Alzheimer's Disease
International

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# Global Perspective

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

## Global call for early diagnosis and intervention

**On 13 September, the launch of ADI's World Alzheimer Report 2011 took place in New York, USA.**

The report, under the title *The benefits of early diagnosis and intervention,* shows that there are interventions for people with dementia and their carers that are effective in the early stages of the disease, some of which may be more effective when started earlier.

The report also contains a strong economic argument in favour of earlier diagnosis and timely intervention. To prepare the report, ADI commissioned a team of researchers led by Prof Martin Prince at the Institute of Psychiatry, King's College London, to undertake the first-ever, comprehensive, systematic review of all of the evidence on early diagnosis and early intervention for dementia.

The report highlights that, currently, the great majority of people with dementia receive a diagnosis late in the course of the disease, if at all, resulting in a substantial 'treatment gap'. This greatly limits their access to valuable information, treatment, care, and support and compounds problems for all involved—patients, families, carers, communities and health systems.

**The World Alzheimer Report 2011 shows that early diagnosis of dementia has health, financial and social benefits**

*Continued on page 8*

## UN dementia recognition

In the week of 19 September, the United Nations held only the second meeting in its history on a global health issue by convening a Summit on Non Communicable Diseases (NCD).

The final political declaration of the summit specifically recognised neurological diseases, including Alzheimer's disease and other dementias, as an important cause of morbidity that contribute to the global NCD burden and that NCD prevention programmes and health care interventions provide equitable access to effective programmes for these illnesses.

We are excited by this recognition of Alzheimer's disease and other dementias as a burden on par with diabetes, cancer, lung diseases and cardiovascular disease. It is a major step forward in public health action on Alzheimer's disease and other dementias, which may be accomplished through improved access to diagnosis and care, chronic disease management programmes and risk reduction programmes. Adding dementia considerations to the health planning effort at the country and World Health Organization level is a major leap toward mobilising the imagination and resources of the public health community.

ADI has become a Full Partner in the NCD Alliance with groups from the other four disease areas. We have to work out our role in the Alliance and this process will start now, as well as the implementation of the topics and commitments agreed during the Summit.

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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 for the next issue of Global Perspective to arrive by 14 November 2011.

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## Editorial

### Marc Wortmann, Executive Director

This year we see an upgrade of September to Alzheimer's Month. Several ADI members are already using the whole month for awareness raising activities. We ourselves have launched the World Alzheimer's Report 2011 on the 13 September and have campaigned hard to get Alzheimer's disease and dementia acknowledged as main non-communicable diseases (NCD) during the NCD Summit at the United Nations on 19 and 20 September. At the moment you are reading this, it will be clear if we have achieved our aim! Following the United Nations meeting, we will be celebrating World Alzheimer's Day on 21 September. That day a meeting with business leaders with take place, hosted by Alzheimer's Society in the UK and ADI.

I have been at ADI now for more than four years and, although there has never been a dull moment, this year there is more going on than ever before. The nice thing is that it does not feel like a burden, because it is a joint effort with many people; first of all the ADI member associations, but also other organisations. For the United Nations NCD Summit we worked very well with – among others – HelpAge International, International Longevity Centre, Global Coalition on Ageing and AARP. We saw a group of people with dementia working together to develop the I *Can! I Will!* initiative that is now available on our website and another group brainstorming their involvement in the next ADI conference, which will take place in London in March next year. This is all very exciting and I think our movement has really come "out of the shadows" and become very visible in the public arena. That does not mean we can relax though. On the contrary, it means more responsibility for our core tasks: to raise more awareness, provide support for people with dementia and their carers and advocate on their behalf at all levels!

I wish you all the best and hope you enjoy this issue of *Global Perspective*.

## Events

**2011**

6 – 8 October 2011
**21st Alzheimer Europe Conference**
Warsaw, Poland
Tel: +35 229 7970
Fax: +35 229 7972
Email: info@alzheimer-europe.org
Web: www.alzheimer-europe.org

13 – 16 October 2011
**The 5th World Congress on Controversies in Neurology (CONy)**
Beijing, China
Tel: +972 3566 6166
Fax: +972 3566 6177
Email: info@comtecmed.com
Web: comtecmed.com/cony/2011

18 – 20 October 2011
**V Congreso Iberoamericano sobre enfermedad de Alzheimer**
Havana, Cuba
Email: scual@infomed.sld.cu
Web: www.alzheimercuba.com

20 – 23 October 2011
**Seventh International Congress on Vascular Dementia**
Riga, Latvia
Tel: +41 22 908 0488
Fax: +41 22 906 9140
Email: vascular@kenes.com
Web: www.ksenes.com/vascular

1 – 3 November 2011
**The 6th UK Dementia Congress**
Liverpool, UK
Email:
shital@hawkerpublications.com
Web: www.careinfo.org/uk-dementia-congress.php

