



Alzheimer's Disease International

October 2008
Volume 18 No.2

Global Perspective

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

ADI releases Global Charter on World Alzheimer's Day

As we go to print we are in the middle of an exciting week of activities surrounding World Alzheimer's Day 2008! A few days ago ADI launched the Global Alzheimer's Disease Charter, a remarkable new document that sends out a clear message to governments around the world detailing the urgent action needed to help millions of people with dementia, their carers and families around the world today and tomorrow to ensure a more positive future!

Promotion of the Charter aims to increase respect for people with dementia as members of the community and argues for appropriate access to health and social care. The plan recognises that the role of family carers is key and that families must be supported.

The full text of the Charter along with translations into many languages is available on the website www.globalcharter.org. The Charter is hosted alongside an online petition where you can endorse the Charter and leave a message of support for the dementia community around the

world. So far we have hundreds of signatures but we still have a long way to go before we reach our target of 10,000 signatures by March 2009.

ADI's Executive Director Marc Wortmann says, 'We are urging everyone to take a moment to participate in this campaign. We need our governments to sit up and take notice! Dementia is a devastating disease and one that affects the whole family. ADI is committed to gaining support for the Charter and using it to lobby governments and organisations to give people with Alzheimer's disease and dementia the attention and care that they deserve.'

ADI members have been promoting the Charter within their own countries alongside their World Alzheimer's Day activities by launching press releases and holding one off events. The Goa chapter of Alzheimer's and Related Disorders Society of India (ARDSI) held a special event where a person with dementia launched the Charter to an audience made up of carers, medical professionals and press and

highlighted the great work that the dementia community around the world is carrying out.

Film: A cup of tea



To aid with the promotion of the charter, ADI produced a short film with the aim of generating interest from the wider public and directing them to the website to read the charter and sign the online petition. The film is titled 'A Cup of Tea' and tells a touching and compelling story intended to question the stigma built around the common misconceptions of dementia and highlight that this is not only a public health issue but also a social one.





Alzheimer's Disease International

The views stated in Global Perspective are personal and do not necessarily reflect the views of ADI. Published by Alzheimer's Disease International, London, United Kingdom. Editor: Jodie Cross. Design: Julian Howell. Printed by Maygray Graphics Ltd. Copyright © Alzheimer's Disease International. All rights reserved. ADI is a not for profit organisation registered in the State of Illinois, USA.

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 December 2008.

Secretariat

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

■ Editorial by ADI's new Chairman, Daisy Acosta



Daisy Acosta
Chairman, ADI

Back in 1994, I founded The Dominican Alzheimer's Association (ADA) together with a patient of mine Mrs Mary De Guerra, who is the mother of the very famous singer Juan Luis Guerra. She came to see me, desperately in need of help, as her mother in law had developed dementia. We both had a shared view that this devastating illness should not be confronted alone and that there needed to be accessible knowledge, information and support for people with dementia and their carers and families.

Since then I have dedicated my life to raising awareness, fighting stigma and ignorance and promoting the early diagnosis of Alzheimer's disease.

I have been involved with ADI for 14 years as active member of the Elected Board and Medical and Scientific Panel but also as a volunteer of a national Alzheimer association. I have welcomed the help and support that this network of people have given and it has taught me that we are not alone in this battle!

Today I am privileged to be the new Chairman of ADI. A position that I never dreamed I would reach. As the first Chairman from a developing country – and whose native language is not English – I am aware of the challenge that I have accepted! I hope I can give ADI a new perspective from my personal knowledge of this illness in the developing world. As a carer, a doctor and as a concerned citizen one of my missions during my Chairmanship is to facilitate the sharing of knowledge and awareness and also the strengths and weaknesses of both the developed and developing worlds, so that together we raise our voices as one. We must make Alzheimer's disease a global health priority so that people with dementia and their families receive the necessary attention from governments and health authorities around the world to gain the treatment and care they deserve.

I am confident that working together, and having God and his wisdom as our centre, we can reach each and every one of our goals to improve the quality of life of people with dementia and their families around the globe.

