



NEWSLETTER

May 2012

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Editorial

The biggest news item in May is the launch of the Finnish national dementia plan: Finland has joined the small group of countries that have made dementia a health priority.



Alzheimer Europe is glad to welcome another three new members to the European Alzheimer's Alliance. We look forward to seeing new and existing members at our upcoming Lunch Debate at the European Parliament.

Our EU projects are progressing well: PharmaCog concluded a successful review and NILVAD has added a new member to the project team.

There has been considerable activity on the European front:

- The European Commission published a study on the involvement of patients in health care, which varies widely across the Member States.
- The Commission also published the 2012 Ageing Report, which details future costs of pensions, health care and long-term care.
- The Commission's FP7 programme will fund research on the safety of antipsychotic drugs in 2013.
- The AGE Platform EU board adopted a declaration that will promote age-friendly environments and a society for all ages across the EU.
- JPND has two new members - Canada and Israel - as well as a new monitoring and evaluation framework.
- The European Medicines Agency launched a new public

website that lists drug side effects.

Our members were also very busy in May:

- Spain won first place in the Spanish Internet Awards for its online activities, including a radio station.
- Scotland launched its Dementia Awards initiative that will recognise excellence in six different categories of dementia care.
- The UK introduced an online dementia training tool for GPs.
- Italy held two training seminars for GPs and also saw the launch of a smartphone app for carers of people with dementia.
- The Netherlands introduced a new "look & feel" on their website and publications, in an effort to raise awareness and speed up the search for dementia treatments.
- Portugal is on its way to issuing diagnostic criteria and care procedures for Mild Cognitive Impairment.

Alzheimer Europe's organisation of the Vienna conference is progressing nicely. The Programme Committee selected over 100 topics for presentation and the final programme is now available online.

Early Bird registration for the conference is still available: delegates can get a reduced rate by registering before the end of June. In addition, both Austrian Airlines and Lufthansa are offering special rates for travel to Vienna.

Jean Georges
Executive Director

Alzheimer Europe

10 May: Lufthansa and Austrian Airlines are the official carriers for the 22nd Alzheimer Europe Conference



Alzheimer Europe is pleased to work with Austrian Airlines and Lufthansa as official carriers for the Vienna Conference. Both airlines are offering special rates for delegates. Please see our website for details:

www.alzheimer-europe.org/Conferences/Vienna-2012/Official-carrier

31 May: Programme for 22nd Alzheimer Europe Conference is now online

The final programme of the Vienna conference is now online. The Programme Committee was very pleased to receive over 160 submissions. The programme was finalised at the end of May and contains more than 100 topics that will be presented during the two day conference. There will be simultaneous English/German translation available for all plenary presentations and also a poster exhibition.

www.alzheimer-europe.org/Conferences/Vienna-2012/Detailed-Programme

www.alzheimer-europe.org/index.php/EN/Conferences/Vienna-2012/Conference-Committees

EU Projects

11 May: PharmaCog team holds annual review



On 11 May, the PharmaCog project team held a successful annual review in Brussels. The review was attended by over 20 team members and IMI staff and was chaired by Dr. Elisabetta Vaudano, Principal Scientific Manager of the project. She welcomed the participants and introduced the three reviewers:

On 11 May, the PharmaCog project team held a successful annual review in Brussels. The review

- Dr. Jim Hagan, CEO, Global Medical Excellence Cluster (GMEC), King's College London
- Dr. Adam Vas, Professor of Medicine, Szeged University, Hungary
- Prof Guido Storchi, Neurologist, Istituto Neurologico Carlo Besta, Milano.

The reviewers followed presentations from all ten Work Packages, interspersed with Q&A sessions and discussion periods. Dr. Jill Richardson, EFPIA Coordinator, highlighted the progress made in both the pre-clinical and clinical groups. She also pointed out some of the challenges and difficulties of managing this large project. Finally, Prof Régis Bordet, the new Academic Coordinator, presented the next steps to be taken. This included the current year and also the remaining lifetime of the project, which will run until 2015.

15 May: Fiona Cregg joins the NILVAD team



The NILVAD project partners are pleased to welcome Ms Fiona Cregg to the team. Fiona joined on 15 May as the Scientific Clinical Project Manager. She holds a BSc and Research Masters in Microbiology from National University of Ireland, Galway and a Diploma in Project Management from the University of Limerick.

Fiona has over six years of research management experience in the public and private sectors. Prior to joining NILVAD, she was the project manager for MarineTT - another EU Framework 7 project. Before that, she was a Programme Management Coordinator at University College Dublin and led Product Development projects for the Irish biotech company Biotrin.

She said: "The role of Scientific Clinical Project Manager with NILVAD is a perfect opportunity to merge my scientific and project management experience, to ensure the successful management of a challenging and highly complex project in a fascinating area."



Alzheimer Europe Networking

On 2 May (London, United Kingdom), Jean met with representatives of GE Healthcare for an exchange of views and to discuss the 2012 AE Conference in Vienna.

On 3 May (Luxembourg, Luxembourg), Jean met with representatives of Novartis for an exchange of views and to discuss the 2012 AE Conference in Vienna.

On 4 May (Brussels, Belgium) Annette met with Grainne Crowley.

On 8 May (Brussels, Belgium) Annette attended the European Parliament - Environment Committee meeting - Health for Growth.

On 10-11 May (Brussels, Belgium) Alex attended the PharmaCog interim review.

On 11 May (Brussels, Belgium) Annette met with Stefania Lukic Zlobec - Alzheimer Slovenia.

On 16 May (Vienna, Austria) Gwladys attended the meeting with BE Perfect Eagle to talk about the organisation of the our annual conference.

On 24 May (Toulouse, France), Dianne presented the recommendations developed by Alzheimer Europe's working group on the ethics of dementia research at the symposium "Éthique et recherche" organised by AMPA (Monaco) in the framework of the 11th Francophone Conference on Alzheimer's disease and related disorders.

European Alzheimer's Alliance

14 May: Three new MEPs join the European Alzheimer's Alliance

On 14 May, three new MEPs joined the European Alzheimer's Alliance: Maria Badia i Cutchet (Spain, S&D), Mario Mauro (Italy, EPP) and Angelika Werthmann (Austria, NI).

