Alzheimer's Disease International

June 2010
Volume 20 No.3

Global Perspective

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

25th International Conference of Alzheimer's Disease International

Making a difference

Living with dementia, current issues in care, developments in advocacy and the latest in research results for treatment and prevention were at the forefront of ADI's 25th International Conference, which took place on 10-13 March in Thessaloniki, Greece.

Over 1100 delegates attended the conference, organised in collaboration with the Greek Association of Alzheimer's Disease and Related Disorders. A delightful opening ceremony spotlighted Greek history and culture with speeches from bishops, a rector and government ministers, followed by a performance of Greek songs through the centuries.

Magda Tsolaki, President of the Greek Association of Alzheimer's Disease and Related Disorders, addressed delegates at the conference opening ceremony

An important session, showcasing a variety of efforts to engage people with dementia in the work of national Alzheimer associations, featured a particularly compelling and humorous talk from Martin Sewell and Edward McLaughlin on

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ADI seeks international Alzheimer's symbol

ADI needs your help! We are looking for an international symbol that will represent the global unity of individuals and organisations working tirelessly to improve the lives of people with dementia and their carers all over the world.

The symbol will be used by ADI and Alzheimer associations around the world to highlight their dedication to the global dementia movement. We are looking for a versatile symbol to be used in both print and electronic formats.

'A real lack of awareness still exists in too many countries,' said Daisy Acosta, ADI's Chairman. 'It is vital that we unite to improve the lives of people with dementia and their carers. In order for this union to be effective, we need an international symbol that will become instantly recognisable across the world.'

A prize of US$500 will be awarded for the winning symbol and professional and amateur designers from around the world are encouraged to enter.

Entries for the competition will be accepted from 21 June until 21 September 2010. To find out how to enter visit ADI's website at www.alz.co.uk/symbol. Five entries will be shortlisted by a panel of experts from both the dementia and design fields and these entries will then be made available on ADI's website for a public vote, which will run from October 2010 to January 2011.

So, if you have a passion for graphic design or simply have a great design idea please do visit the website and enter.

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 30 July 2010.

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Editorial

Marc Wortmann

Welcome to the third issue of Global Perspective in 2010. We produced a special Global Alzheimer's Disease Charter edition in May during the World Health Assembly, the annual meeting of the World Health Organization in Geneva. Thank you again to all of the 54,821 people who took the time to sign the Charter.

We had the pleasure of seeing many of you during our conference in Greece in March, which was a successful event and was highly praised by those who filled in the evaluation survey. Thanks for doing this; the information is extremely valuable in improving our conferences and tailoring them to your wishes. As you may have experienced during the closing ceremony, Canada can't wait to welcome you next year and we are working hard on the programme and other events. It is set to be an exciting conference. Please save the dates: 26 - 29 March 2011.

Research issues were frequently discussed during this year's conference. Thanks to the award for psychosocial research we ran this year with Fondation Médéric Alzheimer for the second time, we've seen a growing interest in this very important field. There is an ongoing debate about prevention and how this can be supported by scientific evidence, which is still controversial, but we need directions from our scientists and ADI is currently working on this with a special research group. Finally, insights are shifting with regards to the pathway to cure Alzheimer's and dementia. We are grateful that Sam Gandy agreed to explain some new findings in the research update of this newsletter.

Thanks for reading this newsletter and remember that ADI is there for you, so don't hesitate to contact us when you need our information or support!

Events

2010

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

25 – 28 September 2010
14th Congress of the European Federation of Neurological Societies
Geneva, Switzerland
Tel: +41 22 908 04 88
Email: efns2010@kenes.com
Web: efns2010.org

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

20 – 23 October 2010
Seventh International Congress on Vascular Dementia
Riga, Latvia
Tel: +41 22 908 0488
Fax: +41 22 906 9140
Email: vascular@kenes.com
Web: www2.kenes.com/Vascular/Pages/home.aspx

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

28 – 31 October 2010
The Fourth World Congress on Controversies in Neurology (CONy)
Barcelona, Spain
Tel: +972 3566 6166
Fax: +972 3566 6177
Email: cony@comtecmed.com
Web: comtecmed.com/cony/2010