■ Events

2008

28 – 30 October 2008
3rd UK Dementia Congress
Bournemouth, UK
Tel: +44 20 7720 2108
Fax: +44 20 7498 3023
Email:
Caroline@hawkerpublications.com
Web:
www.ukdementiacongress.co.uk

2009

19 – 22 February 2009
6th Pan-Hellenic Inter-Scientific Conference of Alzheimer's Disease and Related Disorders
Thessaloniki, Greece
Tel: +30 2310 810 411
Fax: +30 2310 909 000
Email: elpida.alz@gmail.com or ninak@alzheimer-hellas.gr
Web: www.alzheimer-hellas.gr

11 – 15 March 2009
9th International Conference on Alzheimer's and Parkinson's Diseases
Advances, Concepts and New Challenges
Prague, Czech Republic
Tel: +41 22 908 0488
Fax: +41 22 732 2850
Email: adpd@kenes.com
Web: www.kenes.com/adpd

25 – 28 March 2009
24th Annual International Conference of Alzheimer's Disease International
Dementia: Engaging Societies Around the World
Singapore
Tel: +65 6379 5261/2
Fax: +65 6475 2077
Email: admin@adi2009.org
Web: www.adi2009.org

11 – 16 July 2009
International Conference on Alzheimer's Disease (ICAD)
Vienna, Austria
Tel: +1 312 335 5790
Fax: +1 312 604 7837
Email: icad@alz.org
Web: www.alz.org/icad/vienna.asp

2010

11 – 13 March 2010
25th Annual International Conference of Alzheimer's Disease International
Thessaloniki, Greece
Tel: +44 (0)20 7981 0880
Fax: +44 (0)20 7928 2357
Email: info@alz.co.uk
Web: www.adi2010.org



Living with frontal-temporal dementia

'Some friends say my husband was always like this'

When you meet Dutchman Jaap Kloes (aged 55), you do not expect he has dementia. With his fuzzy hair and artistic appearance he looks like a middle-aged hippy. Doctors, family and friends did not notice he had developed frontal-temporal dementia, a relatively rare form of dementia, which often starts at a relatively young age. Jaap and his wife Nel (aged 51) faced many problems. 'A lot of people do not understand', Nel says.

Frontal-temporal dementia has a wide spread of possible symptoms. Some people with frontal-temporal dementia become disinhibited. Jaap became passive. Seven years ago Nel noticed the first changes in her husband's character. 'It seemed that Jaap did not care anymore. At birthday parties he was always very busy. But suddenly he sat quiet in a corner.'

Just like many young people with dementia, Jaap started to notice that things weren't right when he was at work. 'I started doing things my way and did not keep promises anymore', Jaap realises in retrospect. Nel: 'One day a colleague called to ask why Jaap was not there yet. Jaap replied he had forgotten. Then he returned to bed.'

Jaap's disease also caused problems between him and his wife. Nel: 'We frequently had arguments. Once I said: I am leaving you. I do not want to live like this any longer.' Nel points at her head. 'It seemed like there was something wrong up there. When Jaap was fired, I immediately thought: there is something strange going on. Jaap was always a role model for his colleagues. He could not do this on purpose.'



Jaap Kloes and his wife Nel

According to the first diagnosis Jaap was depressed. Nel: 'That diagnosis did not suit Jaap. In the beginning the depression medicine helped, but after three months his situation stabilised. My husband also went to a psychiatrist. Jaap was fine in conversation, but I did not see any improvement. I wanted a new examination, but the doctors said Jaap was too young for dementia and they did not see anything wrong on a scan of his brain.'

More problems arose. Nel: 'When I was working, I was worried about Jaap. He was alone at home, gazing on the couch. He ate and drank very little. I quit my job to care for Jaap. At that moment he weighed no more than 63 kilos, while he always had weighed 76.'

A new examination, five years after the first symptoms, showed Jaap had frontal-temporal dementia. This message was very hard for Nel. As the disease progressed, Jaap struggled more with everyday tasks. 'If he said he had taken a shower, the bathroom was still dry. I did not get the help I needed. Social workers and friends did not recognize my problems. Seven days a week, 24 hours a day, I cared for him. Everything revolved around my husband. When he stood up in the morning, he needed more than two

hours to 'recover'. He spent almost an hour eating a bowl of cereal. Then he drank a cup of coffee, and a second one, and another, while smoking a lot of cigarettes. If I said I wanted to do something, he was annoyed. I had to adapt to his routine and his pace. If I had visited a relative or friend, I immediately had to go home, because he was there alone. Sometimes I did not want to go home. I did not want to see that depressive man sitting on my couch.'

Nowadays Jaap lives in a nursing home with other young people with dementia.