Ms Badia i Cutchet is a member of the Committee on International Trade and a substitute of the Committee on Industry, Research and Energy.

Mr Mauro is a member of the Committee on Foreign Affairs and a substitute of the Committee on Economic and Monetary Affairs.

Ms Werthmann is a member of the Committee on Budgets and the Committee on Women's Rights and Gender Equality. She is a substitute of the Committee on Petitions.



Maria Badia i Cutchet



Mario Mauro



Angelika Werthmann



www.alzheimer-europe.org/Donation

Members of the European Alzheimer's Alliance

Currently, the total number of MEPs in the Alliance stands at 66, representing 22 Member States of the European Union and all 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:



Austria: Becker K. Heinz (EPP), Werthmann Angelika (NI). **Belgium:** Brepoels Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tarabella Marc (S&D). **Bulgaria:** Parvanova Antonia (ALDE). **Cyprus:** Triantaphyllides Kyriacos (GUE-NGL). **Czech Republic:** Cabrnock Milan (ECR), Kohlíček Jaromír (GUE/NGL), Roithova Zuzana (EPP). **Denmark:** Christensen Ole (S&D), Rohde Jens (ALDE), Schaldemose Christel (S&D). **Finland:** Jaakonsaari Liisa (S&D), Jäättteenmäki Anneli (ALDE), Pietikäinen Sirpa (EPP). **France:** Audy Jean-Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Grossetête Françoise (EPP), Juvin Philippe (EPP), Morin-Chartier Elisabeth (EPP), Pargneaux Gilles (S&D). **Germany:** Niebler Angelika (EPP), Roth-Behrendt Dagmar (S&D), Ulmer Thomas (EPP), Weisgerber Anja (EPP). **Greece:** Chountis Nikolaos (GUE-NGL), Koppa Maria Eleni (S&D), Kratsa-Tsagaropoulou Rodi (EPP). **Ireland:** Aylward Liam (ALDE), Childers Nessa (S&D), Crowley Brian (ALDE), McGuinness Mairead (EPP), Mitchell Gay (EPP). **Italy:** Mauro Mario (EPP), Panzeri Pier Antonio (S&D), Toia Patrizia (S&D). **Lithuania:** Vilija Blinkevičiute (S&D). **Luxembourg:** Engel Frank (EPP), Lulling Astrid (EPP). **Netherlands:** De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP). **Poland:** Łukacijewska Elżbieta (EPP). **Portugal:** Carvalho Maria da Graça (EPP), Coelho Carlos (EPP), Matias Marisa (GUE/NGL). **Romania:** Antonescu Elena Oana (EPP), Busoi Cristian (ALDE), Sârbu Daciana Octavia (S&D). **Slovakia:** Mikolasik Miroslav (EPP), Zaboriska Anna (EPP). **Slovenia:** Peterle Alojz (EPP). **Spain:** Badia i Cutchet Maria (S&D). **United Kingdom:** Ashworth Richard (ECR), Hall Fiona (ALDE), McAvan Linda (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Taylor Keith (Greens/EFA), Vaughan Derek (S&D), Watson Graham (ALDE), Willmott Glenis (S&D), Yannakoudakis Marina (ECR).

EU Developments

4 May: Canada and Israel join the JPND



On 4 May, Canada and Israel were approved for JPND membership at the 12th JPND Management Board meeting.

Israel joins as a full member. Full membership of JPND is open to EU Member States and EU-Associated Countries.



Canada's application is the first for Third Country membership of JPND. Canada now participates in JPND according to the recently published JPND Policy on Third Country Participation.

There are now 27 total countries participating in JPND.

www.neurodegenerationresearch.eu/news-events/general-news-events/news-article/?no_cache=1&tx_ttnews%5Btt_news%5D=66&cHash=aff2356e92298a659ec009f7aa4de0f1#maincontent

11 May: AGE Platform EU adopts 2012 Declaration

During its General Assembly on 11 May, AGE Platform EU adopted a Declaration urging EU leaders and Member

States to put employment at the top of their political priorities, to adopt strong measures to boost the EU economy, job creation and social cohesion and to promote a new European society based on greater solidarity, equity and cooperation between and within generations.

The Declaration calls on the EU to establish a European Covenant of Mayors on Demographic Change and to create the political framework for local and regional authorities to promote age-friendly environments and a society for all ages across the EU.

In addition, the Declaration seeks to encourage local and regional authorities to join the World Health Organisation Global Network of Age-Friendly Cities and Communities and establish national programmes to support them.

In this Declaration, AGE Platform Europe and its members acknowledge that together with rights, older people have duties towards other generations, society and the communities they live in, and call on older people to help rebuild trust and confidence in the future and invest in sectors that will create jobs and growth.

www.age-platform.eu/images/stories/EN/AGE_2012_General_Assembly_Declaration_FINAL_14_May_2012.pdf

15 May: European Commission publishes Eurobarometer Qualitative Study on Patient Involvement

On 15 May 2012, the European Commission (DG Sanco) published Eurobarometer's Qualitative Study on Patient Involvement. This study explored views on patient involvement in healthcare across fifteen European Member States. In-depth interviews were carried out with five healthcare practitioners and ten patients in each country. The key conclusions were:

- Practitioners and patients alike see the benefits of patients being more engaged and taking more responsibility for their health.
- Communication and choice were both central to the idea of patient involvement.
- Many patients described a "traditional doctor-patient relationship" where the doctor was seen as beyond questioning and patients felt uncomfortable giving feedback.
- Healthcare professionals tended to be satisfied with the current relationship they have with patients but patients wanted to be able to ask questions and understand how decisions were made.
- The internet as source of information about symptoms and healthcare was seen as positive by patients but was seen more ambivalently by some practitioners.
- Practitioners saw the benefit of "patient involvement" as patients with increased understanding; patients saw the benefits as having more information and options with regard to treatment.
- The two key risks of "patient involvement" were perceived to be the resourcing requirements needed (e.g. additional time and staffing) and the negative impact it might have on the patient/doctor relationship.
- Chronically ill patients tended to have more experience in self-monitoring and other aspects and often had a more tangible understanding of patient involvement.
- Younger patients and those with a better education had higher expectations of their own involvement and tended to be less reluctant to question decisions made about their own healthcare.

