Highlights in this issue

30 June 2011: Nordic Alzheimer associations discuss common challenges ................................................................. 5
18 July 2011: Decide project presents prototype for early diagnosis .................................................................................. 7
20 July 2011: Alzheimer Europe’s international survey examines public perceptions and views on the value of diagnosis .................................................................................................................. 2
20 July 2011: The French President talks about the global crisis of Alzheimer’s disease ......................................................... 4

Table of contents
Editorial ........................................ 1
Alzheimer Europe .......................... 2
European Alzheimer’s Alliance ........ 3
Alzheimer Europe Networking 2011 ... 3
European developments............... 3
Policy watch ................................ 4
Members’ News ............................ 4
Science Watch ............................. 5
Dementia in society ..................... 10
New resources and publications ....... 11
AE Calendar ................................. 12
Future Conferences ..................... 13

Editorial

In July I attended the 2011 Alzheimer’s Association International Conference (AAIC), held in Paris.

There were many interesting presentations throughout the three days but perhaps the most memorable was listening to President Sarkozy’s impassioned speech in which he emphasised the importance of collaboration at international level if Alzheimer’s disease is to be addressed. By taking the lead in how his country addresses dementia, the President has ensured that dementia is a priority in France. He also spoke of the global economic crisis and warned that the cost of investing now is less than the cost of waiting for the development of the disease and the French President called on all governments to choose to invest, as France has done.

During the AAIC meeting, we also presented the results of Alzheimer Europe’s survey, “the Value of Knowing” which was carried out in collaboration with Harvard University. This survey examined public perceptions of Alzheimer’s disease and views on the value of diagnosis. Our findings showed an overwhelming willingness of the public to confront Alzheimer’s disease despite great fears. The media interest in our research was resounding in the five countries that were included in the survey which gives me hope that the results will be useful to promote early diagnosis.

Budgetary considerations were the focus in some countries this month. In the UK the cost of dementia services has been the centre of attention in the recently published report of the All Party Parliamentary Group on Dementia’s “The 20 billion question”. Budgets, or rather a lack of financial support, were also the topic of discussion when the Nordic Alzheimer associations met to discuss their current challenges.

We also report on the National Dementia Summit hosted by the Alzheimer Society of Ireland which facilitated an exchange between people with dementia and carers with government ministers on the issue of what is needed in Ireland to live well with dementia. In Greece, the national association was able to discuss driving and dementia with the Special Driving Committee. These are just some of the many examples how our national member organisations continue to effectively campaign with national policy makers to have dementia recognised as a priority.

On the research front, dementia was identified in a “Nature” article as one of the “grand challenges” for research in the mental health field. We report on the consortium’s findings in more detail and bring you up to date with research news, including many highlights from the AAIC meeting.

In the office, we have been drafting the next issue of the Dementia in Europe magazine which will be published in time for the forthcoming 21st Alzheimer Europe Conference in Poland. The conference programme is very varied and can be consulted online. I am delighted that we have already received over 350 registrations for what promises to be another interesting event.

I very much hope to see you in Warsaw at the conference.

Jean Georges
Executive Director
Alzheimer Europe

In this section, we report on our current news, including our projects and events.

20 July 2011: Alzheimer Europe’s international survey examines public perceptions and views on the value of diagnosis

The survey on “Value of Knowing” examined public perceptions and awareness of Alzheimer’s disease and aimed to identify the views of the general public on the value of diagnosis. The findings were presented on 20 July at the Alzheimer’s Association International Conference 2011 (AAIC 2011).

The survey of 2,678 people was designed and analysed by the Harvard School of Public Health and Alzheimer Europe. Fieldwork was conducted via telephone (landline and cell phone) with nationally representative random samples of adults aged 18 and older in five countries by TNS, an independent research company based in London. Countries surveyed were the USA, Germany, France, Spain and Poland. It was supported by a grant to Alzheimer Europe from Bayer AG. Bayer was not involved in the design of the survey or the analysis of the findings.

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

In four of the five countries, Alzheimer’s disease was the second biggest health fear after cancer. The public were asked to choose which disease they were most afraid of getting from a list of seven diseases including cancer, heart disease and stroke. Around a quarter of adults in four of the five countries say they most fear getting Alzheimer’s disease. Fear of Alzheimer’s gets worse with age, but even young adults are concerned, with approximately one in seven 18- to 34-year-olds reporting Alzheimer’s as the disease they are most afraid of getting from the list provided.

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

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

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

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

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

Full details of the survey results are available on the Alzheimer Europe website.

27-29 July 2011: Alzheimer Europe participates in seminar on ageing and health systems

Dianne Gove, Information Officer, Alzheimer Europe, took part in the Observatory Summer School on Ageing and Health Systems, which was held in San Servola, Italy from 27 to 29 July. Dianne presented Alzheimer Europe’s work on the ethical issues linked to the use of assistive technology for and by people with dementia and organised a workshop in which participants worked on short case studies and then discussed their views with the other members of the group.
European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 54, representing 17 Member States of the European Union and all of the seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their continued support of the European Alzheimer’s Alliance.