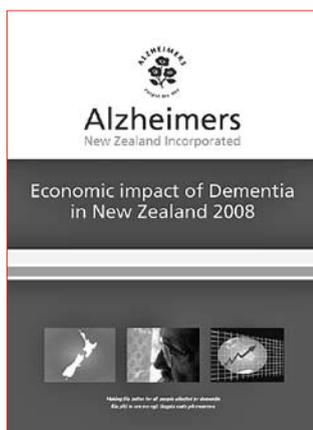
Nel: 'We have had long conversations about moving him. We both agreed it was the best idea. I will never forget the week we moved his things. I cried almost fourteen hours a day. Friends and relatives did not understand and responded harshly. 'You do not want to care for him anymore', they said. Or: 'Jaap was always like this.' I lost some friends. I sometimes wonder: did I make the right decision? But when my husband was at home, he did nothing. In the nursing home he can do whatever he wants, at his own pace. Now he is less tired, he has a better self-esteem and he has more confidence.' Jaap: 'This is the best place for me.'

Members' forum

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

NEW ZEALAND

Alzheimers New Zealand releases hard-hitting report



The Government needs to act now to prevent a crisis of care for people with dementia, says Alzheimers New Zealand, who revealed the results of a report in July showing that the country faces a dementia epidemic.

The report entitled Economic Impact of Dementia in New Zealand (2008), estimates that this year there are 40,746 New Zealanders with dementia. Of these, 12,333 were newly diagnosed in 2008.

Past chairwoman Joy Simpson said New Zealand was potentially

facing a dementia epidemic. 'By 2026, the number with dementia is projected to increase to 74,821. By 2050, there will be 146,699 people with dementia.'

National Director of Alzheimers New Zealand, Lucille Ogston said, 'This is a call to government to develop a national dementia strategy, to plan ahead. We really need to place value and invest money in our future.'

This report is a first of its kind for New Zealand and received a huge amount of national interest and press coverage.

BRAZIL

Brazilian breakthrough

The Brazilian Alzheimer association ABRAz, part of the national federation FEBRAz, has recently taken a series of exciting steps in working with their national government and health ministry. ABRAz has been selected to participate in a committee that will develop a policy on caregiver training, to be implemented throughout the country. This will mean that caregiving will be now

recognized as an official profession in Brazil with a stipulated salary basis, and will include all health ministry employees in the training.

ABRAz is a member of the National Council of Health in Brazil and has also recently been appointed to participate in a group that will prepare the 'Politics of Health of Person with Dementia', a report to be completed in December. This group will study all aspects of the needs of a Person with Dementia including health, social and financial matters. The paper is due to be signed by the President of the Ministries of Welfare, Labor, Health and Social Development. This marks the beginning of a Law that the Brazilian congress is working on together with ABRAz and will ensure that the needs of people with dementia are better met in the future.

ADI congratulates ABRAz for all of their continued hard work and dedication.

FINLAND

Memory Tour

The Alzheimer Society of Finland and The Ateneum Art Museum of The Finnish National Art Gallery have created an art tour that enables people with dementia to enjoy art. The 'Memory Tour' is a guided multisensoral tour for groups of people with dementia. It consists of 11 works of art from among the treasures of the Finnish National Art Gallery treasures with added multisensoral material (for example, a scent to be sniffed or a stone to be stroked).

The Society trained the Museum staff about dementia and a group of nurses was given information about how to use art as a means of rehabilitation. Ten pilot groups were organised to take part in the

MetLife Foundation awards grant to ADI

MetLife Foundation has awarded a \$100,000 grant to ADI and 11 of its member Alzheimer associations. The educational grant will be used for training for emerging Alzheimer associations and for raising global awareness of Alzheimer's disease around World Alzheimer's Day.

Through ADI, grants were awarded to member associations in Argentina, Australia, Brazil, Chile, China, Hong Kong SAR China, India, Japan, Korea, Mexico and the United Kingdom for their work on World Alzheimer's Day. The grant will help people around the world better understand Alzheimer's disease and its impact on families and carers.

This grant is the first of its kind for ADI, and we are delighted that this will benefit so many of our members around the world.

MetLife Foundation

gallery tour. The groups had 3-8 people with moderate or severe dementia and 2 or 3 nurses from the institutional care units and day care centres in each. Experiences of the people with dementia were observed

during the tour and the nurses were interviewed.