The study concludes that patient involvement seems poorly understood by many professionals and patients across the EU.

http://ec.europa.eu/health/healthcare/docs/eurobaro_patient_involvement_2012_en.pdf

22 May: European Medicines Agency publishes information on research activities on medicine safety that may be funded by FP7

On 22 May, the European Medicines Agency (EMA) presented the current call for research activities on medicines safety that can be funded by the European Commission under the Seventh Framework Programme (FP7) in 2013.

One of the priorities is "The long-term safety effects of antipsychotics in patients with dementia".

The research activities will concern experiences with medicines that have been on the market for many years and have shown that potentially serious adverse events may only become apparent long after their marketing authorisation.

Projects to be funded in this topic must generate new knowledge on severe drug reactions and provide scientific evidence for post-authorisation risk assessment of medicinal products. Proposals must be based on pharmaco-epidemiological approaches focusing on adverse drug reaction research.

The European Commission receives a list of research priorities on medicine safety adopted by the Agency's Committee for Medicinal Products for Human Use (CHMP), on the basis of recommendations from its Pharmacovigilance Working Party. The European Commission publishes each year's priority topics in an orientation paper, which includes proposed priorities for health research in the following year.

ftp://ftp.cordis.europa.eu/pub/fp7/health/docs/fp7-health-2013-orientation-paper-120402_en.pdf

www.ema.europa.eu/ema/index.jsp?curl=pages/regulation/document_listing/document_listing_000322.jsp&mid=

23 May: JPND Monitoring and Evaluation Framework published

On 23 May, the JPND has established a monitoring and evaluation framework to develop indicators of success and monitor the merits of the joint programming approach to performing research on the European level.

The framework follows the publication of the JPND Research Strategy (February 2012) and is a deliverable of the JUMPAHEAD project (Commission funded coordination action that supports the implementation of the JPND).

It includes a set of performance indicators and a questionnaire for participating countries to investigate attitudes and opinions towards the JPND initiative.

The framework has relevance for other Joint Programming Initiatives, in particular those in other health domains, to understand the effects of the process of Joint Programming.

http://ec.europa.eu/health/healthcare/docs/eurobaro_patient_involvement_2012_en.pdf

24 May: World Health Assembly adopts a resolution on non-communicable diseases

On 24 May, the World Health Organization adopted a resolution on non-communicable diseases at the 6th World Health Assembly. The resolution seeks to strengthen policies on non-communicable diseases to promote active ageing.

The resolution urges the Member States to encourage older peoples' active participation in society, increase healthy ageing and promote the highest standard of health and well-being for older people by addressing their needs.

A separate committee also approved a resolution on the global burden of mental disorders and the need for a comprehensive, coordinated response from the health and social sectors in member countries.

www.euro.who.int/en/who-we-are/governance/regional-committee-for-europe/news/news/2012/5/world-health-assembly,-day-2-resolution-on-noncommunicable-diseases-approved

www.euro.who.int/en/who-we-are/governance/regional-committee-for-europe/news/news/2012/5/world-health-assembly,-closing-21-resolutions-adopted-during-the-week

25 May: European Commission publishes 2012 Ageing Report

On 25 May, the European Commission presented “The 2012 Ageing Report: Economic and budgetary projections for the EU27 Member States (2010-2060)”. This is the 4th report that analyses the long-term economic and budgetary impact of an ageing population.

The report details the expenditure projections covering pensions, health care, long-term care, education and unemployment transfers for all Member States.

The report is structured in two parts: 1) description of the underlying assumptions: population projection, labour force projection and other macroeconomic assumptions and sensitivity tests; 2) presentation of the methodologies for projecting future expenditure on pensions, health care, long-term care, education and unemployment benefits. A statistical annex gives an overview of the main assumptions by country.

On the basis of current policies, age-related public expenditures (pensions, health-care and long-term care) are projected to increase by 4.1 percentage points to around 29% of GDP between 2010 and 2060. Public pension expenditure alone is projected to rise by 1.5 percentage points to nearly 13% of GDP by 2060. However, the report shows a large diversity across EU Member States, depending notably on progress with pension reforms.

The updated projections of age-related expenditure and the associated sustainability assessments provide important insights to both the economic impact of ageing and the risks to the long-term sustainability of Member States’ public finances reflecting new economic environment, affected by a durable impact of the current crisis, and further reform effort by EU MS.

The 2012 Ageing Report has been jointly prepared by the European Commission, Directorate-General for Economic and Financial Affairs and the Economic Policy Committee Ageing Working Group.

http://europa.eu/epc/pdf/2012_ageing_report_en.pdf

31 May: European Medicines Agency publishes side effect reports online

On 31 May, the European Medicines Agency (EMA) made a new step forward to boost EU transparency with the online publication of suspected side effect reports for medicines authorised in the European Economic Area (EEA).

This is a public website and the reports come directly from the EU medicines safety database (EudraVigilance).

The information presented on the website relates to approximately 650 medicines and active substances authorised through the centralised procedure, in the form of a single report per medicine or active substance.

The EMA aims to present more suspected side effect reports for common drug substances used in nationally authorised medicines within a year.

In June, the Agency will launch the website in the remaining 22 official EU languages.

www.adrreports.eu

31 May: Council reaches agreement on Horizon 2020

On 31 May, the European ministers for Research and Innovation (R&D) reached an agreement on the overall structure of Horizon 2020, the EU’s coming Framework programme for R&D.

The agreement on the overall structure of Horizon 2020 will strengthen research and innovation as growth promoters in Europe. Besides strengthening basic excellent research, Horizon 2020 will mark a new and challenge-driven approach towards strategic research in the EU, focusing on seven grand challenges, such as food security, climate change, an ageing population and the need for intelligent transportation.

Compared to the Commission’s proposal, the agreement reached by the Ministers has an even stronger emphasis on interdisciplinarity.

