs'. Research conducted by the group gave the rest of ADI a good idea of the situation in many of its member countries.

The launch of World Alzheimer's Day during ADI's 10th conference on 21 September 1994, was welcomed and promoted by members. A worldwide news release was developed, along with member media kits to support and provide materials for use in members' events. A video news release was produced and satellite-fed worldwide to promote the occasion. ADI members continue to arrange World Alzheimer's Day activities, with events taking place worldwide over a whole week or month.

In 1999 the first version of the ADI charter of principles for the care of people with dementia and their carers was adopted by ADI.

The 'Facing Dementia: Advancing Care in Europe' forum was set up in 2004, with ADI working alongside Pfizer and Eisai on the project. The aim of the forum was to discover the challenges of dementia on a global scale.

Global Alzheimer's Disease Charter

We see facing public health and social care emergency and immediate action is needed:

Alzheimer's disease is the most common cause of dementia and accounts for 60-70% of cases. Alzheimer's disease and other dementias are progressive, degenerative illnesses that affect the brain. They affect people's abilities, impairing on all aspects of mental and personal abilities to function, particularly those who care for them day by day.

Every year 4.6 million new cases of dementia are reported worldwide. One new case every seven seconds. By 2050, it is projected that there will be 100 million people with dementia in the world. No country is adequately prepared to deal with such a crisis of this magnitude.

Lack of awareness and understanding has led to insufficient research that addresses the crisis. We therefore call attention to the world's growing problem and call for more research. Research continues to be carried out to help this need change the quality of life of people with Alzheimer's disease and other dementias can be transformed. For others, they, their families and carers lack the support that they need and deserve.

We, the members of Alzheimer's Disease International (ADI), representing 77 associations around the world, urge governments and stakeholders to act now, an advocacy action plan consistent with the Kyoto and Paris Declarations should be implemented as follows:

1. Increase public information about the symptoms, treatment and course of the disease
2. Foster ongoing, continuing understanding and awareness
3. Provide training and tools to health care professionals, including social workers and family caregivers, to encourage early diagnosis, diagnosis, appropriate care, and access to ongoing treatment
4. Provide access to primary and secondary health care services, responsive to the needs of people with dementia
5. Increase access to a range of options for long-term care that prioritize maintenance of independence, human and community-based care and support for family carers
6. Make care environments, including (acute) hospital and long-term care institutions, safe places for people with the disease
7. Encourage the full possible participation of those living with the disease, in both of their communities and in decisions about their care
8. Ensure a standard of living adequate for health and well-being, including food, shelter, housing and medical care for people with the disease
9. Provide a legislative framework to regulate and protect the rights of those living with dementia who lack the capacity to manage their receiving care
10. Fund awareness programs to promote greater understanding that the risk of the disease can be reduced
11. Prioritize research into Alzheimer's disease and other forms of dementia are not a natural part of getting older and that effective interventions are possible. Care and services can be provided for the person

September 2000
www.adi.org/advocaction
www.adi.org/interdementia

ADI Global Secretariat: 104 Great South Street, London SE1 0SL, United Kingdom
Telephone: +44 (0)20 7601 6888, Fax: +44 (0)20 7602 2227
Email: info@adi.org.uk, www.adi.org.uk

Over 30,000 people worldwide have signed ADI's Global Charter since it was launched in 2008

Eighteen associations gathered in Copenhagen, Denmark for a three-day Advocacy Alzheimer University programme in January 2006. The event was organised in response to requests from members for more advice on lobbying governments. Another successful Alzheimer University entitled 'Campaigning for Change' was held in Milwaukee in 2007.

Advocacy has remained a large part of ADI's activities. The work of the ADI Advocacy Working Group, set up in 2007, is still very evident, particularly with the launch of the Global Charter on World Alzheimer's Day 2008. The charter has been promoted by member associations worldwide and translated into 15 languages. It is still available to sign at www.globalcharter.org. ADI is also looking into hosting another Alzheimer University on public policy in the near future.

Working with the World Health Organization

The relationship between ADI and the World Health Organization dates back to the very beginning when WHO representatives attended the 1984 international planning meeting at which ADI was founded.

In 1987 ADI was nominated as a collaborating centre of the WHO and, in 1990, was invited by the WHO to take part in developing a statement for a position paper on mental health for the elderly. Two years later ADI entered into an Official Working Relationship with the WHO.

The launch of World Alzheimer's Day in 1994 was supported by the WHO and in the same year the two organisations worked together to publish a 'Help for Caregivers' booklet.

ADI entered into Official Relations with the WHO in 1996 and the election of Dr Gro Harlem Brundtland as Director General brought good news to Alzheimer associations worldwide as she listed mental health as one of her priorities. In 1999, Dr Brundtland supported World Alzheimer's Day by contacting governments with the aim of awareness leading to action.