Belgium: Brepols Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Sterckx Dirk (ALDE), Bulgaria: Parvanova Antonia (ALDE), Cyprus: Triantaphyllides Kyriacos (GUE-NGL), Czech Republic: Cabmoch Milan (ECR), Kohlicek Jaromir (GUE-NGL), Rothova Zuzana (EPP), Denmark: Schaldemose Christel (S&D), Jäätteenmäki Anneli (ALDE), Pietikäinen Sirpa (EPP), France: Audy Jean-Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Grossétié Françoise (EPP), Morin-Chartier Elisabeth (EPP), Dagmar (S&D), Ulmer Thomas (EPP), Weisgerber Anja (EPP), Germany: Niebler Angelika (EPP), Roth-Behrendt Dagmar (S&D), Ulmer Thomas (EPP), Weisgerber Anja (EPP), Greece: Choukitis Nikolaos (GUE-NGL), Koppa Maria Elena (S&D), Kratsa-Tsagaropoulou Rodi (EPP), Ireland: Aylward Liam (ALDE), Childers Nessa (S&D), Mitchell Gay (EPP), Italy: Panzeri Pier Antonio (S&D), Toia Patrizia (S&D), Lithuania: Vilija Blinkeviciute (S&D), Luxembourg: Engel Frank (EPP), Lulling Astrid (EPP), Netherlands: De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP), Portugal: Coelho Carlos (EPP), Malia Marisa (GUE-NGL), Romania: Antonescu Elena Oana (EPP), Slovakia: Mikolask Miroslav (EPP), Zaborska Anna (EPP), United Kingdom: Derek Vaughan (S&D), Hall Fiona (ALDE), Lynne Liz (ALDE), McAvan Linda (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Taylor Keith (Greens/EFA), Watson Graham (ALDE), Willmott Glenis (S&D), Yannakoudakis Marina (ECR).

Alzheimer Europe Networking

From 16 to 21 July (Paris, France), Heike and Jean attended the Alzheimer’s Association International Conference (AAIC). During the conference, they organised meetings with Marc Wortmann from Alzheimer’s Disease International and representatives from various sponsors (Bayer, Bristol Myers Squibb, Janssen, Lilly, Pfizer, Sanofi-Aventis).

On 16 July (Paris, France), Jean participated in the pre-conference symposium "Alzheimer's Disease in Primary Care Settings" where he gave a presentation on “Community resources in Europe”.

On 20 July (Paris, France), Heike and Jean attended the AAIC press briefing for the presentation of the results of Alzheimer Europe’s five country survey on public perceptions of Alzheimer’s disease.

From 27 to 19 July (San Servola, Italy), Dianne took part in the Observatory Summer School on Ageing and Health Systems.

European developments

Here we report on developments from the European institutions and organisations which may impact people with dementia and/or their carers.

21 June 2011: New name announced for EU funding programme

Research, Innovation and Science Commissioner Máire Geoghegan-Quinn announced the new name for the EU funding programme for research and innovation as “Horizon 2020 - the Framework Programme for Research and Innovation”. A competition was launched in March 2011 for a new name for the programme which two teachers (Marcela Endlova, Czech Republic, and Beata Zygier, Poland) won.

Commissioner Geoghegan-Quinn explained that “the new name marks another step in our endeavour to establish research and innovation where it belongs, at the centre of EU policy making.

‘To achieve that in a lasting way, we need to connect with a wider public and give our work a higher profile. So the new name is an important symbol of a new departure and a new adventure. Horizon 2020 is not just a new name for the same Framework Programme. It is the name for the new, integrated funding system that will cover all research and innovation funding currently provided through the Framework Programme for Research and Technical Development, the Competitiveness and Innovation Framework Programme (CIP) and the European Institute of Innovation and Technology (EIT). These different types of funding will be brought together in a coherent and flexible manner.

“This will be a smarter way to support researchers and innovators in Europe – so as to further boost excellence and to help ensure that good ideas reach the market and generate sustainable economic growth and new jobs. Research and innovation funding will focus more clearly on addressing global challenges. Needless red tape will be cut out and participation made simpler.”

18 July 2011: 4th call for proposals launched by the Innovative Medicines Initiative

The Innovative Medicines Initiative (IMI) launched its 4th call for proposals which will enable Alzheimer’s disease experts to be involved with the European Medical Information Framework (EMIF) project. The EMIF call has three sub-topics: 1. The creation of the information framework. 2. Obesity research and 3. Alzheimer’s disease research. The goal of the Alzheimer’s disease research topic is to identify predictors of the onset and progression of Alzheimer’s disease in the general population as well as in patients with mild cognitive impairment by using an extreme phenotype approach. This research is supported by the information framework that facilities access to an increased amount of relevant patient-level data.

The duration of the project is 5 years and a total budget of EUR 24 million is being allocated to the EMIF project by European Federation of Pharmaceutical Industries and Associations (EFPIA) and also matched by financial contributions from IMI. Around a quarter of the total budget will be allocated
For the Alzheimer’s disease sub topic. The closing data for applications is 18 October 2011.

**Policy watch**

20 July 2011: French President addresses delegates at the Alzheimer Association’s International Conference on Alzheimer’s disease

French President, Nicolas Sarkozy, spoke about the global crisis of Alzheimer’s disease and the French national Alzheimer’s Plan when he addressed delegates at the Alzheimer’s Association International Conference (AAIC) in Paris, France. He said that since his election in 2007, he had made the fight against Alzheimer’s disease a priority.

President Sarkozy emphasised that the issues which surround Alzheimer’s disease go far beyond support and treatment, asking that consideration be given to wider issues such as what the proper position of elders and their families is within society. He said, “The humanity of our society is at stake through the place we give to our most vulnerable people and our ability to protect those who cannot take care of themselves” and that “suffering has no borders.”

Whilst highlighting various developments which have arisen out of the implementation of the French Alzheimer’s Plan, President Sarkozy stressed the necessity and importance of working collaboratively on an international level. He talked of the joint programming initiative in which 24 countries are working together and said to the audience “You represent the largest research teams in the world. You know that nothing great is done alone. The international dimension is crucial to serve science and medicine in the area of advanced technology and global health challenges.”

Raising the issue of addressing Alzheimer’s disease within the context the global economic crisis, the President said, “The question is not about debt, but getting in debt for what. If it’s getting in debt for economic progress, or for innovation, then I think it is a source of future profit. This is a major choice that France has made.” With respect to the investment made to the national Alzheimer’s plan, he said, "We have committed EUR 1.6 billion – this is considerable – but I tell you, this is less expensive – giving means to researchers and doctors, than waiting for the wider issues such as what the proper position of elders and their families is within society. He said, “The humanity of our society is at stake through the place we give to our most vulnerable people and our ability to protect those who cannot take care of themselves” and that “suffering has no borders.”

