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100 YEARS OF ALZHEIMER'S DISEASE

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.

100 years of Alzheimer's disease No time to lose!

ADI launches a series of commemorative activities to mark the 100th year since the first diagnosis of Alzheimer's disease

At the end of last year, we were shocked to hear that there are currently 24 million people with dementia worldwide. The numbers are increasing rapidly – at the rate of one new case every seven seconds – so that by 2040 we will be faced with a reality of over 80 million people with dementia worldwide (see *Research update* on page 6). One hundred years since the first diagnosis of Alzheimer's disease, we reflect on the advances made in treatment and care in the last century, but look towards an uncertain future where great challenges still lie ahead.

ADI is using the 2006 centenary year as an opportunity to increase awareness of dementia in the hope that governments worldwide will recognise it as a global health priority. Dementia is an expensive disease which requires more investment and recognition. For the UK's elderly, the cost of dementia is more than that of heart disease, cancer and stroke combined yet research spending is only 10% of that on heart disease and 3% of that on cancer. Governments need to recognise the existence of this large imbalance in funding, not only in research but also in care, services and available treatments.

Our 2006 international advocacy campaign aims to address this imbalance. Special ADI postcards will strongly encourage governments to put dementia on their agenda and make it a national health priority. We ask that governments recognise the urgent need to prepare for a future dementia epidemic.


Sir Cliff Richard

We are happy to announce that Sir Cliff Richard, the British pop star, has agreed to be our centenary patron. ADI is also proud to launch two competitions: the International Photography Competition: Living with Dementia, and the Journalist of the Year Award. Through these two competitions we aim to encourage the media to portray a more positive and accurate image of dementia. We also aim to disseminate reliable information and encourage journalists to write about the disease.


In 1906 Dr Alois Alzheimer described an 'unusual disease of the cerebral cortex' affecting a woman in her fifties, Auguste D. The disease went on to bear the doctor's name and now in 2006, Alzheimer's disease is known to be the most common form of dementia.

World Alzheimer's Day will certainly not go unnoticed this year. The 'Ascent for Alzheimer's' will be taking place in September, when a world team will reach the summit of Mount Kilimanjaro in Tanzania to mark the day on 21 September. Read more about the Ascent and ADI's international competitions on page 8.

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 June 2006**.

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Editorial

Orien Reid
Chairman, ADI

I recently attended ADI's first Alzheimer University training programme focused on advocacy and public policy. With conference facilities and accommodation provided as an in-kind contribution by the Lundbeck Institute, this was an historic event and important beginning of ADI's recognition of the centenary year for Alzheimer's. ADI's core mission is to strengthen the work of our members. The Alzheimer University provided the tools they need to become more effective advocates for people with dementia.

With more than 24 million people around the world living with dementia, and that number set to increase to 81 million by 2040, ADI is proud of its members who are dedicated to raising awareness about the looming health crisis ahead. We know many policymakers have not yet grasped the full impact of this crisis and its possible catastrophic social and economic effects.

In this centenary year with our network of 75 member Alzheimer associations, we are dedicated to raising dementia on health and social policy agendas around the world. We are working to provide services that improve the quality of life for people with dementia and their carers.

Events

27 - 29 April
9th Asia Pacific ADI Regional Meeting
Community Care for Home-Carers
Seoul, Korea
Tel: +82 2 431 9963
Fax: +82 2 431 9964
Web: www.alzza.or.kr

3 - 6 May
IPA European Regional Meeting
Bridges Across Aging: Meeting primary care needs through specialization
Lisbon, Portugal
Email: 2006lisbon@ipa-online.org
Web: www.ipa-online.org

30 May - 2 June
Global Ageing: the North-South Challenge
8th Global Conference of the International Federation on Ageing
Copenhagen, Denmark
Tel: +45 70 23 5056
Fax: +45 70 23 5057
Email: ifa2006@ics.dk
Web: www.global-ageing.dk

3 - 6 June
The Alzheimer's Association US Public Policy Forum
Washington DC, USA
Tel: +1 202 393 7737
Web: www.alz.org/publicpolicyforum