3 – 5 November 2011
**4th Conference Clinical Trials on Alzheimer's Disease (CTAD)**
San Diego, USA
Email: ctad@ant-congres.com
Web: www.ctad.fr

8 – 11 November 2011
**14th Asia-Pacific Regional Meeting of ADI**
Bangkok, Thailand
Email:
mcpc.thailand@hotmail.com
Web: www.azthaimeeting.com

**2012**

7 – 10 March 2012
**27th Annual International Conference of Alzheimer's Disease International**
London, UK
Tel: +44 870 458 4171
Fax: +44 870 442 9940
Email:
adi2012@mci-group.com
Web: www.adi2012.org

VISIT WWW.ALZ.CO.UK/EVENTS FOR MORE CONFERENCES AND ANNOUNCEMENTS

### Corrections

Please note that the 21st Alzheimer Europe conference will be held in Warsaw, Poland from 6-8 October, not in Moscow, Russia as stated in the June issue of *Global Perspective*.

The From the Heart story featured in the March 2011 issue of *Global Perspective* was written by Mina Jahangiri and not Faraneh Farin as we said.

ADI apologises for these errors.

### Join us on Facebook and Twitter

www.facebook.com/alzheimersdiseaseinternational

www.twitter.com/AlzDisInt

# Our mother

**Elli and Ester, Indonesia**

Her name is Naomi. She was born at Tebing Tinggi, a small town in South Sumatra, 78 years ago. She was a brave and courageous mother and had a husband, the late Budjang Sofjan (our father), whom she married in 1951. Our father died in 1978 at the age of 67.

We were four brothers and six sisters, although two had passed away. Thanks to God, all of us grew up to be dutiful children, to love our parents and the fear of God.

At first we did not know our mother had dementia. She had been suffering from type 2 diabetes mellitus since 1991 and her dementia symptoms were clearly visible around 2007. She was often angry, excessively suspicious, experienced memory loss, and sometimes hallucinated, thinking she was looking for her husband or her young children, although her husband had died and her children had all reached adulthood. We were all very confused.

Fortunately, by chance, my sister Ester had been told by her husband to consult his mother's psychiatrist at the Graha Medika Hospital. After the consultation, the doctor prescribed Aricept for our mother. Along with her diabetes, our mother also had osteoporosis, often complained of stiffness in her waist, and could not stand for long, as well as other complaints.

I consulted my sister-in-law; who is a specialist in medical rehabilitation. She recommended taking my mother to the geriatric department of Cipto Hospital to see Dr Wanarani for therapy for these complaints. Dr Wanarani was not alone; she has a team of doctors consisting of Dr Nina, an Internist, and Dr Martina Wiwie, a psychiatrist. According to the diagnosis given by a team of geriatricians, our mother had dementia. In addition to being given medication to treat the disease, Dr Wiwie also recommended that we use the day care services at the Darmawangsa hospital so our mother could socialise with other people with dementia. She would also be able to live side by side with people with dementia there.

In the beginning, living with people with dementia is very difficult and full of surprises. Almost every day unexpected things would suddenly happen.

Here are some of our experiences of living with our mother, who has dementia:

1 Suddenly she wanted to return to her home and when we asked where her home was she did not know.

2 In the middle of night she would suddenly wake up looking for her kids, as she was afraid they would drift away if bathing in the river. Sometimes she asked where her sons were sleeping.

3 If we were out shopping or going somewhere with her, she often wanted to go home, as she wanted to cook for her late husband who was 'waiting at home'.

4 Suddenly she would awake in the middle of night, asking for food. She said that she had not eaten yet, was still hungry, and couldn't sleep.

5 Sometimes she remembered her house being rented and we were told to take the rent and many other odd things.


**Elli, right, with her son and her mother, Naomi**

After being treated by Dr Wiwie, we followed her recommendation to join day care at RS Darmawangsa. Many things are taught there, including the good habits we apply to our mother's daily activities at home. Starting from morning to evening, she does not just sit staring at the house or watching television, but does some activities such as a colouring book, cuttings, and paste coloured paper. As her day is full of activities, she feels tired and easily sleeps at night.

We provide one nanny to assist our mom. She is a patient person and already understands how to assist a person with dementia.

During the bi-monthly meeting at RS Darmawangsa, we also have a lot of input on how to handle, manage or live with people with dementia. There are many other things we can share with friends whose parents also have dementia.

We are happy with the results we get. Changes have occurred with our mother; she is more happy, calm and not demanding anymore.

It is essential that, as children of a person with dementia, we spend our time giving our love and care to her, staying in contact with her, doing something to make her feel happy, maybe talking or sometimes making a joke, bringing snacks and food, and still have many ways to provide support to our parent. Yes, we do all of this, because we love our mom very much.

