



# Global Perspective

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

## New perspectives, new hope

23RD ANNUAL INTERNATIONAL CONFERENCE OF ALZHEIMER'S DISEASE INTERNATIONAL, HELD IN CARACAS, VENEZUELA



The mayor of Caracas welcomes ADI member associations to Venezuela at the ADI Member Reception at the Town Hall. Alongside Orien Reid, Chairman of ADI, and Mira Josic de Hernández, President of the Fundación Alzheimer de Venezuela, he raised a toast and pledged his support

More than 700 people from over 45 countries arrived in Caracas, Venezuela to learn about the year's developments in dementia care and research.

Keynote speakers included Henry Brodaty (Australia), Martin Prince (UK), Nancy Lombardo (USA), Ingmar Skoog and Bengt Winblad (Sweden) and plenary sessions covered a variety of topics that reflected the multidisciplinary nature of the event. Epidemiological findings and the economic impact of the growing numbers of people with dementia around the world were presented to delegates during

the first morning of the conference. This is critical information for anyone working in the field of dementia

and an essential tool for raising awareness and lobbying policy makers.

There was hope for carers and people with dementia as sessions covered new methods and innovations in caring. As knowledge of the condition spreads, stigma is reduced and the path to help and support for those who need it most is cleared.

'ADI events by definition have a real international flavour and unrivalled access to speakers from a variety of countries and professional backgrounds,' said Marc Wortmann, Executive director of ADI. 'We are all encouraged by the sense of community around the event. Despite cultural and language barriers, this conference shows how we are all working together for the same cause.'

ADI ran four workshops during the conference; fundraising, advocacy, *continued on page 7...*



Members of the 10/66 Dementia Research Group came together from all over the world to relay developments to delegates at the ADI conference



## 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 **1 February 2008**.

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## ■ Editorial



**Orien Reid**  
Chairman, ADI

This latest edition of Global Perspective comes to you at the end of another very busy year for ADI. We are drawing breath after our 23rd International Conference in Caracas, Venezuela and after our World Alzheimer's Day 2007 campaign which was commemorated by member associations all around the globe.

As always, it was a delight to see so many ADI members at the conference for a week of fascinating updates and insights into the advances being made in dementia care and research. The highlight of the conference for me is the great mix of people, professional backgrounds and countries represented: high profile speakers in the medical and scientific world learning alongside carers and people with dementia from a variety of associations around the world. It always makes for a very lively experience!

In Caracas we also held our annual Council and Elected Board meetings. We were sad to say goodbye to Ruth Goldberg from Israel who has completed her time on the ADI Board after 6 years. Ruth has been a valuable and respected member of the board and we thank her sincerely for her time and commitment. We also bid farewell to Marilyn Truscott from Canada who is standing down from the board after her diagnosis of Alzheimer's disease was changed to Lyme Disease. We thank her for her time dedicated to ADI and wish her all the very best with her new course of treatment.

I hope that you enjoy this latest edition of Global Perspective with its usual mix of colourful stories and updates. Please get in touch if you have any contributions or comments.

## ■ Events

5 – 9 April 2008  
**16th European Congress of Psychiatry**  
Nice, France  
Tel: +41 22 908 0488  
Fax: +41 22 732 2850  
Email: [aep@kenes.com](mailto:aep@kenes.com)  
Web: [www.kenes.com/aep](http://www.kenes.com/aep)

6 – 8 May 2008  
**1st International Conference: The Dementia Services Development Centre**  
*Embracing the Challenge: Citizenship & Dementia*  
Belfast, Northern Ireland  
Tel: +44 1786 467 740  
Fax: +44 1786 466 846  
Email: [jemma.galbraith@stir.ac.uk](mailto:jemma.galbraith@stir.ac.uk)  
Web: [www.dementiacentreni.org/conferences.asp](http://www.dementiacentreni.org/conferences.asp)

22 – 25 May 2008  
**18th Alzheimer Europe Conference**  
*Breaking Barriers*  
Oslo, Norway  
Tel: +47 231 200 42  
Email: [majja.juva@nasjonalforening.no](mailto:majja.juva@nasjonalforening.no)  
Web: [www.alzheimer-conference2008.org](http://www.alzheimer-conference2008.org)