The President closed by reaffirming France’s commitment by saying ‘I want to assure you of our utter commitment as the government. Like you, we want to abandon the old patterns of decline and national partisanship in favour of protecting each and everyone’s interest. You can count on France for help.’

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**Members’ News**

In this section we report on national Alzheimer associations’ latest initiatives and work.

16 June 2011: National Dementia Summit held in Ireland

On the 16th June 2011, The Alzheimer Society of Ireland hosted a National Dementia Summit at Buswell’s Hotel, Dublin and Dail Eireann (House of Parliament) to mark the 2011 Carer’s Week.

Further to a commitment to a National Dementia Strategy in the Programme for Government 2011, the aim of The Summit was to secure a mandate from carers and people living with dementia on what is needed in Ireland to live well with dementia.

A spokesperson from the Society said that, “The Summit was a phenomenonal success involving 21 family carers and people living with dementia from all over the country.”

Following focus groups sessions in the morning, CEO Maurice O’Connell lead the group across to Dail Eireann, under the invitation of Minister for Disability, Older People, Equality & Mental Health Kathleen Lynch T.D., where there was an opportunity for some of the countries politicians to hear more about the issues raised.

This was then followed by lunch in the Members Restaurant. A number of people had an opportunity to speak to high profile politicians including the Minister for Health James Reilly T.D. and Minister for Environment, Community and Local Government Phil Hogan T.D.

In the longer term the Alzheimer Society of Ireland will be producing a report based on the group’s feedback and what they feel is necessary to live well with dementia in Ireland. This report will then form the cornerstone of lobbying materials that will be used to influence the development of a National Dementia Strategy and the lobbying efforts of The Society for years to come.

23 June 2011: Panhellenic Federation of Alzheimer’s Disease and Related Disorders participates in discussions on driving and dementia with the Special Driving Committee of the Greek Parliament

Magda Tsolaki, the President of the Panhellenic Federation of Alzheimer’s Disease and Related Disorders, was invited by Leonidas Grigorakos, the Chair of the Special Driving Committee of the Greek Parliament, to make a presentation on the issue of driving and dementia on 23 June 2011.

Professor Tsolaki’s presentation, entitled “Dementia – giving up driving: A painful but necessary...”

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We provide full references to articles on our website. Please visit the Alzheimer Europe website on: www.alzheimer-europe.org
condition” highlighted various issues surrounding dementia within the Greek population, including the running of day care centres and the driving ability of people with dementia. Professor Tsolaki presented facts of many studies that have been conducted in Greece and abroad regarding the driving behaviour of elderly people suffering from dementia, the accidents that derive from this condition and the Greek law framework in comparison to the European laws.

After the presentation, a discussion took place among participants. Professor Tsolaki made the proposal that people with dementia could be examined by means of a Mini Mental State Examination. If the score were less than 20 Professor Tsolaki proposed that the driving license be returned. In the event that a patient were able to continue driving then, said Professor Tsolaki, the caregiver should always be with him or her and if he/she understands that the patient is not able to drive then the carer should return the patient’s license.

This proposal has been put on the agenda of the Special Driving Committee and the Chair, Mr Grigorakos, has given his commitment to put this issue forward and discuss it at the parliament’s plenary session.

30 June 2011: Nordic Alzheimer associations meet to discuss their work

The Nordic Alzheimer associations (from Norway, Finland, Sweden, Faroe Islands, Iceland and Denmark) met for three days in Iceland with the aim of “inspiring each other and discussing common challenges and solutions in their work”.

A fundamental problem for the associations was identified as the need for more financial resources. At the present time, participants noted that support from their respective authorities has been both less frequent and the financial amounts reduced. Participants of the meeting shared suggestions for better funding, such as applying to the Nordic Council, the EU and public foundations, ‘going out with the collection box’ and sending letters to relatives of deceased dementia sufferers.

In order to get more members, more support from the public and more support from the politicians, several solutions were suggested. These included raising awareness of the possibilities a person can have when living with dementia, sharing factual information with the public (via TV), asking well-known personalities to be spokespeople for the associations and also asking artists to perform in support of the Alzheimer associations’ work. In addition, it was agreed that prior to general elections that a campaign should be launched whereby postcards would be sent to all politicians, calling them to include issues on dementia in their political campaigns.

Representatives of the associations also discussed the challenge to improve the quality of life for people with dementia and their carers as well as creating better activities for both younger and older people with dementia. It was suggested that this can be achieved by offering more information and better support to people with dementia and their carers, more day care centres and by offering special interest activities (such as high school courses, visits to museums and swimming lessons).

A spokesperson for the Nordic meeting concluded that “the motto for the meeting could be expressed as together we are stronger”.

3-9 July 2011: Alzheimer’s Society organises Dementia Awareness Week in England and Wales

The Alzheimer Society organised its 2011 Dementia Awareness Week campaign, entitled “Remember the Person.” A spokesman explained, ‘the idea of ‘Remember the person’ is encouraging people to be a friend to someone with dementia. It is trying to take the fear out of dementia and make people realise that people living with dementia are just people. It gives them ten simple things they can do to help a family living with dementia that will hopefully get people to support families living with dementia more.”

As part of the campaign, the Society launched a photography competition. Details of the competition and a Remember the person booklet can be obtained from the Alzheimer Society’s website.

5 July 2011: Alzheimer Scotland announces launch of Dementia Research Centre

In collaboration with the University of Edinburgh, Alzheimer Scotland announced it will open a new Dementia Research Centre in September which aims to “provide a high quality environment for dementia research, commission and develop a balanced portfolio of scientific and clinical research, attract external dementia research funding, and develop and maintain a Dementia Brain Tissue Bank.” The Centre will be led by Professor John Star, Co-director of the Centre for Cognitive Ageing and Cognitive Epidemiology.