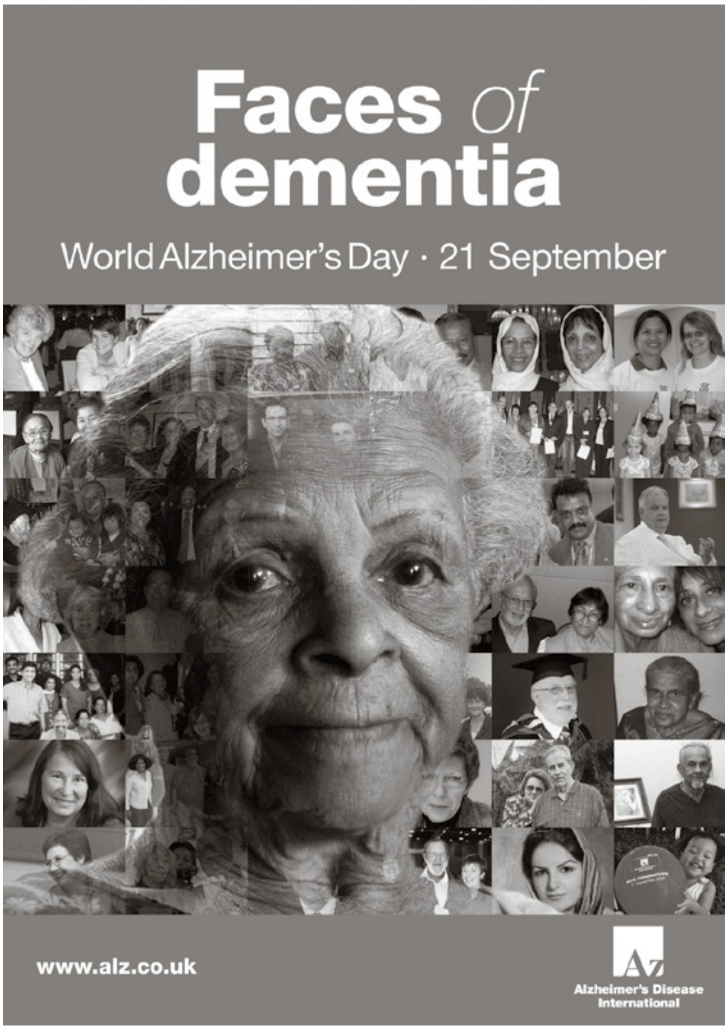
# World Alzheimer's Day 2011

**At the time of going to press, World Alzheimer's Day activities across the globe were in full swing with lively, informative, enjoyable awareness-raising events taking place on a local, national and international level.**

World Alzheimer's Day takes place on 21 September each year and the theme for 2011 is *Faces of dementia*. This year, individuals and groups across the world are being encouraged to recognise the symptoms of dementia in order to ensure a timely diagnosis takes place. It is also a great opportunity to recognise those who represent the faces of dementia, including people with dementia themselves, carers, health care professionals and the hard work of national and local Alzheimer associations across the world.

To find out more about World Alzheimer's Day in your country visit www.alz.co.uk/world-alzheimers-day

To mark World Alzheimer's Day 2011, ADI Chairman, Daisy Acosta, shared the message below.



**Daisy Acosta, ADI Chairman**

As each year goes by I am amazed at how the global dementia movement increases the volume and quality of its awareness-raising efforts on 21 September, World Alzheimer's Day. This work not only increases knowledge of dementia on a local, national and global scale, it also highlights the social, health and economic crisis we are facing as a result of this disease.

With 36 million people currently living with dementia, there is a great need for wider recognition and improved medical and support services for them. While these figures offer a bleak outlook, we must remember those around the world who represent the 'faces of dementia'. From the carers who work so hard to support the individuals; to researchers and scientists whose energies are poured into improving our knowledge and treatment of dementia; to, most importantly, the people with dementia who speak on behalf of those who no longer have this ability, the thoughts and thanks on World Alzheimer's Day 2011 go out to you. Long may your efforts continue.

I wish all of our member associations, and those involved in any of the numerous events taking place worldwide, a very successful World Alzheimer's Day and look forward to hearing of the real long-term benefits of your awareness-raising efforts to those living with dementia and their carers.

# Members' forum

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

AUSTRIA

## The Model of Dementia Service Centers in Austria

*By M.A.S Alzheimerhilfe Austria*

The image of dementia back in 2002 in rural Upper Austria was such that families were trying to keep people with dementia at home until a crisis occurred in the later stages of the disease or a family member broke down due to the burden of the care process. Affected families were too ashamed to visit a doctor because of a "normal process occurring due to old age" and felt obligated to carry the burden all by themselves. With the help of intensive media work, low threshold social work, local politicians, community services, workshops and printed information, families are now encouraged to take action and come forward and get help. The face of the disease has gradually been changing in our area.