As a result, the ability of the Art Gallery staff to guide people with dementia was increased. The tour also stimulated memories and

feelings among the people taking part in the tour. The nurses now have a new method to stimulate their patients. The Memory Tour is also available in Finnish on the Gallery's website.

TWINNING UPDATES

UK AND INDIA

Wise woman photo

Members of Friends of ARDSI – the charity set up in the UK to fundraise for Alzheimer's and Related Disorders Society of India – gathered in Cornwall, South West England to hold a photographic exhibition one summer's evening with the aim of raising funds for resources at 'Harmony Homes' in Kerala, India.

The photographs were taken by three volunteers who had previously visited ARDSI's care facilities and wanted to lend their support. The evening was a triumph with many pictures sold. The local press visited and the town Mayor also called in to lend his support. Coordinator Jo Hague was delighted with the results. 'It was an extremely positive event and a successful evening. We are planning

another exhibition towards the end of the year as we have more stock to shift!'

Friends of ARDSI are still looking for a buyer for the 'Wise Woman' print pictured. If anyone is interested in purchasing this stunning picture please contact ADI.

Friends of ARDSI hosting the photography exhibition display the 'Wise Woman' print which is for sale



CANADA AND TRINIDAD AND TOBAGO

Eldercare Mediation

Debbie Benczkowski from the Alzheimer Society of Canada and Norma Inniss from the Alzheimer's Association of Trinidad and Tobago had the chance to promote the benefits of their twinning relationship at the first world Eldercare Mediation

summit in Ottawa, Canada earlier this year.

The duo presented a workshop on their partnership entitled Building Global Solidarity – Trinidad & Tobago and Canada

Elder mediation is an emerging discipline that works to bring family members and professionals together to address the major life changes inherent in the ageing process.

As the inevitable transitions of ageing occur, there is a need for families to make financial, legal, and emotional decisions within the context of a respectful and inclusive process, and not in the context of disagreement, difficulty, or geographical distance.

'Mediation is a formal yet fluid decision-making process that

continued over...



Debbie Benczkowski and Norma Inniss promote their twinning work

Twinning updates continued...

assists families or individuals to make the necessary decisions to meet ageing challenges,' says Debbie Benczkowski, Chief Operating Officer for the Alzheimer Society of Canada. 'The specialty of elder mediation focuses on developing quality elder care, minimizing family conflict, and increasing wise financial planning. Family mediation can generate the careful and productive dialogue between ageing parents and their adult children that is required to successfully navigate the transitions of ageing.'

World Eldercare Mediation Summit participants included certified mediators from around the world, who have an interest in elder mediation, as well as representatives from Alzheimer associations. Benczkowski and Norma Inniss, President of the Alzheimer Society of Trinidad & Tobago, spoke of their successes and their challenges as ADI twins, and the importance of developing a mutually supportive and caring relationship between

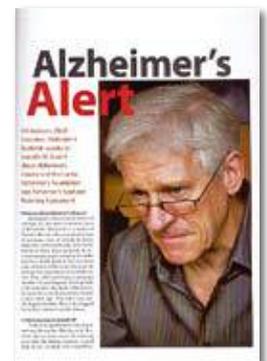
individuals as well as the organizations they represent, that is based on trust and respect. Members of the Elder Mediation International Network were keenly interested in ADI's Twinning Programme as a model for sharing expertise across their network.

Fortunately, the learning went both ways, as both Debbie and Norma's interest and understanding of Eldercare Mediation was enhanced. 'Mediation is new to me, and will be introduced to our members in Trinidad & Tobago during Alzheimer's Awareness Month,' said Inniss.

Benczkowski and Inniss have also talked about their successful partnership at ADI Conferences in Berlin, Germany and Caracas, Venezuela. In Caracas, their presentation was attended by two representatives of the Elder Mediation International Network (EMIN), Judy McCann-Beranger and Lynn Loftus, who invited them to speak at the Ottawa Symposium.

SCOTLAND AND SRI LANKA The awareness business

Jim Jackson, who has recently retired as Chief Executive of Alzheimer Scotland, was featured in a three-page article in the September issue of *Business*



Jim Jackson praises the work of the Lanka Alzheimer Foundation

Today during his visit in June to Sri Lanka. The article coincided with The Lanka Alzheimer Foundation's awareness campaign and was a fantastic opportunity for Jim to speak about the disease and talk about Alzheimer Scotland's recent twinning agreement with the Lanka Alzheimer Foundation.