Science Watch

This section has highlights of the most recent published research on dementia, including research on the prevention, diagnosis, and treatment of the disease.

30 June 2011: Study evaluates effect of training programme on working memory

A study on 20 healthy young adults found that those subjects who participated in a five-week training programme showed a “significantly improved letter-memory performance.”

In addition, findings of the study highlighted the pivotal role of transient neural processes associated with striatal D2 receptor activity in human Working memory functioning.

The study was the result of a collaboration between Swedish (Karolinska Intstitute University of Umeå, Umeå Center for Functional Brain Imaging) and Finnish researchers (Åbo Akademi University, 4Turku PET Center). It was published in the website of Sciencesmag.org.
7 July 2011: Consortium identifies dementia amongst research priorities around the world and calls for urgent action and investment

A consortium including researchers, advocates and clinicians has identified research priorities for improving lives of people with mental illness around the world and has called for urgent action and investment. Mental, neurological and substance use (MNS) disorders constitute 13% of the global burden of disease. As part of the “Grand Challenges in Global Mental Health initiative, priorities for research in the next 10 years that will make an impact on the lives of people living with MNS have been identified”.

The priorities, or grand challenges, were considered to be "a specific barrier that, if removed, would help to solve an important health problem. From an initial 1,565 challenges identified, the top 25 were selected and dementia was included in the top 25.

All of the 25 challenges identified share the following themes:

1. The results underscored the need for research that uses a life-course approach.
2. The suffering caused by the MNS disorder extends beyond the patient to family members and communities.
3. All care and treatment interventions – psychosocial or pharmacological, simple or complex – should have an evidence base to provide programme planners, clinicians, policy-makers with effective care packages.
4. Important relationships between environmental exposures and MSN disorders were underscored in the panel’s responses.

The consortium concluded that:

1. Action on all the challenges will require long-term investment.
2. A wider set of stakeholders need to be engaged.
3. The World Health Organisation (WHO) should disseminate information on the challenges to its member countries’ health ministries and research councils.
4. Consortia and networks, advocacy organisations, universities and partners should organise their activities around one or more of the goals and attendant grand challenges.
5. The World Bank, regional development banks, national development agencies, foundations, non-governmental organisations and the global business community should all participate in addressing the challenges.
6. Incremental progress in addressing the grand challenges in global mental health could lead to significant economic and quality of life benefits – including reductions in inappropriate use of health care and increased productivity for years to come.

A meeting is scheduled in October to develop a strategy for monitoring future progress.

The study, which was published in the journal “Nature”, was carried out by researchers from the National Institute of Mental Health, USA (Pamela Y Collins, Sarah S Joestl, Dana March and Thomas R Insel), the London School of Hygiene and Tropical Medicine UK, Goa, India (Vikram Patel) and from the Rotman Centre for Global Health, Canada (Abdalllah S Daar) and supported by the US National Institute of Mental Health, Maryland, USA and the Global Alliance for Chronic Diseases.

8 July 2011: Mouse study examines the relationship between levels of vitamin D and protein associated with Alzheimer’s disease

A study suggests that by switching off the receptor known as cannainoid-1 (CB1), that mice demonstrated diminished learning and memory capacity. Researchers called for additional research to better understand the role of the CB1 receptors.

The principal author was Professor Andreas Zimmer. The study was conducted by researchers from the University of Bonn and Mainz, Germany, and published in the Proceedings of the National Academy of Sciences (PNAS).

13 July 2011: Mouse study examines relationship between cannabinoid receptor and degeneration

A 10-year study on over 7,000 people over the age of 65 suggests that a person’s likelihood of developing dementia increased if they had certain health problems (including arthritis, poor eyesight, broken bones and skin or chest problems) and that the more problems a person had, the greater the risk of dementia.

The study was conducted by scientists at Dalhousie University, Halifax, Nova Scotia, Canada and published in the journal Neurology.

17 July 2011: Heading: Study investigates the risk of falling in people with early signs of Alzheimer’s disease

A study on 125 older adults has found that falls are more common among individuals with the earliest signs of Alzheimer’s disease (as measured by amyloid imaging using positron emission tomography (PET) with Pittsburgh compound B (PiB)). Researchers found that 48 people experienced at least one fall with a “positive PiB PET image resulting in a greater risk of a fall for each unit of increase on their PiB PET scan”.

Led by Susan Stark, PhD, Assistant Professor of Occupational Therapy and Neurology at Washington University in St. Louis, USA the study was reported on during the Alzheimer’s Association 2011
International Conference on Alzheimer’s disease in Paris, France.

17 July 2011: Study examines the relationship between the retinal changes and Alzheimer’s disease

A small pilot study investigated whether characteristics of blood vessels in the retina might serve as possible biomarkers for Alzheimer’s disease. By examining retinal photographs of people with Alzheimer’s disease, mild cognitive impairment and healthy participants, researchers found that the width of certain blood vessels were different for people with Alzheimer’s disease.

The study was carried out by Shaun Frost, CSIRO Australian e-Health Research Center, and colleagues and reported on during the Alzheimer’s Association 2011 International Conference on Alzheimer’s disease in Paris, France.

17 July 2011: Presentation made on the process of standardizing protocols for hippocampal volume

In Alzheimer’s disease, changes in the part of the brain known as the hippocampus are usually evident by MRI measurement. However, there exist various published protocols for assessing hippocampal volume which differ. As part of a standardisation process, an analysis of the various available protocols was undertaken by Giovanni Frisoni, MD, of San Giovanni di Dio Fatebenefratelli, Brescia, Italy, and colleagues. The researchers found that the protocols differ “because they rely on various techniques of "segmentation" - that is, assigning the electronic image voxels (volumetric pixels) to specific structures, such as the hippocampus, within the brain.”

The next stage of the standardised process will be to identify which elements to include in an international harmonized protocol for MRI-based evaluation of Alzheimer’s disease-related hippocampal shrinkage.