Furthermore, the agreement strengthens simplification and reduces bureaucracy, which will make it easier and more attractive for small and medium-sized enterprises to apply for EU funding.

The negotiations on the budget allocation to the various specific programmes of Horizon 2020 will start soon and will be followed by discussions in the European Parliament.

www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/en/intm/130562.pdf

31 May: Council adopts conclusions on the European Innovation Partnership on Active and Healthy Ageing

On 31 April 2012, the Council adopted conclusions on the European Innovation Partnership on Active and Healthy Ageing (EIP AHA).

The conclusions recall that synergies between the EU and Member States will ensure that innovations with a societal benefit get to the market more quickly. The Council also recalls the Member States’ agreement to take the necessary political decisions on future Innovation Partnerships before they are launched.

The conclusions take note of the Commission’s communication “Taking forward the Strategic Implementation Plan of the EIP AHA presenting the Commission’s response to the Strategic Implementation Plan (SIP) proposed by the steering group of the AHA pilot.

The Council recognises that the EIP AHA pilot – as the first deliverable of the EIP - has the potential to accelerate innovation and exploit synergies within and across the different priorities and policies at EU, national and regional level.

The Council acknowledges the importance of involving Member States by communicating new EIPs and SIPs to the Competitiveness Council and other relevant Council

formations at an early stage. It also underlines that current and future Commission proposals for new EIPs must be endorsed in the relevant sectoral Council formations before being launched.

The Council reiterates that the EIPs must build on certain common principles - such as the whole research and innovation (R&I) cycle - by bringing together the supply and demand side of R&I policy actions, simplifying, streamlining and adding value to the current situation by filling gaps, improving coordination on the basis of initial mapping of all existing initiatives relevant for the EIP and accelerating innovation.

The Council notes the Commission's intention to report regularly on progress achieved with the EIPs and welcomes the Commission's intention to organise an evaluation in 2013 of the overall performance of the pilot EIP as well as the EIPs launched in 2012.

http://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/en/intm/130545.pdf

Members' News

4 May: Portugal seeks to legalise best practices for MCI



In Portugal, a reference document entitled "Therapeutic approach on cognitive changes" has been submitted for approval to the Ministry of Health. The document provides diagnostic criteria for Mild Cognitive Impairment and procedures that doctors can follow before the first signs of cognitive decline. These are derived from best practices in Europe and the United States. The objective is to have these practices officially approved and included in the Portuguese national health system.

This document was developed by the Ministry's Directorate-General for Health and the Portuguese Medical Association, including input from Alzheimer Portugal's Scientific Committee. Alzheimer Portugal is cited in the report as the reference organisation for support and advice.

Maria do Rosário Zincke Dos Reis, Chairperson of the Board of Alzheimer Portugal, said: "This new norm will allow Portuguese citizens to benefit from the latest means and criteria for diagnosis and treatment; it represents a significant step towards improving the life of people with Alzheimer's disease and other forms of dementia, including cognitive impairment."


12 May: Alzheimer Uniti Italy trains GPs for early assessment of dementia



On 12 and 19 May, Alzheimer Uniti Italy organised and led a two-day training course for GPs in Rome. The training focused on the characteristics of Alzheimer's disease, with a particular emphasis on early symptoms. The objective of the training was to enable GPs to identify people with emerging cases of dementia, in order to refer them to specialists as early as possible.

The course was led by geriatricians, neurologists, psychiatrists and psychologists. They discussed the issues of early diagnosis, pharmacological and non-pharmacological therapies and also the importance of the training of caregivers. There were also discussions about legal and ethical issues. The course, using film and slide presentations as well as role-playing, was very lively and created a new, close relationship between the GPs and Alzheimer Uniti.

14 May: UK Alzheimer's Society launches online dementia training tool

 **Leading the fight against dementia**

The UK Alzheimer's Society, along with BMJ Learning, has launched a free online dementia training tool for GPs. The training programme was introduced after a survey by the society revealed that only 37% of UK general practitioners say they have received sufficient basic dementia training.

The survey polled 382 GPs and also found that 71% of them wished to learn more about dementia online, while 75% cited a specific interest in managing the behavioural symptoms of dementia. The free programme includes sections on early diagnosis and non-drug treatments for behavioural symptoms such as hobbies, social interaction and music.

Jeremy Hughes, Chief Executive of Alzheimer's Society, said: "Currently, only 43% of people with dementia get a formal diagnosis. We need to support GPs as much as possible as they have a vital role to play in diagnosing and supporting people with the condition, which is why we are very excited to launch this online learning tool.

"Alzheimer's Society is also on hand to signpost GPs to additional support in the assessment of people with memory problems, as well as the management of dementia. We also offer information about services and support to those who have received or are awaiting a diagnosis, and their families."

The programme was developed by the Society and BMJ Learning, the medical education division of the BMJ Group.

<http://learning.bmj.com/learning/module-intro/.html?moduleId=10032231>

15 May: Scotland's Dementia Awards will recognise excellence in the field of dementia



On 15 May, Alzheimer Scotland announced the launch of "Scotland's Dementia Awards". This award programme will recognise and promote the efforts of professionals and communities who are committed to enhancing the health, well-being and experience of people with dementia and their families.

The campaign will help showcase the creativity, innovation and dedication that makes a real difference to the daily lives of people with dementia and their families. It aims to demonstrate clearly how, across Scotland, policy is being sustainably put into best shared practice.

The award ceremony will take place on 20 September - World Alzheimer's Day - and will include six award categories:

- Best acute care initiative
- Best innovation in continuing care
- Best community support initiative
- Best dementia friendly community initiative
- Best educational initiative
- Most innovative partnership.

Henry Simmons, Chief Executive of Alzheimer Scotland said: "Every day, people with dementia and their families face the challenge of living well with dementia. Thousands of staff, across the health, social care and community sectors, go above and beyond their individual roles to make a real difference to the lives of people with this illness. Scotland's Dementia Awards are a celebration of staff who have risen to the challenge of helping people to live well with dementia in our society."