Dementia is a virtually unheard of disease in Sri Lanka and the Lanka Alzheimer Foundation campaigns tirelessly to raise the profile of the dementia and encourage people who are affected to seek the help and support they offer. One of the ways that Alzheimer Scotland is supporting the foundation is to assist with preparing a training programme for carers, families and healthcare professionals, which is vitally needed in Sri Lanka.

Jim outlined ways people can help the foundation in its cause, by learning about dementia and spreading awareness among those who stigmatise the disease. He also called for more volunteers to get involved and offer their services to the foundation and, for those that can, to donate financially to help complete the building of a dementia centre in Colombo and help finance the activities planned to support people with dementia and their families.

Jim concluded by saying 'I am humbled to have worked for two weeks with people who are volunteers and work out of a commitment from their hearts. I can only pay the highest level of tribute to them'.

ADI regional meetings

Meetings between Alzheimer associations in the same world region can be of great benefit to those involved. Sometimes facilitated by similarities in language and culture, these meetings provide an opportunity to establish and strengthen networks and channels of communication. Within a world region many of the problems and challenges facing Alzheimer associations will be similar: stretched resources; difficulties in getting government recognition for their work; or the challenge of reaching marginalised populations within the country. Regional meetings give ADI members the chance to talk about their associations and learn from, and hopefully be inspired by, the work of their neighbours.



The Choir of Wisdom entertains delegates at the opening ceremony of the ADI Asia Pacific regional meeting in Taipei

Asia Pacific

ADI's 11th Asia Pacific regional meeting took place in June in the wonderful and vibrant city of Taipei. The three-day conference and meeting was organised by the Alzheimer association TADA Chinese Taipei with the inspiring theme 'Fight and Light'. It attracted 650 delegates, with representatives from over 15 Alzheimer associations within the region.

The highlight of the programme was a group of people with dementia called the 'Choir of Wisdom' who sang for participants as part of the opening presentation. This was an inspirational moment and set the tone for the conference to come. The Choir of Wisdom is

part of a service that TADA provides for people with mild to moderate dementia called the 'School of Wisdom'. The philosophy of this service is focusing on strength through expressing one's self through exercise, art and music.

Attending the meeting alongside ADI members were ADI Chairman Orien Reid, Executive Director Marc Wortmann and Membership Development Manager Jodie Cross. ADI regional members and staff met for an afternoon business meeting where they had an opportunity to discuss tangible ways to work better as a region together and how to become a unifying force in getting dementia on the global health agenda. From this discussion a strategy was drafted on how ADI

would go about targeting the World Health Organization (WHO) in the Asian and Pacific regions.

The busy programme concluded with delegates being treated to the best of Taipei's hospitality and all were given an insight to local customs, crafts and culture at a wonderful intimate gala dinner that gave participants an opportunity to reflect on a fantastic few days. The night ended with everyone up dancing and singing along to traditional local music.

Alzheimer Europe

In May, 620 people attended the 18th Alzheimer Europe conference in Norway's capital Oslo. The Norwegian Alzheimer association and Alzheimer Europe put together a great programme that included speeches from several people with dementia. Jan Henry Olsen, who is the former Minister of Fisheries in Norway, spoke touchingly about his diagnosis. Other highlights included a presentation from Florence Lustman who spoke about the progress of the forthcoming French Alzheimer Plan.

Over the last year, a number of steps have been made in putting dementia on the political agenda in several European countries, including France, Scotland, the UK, Norway and Spain. Some 70 members of the European Parliament now have joined the European Alzheimer's Alliance.

continued over...

Regional meetings continued...

Latin American



Dr Eugenio Semino and Victoria Rivas

The beautiful city of Buenos Aires, Argentina, is characterised by its wonderful architecture and changing skyline as much as its love for music and dance. It was here that ADI and Alzheimer Iberoamérica (AIB) held the Latin American and Caribbean regional meeting hosted by the Argentinean Alzheimer association ALMA. Three days of meetings and presentations built around the conference theme 'From early diagnosis towards prevention' gave those present a chance to share their experiences, skills and motivations in supporting people with dementia and their carers throughout the continent.

ADI members held a one-day meeting, which was a chance to update each other on their progress throughout the year and discuss ways in which they can work with each other in the coming year as a whole region and how to support those associations who are developing and were unable to attend the meeting.