The survey of the various existing protocols was presented by Giovanni Frisoni during the Alzheimer’s Association 2011 International Conference on Alzheimer’s disease in Paris, France.

17 July 2011: Study compares brain amyloid imaging results and the impact of genetics and ethnicity

As part of a worldwide Alzheimer’s disease imaging study, researchers investigated whether the relationship between a gene (Apolipoprotein e4 - which is associated with Alzheimer’s disease), age and amyloid deposition is consistent among ethnic groups in three different countries.

They found that: The effect of age and APOE-e4 on amyloid deposition in the Japanese population is similar to Caucasians, despite a lower e4 allele frequency in the Japanese population.

We provide full references to articles on our website. Please visit the Alzheimer Europe website on: www.alzheimer-europe.org

18 July 2011: Presentation made of the first prototype of the DECIDE service for the early diagnosis of the Alzheimer’s disease

The prototype of an application to analyse images on single cases has been presented to the clinical reference community as the Diagnostic of Confidence by an International Distributed Environment (DECIDE) service for the early diagnosis of Alzheimer’s disease.

The SPM-BASED application can evaluate brain metabolism and perfusion (by FDG PET and rCBF/SPECT images) as functional biomarkers in subjects with cognitive decline and people with dementia, supporting physicians in their assessment of possible and probable Alzheimer disease cases.

To use the service, clinicians will need to qualify, after which they can run the algorithm from their laptops, through a normal web browser.

The presentation took place during the FP7 project DECIDE annual workshop “The assessment of imaging biomarkers for the early and differential diagnosis of Alzheimer’s disease” which was held during the International Conference on Alzheimer’s Disease in Paris, France.

The next stage of the DECIDE project is to select a panel of experts and potential users of the early diagnosis service for its further validation and testing.
18 July 2011: Study examines the role of painkillers in treating agitation in people with dementia

A study on over 300 people with moderate or severe dementia has found that painkillers reduced agitation in some people with dementia. Agitation can be a symptom of dementia and can be treated with antipsychotics, but side effects can include a worsening of symptoms, an increase in the risk of a stroke and death. Researchers concluded that some agitation may arise from untreated pain and that if the pain was properly managed that doctors may be able to reduce the number of prescriptions for antipsychotic drugs.

The British (Kings College, London) and Norwegian study was published on the British Medical Journal (BMJ) website.

18 July 2011: Presentation on national clinical trials database made

During the Alzheimer’s Association 2011 International Conference on Alzheimer’s disease in Paris, France, presentation was given about its “TrialMatch” on-line, free and confidential service (www.alz.org/trialmatch). TrialMatch enables individuals to search for Alzheimer’s disease clinical trials and assists in the matching of individuals to clinical trials (to date, more than 2,500 people have been matched to Alzheimer’s disease clinical trials based on their diagnosis, preferences and location). It currently has 131 research studies with 545 trial sites nationwide (USA) and nearly 12,000 individuals have registered.

Dr Denise Canchola, whose mother has Alzheimer’s disease, spoke of how useful they found the Alzheimer’s Association TrialMatch to be for them. "My mother is passionate about the fight against Alzheimer’s,” said Dr. Canchola. "She understands the significance of advancing research through clinical trials and we turned to Alzheimer’s Association TrialMatch to find the trials for which she was qualified, and were near enough for her to travel. The Alzheimer’s Association website made it very simple to set up a profile, and TrialMatch provided my family with immediate information about local clinical trials in Texas,” said Dr. Canchola. "I was concerned since I live out of state, but we spoke with a TrialMatch specialist who has remained in touch with our family throughout this whole process."

18 July 2011: Study compares the likelihood of decline in cognitive function among retired American football players

A study which compared the likelihood of decline in cognitive function, including MCI, among retired American football players and older adults who had not played professional sports found that just over 35% of the retired football players surveyed had an AD8 (Alzheimer’s screening questionnaire) score that suggested possible dementia. This compared with the Alzheimer’s Association 2011 Facts and Figures report of 13% of Americans aged 65 and over having Alzheimer’s disease.

The researchers then identified former players with probable MCI and compared them to two groups (adults with no cognitive changes and adults with a diagnosis of MCI) and found that “the former athletes were clearly impaired compared with the demographically similar nonathletes” although slightly less impaired than other adults with MCI.

The study was conducted by Christopher Randolph, Clinical Professor of Neurology, Loyola University Medical Center, Chicago, USA and colleagues and presented during the Alzheimer’s Association 2011 International Conference on Alzheimer’s disease in Paris, France.

18 July 2011: Study examines relationship between US veterans with traumatic brain injury and dementia

Medical records of 281,540 US veterans aged 55 years and older were reviewed and the database for traumatic brain injury (TBI) and dementia diagnoses was searched. The risk of dementia was 15.3% in those with a TBI diagnosis compared with 6.8% in those without a TBI diagnosis, leading researcher Kristine Yaffe to conclude “The data suggest that TBI in older veterans may predispose them toward development of symptomatic dementia. And they raise concern about the potential long-term consequences of TBI in younger veterans”.

The study was conducted by Kristine Yaffe, Professor of Psychiatry, Neurology and Epidemiology, University of California, San Francisco (USCF), USA and colleagues and reported on during the Alzheimer’s Association International Conference on Alzheimer’s disease in France.

18 July 2011: Study compares effect of antidepressants and placebo on people with Alzheimer’s disease

A study suggests that two classes of antidepressants most commonly prescribed for Alzheimer’s disease are no more effective than placebo at relieving depression. Most of the participants in the trial improved in mood and the authors attributed this to the fact that participants received psychosocial interventions. Lead researcher, Sube Banerjee called for more research into specific non-drug interventions to develop the most effective standard of care for depression associated with dementia.

The study was led by Sube Banerjee, Kings College, London and reported on-line in the Lancet.