The model of Dementia Service Centers has been developed in Upper Austria, starting with one Center in 2002, focusing on rural areas. Six Centers were operating by 2008. The main goal of these Service Centers is the prevention of premature institutionalisation of people with dementia, through early detection and continuing long-term support of the families. We set out with a low threshold, close to the community service, which would be easily accessible and located in small towns and villages. Besides the opportunity for early detection, teaching courses, support groups for family carers, and stage-specific training for people with dementia are also main elements of a Dementia Service Center.

**The Dementia Service Centers aim to prevent premature institutionalisation**

### Who works in a Dementia Service Center?

A Dementia Service Center is operated by a social worker, a psychologist and approximately 10-12 Dementia Trainers. Social workers are responsible for the organisation of the Service Center. They welcome families, provide counselling and information, organise teaching courses for carers, coordinate training for people with dementia, and organise community talks and social events. The social worker also coordinates all other services available for a family in the area (for example, meals on wheels and care services) and keeps contact with the media. The psychologist in the Dementia Service Center performs the psychological testing sessions at intake and every year thereafter. They also supervise the Trainers in carrying out the stage-specific training and discuss necessary training adjustments based on the results of the cognitive tests with the Dementia Trainer. The Dementia Trainer is a specifically trained person who carries out the stage-specific training with the person with dementia either in a group (preferably) or in individual sessions. The Trainer also supports the carer through difficult times. Psychologists and social workers are called in to support the trainer in case of crisis. In regular team meetings interdisciplinary knowledge is exchanged.

### Who can access the Dementia Service Center?

Everybody concerned about their cognitive performance can call a Dementia Service Center or visit in-person in order to receive information or counselling and psychological testing. Private

# Members' forum

CONTINUED

doctors and hospital doctors also refer people to the Center for further support, training and cognitive testing.

**What happens in a Dementia Service Center?**

As a first step, psychological testing of the cognitive performance level is encouraged. If there is significant cognitive deficit evident, the status of medical diagnosis is reviewed. If the family has not initiated a medical diagnosis at this point, this process is encouraged by the psychologist and the family is referred to a medical diagnostic centre or to a private medical specialist. Usually, the social worker is helpful in arranging the medical visit. A report from the medical diagnosis is kept in the records at the Dementia Service Center. The acceptance and importance of obtaining a medical diagnosis has increased over the years and reached about 80% of those coming to the Center. People with dementia are offered a stage-specific training group or, if they are unable to attend the group, individual training at home. Carers are invited on a training course and to the monthly support groups. Since 2002, 1200 people with dementia have been tested in a baseline evaluation. Since 2002, we have developed a database collecting long-term clinical data on this population. Courses for carers and people with dementia not residing in the area are also offered on a regular basis. These courses last 14 days and provide relief for carers and training for the person with dementia. These courses are organised in cooperation with local hotels. Thirty such courses have been held so far with 12 pairs (a carer and a person with dementia) participating in each course.

One of the six Dementia Service Centers operates as an administration centre, coordinating research projects and organising teaching activities (Alzheimer Academy). The Alzheimer Academy develops concepts for carer courses, Dementia Trainer courses, public workshops, conferences, and an international academic course (Dementia Studies) in cooperation with the Donau University Krems (www.donau-uni.ac.at/neuro/demenz).

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## AUSTRALIA

### Fight Dementia Campaign

Alzheimer's Australia has launched the *Fight Dementia* campaign with the aim to get recognition of dementia as a health priority in the 2012 Federal Budget. Alzheimer's Australia is proposing that the Australian Government commit to an additional AU$500 million over the next five years to promote a greater awareness of dementia, improve the quality of care and act on positive solutions to reduce the future numbers of people with dementia.

The general public are being invited to show their support of the campaign in a number of ways. The Dementia Champions initiative sees individuals signing up in an attempt to gather 100,000 Champions for the cause. People with dementia and their carers are also being invited to share their story on the Fight Dementia website to raise awareness.

On 13 October 2011 at Parliament House in Canberra, Alzheimer's Australia will be marching to highlight the priorities of people with dementia and their carers. They are also encouraging people with dementia, carers and members of the public to write to or request a meeting with their Federal Member and Senator to highlight the need for greater funding for dementia.

To find out more about the campaign visit http://fightdementia.org.au

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## NEW ZEALAND

### Lobbying yields great results

ADI was pleased to learn that Alzheimers New Zealand's ongoing advocacy efforts have shown some very positive results following the release of the association's National Dementia Strategy in May 2010.

It was announced earlier this year that an additional NZ$44 million would be allocated to rest homes and respite care for people with dementia in the country's upcoming budget. On top of this Alzheimers New Zealand will receive NZ$250,000 to support a public awareness campaign.