26 – 31 July 2008  
**11th International Conference on Alzheimer's Disease and Related Disorders (ICAD)**  
Chicago, Illinois  
Tel: +1 312 335 5790  
Email: [info@alz.org](mailto:info@alz.org)  
Web: [www.alz.org/icad](http://www.alz.org/icad)

6 – 8 August 2008  
**11th ADI Latin American Regional Meeting and 6th Meeting of Alzheimer Ibero America**  
Buenos Aires, Argentina  
Email: [info@alma-alzheimer.org.ar](mailto:info@alma-alzheimer.org.ar)

20 – 25 September 2008  
**World Psychiatry Association (WPA) XIV World Congress of Psychiatry**  
*Science and Humanism: For a person-centered Psychiatry*  
Prague, Czech Republic  
Tel: +420 284 001 444  
Fax: +420 284 001 448  
Email: [wpa@guarant.cz](mailto:wpa@guarant.cz)  
Web: [www.wpa-prague2008.cz](http://www.wpa-prague2008.cz)

8 – 11 October 2008  
**4th Croatian Congress on Alzheimer's Disease**  
Rovinj, Croatia  
Tel: +385 1 6183 140  
Fax: +385 1 6110 452  
Email: [komercijala@studiohrg.hr](mailto:komercijala@studiohrg.hr)  
Web: [www.studiohrg.hr](http://www.studiohrg.hr)

26 – 28 March 2009  
**24th Annual International Conference of Alzheimer's Disease International**  
Singapore  
Tel: +65 6379 5261/2  
Fax: +65 6475 2077  
Email: [admin@adi2009.org](mailto:admin@adi2009.org)  
Web: [www.adi2009.org](http://www.adi2009.org)



# Lost for words

Gunilla Denton Cook, Australia

Nothing bad comes without a little good on the side, my mum used to say. She, like so many millions of others, died of Alzheimer's. What hurt the most was that she died so young. She was only 63.

I returned home after having buried my mother and then, within days, my in-laws arrived on our doorstep from overseas. I hadn't seen them for a few years and the minute they crossed the threshold I knew straight away that my mother-in-law had some form of dementia.

I soon realised that my mother-in-law was worse than I had first thought. My heart stopped at the shock of seeing so many of the same symptoms in my husband's mother as I had seen in my mum. For my own sanity I chose to try to pretend not to notice it. That didn't work. The two women had so many symptoms in common but they were also different. Still, it was impossible to overlook the similarities and the fact that it was dementia.

My mother was fit, looked and sounded like she always had. What gave her away was that more and more often she asked for one thing while she wanted some other thing. She got the nouns mixed up. Several times she asked for a pillow and what she really wanted was a cup of coffee. When I began to think that pillow meant coffee, it changed to something else. On one occasion



**Gunilla's mother died of Alzheimer's disease when she was only 63**

she asked for a mirror. I opened my handbag and gave her one. She looked at me as if I was totally mad. She then decided that I probably was joking and asked for it again. I still didn't know what a mirror was, if it wasn't a mirror. What she really wanted that time was a glass. For me this was like learning a new language. The biggest problem I had was that the new language changed faster than I could learn.

Almost all of our conversations took a wrong turn because I didn't understand what she tried to tell me or wanted. Her doctor told me that this would most likely only get worse with time. I thought long and hard about what I could do to make life a little easier. That's when I came up

with the idea of the book 'Lost for Words'. I sat up all night and started to make a book with a picture of, for instance, a lamp and the word lamp underneath it. Next page a picture of an egg and the word egg underneath it.

I named the book 'Lost for Words'. Mum called it the yellow book, because of its cover. At least she got the colour right I thought. We used the book in almost every conversation we had and she carried it with her wherever she went. It was the one new thing that she didn't forget.

My mother-in-law died recently of another kind of dementia and it has taken me until now to get as far as sharing the book with all who need it. It isn't the cure and end to all problems connected with dementia, but it was an enormous help to my mother and me and I know that it will be for so many others.

If mum was right and there is a 'little good on the side' of her dying from Alzheimer's, it is this book *Lost for Words*. I know it will be a great help for so many who need it and I'm happy I can provide them with it. Personally I would have preferred to have my mother around for a few more decades.