18 July 2011: Panel discussion held on the issue of Women and Alzheimer’s disease

During the Alzheimer’s Association International Conference on Alzheimer’s disease in Paris, France, the panel discussion was held entitled “Women and Alzheimer’s: A Global Perspective” in which an expert panel discussed the impact of Alzheimer’s disease on women. The discussion included new data from “The Value of Knowing Survey” which revealed:

- In all countries women were more fearful of getting Alzheimer’s compared to other diseases, second only to cancer and women in France were 15 per cent more
afraid of developing Alzheimer’s than their male counterparts.

- Likewise, women in all five countries were more concerned than men about a loved one developing Alzheimer’s.
- Almost 60 per cent of women in the United States and nearly 50 per cent of women in France were aware that Alzheimer’s is a progressive and fatal disease.
- Women in all countries, the highest being 90 per cent of women in Spain, believed that government spending on Alzheimer’s research should be increased, the lowest being nearly 70 per cent of women in Germany.
- Women in all countries were more likely than their male counterparts to be involved in day-to-day care. In Poland there was more than a 10 per cent differential.
- In addition to providing the day-to-day care, women in France and Poland were significantly more involved in the decision-making and financial support of the person living with Alzheimer’s disease.
- Should men or women develop Alzheimer’s, the largest percentage of respondents identified their spouse as the person who would be responsible for their primary care, with men identifying their wives 6-18 per cent more often than wives identifying their husbands. In Spain there was an 18 per cent difference. Also of interest was that women were more likely to rely on children or paid caregivers outside the family than men.

The Survey, which was commissioned by Alzheimer Europe and carried out by Harvard School of Public Health, included data from France, Germany, Spain, Poland and the US.

19 July 2011: Study suggests ways in which to prevent 3 million cases of Alzheimer’s disease

The findings from a study suggest that by reducing the prevalence of certain lifestyle-based, chronic disease risk factors by 25 per cent that, potentially, 3 million cases of Alzheimer’s disease worldwide could be prevented. Researchers used a mathematical model to calculate the percentage of Alzheimer’s disease cases that may be attributable to diabetes, mid-life hypertension, mid-life obesity, smoking, depression, low education attainment and physical inactivity. Large-scale studies need to be carried out to find out whether these lifestyle factors will actually lower the risk of Alzheimer’s disease over time.

The study was carried out by Deborah Barnes, Associate Professor of Psychiatry at the University of California, San Francisco and mental health Research PI at the San Francisco Veterans Affairs Medical Center and colleagues and presented at the Alzheimer’s Association International Conference in Paris, France.

20 July 2011: Study examines the long-term safety of Alzheimer’s drug

A study which monitored the long-term safety of the drug bapineuzumab (an Alzheimer’s disease drug) in an ongoing - Phase II extension study found that the drug was mostly well-tolerated. The researchers findings include the fact that:

- most participants (91 %) in the study population reported adverse events (AEs). AEs in more than 10 % of subjects were: fall (14.4 %), agitation (13.4 %), urinary tract infection (12.4 %), upper respiratory tract infection (12.4 %) and anxiety (10.8 %).
- Approximately 24 % of patients reported AEs that were considered related or possibly related to bapineuzumab; most of these (approx. 85 %) were considered mild or moderate. Reported treatment-related AEs in more than 1 % of study participants included: Amyloid-Related Imaging Abnormalities or ARIA-E (9.3 %), headache (2.1 %), evidence of microscopic bleeding in the brain (1.5 %), convulsion (1.5 %) and flushing (1.5 %).
- Approximately 35 % of participants reported serious AEs (SAEs); SAEs in more than 2 % of subjects included: ARIA-E (6.2 %), fall (2.6 %), hip fracture (2.1 %), convulsion (2.1 %), worsening dementia of the Alzheimer’s type (2.1 %), and confusion (2.1 %).
Phase III trials are now underway.

The study was carried out by Stephen Salloway, Butler Hospital and Brown University, Rhode Island, USA and colleagues and presented during the Alzheimer's Association International Conference in Paris, France.

**20 July 2011: Study examines risk factors for ARIA-E**

A systematic review of more than 2,000 MRI scans from 262 Alzheimer's patients who participated in the Phase II bapineuzumab studies to investigate the occurrence of amyloid-related imaging abnormalities on MRI thought to represent vasogenic edema and sulcal effusions (ARIA-E) was carried out. The researchers found that the risk factors for ARIA-E included both the apolipoprotein E e4 allele (APOE-e4, a common genetic risk factor for Alzheimer's) and a higher dose of bapineuzumab, consistent with previous observations.

The study was carried out by Reisa Sperling, MD, MMSc; Brigham and Women's Hospital, Harvard Medical School, Boston, USA and colleagues and reported on at the Alzheimer's Association International Conference in Paris, France.

**20 July 2011: Study examines the progression of mild cognitive impairment to Alzheimer's disease**

In order to examine the stage at which CSF biomarkers of Alzheimer's disease turn positive, researchers performed a lumbar puncture on 137 people with mild cognitive impairment and then monitored them for nine years.

Researchers found that:

- 54 % of subjects developed Alzheimer's disease and 16 per cent progressed onto other forms of dementia.
- Baseline CSF Aβ42 levels were reduced and T-tau and P-tau were elevated in patients who converted to Alzheimer's during follow-up period.
- CSF Aβ42 levels were equally reduced at baseline in patients with MCI who converted to Alzheimer's within 0-5 years (early converters) compared with those who converted to Alzheimer's between 5-10 years (late converters). However, CSF T-tau and P-tau were significantly higher in the early converters compared with the late converters.
- A ratio of baseline Aβ42/P-tau predicted the development of AD within 9.2 years with a sensitivity of 88 %, specificity of 90 %, positive predictive value of 91 % and negative predictive value of 86 %.

The study was carried out by Henrik Zetterberg, MD, PhD, Department of Psychiatry and Neurochemistry, University of Gothenburg, Sweden and colleagues and reported on at the Alzheimer's Association International Conference.