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

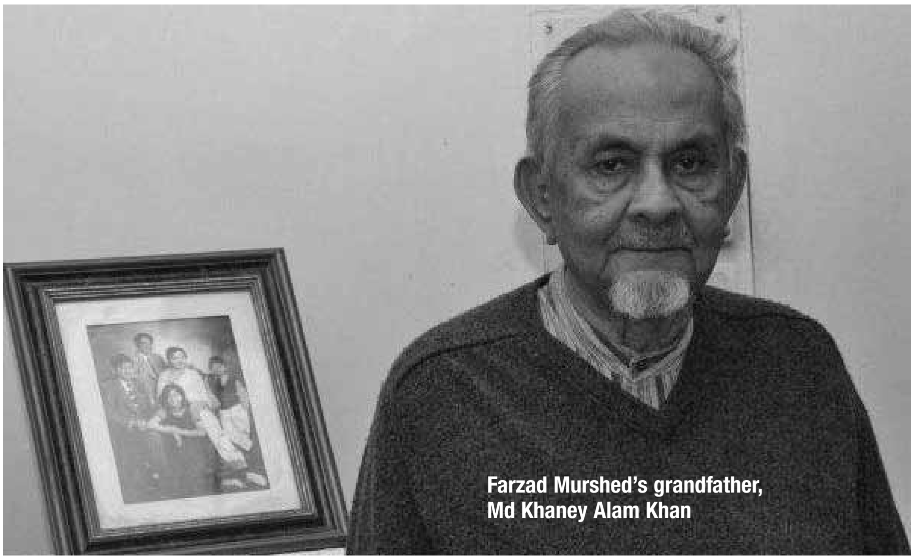
VISIT WWW.ALZ.CO.UK/EVENTS FOR MORE CONFERENCES AND ANNOUNCEMENTS

from the heart

History of an Alzheimer's patient

Farzad Murshed, Bangladesh

Md Khaney Alam Khan was the former Divisional Commissioner of Dhaka Division and retired from Bangladesh Government service as the Chairman of Land Revenue Board. He began his service career as a Deputy Magistrate to the then East Pakistan Government. His service to the government continued in a number of positions and in various locations across Bangladesh. This enabled him to serve this country in a way that made a difference. He was a firm believer in education and its benefits, which led him to open and reconstruct over 100 schools and colleges in various parts of Bangladesh.



Farzad Murshed's grandfather, Md Khaney Alam Khan

Retirement from Government service did not stop him from working and he took up the legal profession. He proved to be a very hard working person and led an extremely successful career throughout his life. At around the age of 87 however, he started being affected by dementia that led to him giving up his working life.

Mr Khan started showing symptoms of Alzheimer's disease in 2003, when he began to lose his memory. He started with short-term memory loss and was not able to recognise certain people he had known before. He started rejecting any unpleasant news. Slowly he started to lose his motor skills, as he found it difficult to walk, get up from the chair and was imbalanced in doing things.

In late 2007 he became bedridden. At that time, his speech skills were severely impaired. It was difficult for many to communicate with him, one reason being he could never answer properly and another being that because of his memory loss, he could not recognise a lot of people.

To monitor his health, in particular his blood sugar and blood pressure counts, a nurse would come to check on him every day, and a physiotherapist would come and help him exercise his legs, neck and hands everyday to ensure his blood circulation was maintained as well as keeping the organs a little bit mobile. Because he had lost the ability to move, it was crucial that he received physiotherapy. This service proved really effective for Mr Khan until his last day, because after being completely bedridden for almost two years he had no signs of bedsores at all. His maidservants would stay with him at all times, always providing conversation. This was also a helpful step, as it worked to keep his brain active. The TV in the room would run 18 hours a day for the same reason. It was seen that even though he could not talk, occasionally he would say one or two coherent words.

Mr Khan passed away on 30 November 2009 from what seemed like a cardiac arrest. If it had not been for the constant attention he had received from his maidservants, then many unfortunate incidents would have definitely occurred at the time of his death. This is why it is important that Alzheimer's patients receive constant attention. Preferably, it should come from loved ones, despite how hard it may be for them. Family members can provide the love and attention that nurses or doctors cannot, and that makes things easier for patients of Alzheimer's. Communication helps too, as it helps to keep the brain active.

A hard fact to deal with Alzheimer's is that there is no cure for it as of yet. The impact can be long term and slow. This can be sad, especially for friends and family of the patient. People around the patient should strive to keep the patient physically well. At times like those, that is the best way to go. Doctors these days say that as long as the patient is alive, the best measure to take is to make sure that they are as comfortable as possible. When one is taking care of an Alzheimer's patient, he or she must act in such a way as to ensure that the patient suffers from no illness or physical pain, and provide the patient with love and care. Also, more importantly, we as family and friends should not give up hope for one moment. For now this is the treatment we must use.

At present Farzad Murshed is working as a volunteer for Alzheimer Society of Bangladesh, a voluntary organisation working to raise awareness among the general public.

Members' forum

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

DOMINICAN REPUBLIC

Asociacion Dominicana de Alzheimer hosted a conference on 16 April in the province of San Pedro de Macorís, where they were invited to talk to a group of professionals including both general practitioners and carers. ADI's Chairman, Daisy Acosta, was the principle speaker at the event, where participants were informed of the global impact of dementia as detailed in the World Alzheimer Report 2009.

Ramón Asensio, who has been caring for his wife since she developed dementia nine years ago, also attended the event. Mr Asensio, who is well regarded in San Pedro, spoke openly about his experiences and expressed a willingness to start a chapter of the national association in San Pedro.

A lively questions and answers session took place following the presentation and feedback from the event was very positive, highlighting in particular that the general practitioners in attendance understood the importance for them to detect dementia and make an early diagnosis.

Ramón Asensio speaks to Daisy Acosta during the conference

UK

Successful collaboration with leading health provider

Comedian and actor Hugh Dennis and performer Sophie Mei at the launch of the Bupa Great Yorkshire Run

Bupa, a leading care home and health provider, has nominated the Alzheimer's Society and Alzheimer Scotland as charities for the Great Run Series for 2010. The Great Run Series, which takes place from May 2010 to January 2011, consists of eight separate runs covering many areas of England and Scotland.

This fundraising initiative marks just one of a number of recent collaborative efforts between Bupa and the Alzheimer's Society. In September 2009 they launched the Dementia Champions campaign in 130 Bupa care homes across the UK. The aim of the campaign was to establish in-house leaders in each care facility to champion good dementia care. Bupa, with nearly a quarter of their beds occupied by people with dementia or Alzheimer's disease, are the only care group to provide care staff trained by the Alzheimer's Society.

In 2009, Alzheimer's Society and Bupa Foundation, Bupa's medical research charity, also launched an international competition calling for projects focussed on the cause, cure, care and prevention of dementia, offering grants over two or three years.