Johan Vos, National Director of Alzheimers New Zealand, said, 'The Minister of Health and I have developed an excellent relationship and have had good meetings. His Ministry has also been very supportive of our work having worked closely with his policy advisors. This has been the result of a deliberate strategy, intense communications, media releases and generally applying gentle pressure.'

Alzheimers New Zealand is keen to continue these efforts, and is currently working with Bupa Care Services on a collaborative development of a dementia action alliance.

For more information about the work of Alzheimers New Zealand visit www.alzheimers.org.nz

## SRI LANKA

### Gaining recognition

**Lorraine Tamitegama was awarded for her commitment to the dementia cause**

Lorraine Tamitegama, who has been a volunteer for the Lanka Alzheimer's Foundation (LAF) since its founding in March 2001, has been presented with the Outstanding Recognition honour at the Zonta Woman of Achievement Awards for her work raising awareness of dementia and improving services in Sri Lanka.

Lorraine, who founded the Foundation alongside her husband Tami, works closely with people with dementia and carers in a number of ways. Since 2002, she has invited carers into her home for LAF's monthly Caregiver Support Group meetings, and offers a counselling service to people with dementia and their carers. She is also responsible for producing LAF's bi-monthly newsletter, which is circulated globally, and plays a leading role in the ten to twelve weeks of activities in the lead up to World Alzheimer's Day.

Lorraine said of receiving her award: 'I gain an incredible amount of satisfaction from the work that I do and I felt that an award was unnecessary. However, Yasmin [Cader, one of the founder Trustees of LAF] managed to convince me because she pointed out that the award would bring more attention to the cause that we are dedicated to. So I agreed.'

ADI would like to congratulate Lorraine on the well-deserved recognition of her hard work.

The Lanka Alzheimer's Foundation's new centre is due to be formally opened on 21 September and more information about the opening and centre's facilities will appear in the next issue of *Global Perspective*.

## TADA CHINESE TAIPEI

### Schools of Wisdom

In June, ADI was informed that the Ministry of Interior had asked TADA Chinese Taipei to develop a proposal for the association to set up a School of Wisdom in each city in 2012.

The School of Wisdom, which was first developed in 2004, is a therapeutic group activity, which encourages people in the early stages of dementia to exercise their bodies and minds, while providing respite for carers. Examples of classes include 'The Brain Exercise Class' and 'The Tradition Passing Class'. Classes include a range of activities, such as creative arts, music and physical exercise.

The School, which has been attended by more than 200 people since its creation, has seen a great number of success stories with participants showing visible signs of an improved quality of life since attending the sessions.

For more information about TADA's work visit www.tada2002.org.tw

## Dementia newsflash

### Belgium

**Christine Van Broeckhoven, a member of ADI's Medical and Scientific Advisory Panel, has been awarded the European Inventor Award 2011 for her research into Alzheimer's disease.**

### The Netherlands

**Alzheimer Nederland has developed the Alzheimer Experience, a new interactive, cross-media production that allows you to experience what it is like to have Alzheimer's disease.**

### South Africa

**ADI would like to welcome Ilse Koen, the new Executive Director of Alzheimer's South Africa, and wish an enjoyable retirement to former director Sheila Cooper.**

### UK

**The UK's government has announced an £800 million investment in health research over the next five years, including £18 million for dementia research.**

### USA

**Harry Johns, president and CEO of the Alzheimer's Association, is among those selected to the Advisory Council on Alzheimer's Research, Care and Services of the country's National Alzheimer's Project Act.**

### Venezuela

**Fundación Alzheimer de Venezuela is developing a publication highlighting the status of dementia within the Latin American region, including data, statistics and first-person experiences.**

# Global call for early diagnosis and intervention

*Continued from front page*

'There is no single way to close the treatment gap worldwide,' said Prof Prince. 'What is clear is that every country needs a national dementia strategy that promotes early diagnosis and a continuum of care thereafter. Primary care services, specialist diagnostic and treatment centres and community-based services all have a part to play, but to differing degrees depending upon resources.'

'Failure to diagnose Alzheimer's in a timely manner represents a tragic missed opportunity to improve the quality of life for millions of people,' said Dr Daisy Acosta, Chairman of ADI. 'It only adds to an already massive global health, social, and fiscal challenge—one we hope to see in the spotlight at next week's United Nations Summit on Non-Communicable Diseases.'

As many as three-quarters of the estimated 36 million people worldwide living with dementia have not been diagnosed and hence cannot benefit from treatment, information and care. In high-income countries, only 20-50% of dementia cases are recognised and documented in primary care. In low- and middle-income countries, this proportion could be as low as 10%.