The business concluded with the leadership of Alzheimer Iberoamérica being passed from Mira Josic de Hernandez from Fundación Alzheimer de Venezuela to Emilio Marmaneu from CEAFA, Spain.

The next meeting will be held in Puerto Rico in 2009.

Alzheimer University 2008

'What an exceptional, positive experience. I feel lucky to have a clearer vision of our future plans. I am very enthusiastic to put what I have learnt into practise.'

HOVHANNES MANVELYAN, ARMENIA

April, London, UK

'ADI's support will be our force!'

AMEENAH SOREFAN, MAURITIUS

Volunteers from emerging Alzheimer associations in Armenia, Aruba, Ethiopia, Kenya, Mauritius and Suriname travelled from across the world to attend the Alzheimer University training programme in London.

The interactive programme was led by participants from established Alzheimer associations, a leading professional training body and ADI staff who ran lively sessions and equipped attendees with the skills to develop and run a sustainable Alzheimer's association. Energetic workshops were given on governance, support groups, fundraising, recruiting volunteers and providing information and trainers took participants step by step through the most important starting and sustaining points for any organisation.

As part of ADI's commitment to including people with dementia in their activities, on the final day Keith Turner, UK, who was diagnosed with dementia four years ago, joined participants. Together with his wife and carer Lillian they spoke about the impact of involving people with dementia in association activities such as campaigning and the importance of holding support groups for both the carer and person with dementia. For many, this was the first time they had heard a person with dementia speak in this capacity.

Despite the differences in culture, politics and demographics of



Keith Turner and Patricia Nobrega at the Alzheimer University for emerging associations, London, UK

the countries represented at this event, everyone bonded through a shared goal to provide better services to help people with dementia and carers. The training formed a common union between associations around the world and ADI staff and participants returned home enthusiastic and ready to share what they had learnt.

June, Taipei

'Today has taught me to be optimistic and more positive about fundraising for my association.'

NORIYO WASHIZU, JAPAN

For the first time ADI conducted a one-day Alzheimer University training event centred entirely on Fundraising. The event took place during ADI's Asia Pacific regional meeting in Taipei in June 2008. Participants from 12 Alzheimer associations within the Asia Pacific region took part in a full day of workshops and group activities all aimed at building their capacity to fundraise effectively. The inspirational leading of the

programme by Frank Schaper, CEO of Alzheimer's Australia WA, was very much appreciated. ADI Chairman Orien Reid and Executive Director Marc Wortmann gave presentations and the group heard examples of successful fundraising events and techniques employed in India, Pakistan and Sri Lanka from fellow participants.

The highlight of the afternoon was a lively practical session. The group was split into three teams and each was given a situation to build an event or strategy around. This gave the group a fantastic opportunity to exercise their skills – and develop new ones – in how to effectively fundraise in a team with the constraints of a limited budget and resources. The day concluded with each team presenting their plan in front of the group and having the opportunity to receive constructive feedback from their peers, which everyone found particularly helpful.

New ideas from the day included a 'Fundraising Manual' initiative



Participants at the training day in Taipei

where each of the 12 associations would identify one fundraising idea that was successful in their country and send a brief plan to ADI, who would collate the ideas and plans – along with a few ideas of their own – and produce a document full of tried and tested fundraising ideas. This is now in process; several

countries have submitted their ideas and the highlights include a 'curry night toolkit' and a 'memory bank' collection box scheme. ADI hopes to build on this concept by sharing these ideas with other regional groups and having them make their own contributions.

World Alzheimer's Day 2008

In addition to the Global Charter launch many of our members have been carrying out their World Alzheimer's Day activities with the clear message 'No time to lose'.

This year saw a focus on carers and the importance of their partnership with people with dementia. For every person with dementia in the world there is at least one carer and often more. There are an estimated 30 million people with dementia, and a vast number more who are affected by this devastating disease. Supporting the carer and family is an essential part of meeting the challenge of dementia. Listening to the experience of carers in different parts of the world, it is apparent that the support available to people with dementia and their carers varies dramatically.

Sunday 21st September 2008 saw Alzheimer and dementia associations around the world celebrate the contribution made by carers to society as called out to governments to recognise the challenges of an ageing population and provide better support services for carers and people with dementia. Lack of services, financial support and understanding can lead to discrimination which results in carers paying with their health, their finances, their careers and being denied the opportunities to have a life outside of caring. Alzheimer associations are campaigning to bring this to an end.