To complement this collaboration a Bupa television advert focussed on the standards of care for people with dementia in their care homes was produced and is regularly broadcast on the country's leading television channels.

ADI welcomes new members

ADI are pleased to announce that three new associations were accepted for membership of ADI at the Council meeting in March.

Alzheimer's Disease Armenian Association, founded in 2002, currently offer an Alzheimer's and dementia school consisting of weekly lectures and training. They also hold a daily clinic and national database of people with dementia and have had papers published in various journals in both Armenian and Russian.

Fundacion Alzheimer Aruba has developed a range of services since their formation in 2003, including home counselling, Alzheimer's social club and education and training programmes. Melva Croes-Yanez, president of FAA commented, 'We are a small island of only 100,000 inhabitants, but we hope to make a contribution to ADI and make new friends.'

Michail Aghajanov from the Alzheimer's Disease Armenian Association at the Alzheimer University in 2008

Alzheimer Association Mauritius, set up in 1995, run a day care centre, helpline and offer free consultations. The association also prepare monthly activities for people with dementia. Ameenah Sorefan, President of the association, expressed her gratitude to Council, adding, 'The work starts now. We are really committed to the cause and look forward to being a part of the ADI family.'

LEBANON

Launch of *Breaking Barriers* workshops

In collaboration with the Scientific Committee at Notre Dame Du Liban-Jounieh Hospital and the Faculty of Public Health at the Lebanese German University, Alzheimer's Association Lebanon launched its first workshop on training of staff in Lebanese hospitals, at the Lebanese German University, Sahel Alma in February.

126 nurses and students from five different hospitals attended the workshop, for which they received a certificate of attendance.

After a welcome from Dr Paul Makhlouf, Dean of the Faculty of Public Health at the Lebanese German University, the workshop programme commenced with a testimony from Mr Elie Ghazal. Dr Nabil Naja presented an overview of Alzheimer's disease and Diane Mansour, President of Alzheimer's Association Lebanon, spoke on the issues surrounding dignity and human rights. A questions and answers session followed a speech by Miss Dima Oubary who highlighted the benefits of sensorial communication.

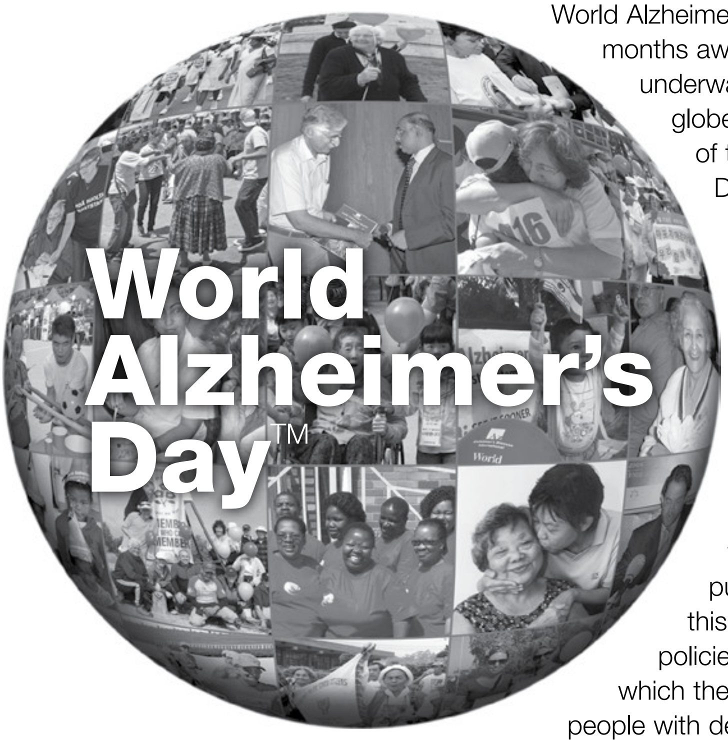
This workshop, which is part of Alzheimer's Association Lebanon's 2010 programme, aims to provide training to staff in different hospitals throughout Lebanon, creating an atmosphere of harmony and understanding and enhancing the quality of care for thousands of people with Alzheimer's disease.

Further workshops have taken place in recent months and will continue throughout the year.

The workshops aim to improve the level of service for people with dementia across Lebanon

Members' Forum CONTINUED

It's time for action!



World Alzheimer's Day™ 2010 is just three months away and plans are well underway for activities around the globe. ADI, with the assistance of the World Alzheimer's Day working group, have developed a range of materials which are available online now for members to translate and adapt.

The theme for World Alzheimer's Day this year is *Dementia. It's time for action!* ADI and Alzheimer associations across the world will be looking to really put pressure on governments this year to evaluate their current policies and consider ways in which they can improve services for people with dementia and their carers. ADI are also eager to assist members in raising awareness among the general public, encouraging individuals to educate themselves about dementia and work together with their national association.

Materials available for members include bulletins, stickers and bookmarks in English and Spanish

To find out more about planned events in your country visit www.alz.co.uk/WAD2010

ADI to launch World Alzheimer's Month

Each year ADI members across the world arrange a host of activities for World Alzheimer's Day with many events extended over a couple of weeks or a month. In response to this and requests from many members, ADI's Board have agreed to the introduction of September as World Alzheimer's Month.

'World Alzheimer's Day is a strong brand and this should not be given away,' said ADI's Executive Director, Marc Wortmann, 'but we believe there are many advantages to giving our members the freedom of a whole month.'