*For more information about the publication 'Lost for Words' visit [www.lostwords.com.au](http://www.lostwords.com.au)*

# World Alzheimer's Day 2007

**World Alzheimer's Day 2007 was commemorated around the globe with a great variety of colourful events and activities. The theme, 'No time to lose – people with dementia speak out!' was embraced by member associations around the world, many of whom used the day to focus on the reality of life with dementia as seen by the people with the disease themselves.**

As the tradition of World Alzheimer's Day grows and ADI's membership expands we are very pleased to see the day being celebrated by many new and emerging Alzheimer associations. The Caribbean island of Aruba launched the Alzheimer's Teal Ribbon Week, a campaign which involved a well attended 'Jazz in White' Gala Dinner fundraising concert. In Lithuania, a marathon was held in honour of the day in the country's capital, Vilnius, and in Armenia a memory walk and round table attracted the attention



**Students in the Philippines parade through Baguio City to raise awareness of dementia**

of the country's media and research community.

Alzheimer's Jamaica was fortunate to receive a visit from Keith Turner from the UK, a man living with dementia who flew to Jamaica for World Alzheimer's Day with his wife Lillian to help raise awareness of the disease. After meeting Keith and Lillian at an ADI Alzheimer University, Alzheimer's Jamaica were inspired by the role

people with dementia can play within an Alzheimer association and how they can help to attract the attention of the media. The association in Jamaica also received a visit from Orien Reid, chairman of ADI, which secured them three television interviews and provided a great start to their awareness campaign.

The participation of governments and policy makers was another prominent feature of World Alzheimer's Day 2007. In Argentina the Ministry of Health sponsored a documentary on dementia which was screened on the day; in China a public seminar in Beijing was attended by the government's vice premier and leaders of the public health ministry, and in the Philippines the president of the Republic, Gloria Macapagal-Arroyo, issued a presidential declaration announcing that the 3rd week of every year be recognised as National Alzheimer's Disease Awareness Week.

The day was also used as an opportunity to launch new research and products to help improve the quality of life for people with dementia. In Turkey, a press conference was held to introduce a new belt to help locate patients with a tendency to wander. The launch was well covered by television and the print media.

## Alzheimer Society of Canada receives \$1 million gift on World Alzheimer's Day

World Alzheimer's Day was a day to remember for the Alzheimer Society of Canada due to the receipt of a CA\$1 million legacy gift.

The donation, the largest single legacy gift in the Society's history, will be used to help fund critical dementia research and to support ongoing programmes and services. The funds were left to the Alzheimer Society of Canada through the will of an Ottawa resident who had seen the far reaching effect dementia has on the local community.

'We continue to be humbled by the generosity of Canadians, and are particularly grateful for the thoughtfulness behind this very important gift,' said Scott Dudgeon, Chief Executive of the Alzheimer Society of Canada. 'Legacy giving is a very satisfying and meaningful way for people to make a difference. It is within reach of everyone, regardless of their economic status, and can be done in a way that doesn't impact their lifestyle, or that of their family.'

A portion of the funds will be used to support the Alzheimer Society's Research Program. Celebrating its 20th anniversary in 2007/08, the research program helps support some of the country's best and brightest minds find answers in prevention, treatments, and most importantly, a cure.

Keith and Lillian Turner with members of Alzheimer's Jamaica



ABOVE The Federazione Alzheimer Italia organised a concert at Milan's Theatre La Scala to commemorate World Alzheimer's Day. The Filarmonica della Scala was conducted by Zubin Mehta, pictured here with Gabriella Salvini, president of the association



RIGHT The Malta Dementia Society organised its third Memory Walk, a successful event attended by over 50 people including committee members, caregivers and people with dementia. Two politicians were also present: Helen D'Amato, Parliamentary Secretary for the Elderly, and Joseph Muscat, Member of the European Parliament. Mr Muscat is part of Alzheimer Europe's Alliance in the European Parliament



A Memory Walk in Guatemala City organised by ERMITA, the Guatemalan Alzheimer association

As in previous years, ADI produced materials to help members raise awareness. Brightly coloured posters,

bulletins and balloons were sent to members all around the world. We are proud that the global dementia

community continues to unite each year to remind the world that people with dementia have 'no time to lose'.