'Over the past year, the research team has reviewed thousands of scientific studies detailing the impact of early diagnosis and treatment, and we have found evidence to suggest real benefits for patients and caregivers,' said Marc Wortmann, Executive Director of ADI. 'Earlier diagnosis can also transform the design and execution of clinical trials to test new treatments. But first we need to ensure that people have access to the effective interventions that are already proven and available, which means that health systems need to be prepared, trained and skilled to provide timely and accurate diagnoses, communicated sensitively, with appropriate support.'

More information about the launch event and global promotion of the report will appear in the December issue of *Global Perspective*.

To find out more and to read the report, visit www.alz.co.uk/worldreport2011

# UN dementia recognition

*Continued from front page*

**Marc Wortmann, ADI Executive Director, said of the news: 'I am very proud that Alzheimer's disease and other dementias are part of the Political Declaration that was agreed on during the Summit. This is a result of extraordinary public policy efforts of the entire Alzheimer's movement and dementia advocates in many countries as well as our umbrella bodies Alzheimer Europe and Alzheimer's Disease International. We also mobilised great support with ten international partners, all organisations dedicated to ageing issues, who successfully campaigned to get ageing, dementia and care issues recognised during the Summit.'**

**Jan Killeen from Alzheimer Scotland represented ADI at a recent UN meeting in New York**

## Living with dementia

# Why diagnosis is important

### John du Preez, South Africa

Early diagnosis is important as it will allow and prepare the caregiver for what to expect and how to treat the illness. Diagnosis is therefore the first step in planning the future of the patient.

There are no simple proven tests to assist with a diagnosis. By means of questioning a close friend or member of the family, the history of the patient's problem and his or her physical and medical condition have to be recorded thoroughly. It is further important that other kinds of dementia illnesses that can cause amnesia be eliminated when diagnosing Alzheimer's. Nowadays brain scans seem to be used more often to diagnose Alzheimer's. I shall not go into detail here. Diagnosis is still tricky. It is hard to distinguish symptoms of Alzheimer's from a number of other ailments such as vitamin B deficiency, anxiety and poor education.

I have been involved with Alzheimer's disease and its complications for about seven years now. First, as a provider of a caring service in our own private *Home for the Aged* and, for about four years, as a sufferer of the sickness myself. When I received the confirmation that I have in fact without doubt incurred Alzheimer's disease I was devastated, although I had suspected it for a quite a while. I am a member of my local Alzheimer's Support Group. I am 75 years of age and still clear of mind. From my research and personal experience I have found a method to counter the disease and lead a reasonably normal life.

I went though a denial phase at first and then I decided to read up more about this. The more I read the more I, at first, despaired. Then I decided to fight the disease and try to stay healthy until a drug is found to delay the sickness from going over to the second phase.

Specialist psychologists and advanced imaging techniques have a 90% accuracy rate in diagnosing dementia. Even so, most people are already well into the disease by the time they are diagnosed.

I think that I am one of the lucky ones who were diagnosed at a relatively early stage of the sickness. Thus I could plan the road ahead because I could still think coherently.

What really are needed are a simple blood test and a drug that will reverse the condition.

Early diagnosis enables the Alzheimer's patient to delay the sickness for a number of years. This happened to me and can happen with many thousands (even millions). There are already drugs in the market that are able to slow the process.

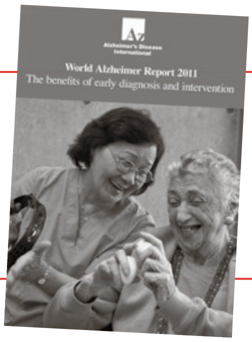
I am sure I need not quote the early signs that are well known to carers (or should be), but it is the general public who should be made more aware. It is only logic that early diagnosis will enable caregivers to start with nutritional programmes and medicines – 'to adjust the chemical balance in the brain and stall the decline for about year.' *(Readers Digest – October 2009)*

'Whenever I meditate about a disease,' observed Louis Pasteur, 'I never think of finding a cure, but rather a means of its prevention.'

Also, according to the Readers Digest of October 2009: 'There are around 100 or so compounds in the pipeline for Alzheimer's research…' So there is hope for the youth and younger people in time to come. Hope that the sickness can be prevented in the first place or, failing that, that the sickness can be reversed.