ADI plan to co-ordinate pilot World Alzheimer's Month activities in a few countries this year with the aim of full implementation from September 2011. ADI are also currently working on an international campaign for the introduction of World Alzheimer's Month.

ADI has been informed that **Alzheimer Portugal** has made the decision to cease their ADI membership as they wish to prioritise their work within Portugal and Europe. Alzheimer Portugal was accepted for provisional membership in 2004 and became a full member two years later. ADI would like to thank the association for their involvement and support since becoming a member and wish them all the best for the future.

Making a difference CONTINUED FROM FRONT PAGE

the work of the Scottish Dementia Working Group (SDWG), which is run by people with dementia. Yoko Mizutani described efforts in Japan to integrate the voices of people with dementia in their governmental advocacy appeals and Peter Ashley, who has dementia with Lewy bodies, presented the Life History Network's *Portrait of a Life* toolkit, which promotes well being and helps people with dementia to maintain relationships.

Strong emphasis was placed on non-pharmacological treatment for helping people with dementia and their carers throughout the conference. Topics included support groups for people in the early stages of dementia, stress management programmes for carers, implementation of "smart house" technologies to support families coping with dementia, nutritional interventions, and a variety of other methods for increasing physical activity, mental stimulation and social connectedness among people with dementia.

An interesting session on the arts and dementia included creative and thought-provoking work, including an innovative photographic awareness campaign organised by German photographer Michael Hagedorn, an art therapy programme in Croatia, a touching film about a mother's 'second life' as she lives with dementia, and a *Show Compassion* benefit concert held in Australia in 2009. Judith Fox talked about her experience photographing and caring for her husband during the creation of her new book, *I Still Do* and Berna Huebner presented an excerpt from her feature-length documentary about the positive impact of the arts on people with dementia.

Delegates at the conference were informed of new findings in dementia medical treatments and diagnosis. Dr Sam Gandy described new treatment developments in dementia, including therapies that have the greatest potential for entering clinical practice in the next few years. Prof Frank Jessen covered recent advances in neuroimaging and its benefits for both better and earlier diagnosis and increased understanding of the progression of the disease. Prof Bengt Winblad presented ongoing trials into dementia, summarising the most positive medications currently being tested. Pieter Jelle Visser addressed the relationship between mild cognitive impairment and early diagnosis of dementia.

Martin Sewell and Edward McLaughlin presented the work of the Scottish Dementia Working Group

Conference delegates were also informed of the activities of ADI's recently developed prevention working group, which seeks to guide the development of effective dementia prevention approaches.

A thoughtful symposium, combining a presentation from Prof Roy Jones and footage from a 6-year video case history conducted by Daniel Christensen, highlighted obstacles to diagnosis and treatment of dementia, including reasons for delay in seeking medical intervention, choices to continue or discontinue drug treatment, and perceived caregiver burden.

A variety of discussions and presentations throughout the conference focused on the formation of a Global Alzheimer's Movement and improving dementia care and treatment. Others touched on ethical issues in dementia and fundraising in the current difficult economic climate.

Videos and abstracts from the 25th International Conference of Alzheimer's Disease International are now available at www.alz.co.uk/conference.

Registration for the 26th International Conference of Alzheimer's Disease International opens on 1 July 2010 and more information can be found at www.adi2011.org.

Active life with dementia

ADI's Photography Competition result

To mark its 25th anniversary Alzheimer's Disease International (ADI) ran an International Photography Competition with the theme Active life with dementia. Amateur and professional photographers were invited to submit photographs depicting people with dementia continuing to live a mentally or physically active life after diagnosis.

Thirty-seven photographs were received from twelve countries across the world, including two taken by people with dementia.

The judges for the competition were Graham Browne, a person with dementia from the UK, Phil Coomes, Picture Editor and Photographer for BBC News Online, Eamonn McCabe, Photographer for The Guardian newspaper, Paul Sanders, Picture Editor for The Times newspaper, Boris Spremo, a professional photographer based in Canada and John Voos, Editor in Charge of UK Pictures at Thomson Reuters.

The winners of the competition were announced during ADI's 25th International Conference in Thessaloniki, Greece in March. The top six entries in each category and the two submissions from people with dementia were displayed throughout the conference and published in the conference programme book.

Antigoni Diakou, from the Cyprus Alzheimer Association said of winning the award, 'This is great news and an honour for Cyprus and the stigma breakthrough of ADI'.

Phil Coomes, one of the competition judges, shared his experience of taking part in the competition on his BBC blog, which can be found at www.bbc.co.uk/blogs/photoblog/2010/03/picturing_an_active_life_with_dementia.html

AMATEUR
1st Katherine Leong Peck Fun, Malaysia
2nd Theresia Jelmini-Nobel, Switzerland
3rd Janet Wood, Zimbabwe

1st

2nd

3rd

PROFESSIONAL
1st Andreas Philippides, Cyprus
2nd Leonardo Ramirez, Venezuela
3rd Paula Ines Conti, Argentina
3rd Andreas Philippides, Cyprus

1st

2nd

3rd

3rd

Living with dementia

Christine Bryden, Australia

This journey with dementia is like a slow roller coaster, with corners, ups, downs and upside-downs!

It's been a long journey for me since the day of my diagnosis with dementia in May 1995. I rushed off that morning to the neurologist, for the results of my scans and tests, planning to rush back to chair a meeting; the rest of the day planned to the minute. But that was not how it was to be.