13 - 16 June
9th ADI Latin American Regional Meeting
Monterrey, Mexico
Tel: +52 8183 333619
Fax: +52 8183 478651
Email: gutierrezrf@hotmail.com

29 June - 1 July
16th Alzheimer Europe Conference
Alzheimer's 100 Years On
Paris, France
Tel: +33 1 42 97 52 41
Fax: +33 1 42 96 04 70
Email: conferenceparis@francealzheimer.org
Web: www.alzheimer-conference.org

15 - 20 July
Alzheimer's Assocation 10th International Conference on Alzheimer's Disease and Related Disorders
Madrid, Spain
Tel: +1 312 335 5790
Email: researchconference@alz.org
Web: www.alz.org/icad

11 - 14 September
14th Annual Alzheimer's Association Dementia Care Conference
Atlanta, Georgia, USA
Tel: +1 312 335 5790
Email: careconference@alz.org
Web: www.alz.org/careconference

16 - 20 September
5th European Congress of Biogerontology
Presented by International Association of Gerontology
Istanbul, Turkey
Tel: +90 312 304 3306
Fax: +90 312 304 3300
Email: sakman@gata.edu.tr
Web: www.biogerontology2006.org

12 - 14 October
22nd International Conference of ADI
Dementia - a Challenge for the 21st Century. 100 Years of Alzheimer's Disease
Berlin, Germany
Tel: +49 30 85 99 62 0
Fax: +49 30 85 7 98 26
Email: alzheimer@ctw-congress.de
Web: www.alzheimer2006.de

6 - 7 November
Reflecting on 100 Years of Alzheimer's: The Global Impact on Quality of Lives
University Memory and Aging Center, Case Western Reserve University
Cleveland, Ohio, USA
Tel: +1 216 368 4945
Email: IAConference@case.edu
Web: fpb.case.edu/CFA/announce.shtm

6 - 8 November
28th National Conference of Alzheimer Society of Canada
Alzheimer Research and Innovation: Yesterday, Today, Tomorrow
Toronto, Canada
Tel: +1 416 488 8772
Fax: +1 416 488 3778
Email: conference2006@alzheimer.ca
Web: www.alzheimer.ca/english/newsevents/conference-intro.htm

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

from the heart

Francisca Távora, Portugal

Living one day at a time

Alzheimer's disease was the last thing my brothers and I thought would affect someone like our mother. My mother had dedicated her life to helping others, working as Chief Nurse but eventually giving up her profession to fully dedicate herself to the family. She always maintained a wide range of interests and a huge thirst for knowledge which she would satisfy through reading, studying and tireless charity work. We believed that she would take care of us forever.

It was only when she was in her 60s that we noticed strange things develop in our mother's behaviour. She would call us and ask the same question over and over again. She would leave us all sorts of puzzling notes, where she expressed her fears about leaving the front door open, the shopping she might forget, worries about everything and nothing. She would even write those notes to herself. The messages were numerous but her big distinctive handwriting became more and more feeble and flawed.

At home, things started to become difficult to manage. Each day, our mother was getting sadder. We took her to a doctor and then consulted a neurologist, who took over a year to diagnose Alzheimer's disease since the symptoms were disguised as depression. I will never forget those appointments and our mother's efforts to hide her confusion at the doctor's questions for which she sadly could not find an answer. Showing great dignity and composure she tried to maintain distant, avoiding the question or answering them with other questions or comments to change the subject. Before leaving she would invariably give her apologies to the professor for the trouble she had caused, arguing that her daughter insisted on taking her to the appointment, knowing that the professor had so many serious patients to attend to. When we were alone, she would tell me, 'It was very mean of you to take me here without a warning about the kind of questions he would ask, to allow myself to prepare for them!'

Some time after our mother's death, we came across evidence of how hard this initial phase must have been for her. We found a little note with her fragile handwriting saying: 'I think I have Alzheimer disease'.

Francisca and her mother Dígia

We all gradually became aware that our mother was losing touch with reality. It was time to assume the inversion of family roles, to turn anger into acceptance, to soothe the symptoms. We found comfort in the certainty that mother was no longer in pain, but now our priorities had to change and we developed certain ways of dealing with the disease. We would give our mother as much love and affection as possible, never giving up on her, even during the last stages of increasing distance, when nothing seemed to attach her to us. It was like we were making up for every single withheld kiss, for every loving statement untold.