Scotland's Dementia Awards is a partnership between Alzheimer Scotland, NHS Education for Scotland, NHS Health Scotland and the Scottish Social Services Council.

<http://dementiascotland.org/scotlands-dementia-awards/>

17 May: Fundación Alzheimer España wins top spot in Spanish Internet Awards



On 17 May, Fundación Alzheimer España (FAE) was voted one of three finalists in the 14th edition of the Spanish Internet Awards. The Madrid-based association won the award for "best non-profit initiative". Finalists were chosen from over 600 nominations, based on 45,798 votes cast by internet users.

The award is a tribute to the online efforts made by FAE during the past year. The association has continued to increase the use of virtual media to help and accompany families and caregivers of people with Alzheimer's disease. This includes a new website, increased presence in social networks and an online radio channel with programming dedicated to people with Alzheimer's disease and their families.

The award ceremony took place in the Spanish Senate and was attended by FAE members Micheline Selmes (President), Jacques Selmes (Secretary) and Celia Selmes (Virtual Media Coordinator).

22 May: Alzheimer Netherlands presents a new look and logo



Alzheimer Netherlands has introduced a new look and logo as part of a campaign to step up the fight against dementia. The principal aims of the campaign are to raise awareness - by reaching many more people with dementia, carers, volunteers and donors - and also to help speed up the search for dementia treatments.

www.alzheimer-nederland.nl/

31 May: Federazione Alzheimer Italia launches smartphone dementia app



Federazione Alzheimer Italia is launching a new iPhone and Android application

that is dedicated to the families of people with Alzheimer's disease. The "Alzheimer App" can be freely downloaded from the Apple Store and Android Market from Friday 1 June.

The interactive application will provide detailed information about Alzheimer's disease and caring for people with the disease. It will include advice on how to deal with loss of memory and aggressive reactions, how to deal with fears and obsessions and many other topics. Users will also have access to Pronto Alzheimer's, the dedicated telephone hotline operated by Federazione Alzheimer Italia.



The Alzheimer App was entirely designed and built by Federazione Alzheimer Italia. There are approximately one million people with dementia in Italy, including 600,000 people living with Alzheimer's disease.

Policy Watch

8 May: Finland launches national dementia plan



On 8 May, Finland launched a national dementia plan called the "National Memory Programme 2012-2020". The plan aims to create a "memory-friendly Finland" and was prepared by the Ministry of Social Affairs and Health along—with other organisations. According to Dr. Eila Okkonen, Executive Director of Muistiliitto (the Finnish Alzheimer Society), there will be four main areas of activity:

- The promotion of lifelong brain health and the prevention of memory-related diseases. Brain health will be promoted both on a personal level and on a very broad level across society, including social and health services and education.
- The ageing of the population is causing a marked increase of memory-related diseases in Finland. The plan will promote positive attitudes towards people with dementia in order to guarantee their basic human rights, including the right to self-determination.
- Good care and rehabilitation is essential. It is important that memory-related diseases be recognised, diagnosed and treated as early as possible. There will be a particular focus on the entire care chain and its quality.
- Support for high quality research and competence of professionals are important. Research efforts must be adequately resourced, in order to support the areas above and also to ensure further development. This includes developing the knowledge and competencies of health care professionals.

Muistiliitto has been a key supporter of the Memory Plan for many years. Mr Pekka Laine, the former head of the society, was particularly active in rallying support for the plan: the society has been part of the working group that planned the programme since 2010. Muistiliitto has also commissioned Memory Surveys and was a key player in preparing a national framework for high-quality services and care for older people.

There are currently some 120,000 Finns with memory-related diseases, of which 7,000-10,000 are of working

age. Approximately 13,000 new diagnoses are made every year. Muistiliitto will continue its efforts to ensure that people with dementia and their carers can have a comfortable and meaningful life.

Science Watch

2 May: New fluorene compound disrupts amyloid formation

Researchers at the University of California (UC) have shown that small molecules called spin-labelled fluorene compounds can be used to detect amyloid in imaging studies, to disrupt the formation of amyloid and to reduce inflammation.

Fluorene compounds are small, three-ringed molecules that were originally developed as imaging agents to detect amyloid with PET imaging. In the current study, researchers "labelled" the fluorine compounds by adding a nitroxide molecule. This allows the activity of the compound to be visible using electron paramagnetic resonance (EPR) spectroscopy.

The group found that spin-labeled compounds disrupted A β peptide formation more effectively than did non-labeled fluorenes. In addition, the antioxidant properties of the nitroxide molecule contributed to the protective effects on neurons. Another benefit is that the compounds can easily pass through the blood-brain barrier.

"We have found these small molecules to have significant beneficial effects on cultured neurons, from protecting against toxic compounds that form in neurons to reducing inflammatory factors," said John C. Voss, Professor of Biochemistry and Molecular Medicine at the UC Davis School of Medicine and the principal investigator of the study. "As a result, they have great potential as a therapeutic agent to prevent or delay injury in individuals in the earliest stages of Alzheimer's disease, before significant damage to the brain occurs."

www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0035443

4 May: Pyroglu beta-amyloid may trigger Alzheimer's disease

A new study shows that a specific, highly toxic form of beta-amyloid causes increased toxicity of other beta-amyloid forms. This may be a trigger for the advent and development of Alzheimer's disease. The study was carried out by researchers at the University of Virginia (UVa) and German biotech company Probiadrug.

George Bloom, Professor of Biology and Cell Biology at UVa, said: "This form of beta-amyloid, called pyroglutamylated (pyroglu) beta-amyloid, is a real bad guy in Alzheimer's disease. We've confirmed that it converts more abundant beta-amyloids into a form that is up to 100 times more toxic, making this a very dangerous killer of brain cells and an attractive target for drug therapy."

Prof Bloom further explained that the process is similar to various prion diseases, such as mad cow disease or chronic wasting disease, where a toxic protein infects normal proteins that spread through the brain and ultimately destroy it.