Christine, front right, and husband Paul, front left, at their daughter's wedding in September 2009, a day Christine thought she'd never live to see.

I had struggled for years with, what I thought was the result of stress: frequent migraines, getting lost on familiar routes, and making mistakes in speech and writing. All not surprising, given my unhappy marriage, my senior civil service job, and my MBA studies. After my divorce in 1994, I was delighting in my new single life with my three girls aged 9, 14 and 19, but finding it increasingly difficult to cope.

Finally my doctor sent me for routine brain scans to check for a reason for my headaches. The result: generalised atrophy like someone in their 90s, but not a 46-year-old. More tests were done, and the neurologist was to give his verdict - and what a life sentence it was! I caught snatches of it in my shock – 'You have dementia… You must retire immediately… You'll be in a nursing home within about 3 to 5 years… You'll probably be dead in about 5 to 8 years.'

It was a muddle of confusion, struggling to cope with the fear of the future, for me and my girls. The trauma of diagnosis and its aftermath had a terrible toll on all of us – as did the early anti-dementia medication. By 1998 I had managed to write a book about my fear of dying with dementia and some of my experiences: *Who will I be when I die?* (HarperCollins). Then I plucked up courage to approach the local Alzheimer association, and found support on what has been a long journey in the slow lane of dementia.

They encouraged me to live positively with dementia – so much so that I even joined an introductions agency, meeting Paul, my husband and carer. What a wonderful man – taking me and my girls on, despite our trauma and uncertain future! With Paul's help, I was able to speak out for all those living with dementia that could not express their feelings and needs. I was the first person with dementia to speak at an ADI conference, in 2001, attending together with my other friends with dementia that I had met on the internet through the Dementia Advocacy and Support Network International (www.dasninternational.org).

At the 2003 ADI conference I was honoured to be elected to the Board of ADI, and did my best over the next few years to continue to be a voice for people with dementia. The 2004 conference marked a big change in the care and support of people with dementia and their families in Japan. My second book, *Dancing with dementia* (Creates Kamogawa and Jessica Kingsley Publishers), was released at that conference. The book talks of my journey, its ups and downs, what it feels like and how to help. I could not have written it without the amazing inspiration of all my friends – with and without dementia - in the worldwide "Alzheimer's Family" of ADI.

By the time we went to the 2006 ADI conference, I was burnt out and exhausted, and the next year or so I was not well at all. This journey with dementia is like a slow roller coaster, with corners, ups, downs and upside-downs! This year I am surviving, feeling better than before, and was able to go to the 2010 ADI conference. We plan to go again next year, marking a decade since I first spoke in New Zealand.

All I can say after so many years of surviving this bumpy ride with dementia is don't give up hope. Enjoy the moments of clarity, manage your energy levels, treasure your caring family, and remain engaged with life. ADI is truly wonderful in the way it has nurtured all of us living with dementia – both those with the diagnosis and our family carers. Thank you.

Research Update

Friedman Brain Institute research causes a 'paradigm shift' in the focus of Alzheimer's research

Sam Gandy, MD, PhD, Professor of Alzheimer's Disease Research, Mount Sinai School of Medicine, USA

Alzheimer's disease (AD) is the most common cause of the clinical syndrome of dementia, a state that literally means 'loss of the ability to think'. Dementia affects half of the over-85 population, and AD is responsible for about two-thirds of all dementia. The signature change in the brains of Alzheimer's patients is the build-up of structures called plaques that are composed of a substance called amyloid-β. Clinicians and neuropathologists have long recognised that amyloid plaque levels (or 'plaque burden') is a poor predictor of cognitive function at the time of death. As more refined techniques for measuring different forms of amyloid-β have become available, this correlation has been revisited again and again. This is the backdrop for why the current set of experiments was undertaken.

Amyloid-β normally floats around and between brain cells, but in AD, the amyloid-β sticks together and forms two types of abnormal structures: (1) string-like fibres that build up to form the amyloid plaques, and (2) less organised clumps called oligomers. 'Oligo' means 'few'. Oligomers composed of two amyloid-β molecules is called a dimer; oligomers composed of three amyloid-β molecules is a trimer, and so on. An oligomer composed of twelve amyloid-β molecules is a dodecamer. Oligomers and plaques seem to be on different pathways, and there is some evidence that drugs that turn oligomers into plaques might even be beneficial. This concept would've been nearly laughable ten years ago. Now this seems likely to be true.

Brain amyloid-β comes in various lengths, typically abbreviated as 'short amyloid-β' for the form composed of 40 building blocks and 'long amyloid-β' for the form composed of 42 building blocks. This 'long amyloid-β' is much stickier than the short amyloid-β40, and long amyloid-β is believed to initiate the formation of all types of structures: oligomers, fibres, and plaques. Both long and short amyloid-β are products of normal metabolism of all cells in the body, although the brain makes more than any other organ. The genetic forms of AD all lead to amyloid-β with changes in the building blocks. These changes are called mutations and they often cause the brain to produce abnormally high levels of the 'super-sticky' long amyloid-β.

The fact that genetic mistakes in amyloid can cause AD provides irrefutable proof that mistakes in amyloid metabolism can cause AD. In fact, of all the forms of AD that have been studied, the only starting point that we are certain about involves amyloid metabolism. Furthermore, any model of how any form of AD occurs must account for why amyloid builds up.