The grandmother and mother was regressing back to her childhood, she was leaving our world behind. So we had to step into her world, playing along, singing the children's songs that she loved. On special occasions, we even got a smile or applause from her which would fill us with joy. In situations like this we must live each day at a time!

Most importantly we insisted on maintaining our mother's dignity until the end. Let me share with you some of the 'tricks' that the family used for this purpose: Uncle José added small hidden wheels to a little sofa to transport our mother around without having to use a normal wheelchair; we made dolls filled with rice and other toys; we kept up meaningless chats with our mother, whilst she was able to talk, just to keep her happy and give her a sense of belonging. Meanwhile, we all came to the understanding that dignity was an important value to preserve in the presence of a disease as overwhelming as Alzheimer's.

We have grown by enduring such a drama. Today, we feel that we have to keep on helping others by sharing our testimony. This explains why I am a member of the Alzheimer's Portugal board – a fundamental help for all relatives and friends of people with dementia. In my cooperation with APFADA, I found a way to mourn the sorrow and to overcome the sense of absence.

Members' forum

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

Carnival time in Goa!

Young doctors in Goa, India have been adding colour to lives by participating in the Goa Carnival with a float on dementia.

The float, carrying the theme 'Add colour to the lives of people with Alzheimer's Disease', was organised by the Dementia Society of Goa (a chapter of the Alzheimers & Related Disorders Society of India) in association with the Young Doctors for Dementia Group from Goa Medical College. Marking the centenary year of Alzheimer's disease, the message focused on the importance of adequate care for people with dementia as well as the need to recognise dementia as a disease rather than a natural part of ageing. Thousands of leaflets were distributed spreading the 'No time to lose!' centenary message.

Adding colour to lives at the Goa Carnival, India

Dr Amit Dias, the Honorary Secretary of The Dementia Society of Goa told us about the impact the Carnival had on general awareness of dementia: 'We have received a number of calls and many more have volunteered to help out. Some have volunteered to support our work financially.'

As part of the centenary celebrations, the Society will be establishing a memory Clinic at the Goa Medical College. They also plan to intensify efforts to integrate dementia services within primary health care in Goa. The Society has recently developed and evaluated a need based intervention for families of people with dementia in Goa with the support of the World Health Organization.

Dr Dias also emphasised the fantastic commitment and enthusiasm shown by the medical students. 'The Group spent two sleepless nights preparing for the Carnival and are really charged! At this rate we are pretty confident that we can build Rome in a day!'

ADI announces twins

The new year sees the first six Alzheimer associations embark on ADI's new Twinning Programme. Each partnership is to be made up of one developed association and one developing. Following completion of the application process we are very pleased to announce our first twins!

They are, Greece and Ireland, Pakistan and Western Australia, and Trinidad & Tobago and Canada.

The first step is for the developed association to make an assessment visit to their twin to establish their objectives, create an action plan and begin building a partnership!

Norma Inniss, President of Alzheimer's Association of Trinidad and Tobago eagerly anticipates their visit from Canada: 'We are looking forward to using the experience to become a very vibrant organisation that will meet the needs of persons with dementia and their caregivers'.

We are very excited about the potential for learning and growth that this programme presents and anticipate that it will offer many benefits for Alzheimer associations in the future.

WHO puts mental health on the human rights agenda

People with mental disorders are amongst the most vulnerable in society. According to the World Health Organization (WHO), they face an alarming range of human rights abuses in countries throughout the world. The stigma of mental illness can lead to abuse, rejection, and exclusion from health care services. This is why WHO Human Rights Day on 10 December 2005 was dedicated to the human rights of people living with mental illness. 'There are still far too many violations of the human rights of people with mental disorders. However, too often both the health and human rights agendas overlook these problems, and as a result, they slip between the cracks,' said Dr Lee Jong-wook, Director General of the WHO.

To mark International Human Rights Day, WHO produced an online photo essay, *Denied Citizens: Mental Health and Human Rights* available at www.who.int/features/2005/mental_health/en

UK access to dementia drugs in jeopardy

Dementia drugs may be denied to British people in the mild and severe stages of Alzheimer's disease if proposed recommendations from a government advice board are approved.