The research team is now looking for other proteins that are needed for pyroglu beta-amyloid to become toxic.

www.nature.com/nature/journal/vaop/ncurrent/full/nature11060.html

7 May: New MRI test may provide earlier AD diagnosis

Doctors at the University of Pennsylvania's Perelman School of Medicine (Penn) have developed a form of MRI called arterial spin labeling (ASL-MRI) that may be useful to diagnose early dementia. ASL-MRI is used to detect changes in blood flow and the uptake of blood sugar, or glucose, in the brain's memory centres.

John Detre, Professor of Neurology & Radiology at Penn, said: "Increases or decreases in brain function are accompanied by changes in both blood flow and glucose metabolism. We designed ASL-MRI to allow cerebral blood flow to be imaged noninvasively and quantitatively using a routine MRI scanner."

ASL-MRI was tested against PET scans on a small trial group and the results were similar in effectiveness. PET scans include an injection of radioactive dye, while ASL-MRI is noninvasive and also much cheaper.

The researchers expect to continue this project with a much larger trial population.

www.ncbi.nlm.nih.gov/pubmed/22018493

7 May: Protein keeps synaptic pathway open, reducing neuron death

Scientists at the University of Leicester have identified a major pathway leading to brain cell death in mice with neurodegenerative disease. The team was able to block the pathway, preventing neuron death and increasing survival in the mice.

In human neurodegenerative diseases, proteins misfold in a variety of different ways, resulting in the plaques found in Alzheimer's and the Lewy bodies found in Parkinson's disease. In this case, the researchers studied mice with neurodegeneration caused by prion disease - the mouse equivalent of Creutzfeldt-Jacob Disease. They found that the build-up of misfolded proteins activates a natural defence mechanism in cells. This switches off production of new proteins and would normally switch back on again, but the continued build-up of mis-shapen protein keeps the switch turned off. This in turn leads to neuron death, as the key proteins essential for neuron survival are not produced.

However, by injecting a protein that blocks the "off" switch of the pathway, the scientists were able to restore protein production and halt neurodegeneration. The brain cells were protected, protein levels and synaptic transmission were restored and the mice lived longer.

Professor Giovanna Mallucci, who led the team, said, "What's exciting is the emergence of a common mechanism of brain cell death, across a range of different neurodegenerative disorders, activated by the different mis-folded proteins in each disease. The fact that, in mice with prion disease, we were able to manipulate this mechanism and protect the brain cells means we may have a way forward in how we treat other disorders. Instead of targeting individual mis-folded proteins in different neurodegenerative diseases, we may be able to target the shared pathways and rescue brain cell degeneration irrespective of the underlying disease."

www.nature.com/nature/journal/v485/n7399/full/nature11058.html

9 May: New carrier brings more antibodies across the blood-brain barrier

Researchers from biOasis Technologies successfully used their carrier product to bring anti-AB antibodies and other drug molecules across the blood-brain barrier, at a higher concentration than that with drug molecules on their own.

The drug carrier, named "Transcend Vector", does not have any medicinal effect itself. Instead, it acts as a courier to deliver packages of medicinal molecules across the barrier that protects the brain. In this study, scientists tested delivery of the anti-AB antibody called Herceptin. Results showed that Transcend successfully delivered greater than four times more anti-AB into the brain when compared to anti-AB on its own.

biOasis is a private Canadian biopharmaceutical company. This study also involved the National Research Council of Canada (NRC) and the iCapture Centre at St. Paul's Hospital in Vancouver.

www.bioasis.ca/news/2012/120508.htm

11 May: Excess hippocampal activity may presage MCI

A research team from Johns Hopkins University (JHU) has developed a potential new therapeutic approach for people with amnesic mild cognitive impairment (aMCI). In amnesic MCI, people's memories are worse than would be expected in healthy people the same age.

The study focused on the excess brain activity commonly associated with conditions that cause mild cognitive decline and memory loss. Previously, it had been thought that this neural hyperactivity in the hippocampus was the brain's attempt to compensate for a weakness in forming new memories. Instead, the team found that the excess activity contributed to conditions such as aMCI.

Dr. Michela Gallagher, Professor of Psychological and Brain Sciences and Neuroscience at JHU said: "In the case of aMCI, it has been suggested that increased hippocampal activation may serve a beneficial function by recruiting additional neural 'resources' to compensate for those that are lost. However, animal studies have raised the alternative view that this excess activation may be contributing to memory impairment."

Dr. Gallagher's team administered a low dose of levetiracetam, a drug clinically used to treat epilepsy. They found that subjects who had been treated with an effective dose of the drug did better on a memory task, pointing to the therapeutic potential of reducing this excess activation of the hippocampus in patients with aMCI.

These results support the view that increased hippocampal activation in aMCI is a dysfunctional condition and that targeting excess hippocampal activity has therapeutic potential.

www.sciencedirect.com/science/article/pii/S089662731200325X

16 May: New drug trial will focus on people at risk of early-onset Alzheimer's disease

A new clinical trial will test the drug crenezumab on 300 people who are cognitively normal but at very high risk of developing early-onset Alzheimer's disease.

The trial will begin in 2013 and will run for five years. According to Dr. Eric Reiman, executive director of Banner Alzheimer's Institute and co-leader of the project, tests may already indicate whether the drug helps delay memory decline or brain changes within two years.

Most of the trial participants will come from a large extended family of 5,000 people who live in Medellín, Colombia. Many of these family members carry a specific mutation of the presenilin-1 (PSEN1) protein. PSEN1 is known to be active in the development of Alzheimer's disease type 3 (AD3). Carriers often suffer the first signs of cognitive impairment around age 45 and many of them advance to dementia. The trial will include participants as young as 30.

During the study, 100 people will receive crenezumab every two weeks and another 100 will receive a placebo. The researchers will take regular physiological measurements from PET and MRI scans and CSF tests. They will also administer memory and cognitive tests and will monitor changes in people's emotional state.

Crenezumab is a humanized monoclonal antibody developed by Swiss-based AC Immune and licensed to Roche's Genentech. It is already being tested in two Phase 2 trials (see links below). The current trial is among the first projects in the new American Alzheimer plan. It will be funded for up to USD 100 million by Banner Alzheimer's Institute, Genentech and the National Institute of Health.