Another piece of evidence pointing to oligomers came from scientists who took extracts from the brains of people with Alzheimer's disease and applied the extracts to nerve cells in a dish. When they looked at these extracts under the microscope, they were surprised to see that the extracts that killed the nerve cells in the dish most potently were not filled with plaques but rather with oligomers.

A few years ago, my colleague, Dr Michelle Ehrlich, Professor of Pediatrics and Neurology and lab head in the Friedman Brain Institute, created a mouse into which she placed a human Alzheimer's gene. These mice developed no plaques, but they could not form new memories very well.

At the time, we didn't understand why they had such poor memories, and we didn't figure that out until we developed a method for measuring oligomers. Sure enough, the level of oligomers

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predicted the severity of the memory problems. Then, just to see what would happen with plaques, Dr Ehrlich added a second Alzheimer's gene that would cause plaques to develop on top of the oligomers. These mice were still unable to form new memories well, of course, but they were no worse off than the 'oligomer-only' mice. Again, after the mice died, we measured the levels of oligomers in their brains. Again, the severity of the memory problem was related to the levels of oligomers, but we were also able to determine that the memory problems had no relationship to the burden of plaque build-up. We concluded that oligomers are more important than plaques.

This is especially important as we develop new brain scans that show amyloid build-up. Even the very newest research scans show only plaques and not oligomers. One goal of our research group is to develop brain scans that reveal oligomer build-up even before any memory problem develops. Someday, we might be able to perform 'oligomer brain scans' that predict exactly who will develop AD and perhaps even predict when that will happen. We cannot do this yet, but we are optimistic that this might be possible. Does this mean that plaques are totally unimportant? Probably not. Our working model is very simplistic. There may well be oligomers trapped in plaques along with the stringy fibres, for example. We are not ready to discard plaques altogether, but we must think about effectively preventing build-up or accelerating clearance of brain oligomers as well as brain plaques.

Psychosocial research

ADI Executive Director Marc Wortmann and FMA's Michèle Frémontier present Dr Amit Dias, centre, with the award for best evidence-based psychosocial research

ADI and Fondation Médéric Alzheimer (FMA) presented two awards for psychosocial research in Alzheimer's and dementia at ADI's 25th International Conference in Thessaloniki, Greece in March.

Psychosocial research involves or relates to both the social and psychological aspects of a patient's life. Often this includes the relationship between the personal, internal environment and the wider social world, such as the influence of social and environmental factors on an individual's state of mind and/or behaviour.

The first award was given to Dr Amit Dias, Lecturer at the Department of Preventive Medicine at Goa Medical College, India, for the best evidence-based psychosocial research. Dr Dias received 18,000 euros to spend on dissemination of the research findings of his project, *Effectiveness of a community based psychosocial intervention for supporting people with dementia and their caregivers in developing countries.*

Dr Dias and his team conducted a randomised, controlled trial in India using a flexible, stepped care approach to address the needs of families of people with dementia. This is one of the first evidence-based interventions in Asia on non-pharmacological means to address the needs of people with dementia and their families.

'The project showed that home-based support for caregivers of persons with dementia, which emphasises the use of locally available human resources, is feasible and acceptable,' Dr Dias explains. 'The support leads to significant improvements in caregiver mental health, reduction of the burden of caring, and has an impact on the quality of life of the people with dementia.'

The research findings are published in the peer reviewed scientific journal PLOS One and are freely available

award

Anne Margriet Pot addressed delegates at the conference after receiving her award

on the Internet. The project was initially funded by the World Health Organization and the Government of India's Ministry of Social Justice and Empowerment.

Dr Dias is Secretary of the Dementia Society of Goa, a chapter of the Alzheimer's and Related Disorders Society of India, and coordinator of the national association's Medical and Scientific Advisory Panel. He is also responsible for coordinating the 10/66 Dementia Research Group in India.

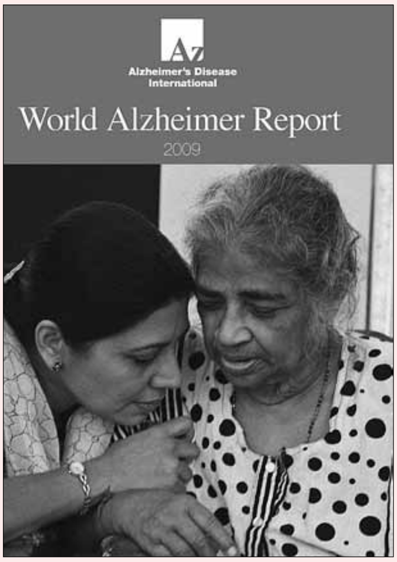
The jury, made up of representatives from FMA and ADI, along with medical professionals, a person with dementia and the winners of the 2009 award, were particularly aware of the effectiveness of the intervention in developing countries. A special recommendation in this category went to Prof dr Rose-Marie Droës for her application *Implementing of the Meeting Centres Support Programme in Europe*.

A second award was given in the category of most promising evidence-based psychosocial research. Prof Anne Margriet Pot of the Free University in Amsterdam, Netherlands received 7,000 euros for *Mastery over Dementia: an innovative e-mental health intervention for family caregivers of people with dementia*. The award will be used for translation and further spread of this programme throughout the membership of ADI. The jury gave a special recommendation in this category to Prof Li-Chan Lin from the National Yang-Ming University in Chinese Taipei for her project, *The Efficacy of Acupressure and Montessori-based Activities to Reduce Agitated Behaviour in Demented Elders*.