A collaboration between ADI's 10/66 Dementia Research Group and the WHO took place in 2000, to evaluate and develop services for people with dementia in the Dominican Republic, PR China, Russia and India. One year later, ADI was invited to deliver a statement on World Health Day. An invitation to participate in a working group on mental health in 2003 helped to maintain the relationship.

More recently ADI has been working to encourage the WHO to increase the priority of dementia globally.

■ Living with dementia

Graham Browne, UK

My life changed completely in June 2006 when, after visiting my consultant, he gave us the news that I had Pick's disease (a form of fronto-temporal dementia) and that there was no treatment.

On the way to the hospital me and my wife Debbie had discussed what it could be, but never anything like this. In weeks prior to the visit we had spoken about the possibility of me having something, but if he had said nothing was wrong, what a bonus! So, in a way, we had prepared for the future and the worst outcome. What do you do next? We had no one at the hospital for advice or any leaflets on this. Debbie had to go to work the next day at our local hospital and look on the web and find all the hard facts on her own.

We went home from the hospital and told all of the family and for a couple of days sat around in stunned mode taking in everything that had happened in the last seven days and trying to work out why it had happened to me. I then thought 'That's it, I am not going to sit and feel sorry for myself, but try and do something positive, and let people know that although we have this thing called dementia, we still have lives to lead'.

That's where the Alzheimer's Society came in. While looking on the web Debbie found their site and through this our local branch and then a club I attend called 'The Towner Club'.

After six months of attending, the Alzheimer's Society press office sent a team down to visit us and they asked if I would do an article for them about my friend Pick's, so I obliged. This was printed and then I had another visit from the Society to ask if I would like to join the Living with Dementia Team.

From then on in it just snowballed: talking at government Party conferences, congresses, live radio,



Graham Browne spoke about the benefits of support groups at ADI's Alzheimer University in July

meeting celebrities and helping with the launch of 'Dementia: Out of the Shadows' [an Alzheimer's Society report giving people with dementia an opportunity to speak about the impact of stigma and diagnosis on their lives]. I have also spoken at the ADI Alzheimer University this year and would like to think I could do it again. Locally I have attended functions and every year I talk to second year medical students at Brighton University – we have a joke saying I am busier now than when I was working.

I also sit on the Board of six committees representing people with dementia. I do this, not just for me, but for those people who cannot or

will not speak up. I am just one of several who speak up for others.

Earlier this year I was asked by the Alzheimer's Society if I would like to become one of a selected few known as 'Ambassadors', which was a very proud moment for me and my family.

People often look at you when you say 'I have dementia' and their reply is 'but you look ok'. It's not on the outside, but inside that hurts.

I can't really say how Pick's has affected me because I do not know anyone else with it who I could compare with. All I know is we were told 'you have two to ten years' and it went back five years [before diagnosis]. So now I have had eight years, but I still feel the same old me. Debbie obviously sees signs of deterioration, but not a great deal. I recently had my yearly check-up with my GP and he thinks, by keeping as busy as I am, it is probably slowing my progression.

So that fateful day in June 2006 changed my life, not I think for the worst, but by giving me an objective in life and that is to make the voice of dementia heard and recognised.

You do lose what you thought were friends, but you gain a whole new family who understand your situation, not just locally and nationally, but also internationally.

The Alzheimer's Society's 'Dementia: Out of the Shadows' can be viewed at www.alzheimers.org.uk/outoftheshadows

Novartis grant for people with dementia involvement

ADI has received a grant from Novartis allocated specifically to involving people with dementia. The grant will be used to fund travel and accommodation for people with dementia at ADI's International Conference in 2010 and other meetings throughout the year, including the WHO regional meetings. We hope this grant will enable us, and our members, to engage further with people with dementia while giving them an opportunity to have their voices heard.

■ Research update

Lived experience and information needs of adolescents whose grandparent has dementia

Els Steeman (els.steeman@ugent.be), Tom Defloor, Mieke Grypdonck · Nursing Science, Ghent University, Belgium

A short survey among 746 high school students in Belgium revealed that 11% of them had a grandparent with dementia. So a relatively high number of high school students are confronted with dementia in their family.

These students are in the midst of their identity development and being confronted by a grandparent with dementia may be a difficult experience. A better understanding of dementia may help the adolescent to deal more positively with their grandparent's dementia and hence may support the relationship with the grandparent. However, information about dementia tailored to adolescents dealing with dementia in their family is scarce.

In order to develop adequate information we began by conducting in-depth interviews with 28 adolescents who had a grandparent with dementia. The aim of the interview was to explore what it meant for these adolescents to have a grandparent with dementia and what information needs they had.

From the survey and the interviews we learned that these adolescents experience difficulty in dealing with their grandparent and encounter problems communicating with them. They can no longer tell their story to their grandparent, nor can they understand the confused story of their grandparent. There is no way for them to know what goes on in their grandparent's mind. The often unpredictable and strange behaviour of their grandparent may be experienced as frightening or annoying. The same goes for the behaviour of other residents with dementia in a nursing home.