**To find out more about John's story visit http://dementiaand.com/my-story**

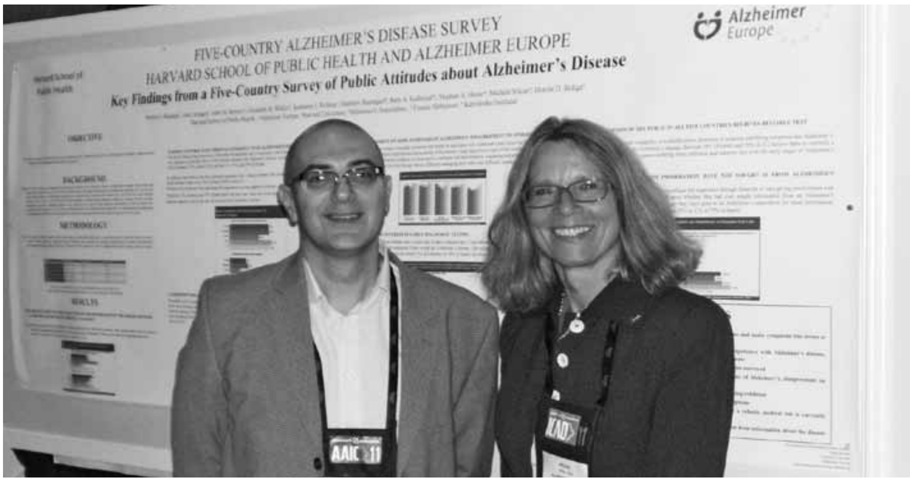
**John's testimony is just one of those that appears in the** *World Alzheimer Report 2011***.**
**To view the report visit www.alz.co.uk/worldreport2011**



## Research update

# International survey highlights public desire for early diagnosis

### Alzheimer Europe



**Alzheimer Europe Board member, Charles Scerri, and Chairperson, Heike von Lützau-Hohlbein, present the survey findings at the Alzheimer's Association International Conference**

Results of an international survey[1] reveal that over 85% of respondents in the five countries surveyed say that if they were exhibiting confusion and memory loss, they would want to see a doctor to determine if the cause of the symptoms was Alzheimer's disease. Over 94% would want the same if a family member were exhibiting the symptoms.

The survey, conducted in the USA and four European countries – France, Germany, Spain and Poland – was designed and analysed by Alzheimer Europe and the Harvard School of Public Health.

In four of the five countries, Alzheimer's disease was the second biggest health fear after cancer. The public were asked to choose which disease they were most afraid of getting from a list of seven diseases including cancer, heart disease and stroke. Around a quarter of adults in four of the five countries say they most fear getting Alzheimer's disease.

Fear of Alzheimer's gets worse with age, but even young adults are concerned, with approximately one in seven 18- to 34-year-olds reporting Alzheimer's as the disease they are most afraid of getting from the list provided.

The findings from this study were presented at the Alzheimer's Association International Conference (AAIC) in July. To find out more about other findings presented at AAIC this year visit www.alz.co.uk/news/aaicad-2011

The survey found a large proportion of the public has had some experience with Alzheimer's disease. Majorities in all five countries say that they know or have known someone with Alzheimer's disease, including about seven in ten in France (72%), Germany (73%), Spain (77%), and in the U.S. (73%), and 54% in Poland. In addition, about three in ten have personal experience with a family member with Alzheimer's disease. Experience with a family member ranges from 19% in Poland to 42% in the USA.

This high level of contact with Alzheimer's disease is likely to have contributed to the wide recognition of common symptoms such as confusion and getting lost, which were recognised by at least 86% and 88%, respectively.

Few people recognised the severity of Alzheimer's disease with approximately 40% knowing that it is a fatal condition (33-61%). In fact, Alzheimer's is the seventh-leading cause of death in high income countries and the only cause of death among the top 10 that cannot be prevented or cured.[2]

Many of the respondents believe there is now an effective medical or pharmaceutical treatment to slow the progression of Alzheimer's disease and make the symptoms less severe (27%-63%). Also, nearly half believe there is a reliable medical test to determine if a person suffering from confusion and memory loss is in the early stages of Alzheimer's disease (38%-59%).

The survey also found public interest in predictive testing. Approximately two thirds of respondents said that they would get a medical test, which would tell them whether they would get Alzheimer's disease before they had symptoms.

Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe, said: 'The results demonstrate the importance of being honest with patients when diagnosing Alzheimer's disease. As a former carer myself, I recognise how valuable it is for people to have first-of-all a name for all the uncertainties of their condition and then have the time to get their affairs in order. It will always be difficult to receive such a diagnosis but doctors need to empower patients and their loved ones to take the appropriate steps. The findings also show there is high awareness of Alzheimer's disease, which is a testament to the success of the many awareness campaigns coordinated by Alzheimer societies.'

Dr Robert Blendon, Professor of Health Policy and Political Analysis from the Harvard School of Public Health said: 'Many of the public have high expectations about the possibilities of treatment alternatives and medical testing. It is important for doctors to talk to patients about what treatment and testing options are or are not available.'

Florence Lustman, Coordinator of the French Alzheimer Plan, said: 'Alzheimer's is a fatal condition that affects most people's lives at some time. One of the key priorities of the French Alzheimer's Plan is early diagnosis, and the survey results support this focus. The findings demonstrate overwhelming public support for receiving diagnosis.'