'This award shows how much teams, wherever they are located in the world, prove to be creative in order to enhance the life conditions of people with dementia,' said Bruno Anglès d'Auriac, Chairman of FMA. 'These teams are initiators of experiences and knowledge on innovative ways of taking care of people with dementia and their carers.'

Due to the success of the award in its first two years FMA and ADI announced during the ADI conference that they would be running the award for a third year. More details of this can be found at www.alz.co.uk/award

World Alzheimer Report 2010



The World Alzheimer Report 2009 presented the most comprehensive global prevalence study of dementia to date

There are currently 36 million people worldwide living with dementia and this number is expected to rise to 66 million in 2030. By 2050, it is projected that this number will increase to 115 million and the World Alzheimer Report 2009, released on World Alzheimer's Day last year, provided us with an insight into the impact of this increase on societies around the world.

On World Alzheimer's Day 2010, ADI will release the second World Alzheimer Report. This document, researched by Prof Anders Wimo and his team at the Karolinska Institutet in Sweden and Prof Martin Prince of King's College London's Institute of Psychiatry, who leads the 10/66 Dementia Research Group, will consider the economic impact of dementia, offering detailed estimates of the cost of dementia worldwide and per world region.

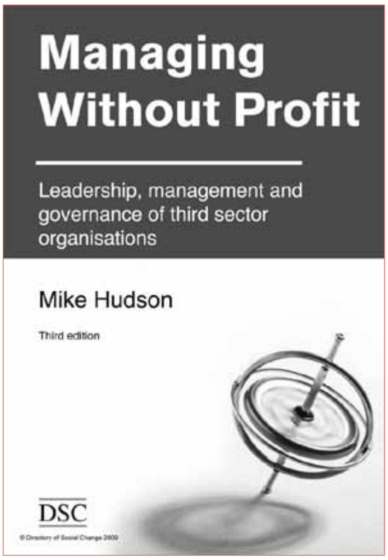
The report will be used by ADI and its members as an advocacy tool to strengthen awareness campaigns across the world and encourage policy-makers to improve services for people with dementia and their carers.

These reports can be viewed in full at www.alz.co.uk/worldreport.

The life cycle of an organisation

At the Alzheimer University for emerging associations ADI provides participants with a book entitled *Managing without profit* by Mike Hudson, which contains a section on organisational development. This inspired us to consider the life cycle of an Alzheimer association. Although the following information may not reflect cultural differences, we believe there are some elements that can be useful for every organisation.

For more information on this topic, see *Managing without profit*, Mike Hudson, Directory of Social Change, ISBN 978-1903991992



Just like a human being an organisation can have a life cycle. All ADI members have experienced the first stage of pioneering, or the emerging stage, and many are still going through this process. In the emerging stage a group of very dedicated volunteers, often guided by the founder, carry out all the work of the association. They organise meetings, approach the media, create awareness campaigns, set up support groups, produce a newsletter, recruit other volunteers and talk to the government. It is often amazing to see the passion of a small group of people doing so much work and making a lot of progress.

For those who have just started it is important to remember that this stage has taken place in the development of every association. In the Netherlands, the association started at the kitchen table of Henk and Vera ter Haar, who contributed to the first television programme on Alzheimer's in 1984. The programme generated a high level of response and it was this response that encouraged this small group of people to start the association. This group carried out all the work of the association as volunteers, until they were able to apply for a grant from the government some years later. The grant was enough to start an office with a few staff and initiate a helpline.

Staff hire is a landmark of the second, or developing stage, that often starts with one or a few members of staff. This can coincide with the development of new Board leadership, another feature of this stage that can be a change of Chairperson or enlargement of the Board. The Board is still very much involved and offers direction to staff on effective ways to carry out the work. At this stage more funding is achieved and often staff members start to develop systems and procedures for activities like support groups or helplines. One of the challenges that organisations meet is working on the basis of consensus (which normally happens in the pioneer group) and consulting as part of the governing process. At this stage the Board has to learn not to interfere in the day-to-day decisions, although they will need regular reports on what is happening. The Board is responsible for making policy decisions on major issues like the budget, new projects or the set-up or inclusion of local or regional chapters or branches. In a small association the Executive Director reports to the Board about activities on an individual basis, but as the organisation grows there will be a need for more specific activities reports.

In the third stage the organisation is becoming established. The number of staff has increased and it performs all kinds of functions like information and service provision, advocacy, fundraising and possibly a scientific department. The work is more structured and systems are established in the whole organisation. There is also enough money for the main activities and the organisation is well recognised as a main player in the field with chapters or branches covering most of the country.