These adolescents want to treat their grandparent in a respectful way, but they often feel uncomfortable doing this. Adolescents often use humour to deal with the situation and, although humour can be very powerful in dealing positively with dementia, they often questioned whether their own use was respectful.

Despite difficulties with communication, some adolescents experience pleasure in maintaining contact with their grandparent. They also experience pleasure in little signs of recognition from the grandparent or in being able to provide company or care for the grandparent.

Although adolescents may experience problems in dealing with their grandparent, the results showed that most adolescents experience very few difficulties. They feel it provides a unique opportunity to bond with the grandparent.

Somewhat surprisingly, only a minority of the adolescents indicated a need for more information. However, the interviews revealed that many questions are present for which no answers are obtained or sought. These questions often related to the 'technical' aspects of dementia such as what dementia does to the brain. Yet most adolescents are keen to know how to effectively relate to their grandparent. Most expressed that their parents are the most important source of information and their role model in dealing with dementia. It was found that the Internet is rarely used for this purpose. Parents also have an important role in setting

a good example for dealing with dementia as adolescents learn from their parent's behaviour.

To conclude, it could be suggested that adolescents do require information in dealing with their dementia, although they do not always explicitly ask questions. Information should be touching, but not too intense. It should be recognisable, appealing and practical. The information must support the adolescent in respectfully communicating with their grandparent.

Parents should be closely involved in informing and supporting their adolescent children and should encourage them to make regular contact with their grandparent. It is advisable to prepare grandchildren for their first visit to the nursing home. Care staff in nursing homes may do so by providing welcome, pro-active and well-balanced information and by guiding family members through difficult situations and supporting enjoyable contact.

Based on the results of the interview, an information booklet was developed with practical information for adolescents and illustrated with entertaining cartoons.

ADI and FMA award 2010

The deadline for the ADI and Fondation Médéric Alzheimer (FMA) psychosocial research award has now passed. Entries have been received from 17 researchers in 13 countries across the world. More information on the short listed entries will be in the next issue of Global Perspective and the winner will be announced during the ADI International Conference in Thessaloniki, Greece in March 2010. To register for the conference please visit www.adi2010.org

World Alzheimer Report 2009

On World Alzheimer's Day ADI launched the World Alzheimer Report 2009, the first of two in-depth studies detailing the current global prevalence and impact of dementia and recommendations for action.

Representatives from ADI's member associations, Elected Board and Medical and Scientific Advisory Panel witnessed the launch of the report in New York, USA alongside attendees from international organisations and pharmaceutical companies.

The report, edited by Professor Martin Prince from ADI's 10/66 Dementia Research Group and Jim Jackson, former Chief Executive of Alzheimer Scotland, suggests that in 2010 around 35.6 million people worldwide will be living with dementia. The report also offers a breakdown of this figure estimating dementia prevalence by world region.

ADI Chairman Daisy Acosta, who delivered a thought-provoking presentation on the reality of living with dementia, chaired the launch.



Martin Prince offered an overview of the contents of the report

Martin Prince summarised the findings contained within the report in a detailed talk explaining how the studies had been analysed. During the interval, attendees were treated to a performance from Australian singer Jay P, who has worked closely with Alzheimer's Australia VIC and whose father has dementia.

Marc Wortmann, ADI's Executive Director, initiated a lively discussion on the next steps to take in order for dementia to be recognised as a global health priority. The launch was concluded with a presentation

from William Thies, Chief Medical and Scientific Officer from the Alzheimer's Association, who gave an insight into the impact of dementia from the perspective of the USA.

The report, which is now available online, features pictures taken by photographer Cathy Greenblat during her visits to care facilities in France, India, Japan and the USA. An Executive Summary of the report is available and can be downloaded, along with the full report, from www.alz.co.uk/worldreport.

Members help to promote the World Alzheimer Report

ADI members across the world rallied to influence policy change around World Alzheimer's Day by promoting the World Alzheimer Report 2009 in their activities.

Press releases and copies of the report were distributed to the media, local and national governments and pharmaceutical companies.

Representatives from member associations gave interviews for television and radio and press coverage and translations were prepared by several countries in advance. The information contained in the report was delivered during



Jacob Roy of ARDSI handed a copy of the report to India's Minister of Health

seminars and press conferences arranged by members.

A number of associations plan to continue their promotion into next year, with a few hoping to coincide with ADI's International Conference

in March. Some have promoted the report through their websites by posting a link to the report and featuring press releases and news stories on the new prevalence figures.

ADI would like to thank our members for all of their support and promotion of the report. We hope it will continue to be useful for future advocacy work and help towards our aim of getting dementia recognised as a health priority both nationally and internationally.

Translations of the World Alzheimer Report will soon be available to view on the ADI website.