<http://clinicaltrials.gov/show/NCT01397578>
<http://clinicaltrials.gov/ct2/show/NCT01343966>



17 May: ApoE4 gene causes blood-brain barrier degradation

Scientists from various universities have been investigating why the ApoE4 gene makes people more prone to developing Alzheimer's disease. People who carry two copies of the gene have roughly eight to ten times the risk of getting Alzheimer's disease than people who do not. The researchers determined that ApoE4 works through cyclophilin A (CyPA), a protein found in intracellular fluid.

The presence of ApoE4 causes CyPA to accumulate in large amounts in the cells that help maintain the blood-brain barrier. ApoE4 creates a cascade of molecular signaling that weakens the barrier, causing blood vessels to become leaky. This makes it more likely that toxic substances will leak from the vessels into the brain, damaging neurons and reducing blood flow.

Dr. Robert Bell, researcher at the University of Rochester, said: "We are beginning to understand much more about how ApoE4 may be contributing to Alzheimer's disease. In the presence of ApoE4, increased CyPA causes a breakdown of the cells lining the blood vessels in Alzheimer's disease in the same way it does in cardiovascular disease or abdominal aneurysm. This

establishes a new vascular target to fight Alzheimer's disease."

The research team consisted of scientists from the University of Rochester (New York), the University of Southern California, Washington University School of Medicine and the Karolinska Institutet in Sweden. The study was funded by the National Institute of Neurological Disorders and Stroke and the National Institute on Aging.

www.nature.com/nature/journal/vaop/ncurrent/full/nature11087.html

23 May: Semantic memory is critical for episodic future thinking

Researchers from Neuroscience Research Australia (NRA) have found that our ability to imagine and plan our future depends on brain regions that store general knowledge.

NRA's Dr. Muireann Irish found that people with dementia who no longer recall general knowledge - for example, the names of famous people or popular songs - are also unable to imagine themselves in the future.

"We already know that if memory of past events is compromised, as is the case in Alzheimer's disease, then the ability to imagine future scenarios is also impaired," she said. "We have now discovered that damage to parts of the brain that store knowledge of facts and meanings can also produce the same effect."

Thinking about the future is an important ability because it helps us to plan and anticipate the consequences of our actions. Dr. Irish explained: "A person with dementia may leave the oven on, partly because they forget the appropriate action, but also because they cannot project forward in time to anticipate the dangerous consequences this might have."

The research team used MRI to study people with Alzheimer's disease (where memories of past experiences are lost) as well as patients with semantic dementia who have lost the ability to remember facts (semantic memory) but have little problem remembering past experiences.

Results showed that the semantic dementia group was as impaired as the Alzheimer's group when imagining future events, even though their memory of past experiences was relatively intact.

Dr. Irish concluded: "This is an important finding, as it points to multiple regions in the brain that are responsible for our ability to imagine and plan for the future."

<http://brain.oxfordjournals.org/content/early/2012/05/22/brain.aws119.abstract?sid=711dd953-42ab-4517-8fd4-4bb1ceec88f7>

23 May: FP7 will fund research to test safety of antipsychotics in people with dementia

The European Commission's Seventh Framework Programme (FP7) will provide funds to research the long-term safety effects of antipsychotics in people with dementia. This decision is based on a recommendation by the European Medicines Agency (EMA).

Antipsychotics are divided into typical and atypical groups. In 2005, it was determined that atypical antipsychotics caused a higher mortality rate among elderly people with dementia. However, it was not known whether this effect also extended to the typical antipsychotics.

The EMA's Committee for Medicinal Products for Human Use (CHMP), which investigated this issue, found some evidence that the risk of increased mortality was higher in typical antipsychotics. However, methodological limitations prevented firm conclusions. The CHMP also concluded that it was not possible to differentiate between different antipsychotics and that further research was needed. This led directly to EMA's recommendation to the Commission.

The objective of the research will be to investigate and quantify the increased risk of mortality in elderly people with dementia treated with antipsychotic drugs and to explore risk factors and the underlying mechanism(s) for any observed increased risk. Variables to be studied include dose, renal impairment, body weight, treatment combinations and co-medication. The research should generate data that will allow the comparison of different antipsychotic drugs with regard to their risk of serious cardiac and cardiovascular events and mortality in elderly people with dementia.

www.ema.europa.eu/docs/en_GB/document_library/Other/2012/05/WC500127477.pdf

24 May: Microglia brain cells destroy healthy synapses

A study from Boston Children's Hospital shows that brain cells known as microglia specifically seek out and destroy unneeded synapses, the connections between neurons.

Microglia are the first and main form of active immune defence in the central nervous system. They operate inside the blood brain barrier and act as scavengers, ridding the body of damaged neurons, plaques and infectious agents. This study is the first to show that microglia also attack healthy synapses.

The study showed that microglia take their cues from neurons' activity patterns and from a set of signals called the complement cascade, used by the immune system to rid the body of unwanted pathogens and debris. When complement signaling was disrupted, pruning of synapses diminished.

Dr. Beth Stephens and Dr. Dori Schaffer, co-leaders of the study, demonstrated that microglia have receptors that recognize the complement protein C3 - the same protein found on synapses that are destined for elimination. Dr. Schaffer said: "We think that weaker synapses are being tagged with C3, and that microglia are eliminating them just as macrophages would eliminate bacteria. C3 is like an 'eat me' signal."

The findings may have implications for understanding neurodegenerative diseases in which synapses are lost, including Alzheimer's and Huntington's diseases and ALS.

www.sciencedirect.com/science/article/pii/S0896627312004291

29 May: Lundbeck compound reaches primary endpoint in Phase 2 trial

On 29 May, Danish drug company Lundbeck announced that Lu AE58054 has met its primary endpoint in a fixed dose, randomized, placebo-controlled clinical study in 278 patients suffering from Alzheimer's disease. Lu AE58054 is a selective 5HT₆ receptor antagonist.