World Alzheimer's Day poster

The full World Alzheimer's Day report will be published in the next issue of Global Perspective.

■ Advocacy for caregivers

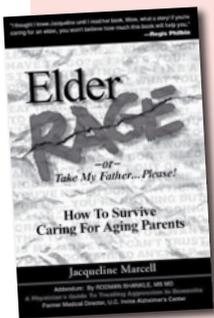
The story of Jacqueline Marcell



Caring with a passion

Jacqueline's passion to save others from a similar experience led her to educate families, as well as healthcare professionals about Alzheimer's. She also teaches creative behavioural techniques to manage people with dementia: distraction, redirection, reminiscence and validation. And instead of using the usual slide presentation, Jacqueline puts on a show using humour to bring her caregiving experiences to life. She is

the author of the best-selling book 'Elder Rage', and host of 'Coping With Caregiving', an Internet radio programme available worldwide.



To learn more visit
www.ElderRage.com

This year ADI's focus on World Alzheimer's Day is the role of the caregiver. Jacqueline Marcell, a well-known eldercare advocate in the USA, dedicated her life to the Alzheimer's movement after both of her parents were affected, but not properly diagnosed for over a year. This is part of her true story.

I was completely uneducated about Alzheimer's when my father started to develop short-term memory loss and intermittent odd behaviours. It was so strange because he could be so sweet to me one minute, but then get furious over some trivial little thing, scream obscenities and throw me out of the house the next. Every caregiver I hired to help him sighed in exasperation and quit within a few days.

His doctor said that it was just a normal part of aging and probably the stress of caring for my ailing mother for many years. I could not believe it when she looked at me as if I was the crazy one. Much later I found out my father told her not to listen to anything I said, because all I wanted was his money! Boy I wish he had some.

Finally a friend suggested I contact the Alzheimer's Association, but I didn't think my father could have Alzheimer's – he knew what he was doing! But when I did they explained the Ten Warning Signs to me and I started to understand what was happening to my parents. With the right diagnosis and treatment from a team of Dementia Specialists, my parents finally received the help they so desperately needed.

What is so shocking is that none of the many healthcare professionals who treated my parents that first year ever discussed the possibility of Alzheimer's with me. Since nearly one out of every two persons by the age of 85 is afflicted – I should have been alerted.

Ten warning signs of dementia

- **Memory loss**
- **Difficulty performing familiar tasks**
- **Problems with language**
- **Disorientation of time and place**
- **Poor or decreased judgment**
- **Problems with abstract thinking**
- **Misplacing things**
- **Changes in mood or behaviour**
- **Changes in personality**
- **Loss of initiative**

■ Research update

11th International Conference on Alzheimer's Disease 2008 in Chicago

Diagnosics and therapeutics move forward despite some disappointments



**Sam Gandy,
MD, PhD
Chairman
Emeritus, US
Alzheimer's
Association**

Over 5,000 Alzheimer's clinicians, carers, and researchers converged on Chicago, Illinois, USA, the last week of July for an intense whirlwind of information exchange. So intense, in fact, that ICAD is now an annual event, with the 2009 event coming next summer in Vienna.

A few stories broke just as we were all packing our bags. In the 18 July issue of *The Lancet*, we learned that autopsies of eight patients who had been vaccinated with amyloid showed evidence of pathological efficacy (ie, the plaques were gone!) but sadly no attenuation of clinical progression. While many interpreted this as the 'death knell' of 'the amyloid hypothesis', in fact, the more likely message is that we must work harder to begin anti-amyloid therapy or vaccination earlier and earlier, ideally pre-symptomatically, if we are to have any chance of having a major impact on the disease.

This shouldn't come as much of a surprise, since mouse studies predicted that this would be the case. 'Amyloid-forming' transgenic mice vaccinated prior to the age at onset of amyloid deposition could be totally protected from plaque formation, but if vaccination were delayed until plaque load

was substantial, only about 50% protection was afforded.

The slightly sombre mood of the vaccinologists was not much improved later in the week, at ICAD, when Elan and Wyeth announced disappointing results from the mid-stage trial of anti-amyloid antibody infusion known as 'bapineuzumab' ('bap' for short). APOE4-positive subjects (about one-quarter to one-third of the Alzheimer's-affected population) were not only not helped by 'bap', but they were at risk for a side effect known as vasogenic edema (VE). VE was usually an asymptomatic event seen on MRI, but at least one subject required admission to hospital and immunosuppressive therapy.