**26 July 2011: Mouse study examines the relationship between sleep and memory**

A mouse study which examined the relationship between memory and sleep continuity concluded that “regardless of the total amount of sleep or sleep intensity, a minimal unit of uninterrupted sleep is crucial for memory consolidation.”

The study was carried out by researchers at Stanford University, USA and published in the Proceedings of the National Academy of Sciences (PNAS).

**28 July 2011: Study investigates cell transplant**

A study in which the skin sample of a 55 year old woman was converted into functioning brain cells, was done by using microRNA (tiny strands of genetic material that regulate processes in cells) to re-programme cells. It is suggested that this approach may be beneficial in avoiding genome modifications when transplanting cells. Researchers hope that this finding may lead to treatment therapy for neurodegenerative diseases such as Alzheimer’s disease, however further studies are called for.

The study was carried out by Sheng Ding, Gladstone Institutes, University of California San Francisco in collaboration with Stuart Lipton, Aging and Stem Cell Research Center, Sanford-Brunham Medical Research Institute, USA and reported on in the journal Cell Stem Cell.

**28 July 2011: Study examines the effects of hypertension drug on memory decline**

A study on monkeys found the drug guanfacine (a licensed hypertension drug) prevented the accumulation of a protein (cAMP, which was associated with impaired memory function) and that memory function was restored.

The study was carried out by researchers from Yale University, USA and published in the journal Nature.

**29 July 2011: Study explores the effectiveness of music intervention against agitated behaviour in people with dementia**

A study on 100 elderly people with dementia has found that agitated behaviour can be alleviated by group music intervention. The researchers concluded that group music intervention in routine activities could be incorporated into nursing facilities for elderly people with dementia in order to “enhance emotional relaxation, create inter-personal interactions and reduce future agitated behaviour.”

The study was carried out by Yu Lin, from Taipei Medical University, Taiwan and colleagues. It was published in the journal of Geriatric Psychiatry.

**Dementia in society**

In this section we report on how dementia is portrayed by the general media (for example, on television and in films).

**17 July 2011: Recognition given to researchers for their work on Alzheimer's disease.**

Four scientists have been recognised for their “extraordinary contributions to Alzheimer’s disease research”.

The honorees are:
1. Kaj Blennow, MD, PhD, Department of Neuroscience and Physiology the Sahlgrenska University Hospital in Sweden, received the 2011 Henry Wisniewski Lifetime Achievement Award for his “ground-breaking contribution to a greater understanding of cerebrospinal fluid (CSF) biomarkers for Alzheimer’s disease.”

2. John Hardy, PhD, Department of Molecular Neuroscience and Reta Lila Western Laboratories, UCL Institute of Neurology United Kingdom, received the 2011 Khalid Iqbal Lifetime Achievement Award. Geneticist, John Hardy, led the research group that found the first amyloid mutation related to Alzheimer’s disease and formulated the amyloid hypothesis.

3. Margaret Pericak-Vance, PhD, John P. Hussman Institute for Human Genomics University of Miami, Miller School of Medicine received the 2011 Bengt Winblad Lifetime Achievement Award. For more than two decades, she has played a major role in advancing the understanding of the genetics contributing to Alzheimer’s.

4. Bruce Lamb, PhD, Department of Neurosciences, Lerner Research Institute of the Cleveland Clinic; Cleveland Clinic Lerner College of Medicine; Departments of Neurosciences and Genetics at Case Western Reserve University, received the 2011 Zaven Khachaturian Award. Bruce Lamb spearheaded and chaired the Alzheimer’s Association’s Breakthrough Ride in 2010. In Washington, Lamb and his fellow riders and researchers delivered more than 110,000 petition signatures urging Congress to make Alzheimer’s disease a national priority.

The awards were announced during the Alzheimer Association International Conference (AAIC) 2011 in Paris.

**New resources and publications**

By reporting on recently published books, reports and information videos on dementia we hope to offer updates on the current resources available to anyone who is affected by dementia.

**30 June 2011: Guide to dementia, sexuality, intimacy and sexual behaviour in care homes published**

The free guide, “The last taboo: A guide to dementia, sexuality, intimacy and sexual behaviour in care homes” has been published by the International Longevity Centre (ILC) UK. The guide is aimed at care home workers and managers with advice is given on current work-based practices. Topics include:

- A brief guide to dementia.
- Dementia, relationships and sexuality in care homes.
- Individual sexual behaviour and expression.
- Older people from the lesbian, gay, bisexual and transgender (LGBT) community.
- Safe sex.

How to develop good practice on policy on dementia, sexual expression, behaviour and intimacy.

Policy framework for dementia, sexuality, intimacy and sexual behaviour in care homes.

The guide also includes a test yourself quiz.

The 56-page Guide is available on the ILC-UK website.

**30 June 2011: GPs receive “Dementia Information Pack”**

The Dementia Services Development Centre (DSDC) sent out its “General Practitioners Information Pack” to GP practices. The packs contained:

- 10 Questions to consider – A Guide for General Practitioners: This booklet aims to assist GPs in managing the care of people with dementia and includes information on various types of dementia, problem behaviours, environmental support and carer support and training.
- 10 Helpful hints for dementia design at home: Practical design solutions for carers living at home with someone who has dementia. This booklet aims to provide practical design solutions so that people with dementia can live independently for as long as possible with information on lighting, interior décor, sound and use of assistive technology.
- 10 Helpful hints for carers: Practical solutions for carers living with people with dementia. This booklet includes topics such as how to cope with aggression, creating relaxing environments, ‘wandering’, sleeplessness and how to cope with dementia and depression.
- Supporting people with dementia, their families and carers throughout Northern Ireland – Dementia Helpline. This leaflet contains information on the Dementia Helpline.

Each booklet can be purchased individually from the publications department of the DSDC. (10 Questions to consider GBP 15, 10 Helpful hints for carers GBP 7.50 and 10 Helpful hints for dementia design at home GBP 7.50).