NICE (National Institute for Health and Clinical Excellence), part of the UK's National Health Service (NHS), have proposed that donepezil (Aricept), galantamine (Reminyl), and rivastigmine (Exelon) be used as a treatment for moderate stages of Alzheimer's disease only, thus effectively excluding their use by people in the mild and severe stages. Furthermore, the recommendations propose that memantine (Ebixa), used to treat more severe stages of the disease, only be available through clinical trials.

This consultation paper comes after initial proposals in March 2005 that all dementia drugs should be withdrawn for the treatment of Alzheimer's disease. There was public outcry at this proposal and UK dementia institutions quickly rallied to form the Action on Alzheimer's Drugs Alliance to lobby against the recommendation. The Alliance has had a partial victory in getting NICE to acknowledge the benefit of the drugs for some, but action is still needed to prevent discriminatory measures being taken against people with the mild and severe forms of Alzheimer's disease.

The NICE appraisal committee meets again on 27 April 2006 once it has considered feedback from the consultation process but a final decision is not expected until late spring. In Germany, a decision from a similar appraisal is awaited in March. We hope that these proposals do not set an international precedent.

Neil Hunt, chief executive of the Alzheimer's Society (right) is joined by British TV personality Linda Bellingham (left) at 10 Downing Street. With them are David Whitcomb, who has dementia, and his wife, Sue to protest against the NICE recommendations

Argentina puts dementia on the stage

The theatre has always been a popular way of spreading a message and now in Buenos Aires, Alzheimer's disease is stepping into the spotlight.

'Notas que saben a Olvido', a play produced in conjunction with ALMA, the Alzheimer's association of Argentina, addresses the effect of dementia on the family. The play, the title of which translates literally as 'Musical notes that taste of forgetting', is directed by Marcelo Mangone, a prominent theatre director in Buenos Aires and his brother Dr Carlos Mangone, a neurologist and former member of the ADI board. The project aims to commemorate the centenary year of Alzheimer's disease by raising public and political awareness.

The play, which has been subsidised by the Buenos Aires Secretary of Arts, explores the story of one woman and her family living with dementia: the daughter's anger, the husband's helpless protest and impotence against the disease. However, one family's struggle against Alzheimer's eventually turns into a forum for comprehension and compassion.

A scene in the play where Ana, who has Alzheimer's disease, celebrates her birthday with her husband Juan

The whole production company thoroughly researched their topic before embarking on the project. 'The director, author of the play and actors all visited my Memory Clinic at the Santojanny Hospital. They also attended ALMA's support groups for 6 months in their preparation for the play. The whole team has a deep understanding of the disease and frequent conflict that can arise within the family,' said Dr Mangone.

For more information (in Spanish) on the play visit www.notaquesabeaolvido.com.ar

Research update

Worldwide cost of dementia

Dementia is an expensive disease. It is a major driver of costs in health care and social systems and worrying estimates of future dementia prevalence suggest that the cost is set to soar.

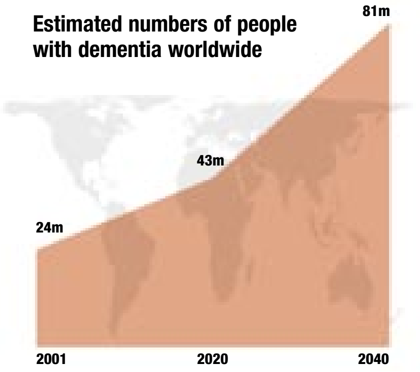
A study by a group of Swedish researchers has announced that the worldwide direct costs for dementia in 2003 are estimated at US$156 billion. 92% of the costs are incurred in developed nations which only have 38% of the prevalence. These substantial costs are expected to rise even further as the demography in developing countries shifts towards an ageing population.