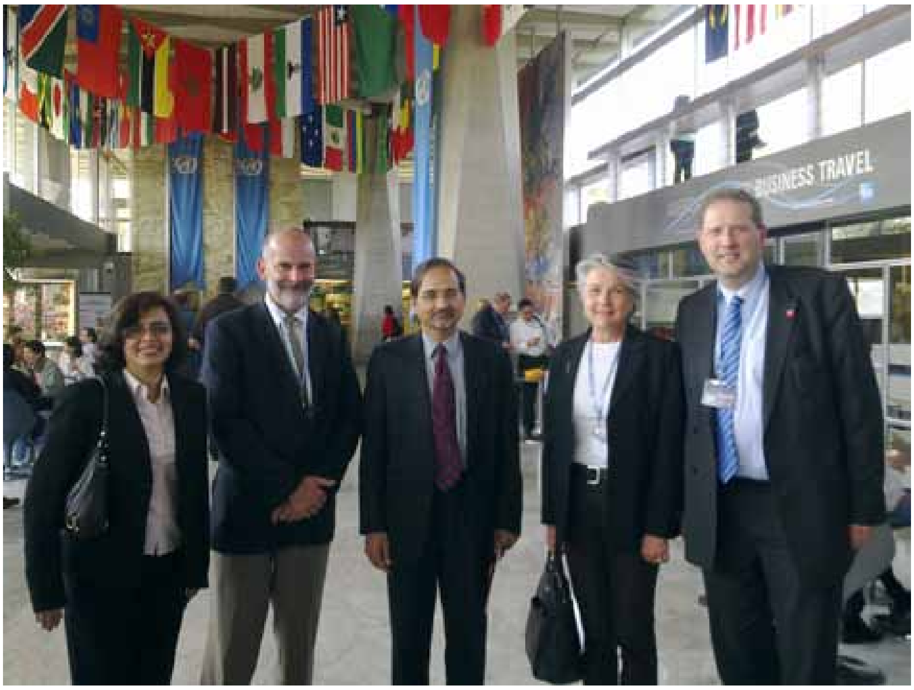
Within the Alzheimer's movement around 10 associations have entered the established stage. The one remaining stage in the cycle is the point at which the needs of the organisation change and a period of rejuvenation is required. Some of the most developed Alzheimer associations are currently looking at improvements after reaching the established stage. Many others are in the process of transformation from one stage to the other. This is often an ongoing process without a clear moment of change. The period between each stage can be a difficult time with a lot of discussion or a clash of opinions and some people may leave the organisation because they do not agree with the steps that are taken. Knowledge of these stages of development may help those within the organisation to accept the challenging situations they face. It also may help to visualise the organisation as a child growing up and gaining independence.

The role of the founding volunteers differs in each stage. In the emerging stage they need to be flexible, always available and have the ability to multi-task. They are very involved in all decisions, which are often based on consensus. However, in the developing stage they are required to hand over some tasks to the staff while retaining control of many issues. In the establishing stage the separation of governing and doing the work becomes clear. The tasks of the founding volunteers become more specific and they are more likely to take on a governing role. Volunteer policies are developed and volunteers, like Board members, get role descriptions.

Emerging stage	**Developing stage**	**Establishing stage**
Phase of pioneering	Phase of growth	Phase of professionalising
• Small dedicated group • 'Founders passion' • Focus on: awareness, information, education, some support • Few systems • Little resources/funding • Flexible, opportunistic • Informal decision process/ consensus • Volunteers are flexible, always available and multi-tasking, performing all of the required tasks	• Some staff • New leadership • Attempts to develop systems • Confusion between consensus and consultation • More funding • First chapters/branches • Reporting starts • Volunteers hand over specific day-to-day tasks to staff but are still in control of many issues	• Lots of staff • Board governs • Managers manage • Systems established • Clear reporting • Good funding • Chapters/branches covering most of the country • But: loss of ownership • Specific tasks for volunteers with job descriptions • Volunteer policy

News

WHO is heading our way!



Tarun Dua, Martin Prince, Shekhar Saxena, Birgitta Martensson and Marc Wortmann at the World Health Organization headquarters in Geneva

A small delegation formed of Martin Prince, leader of the 10/66 Dementia Research Group, Marc Wortmann, Executive Director of ADI, and Birgitta Martensson, Executive Director of Association Alzheimer Suisse in Switzerland, took part in an exciting and interesting meeting at the World Health Organization (WHO) Head Quarters in Geneva on the 20 April.

A one-hour exchange took place with the Assistant Director-General, Dr Ala Alwan who is responsible for non-communicable diseases and mental health at the WHO. Dr Alwan made clear that the WHO is keen to carry out more work into dementia and understands the growing problem and the need for better services, both in developed and developing countries. During the meeting ADI were asked to develop a joint work plan with the WHO staff, with a focus on vision, roadmap and implementation.

The discussion had been prepared together with Dr Shekhar Saxena and Dr Tarun Dua, both working in the department of Mental Health at the WHO, who encouraged a lively, open and constructive discussion. ADI expects both Dr Saxena and Dr Dua to be important partners in the development of the project.

'It is clear that ADI is seen as a very serious and active partner,' said Birgitta Martensson, following the meeting, 'and that all the facts and figures published in recent years, including the 10/66 data on prevalence and care around the world, the Global Alzheimer's Disease Charter and the World Alzheimer Report, have been duly recognised for their outstanding input in the debate. The constant presence of ADI representatives at every WHO regional meeting in recent years has not gone unnoticed.'

It is expected that the benefit of recognition from the WHO will be extremely valuable, both in developed and developing countries. ADI are grateful to all members who have dedicated time, effort and support to this cause. We are hopeful that it will prove to be an excellent investment.

An advocacy special will feature in the next issue of Global Perspective, with an update on the WHO and members' campaigns.

The Changing Face of Dementia

On 1 July, registration for ADI's 26th International Conference in Toronto, Canada will open. ADI and the Alzheimer Society of Canada invite you to take part in what promises to be an exciting and enlightening event. The conference will run from 26-29 March 2011 and early bird registration will close on 14 January 2011.

Online abstract submission for the conference is now open and applications will be accepted until 1 October. For registration and abstract submission or for more information about the conference visit www.adi2011.org.

During ADI's Board meeting in March it was agreed that ADI's International Conference would be held in Cairo, Egypt in 2013. ADI looks forward to working with the Egyptian Alzheimer Society who will co-host the event.