## ■ Living with dementia

# You are never alone

Barry Pankhurst, Indonesia



Barry at home in Indonesia communicating through the Alzheimer's Forum

I am a British man and have been living in Indonesia with my Indonesian wife Sumi and stepdaughter Yuni for the last 15 years.

Almost three years ago I was diagnosed with Mixed Dementia and Alzheimer's. I live in a small traditional farming village and apart from my neurologist there is no understanding of dementia here. I'm sorry to say that even my wife and stepdaughter have problems trying to understand my illness. I don't have the benefit of support groups or day care and there is no form of support for my wife either.

Although I have lived here for many years, the differences in cultures, customs, and traditions have started to become more difficult and confusing for me. I am told my illness is a curse – black magic. My wife has even had spiritual men come to our house to have the devil cast out of me!

Some might ask why I do not return to the UK. This is not as easy as it might sound as I have strong family ties here and there is no way my wife would leave her mother

or daughter. Fortunately I have a good doctor who is helping me explain my illness to my wife in her own language. I can speak some Indonesian but I can't explain the technicalities of dementia as it's too complicated. Communication is a big problem as my illness has reduced my ability to speak Indonesian. My wife can only speak broken English and has no idea of how to use a computer. I have had to pre-write letters for her just to post in readiness for 'as and when' or else she would not know what to do.

However crying about our illness will never make it go away. Unfortunately it's here to stay and we must learn to cope with it as best we can.

Very fortunately I own a computer. Over two years ago I found 'Alzheimer's Forum and Friends' (AF) on the internet which, without doubt, has been my saving grace. At the start I was communicating once a week by sending articles and poems by e-mail for the website. I have now become more involved and write articles for the site everyday. I make slide show movies

for AF to encourage other sufferers to fight the illness. It has become my coping strategy. If I were in the UK I would be out campaigning and trying to broaden awareness of dementia but as I'm not, I'll raise awareness from here through my poetry, articles and videos. I will support my fellow sufferers worldwide as best I can.

The Forum has made me feel like one of the group and I look upon the day centre in West Kent as my day centre. My home has become like my own sub office. It has become a driving force within me and given me the will to fight.

Recently, with the help of my main contact at AF, I have learnt how to use 'Instant messenger' (IM) on my computer. This has opened up a whole new world to me. Alzheimer's Forum has become my own help line over the internet and my backbone in fighting this illness alone.

'You're never alone no matter where you live in the world, thanks to Alzheimer's Forum.'

*The Alzheimer's Forum – [www.alzheimersforum.org.uk](http://www.alzheimersforum.org.uk) – is an initiative of the Alzheimer's Society (England, Wales and Northern Ireland).*



Barry was recently awarded the William Brooks Award for Volunteers for his tireless work for Alzheimer's Forum and the support he offers to other people with dementia around the world

*New perspectives, new hope ... continued from front page*

10/66 and the Twinning Programme. The ADI twinning workshop was presented by speakers from Mexico and the Los Angeles Chapter of the US Alzheimer's Association and Trinidad & Tobago and Canada who have been successful participants in the programme since 2006. The workshop generated a lot of interest in the programme and ADI announced new places for a further six associations in 2008.

Many members of the 10/66 Dementia Research Group were present at the conference. Their workshop explained how the

majority of 10/66 centres have now finished collecting the data to determine the prevalence of dementia in various communities and are now working on a dissemination strategy. The group is also making preparations for a paper on international prevalence for 2008.

*The next International Conference of ADI will take place in Singapore, from 26-28 March 2009.*

**Simon Diaz, a well known Venezuelan singer, entertained delegates at the opening ceremony**



## ■ Research update

# Transdermal drug administration

Professor Bengt Winblad, Karolinska Institutet Alzheimer Research Center, Sweden

I was very happy to see that in July this year the US Federal Drug Administration (FDA) approved the rivastigmine (Exelon) transdermal patch for use in the USA. This is a patch that delivers the drug via the skin for the treatment of Alzheimer's disease and Parkinson's disease.

In August the Committee for Medicinal Products for Human Use (CHMP) gave a positive rating of the patch, raising hopes that approval will be provided in Europe for patch treatment of Alzheimer's disease very soon.