These estimates must be of great interest for policy makers. Up until now, policies about older people have been designed with a youthful society in mind. From this point onward policies must be designed with an ageing society in mind: a society where soon, every third individual will be over the age of 60.

http://content.karger.com/ProdukteDB/produkte.asp?Aktion=ShowAbstract&ProduktNr=224226&Ausgabe=231607&ArtikelNr=90733

New dementia case every 7 seconds

A new case of dementia arises every seven seconds, reported an article in The Lancet. The report, produced for ADI, comes 100 years after the first description of Alzheimer's disease and estimates that 24.3 million people currently have dementia, with 4.6 million new cases annually. By 2040 the number will have risen to 81.1 million.


Estimated numbers of people with dementia worldwide

The study highlights that most people with dementia live in developing countries: 60% in 2001 rising to 71% by 2040. The rate of increase is predicted to be three to four times higher in developing regions than in developed areas. Already, many more people with dementia live in China and its neighbours (6 million) than in either Western Europe (4.8 million) or North America (3.4 million). By 2040 there will be as many people with dementia in China alone as in the whole of the developed world put together.

There is already a great need for community based services, welfare and support for people with dementia and their carers. These new figures show that pressure on governments for dementia services will increase dramatically in the next few years, and governments must be prepared.

The report concluded that there needs to be a climate for change, but this must start by correcting a fundamental lack of awareness among policymakers, clinicians and the public.

http://www.thelancet.com/journals/lancet/article/PIIS0140673605678890

Living with dementia

Giving people with dementia the chance to speak out


Mr Ochi, a Japanese man with dementia, talks about his diagnosis at the Kyoto conference in 2004

ADI international conference, Berlin, Germany October 12-14, 2006

People with dementia will receive an especially warm welcome this year at the ADI international conference in Berlin. We are currently working on a conference programme which will have specific involvement from people with dementia. ADI also has a small fund to assist people with dementia with the costs of attending the conference.

ADI is committed to increasing recognition of the voice of people with dementia. Our conference provides a great opportunity for people with dementia to give talks at workshops, to network and participate in discussions.

Previous participation of people with dementia at our conferences has acted as a catalyst for change. At the Kyoto conference in 2004 Mr Ochi, a Japanese man with dementia, addressed a plenary audience of over 3000 people with his experiences of the disease. Yoshio Miyake, Secretary General for the 20th International Conference of ADI, told us, 'The 2004 Kyoto conference had a very big impact on awareness. Japanese people now recognise that people with dementia are human beings with a heart. Since the conference, support for people in the early stages of dementia has become an important part of our activities and we have launched services at community level.'

We hope that participants will disseminate the best practice shared at our events to improve the quality of life for people with dementia and their carers globally. It is only by encouraging people with dementia to speak out at our events that we can truly achieve this aim.

If you have dementia and wish to attend our conference, particularly for the first time, please talk to your national Alzheimer association about ADI support or contact Helen Regan, membership and events manager at h.regan@alz.co.uk

■ Alzheimer University on Advocacy

Lobbying for change

In 2003 ADI carried out a survey to determine the needs of its members. Member associations expressed a desire to learn the basics of lobbying governments and advocating to the media on behalf of people with dementia.

To meet this need for training, ADI organised an advocacy-based Alzheimer University in January. Alzheimer associations from eighteen different countries met in Copenhagen, Denmark making this event the largest Alzheimer University yet!

Participants embarked on a three-day interactive training programme, supported by the Lundbeck Institute, which was designed to equip them with the skills to address dementia policy and advocacy issues.

On the first evening Orien Reid welcomed participants at a candle lit reception, giving the group a chance to get to know each other. As the evening drew on the group discovered that although they had travelled from all corners of the world they had much in common.

The first day began with each association making a short presentation outlining the political situation they work in, their current advocacy work and their future plans. Shelley Ann de la Vega from the Philippines explained how the instability of her government had resulted in constant changes of policy, which had made it difficult to successfully lobby at the right time and to the right policy maker. Many other participants identified with this issue.

The programme continued with a number of case studies and examples of national advocacy campaigns. Glenn Rees, Executive Director of Alzheimer's Australia, gave a presentation based on the recent success of the Australian government's commitment to make dementia a National Health Priority. Addressing the group, he commented, 'It is clear that our situations are very different in the scale and complexity of the problems we face, but we have a lot to learn from one another. The Australian story shows how the different elements of advocacy can come together.'