The situation for APOE4-negative subjects was more promising. There was evidence of benefit from 'bap' on the ADAS-COG test of brain function. Three other tests were less persuasive. 'Bap' has now moved on to late phase clinical trials.

Also disappointing on the anti-amyloid front was the failure of Flurizan (tarenflurbil) to slow progression of dementia. Additional details were provided at ICAD, reinforcing the notion that intervention must be much earlier.

Giving 'bap' a run for the money in getting across the finish line for approval by the US Food and Drug Administration is the surprisingly well-performing drug Dimebon (dimebolin hydrochloride). This compound has a complicated history that is probably unrelated to

its effect in Alzheimer's, including antihistamine properties, cholinesterase inhibitor properties, and glutamate receptor blocking properties. The effect in Alzheimer's seems too potent to be explained by any of these, so that is something to be worked on.

In the meantime, there is much experience with this drug (Dimebon) in Russia, and its safety profile is very favourable. Its benefits are startling: cognitive function in Alzheimer's is claimed to improve for several months and then, as we heard at ICAD, stabilize for up to 18 months at the improved level. This is better than anything that we currently have on the market. The US California biotech company Medivation is developing Dimebon, and this is certainly one to watch!

ICAD brought the announcement of the first two anti-tangle drugs; one a nasal spray and the other a pill. These are still in early phases of clinical trials, but anti-tangle drugs are important for building our armamentarium against dementia, so these also bear watching. The nasal spray is being developed by Prof Don Schmechel at Duke University, together with the biotech company, Allon, while the pill is being developed by Prof Claude Wischik of the University of Aberdeen, together with the biotech company TauRx.

News on amyloid imaging was also blowing around the Windy City.

continued over...

Research update continued...

The biotech Avid Pharmaceuticals has developed a compound that promises to overcome some of the technical limitations of Pittsburgh compound B and make amyloid imaging much more widely available.

New risk factor information reinforced old suspects as well as implicating new ones. More evidence emerged linking diabetes and metabolic syndrome to dementia, but we learned that exercise can slow brain atrophy even if begun after dementia has already set in. So, for exercise, mild dementia is not too late. Unmarried status increases risk for dementia, while an obsessive personality decreases risk. Perhaps this dovetails with existing knowledge about synaptic activity: more synapses are firing during socialization or obsessing than, for example, during more vegetative activities.

What were the breakthroughs at ICAD? One must always manage expectations in situations such as these when so many are so desperate for any hope at all. The closest contender would have to be Dimebon. One also hates to estimate how long until we have a 'cure', and there is no evidence yet whether Dimebon will be symptomatic, disease-modifying, or both, but, if the repeat late stage trial is positive after the first six months, this drug could be approved in under two years. It is fair to say that this is the closest that we have been to a new drug since Namenda (Ebixa, memantine) was approved 5 years ago. That alone is worthy of celebration, as is having achieved a new milestone in initiating trials of the first anti-tangle drugs. Anticipation on all these fronts is fierce, and with continued support and research, we will soon succeed in our quest to bring new and better medicines to our patients and loved ones.

UPDATE

ADI Conferences

2009 Singapore



IMAGE COURTESY OF THE SINGAPORE TOURISM BOARD

We are pleased to announce that registration and abstract submission for the 24th ADI conference in Singapore next March are now open! It promises to be an exciting and popular event, so register now! The early bird registration deadline is **15 December 2008**. We invite everyone to submit an abstract on one or more of a number of topics to be a part of a varied and interesting scientific programme. The list of abstract topics can be found on the website and reflect the conference theme 'Dementia: Engaging Societies Around the World'. The abstract submission deadline is **15 November 2008**. All this and more can be found at www.adi2009.org. We and the Alzheimer's Disease Association of Singapore look forward to seeing you there and welcoming you to beautiful Singapore.

2009 conference information at www.adi2009.org

2010 Thessaloniki

We are also excited to launch the website for the 25th International conference of Alzheimer's Disease International in Thessaloniki, Greece in 2010 www.adi2010.org. Hosted together with the Greek Association of Alzheimer's Disease and Relative Disorders it will be a time to bring everyone together to take action on the conference theme of 'Dementia: Making a difference'. The abstract topics are available for viewing. Why not register your interest now? Join the mailing list to receive the latest conference news and recommend friends and colleagues to join as well!

2010 conference information at www.adi2010.org