These approvals are largely based on the findings of the large 'IDEAL study', which were recently published in the *International Journal of Geriatric Psychiatry*<sup>1</sup>. The findings showed that the rivastigmine patch (9.5 mg per 24 hour dose) provided similar clinical effects (for example, in memory and thinking, activities of daily living and concentration) as the highest doses of rivastigmine capsules, but with three times fewer reports of nausea and vomiting.

Since nausea and vomiting can be a barrier to reaching higher doses of oral dementia therapies, this was an important finding. It suggests that, with the patch, people with dementia should be able to reach target doses more easily with greater potential to obtain maximum treatment benefits.

Transdermal drug administration is increasingly widely used in medicine. It allows smooth, continuous drug delivery into the circulatory system. It is thought by many experts that a patch may provide additional benefits for people with Alzheimer's disease, including sustained drug levels throughout the day, continuous duration of therapeutic action, reduced side effects, more convenient titration (increasing the dosage), and easier access to higher doses. Moreover, these advantages may enable people to stay on (and potentially benefit from) treatment for



longer periods of time. In the IDEAL study, more than 7 in 10 carers said they preferred the patch to capsules for the treatment of loved ones' dementia symptoms.<sup>2</sup>

I would like to take this opportunity to thank all the IDEAL study investigators, carers and people with dementia for their contributions. I hope that, in time, many people with dementia will be able to benefit from their work and participation through access to this novel patch treatment.

1 Winblad B et al. *Int J Geriatr Psychiatry* 2007;22:456-67.

2 Winblad B et al. *Int J Geriatr Psychiatry* 2007;22:485-91.

# Members' forum

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

## CANADA

### British Columbia to spend \$70 million on three-year Alzheimer's drug study

The British Columbian government will invest CA\$70 million in a study into the effectiveness of three Alzheimer medications.

Premier Gordon Campbell announced that the province will provide Pharmacare coverage for three cholinesterase inhibitors as part of a study to gather evidence into the benefits of the drugs for people in the mild to moderate stage of Alzheimer's disease.

The study, which began in October 2007, is expected to last up to three years and involve more than 25,000 British Columbians. It will also help the government decide whether Pharmacare should cover the drugs.

## INDIA

### Friends of ARDSI to be registered as a UK charity

ADI's member association in India, ARDSI, has been making great progress of late. Signed up to the ADI Twinning Programme, it has been working closely with the Alzheimer's Society (England, Wales and N. Ireland) to find new ways to fundraise, develop its care services and tackle stigma. In return the Alzheimer's Society will build up capacity and experience to engage better with the Indian population in the UK.

Friends of ARDSI is a small group of people based in the UK who have been assisting their Indian colleagues with fundraising and training. At a successful meeting between ARDSI and the Alzheimer's Society at the Oriental



**Members of the European Parliament pledge to support Alzheimer Europe's campaign to make dementia a European health priority**

Club in London in November, more volunteers joined this group and it was decided that Friends of ARDSI should be registered as a UK charity. This event followed a meeting in October at the Indian High Commission. The meeting was hosted by Mrs Sharma, the wife of the Indian High Commissioner and a dedicated supporter of ARDSI. A group of 15 attended, including ADI staff. All were people who are working in the field of dementia to help south Asian communities in the UK and India tackle the disease.

## LATIN AMERICA

### Latin America regional meeting

Alzheimer Ibero-America (AIB) is the Latin American regional network of Alzheimer associations. On 9 October, the group held their 5th regional meeting in Caracas to update one another on the year's activities and events. Board elections took place at which Emiliano Marmaneu from Spain was voted in as President and

Victoria Rivas from Argentina took on the vice-presidency. The next regional meeting will take place in Buenos Aires from 6-8 August 2008.

## EUROPE

### Dementia on its way to becoming a European health priority

42 members of the European Parliament from 19 different countries have pledged their support to Alzheimer Europe's campaign to make dementia a European public health priority. The pledge came at the end of a week-long exhibition in the European Parliament, hosted by Astrid Lulling, MEP (Luxembourg), for World Alzheimer's Day.

During the launch of the exhibition on 18 September, Astrid Lulling said, 'As European policy makers, we support the urgent call of Alzheimer Europe to give dementia a higher priority on the European health and social agenda. We owe it to the 6.1 million Europeans living with Alzheimer's disease or another form of dementia, as well as their families, to act now.'