Martin Prince presents results from 10/66 research projects

Renu Vohra, a volunteer from the Alzheimers & Related Disorders Society of India, addresses the group

Steve McConnell, Senior Vice President for Advocacy & Public Policy of the Alzheimer's Association (USA) added how we 'should always be looking to strengthen our association whilst achieving our advocacy goals.' His experience of improving services gave people realistic targets and ideas on how to improve situations in their own countries. Presentations from Steve Rudin of Canada and Jan Killeen from Scotland also contributed to the comprehensive programme.

Participants took part in a media training session that included writing a press release and a filmed mock interview. Many felt that developing their confidence in talking to the media empowered them to focus on their message and get it into the public domain.

The programme concluded with each participant outlining realistic objectives for the coming year. Zimbabwe plan to launch a centenary 'No time to lose' awareness campaign and Trinidad & Tobago plan to lobby the government to make dementia a health priority.

The shared experiences and collaboration between participants was inspiring. Sue Cox from Zimbabwe commented, 'We certainly do feel we are part of the global team and will do everything we can to keep up with events and expectations to the betterment of people with dementia and their carers in Zimbabwe.'

ADI is planning a further Alzheimer University this year, which will provide training for emerging associations. This will take place in London in May.

Ascent for Alzheimer's: World Team

The summit of Mount Kilimanjaro in Tanzania will be the stage for World Alzheimer's Day this year. From Canada to Hong Kong, ten people from eight different countries will be climbing Africa's highest mountain in a symbolic act of international unity against dementia.

As we go to press the World Team is made up of individuals from the Dominican Republic, USA, Canada, UK, Hungary, Romania, Denmark, and Hong Kong SAR China. The team members have each pledged to raise $10,000 in sponsorship money for their associations.

ADI is coordinating the Ascent for Alzheimer's: World Team with help from the Alzheimer's Society of British Columbia (ASBC), Canada. In the last eight years ASBC has helped put over one hundred people on the roof of Africa and raised over one and a half million dollars.


The impressive Mawenzi Peak, Mount Kilimanjaro

Sandy Riley, the past president of ASBC who reached the summit of Kilimanjaro in 1999, said: 'It is going to be a journey to remember. I hope that the Ascent will draw worldwide attention to dementia and raise much needed funds for a disease that is growing at an alarming rate. Let's show the world that there really is no time to lose and that the time to act is now.'

To read more about the individual climbers and see how you can support this event please visit www.alz.co.uk/ascent. We really need your support for this venture. Please help us to raise money and awareness of dementia by publicising the Ascent through your association. The more publicity we get, the more of an impact the climb will make!

Centenary year competitions

International Photography Competition: Living with Dementia

How can I take part?

The competition has two categories, one for members and the other for professional photographers. Under the member category, Alzheimer associations are asked to publicise the competition to their staff and members and submit a maximum of three photos to ADI. Alzheimer associations might like to consider holding their own national competition to decide on their entries for the international competition.

For the professional category, member associations are asked to look for images in the media and approach photojournalists about the competition to encourage them to submit an image.

A panel of judges will decide the winners and runners-up from both categories. ADI has secured representatives from Reuters, BBC Online, Time magazine and UK newspaper The Times to be on the panel.

The last date for entries in both categories is 1 September 2006. The winning photographs will be exhibited and prizes awarded at ADI's international conference in Berlin from 12-14 October 2006.

Journalist of the Year Award

How can I take part?

The aim of the competition is to disseminate information and encourage journalists to write about dementia. Member associations are asked to approach journalists who have written interesting and informative news stories on an aspect of dementia. Each association should shortlist one article, and with permission from the journalist, submit it to ADI by Friday 1 September 2006.

Articles in languages other than English should be sent in with a summary, written in English. The summary should be fairly detailed, giving a clear idea of the article's content. If the article is shortlisted for the competition ADI will then ask you to translate the whole article.

In the run up to the conference in Berlin, a panel of judges from ADI's Medical and Scientific Panel will choose the article which, in their view, has best advanced knowledge and understanding of dementia. At the conference, representatives of the association will be presented with a prize to take back to the journalist. The winning article will be distributed to all ADI members for use in their newsletters and websites.

For further information and instructions on both competitions please see www.alz.co.uk/centenary