For further information about the study contact Jean Georges jean.georges@alzheimer-europe.org

## References

1 Blendon RJ. Georges J. et al Key Findings from a Five-Country Survey of Public Attitudes about Alzheimer's Disease. Poster presented at AAIC, July 2011

2 WHO fact sheet. The top ten causes of death. Factsheet available at: http://www.who.int/mediacentre/factsheets/fs310.pdf

# Alzheimer University

**So far this year, ADI has hosted two highly successful Alzheimer University programmes**

## Berlin, Germany

ADI was delighted to welcome participants from 20 countries across six world regions to an Alzheimer University programme centred on advocacy, which took place in the Berlin in June.

Speakers from Canada, New Zealand, Pakistan, the UK and the USA covered subjects including 'The basics of building relations with politicians and policymakers', 'The art of empowerment' and a tactics morning, allowing participants to share ideas and previous experiences.

For the first time, a two-track programme provided targeted information to the different audiences present. Those from a policy background were invited to attend separate sessions, discussing such topics as 'Managing your advocates and programmes' and 'Integrating advocacy into your organisation'.

**Participants from Scotland, Peru and Bangladesh at the advocacy Alzheimer University in Berlin**

A social event with staff from Deutsche Alzheimer Gesellschaft, ADI's member association in Germany, took place during the event and participants were also invited to an organised tour of the Bayer Pharma's research facilities.

## London, UK

ADI's annual programme for emerging associations took place in London in August with participation from association representatives in Egypt, Gibraltar, India, Macau, Romania and Tunisia.

The three-day programme featured a number of the sessions from the standard programme, including 'Setting up support groups' and 'raising profile and awareness' as well as some new and popular sessions on 'Governing documents and business plans' and 'Working with the media'. Speakers from Alzheimer's Society and Alzheimer Scotland in the UK and Alzheimer Nederland in the Netherlands offered guidance and information based on their own work and experiences.

ADI welcomed emerging associations who are on ADI's Member Development Programme, and also some of ADI's current member associations. For less established member associations with new staff who have not been involved with ADI, the programme offered the opportunity to benefit from the knowledge and information previously provided to others within their association.

**Participants from Romania and Gibraltar practice promoting their cause**

ADI would like to thank all who have taken part in the Alzheimer University so far this year and, in particular, Mike and Sandy Splaine for their invaluable assistance with the programme in Berlin.

# Stand up, speak out!

Send Us Your Ideas!

What ideas do YOU have to stand up and speak out about dementia? Contribute your idea for raising awareness about dementia to the I CAN! I WILL! library.

Welcome to the I CAN! I WILL! Library

I CAN! I WILL! is a library of ideas to help people around the world stand up and speak out about Alzheimer's disease and related disorders.

These ideas, which raise awareness about dementia and help to erase the stigma, have been contributed by people just like you - people with dementia, care

**The new ideas library encourages individuals across the world to stand up and speak out**

Earlier in the month, ADI launched the *I CAN! I WILL!* website, a library of ideas to help people around the world stand up and speak out about Alzheimer's disease and related disorders.

The project, which was spearheaded by Richard Taylor who has been living with Alzheimer's disease in the USA for ten years, allows people with dementia, carers, medical professionals, volunteers and advocates to contribute their awareness-raising ideas and experiences. The site gives visitors first-hand access to the real-life stories that exist behind the disease in an effort to reduce the stigma currently associated with dementia around the world.

There are three ways in which the website can be used. Visitors are invited to view the ideas library, by selecting the book that relates to them, to find some inspiring awareness-raising ideas that can be used within the family, community or country. Individuals are also welcomed to share details of successful campaigns, future plans or past experiences. Visitors are also able to comment on any of the ideas features in the library, giving practical advice, opinion or support to those ideas or stories featured.

Richard, who worked alongside Laura Bramly from Canada to develop the website following the initial discussion session at ADI's conference in March, said of the site: 'Together we can spread awareness of what it is like to live with dementia, address the myths and stigma that accompany the diagnosis of dementia, and encourage, enable and support people living with dementia to be more open with others about their disability.'

You can find the site and share your ideas at www.alz.co.uk/icaniwill

# Future ADI conferences

We are pleased to announce that the locations of our annual International Conferences up until 2016 have been decided *(see right).*

## 2012 abstract submission

Abstract submission for the 2012 annual International Conference closes on 14 October 2011. If you have something you would like to share with the global dementia community then please do submit an abstract. Visit the conference website at www.adi2012.org for a full list of abstract topics.

**2012: London, UK**
7 – 10 March
www.adi2012.org

**2013: Taipei, Chinese Taipei**
17 – 20 April
www.adi2013.org

**2014: San Juan, Puerto Rico**

**2015: Perth, Australia**

**2016: Cairo, Egypt**