The initiative was funded by the Atlantic Philanthropies and the Department of Health, Social Services and Public Safety.

**12 July 2011: Report published on cost effective dementia services**

In the UK, the report, “The £20 billion question – an inquiry into improving lives through cost effective dementia services” has been published. The report is a summary of the findings of an inquiry carried out by the All-Party Parliamentary Group on Dementia (APPG).

The inquiry concluded “that given the high costs of dementia (in the UK the financial cost is estimated to be GBP 20 billion a year and estimated to be over GBP 27 billion by 2018) and the human cost of failing to provide good quality care, service commissioners...”
and planners must treat dementia as a priority area for improving cost-effectiveness. Cost effective dementia services could play a key role in supporting health and social care services deliver savings required of them by the government.”

The inquiry highlighted the need to focus on early intervention and prevention to reduce early entry to residential care and reduce unnecessary hospital admissions. It also calls on the health and social care system to work closely to improve the efficiency and quality of dementia services.

**15 July 2011: Data on the French survey on the perception of Alzheimer’s disease now available in English**

The results of the French survey “Alzheimer’s Disease Opinion Survey Programme” (DEOMA) have been published in English. The survey, which includes seven surveys carried out between 2008 and 2010, “offered different perspectives on perceptions of general public, caregivers, general practitioners and Alzheimer disease patients” and was carried out within the framework (measure 37) of the French National Alzheimer Plan (2008-2012).

**21 July 2011: UK Department of Health launches ‘dementia toolkit’**

A “dementia commissioning pack”, which “provides a set of tools and templates for health and local authority commissioners, helping them to design services that are suited to local needs and are cost effective”, was launched by the UK Care Services Minister, Paul Burstow. The pack aims to support planning across the whole spectrum of dementia, from early diagnosis to end of life care by:

1. Improving quality of services for people with dementia by placing patient outcomes and patient choice at the heart of the commissioning process;
2. Driving efficiency by reducing unwarranted variation in services;
3. Reducing bureaucracy for commissioners by providing tailored documents and templates, bringing together the different aspects of commissioning (clinical, financial, commercial, contractual and procurement).

The pack was developed in consultation with a range of health and social care experts, including people with dementia and their carers.

Andrew Chidgey, Head of Policy and Public Affairs, Alzheimer’s Society, said: “It is incredibly important that dementia care is prioritised on a local level. People with dementia and their carers need access to the right local support services to meet their needs. We hope this new tool will help ensure that happens.”

“The National Audit Office and All Party Group on Dementia have both identified that only offering care and support for people with dementia at crisis point is far too late. Millions of pounds are wasted on poor quality care when earlier intervention would save money in the long-term. By investing well in the right services across a wide range of sectors, good quality commissioning will improve the lives of people with dementia and bring long term savings across the health and social care sectors.”

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**AE Calendar**

The following meetings will be attended by representatives of Alzheimer Europe

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<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE Representative</th>
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<tr>
<td>23-24 August 2011</td>
<td>Second meeting of the working group on the ethics of dementia research (Brussels, Belgium)</td>
<td>Dianne and Jean</td>
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<td>5 September 2011</td>
<td>INTERDEM meeting (The Hague, the Netherlands)</td>
<td>Dianne</td>
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<tr>
<td>5-9 September 2011</td>
<td>IPA 15th International Conference (The Hague, the Netherlands)</td>
<td>Iva and Dianne</td>
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<td>6 September 2011</td>
<td>EADC workshop on non-pharmacological interventions (the Hague, the Netherlands)</td>
<td>Dianne</td>
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<td>13 September 2011</td>
<td>Decide Workshop (Rome, Italy)</td>
<td>Jean</td>
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<td>26 September 2011</td>
<td>Steering Committee Meeting RightTimePlaceCare (Barcelona, Spain)</td>
<td>Jean</td>
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<tr>
<td>27-29 September 2011</td>
<td>AAL Forum 2011 (Lecce, Italy)</td>
<td>Dianne</td>
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<td>Date</td>
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<td>1-4 September 2011</td>
<td>Joint Conference on Ageing and Neuro-degeneration presented by the German Center for Neurodegenerative Diseases (DZNE) and the Max Planck Institute for Biology of Ageing (MPI), <a href="http://www.conference-ageing-neurodegeneration.de">www.conference-ageing-neurodegeneration.de</a></td>
<td>Bergisch Gladbach, Germany</td>
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<tr>
<td>20-21 September 2011</td>
<td>3rd International Conference “Senior’s training and nonpharmacological interventions for Alzheimer’s disease”, <a href="http://www.alzheimer.sk">www.alzheimer.sk</a></td>
<td>Bratislava, Slovakia</td>
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<tr>
<td>14-17 October 2011</td>
<td>5th World Congress on Controversies in Neurology (CONy), <a href="http://www.comtecmad.com/cony/2011">www.comtecmad.com/cony/2011</a></td>
<td>Beijing, China</td>
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<td>2-3 November 2011</td>
<td>Ageing Globally – Ageing Locally: Planning for all our futures</td>
<td>Dublin, Ireland</td>
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<tr>
<td>2-4 November 2011</td>
<td>38th Congress of European Association of Geriatric Psychiatry (EAGP), <a href="http://www.augmentonspsiquiatria.com">www.augmentonspsiquiatria.com</a></td>
<td>Porto, Portugal</td>
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<td>3-5 November 2011</td>
<td>4th edition of our Clinical Trials for Alzheimer’s Disease CtaD 2011, <a href="http://www.ctad.fr">www.ctad.fr</a></td>
<td>San Diego, USA</td>
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<td>8-11 March 2012</td>
<td>The 6th World Congress on Controversies in Neurology (CONy), <a href="http://www.comtecmad.com">www.comtecmad.com</a></td>
<td>Vienna, Austria</td>
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