Augmentation therapy with Lu AE58054 (plus10mg/day donepezil) at the selected dose resulted in statistically significant improvement in cognition, as measured by the

ADAS-cog (Alzheimer's Disease Assessment Scale-cognitive sub-scale) over a 24 week treatment period versus placebo (plus 10mg/day donepezil). Secondary endpoints, including measures of global status and activities of daily living also showed positive trends with the addition of Lu AE58054, compared with patients who only received donepezil.

Lundbeck is now evaluating the future development strategy of Lu AE58054 with the intention to initiate a major pivotal clinical programme.

<http://investor.lundbeck.com/releasedetail.cfm?ReleaseID=677436>

Dementia in Society

17 May: Cardinal warns against dehumanisation of elderly people

Cormac Murphy-O'Connor, Catholic Cardinal and ex-Archbishop of Westminster, recently spoke out against treating elderly people as a burden. He said there was a subtle and silent process of dehumanising older people at work through common attitudes. He added that a loss of reverence for humanity meant that some of the most vulnerable people in society are now routinely viewed as a problem or threat.

The Cardinal warned that political decisions to cut back on vital care services amounted to denying older people's fundamental right to life: "When society only sees age as an expensive inconvenience, a threat to resources and lifestyles, it no longer sees a person but a problem. If we load the elderly, or indeed any group, with fears – the fear of dementia and Alzheimer's, the fear of growing dependence and the loss of autonomy, the fear of exhausting resources – you sanction violence against them."

23 May: Ballet rehearsal raises funds for dementia in Portugal



More than 600 people paid to attend a "Solidary Rehearsal" of the Portuguese National Ballet Company performing works by João Botelho and Olga Roriz.

All the proceeds were donated to the Alzheimer Portugal Association. They will help to fund "Rosemary's House", a nursing home designed specifically for people with dementia. Rosemary's House will be home to 30 people with dementia and will host a further 15 people on a daily basis. In addition, staff will provide external support services to 50 homes in the area.

This initiative was part of the Solidary Rehearsal project, which aims to support associations that are facing serious financial difficulties with day-to-day activities and new projects.

New Publications & Resources

15 May: New guide provides resources for developers of dementia friendly communities



A new guide called "Developing Dementia Friendly Communities – Learning and Guidance

for Local Authorities" is freely available online (see link

below). This was produced by Innovations in Dementia, a community interest company in the UK.

The guide is the result of the company's effort to support the Sheffield and Hampshire councils with their work in developing dementia friendly communities. It is essentially a resource toolbox for local authorities and includes the following:

Finding out what a dementia friendly community means to people with dementia and carers: guidelines for engaging people with dementia and carers.

A toolkit to encourage participation of local businesses and their employees. This contains:

- Dementia awareness raising options for staff
- Help-pack for customer-facing staff
- Checklist for dementia friendly environments
- Thinking about a "Memory Aware" high street scheme.

Innovations in Dementia works throughout the UK with people with dementia, partner organisations and professionals with the aim of developing and testing projects that will enhance the lives of people with dementia. The guide was part of the Ageing Well initiative and was published by the Local Government Association. This project was funded by the UK Department for Work and Pensions.

www.local.gov.uk/web/guest/ageing-well/what-makes-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE

www.innovationsindementia.org.uk



Contact Alzheimer Europe at:

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AE Calendar

Date	Meeting	AE Representative
1 June	Meeting with A. Garvey to discuss the Transparency Directive (Brussels, Belgium)	Annette
6 June	Annual IMPACT Consortium Meeting (Trondheim, Norway)	Dianne
7 June	European Parliament – Hearing on ‘the prevention of age-related diseases in women’ and Experts Roundtable on ‘active ageing in a lifetime’ (Brussels, Belgium)	Annette
12 June	AGE Platform – WeDo partners meeting (Brussels, Belgium)	Annette
14-15 June	First meeting of Alzheimer Europe’s working group on the ethical issues related to the deprivation of freedom (Brussels, Belgium)	Dianne
19 June	AGE Platform thematic seminar on the ‘impact of the crisis on older people’ (Brussels, Belgium)	Annette
19-20 June	Symposium “Biobanks and biomedical collections – an ethical framework for future research” organised by the Council of Europe (Strasbourg, France)	Dianne
25 June	Alzheimer Europe Board (Brussels, Belgium)	AE Board & Staff
26 June	Company round table (Brussels, Belgium)	AE Board
26 June	Lunch debate “The place of Alzheimer’s disease in the new European public health and research programmes”	AE Board, members and staff
26-27 June	AE Workshop on national dementia strategies (Brussels, Belgium)	AE Board, members and staff
27 June	Meeting with Fondation Médéric Alzheimer	Heike and Jean
9 July	PharmaCog EPMT and Steering Committee meeting (Stevenage, UK)	Alex

Future Conferences

Date	Meeting	Place
11 June 2012	Creative Dementia Arts Conference, www.eminence-grise.co.uk	London, UK
14-15 June 2012	4th Biannual NUBIN Symposium on Biomarkers in Neurodegenerative Disease, http://www.vumc.nl/afdelingen/NUBIN	Amsterdam, Netherlands
14-16 June 2012	6th Kuopio Alzheimer Symposium, www.uef.fi/kuopioadsymposium	Kuopio, Finland
12-13 July 2012	International Academy on Nutrition and Aging (IANA), www.iagg.info	Albuquerque, New Mexico
5-7 September 2012	7th International conference on creative expression, communication and dementia, www.cecd-society.org	Worcester, UK
8-11 September 2012	16th Congress of the European Federation of Neurological Societies (EFNS), efns2012@kenes.com	Stockholm, Sweden
4-6 October 2012	22 nd Alzheimer Europe Conference “Changing perceptions, practice and policy”, www.alzheimer-europe.org/EN/Conferences	Vienna, Austria
18-20 October 2012	7. Kongress der Deutschen Alzheimer Gesellschaft, www.kukm.de/alzheimer2012	Hanau, Germany
18-20 October 2012	41st Annual Scientific and Educational Meeting: “Aging in a Changing World”, http://www.cagacg.ca	Vancouver, Canada
29-31 October 2012	5th Clinical Trials Conference on Alzheimer Disease (CTAD), www.ctad.fr	Monte Carlo, Monaco
8-11 November 2012	International Conference on Clinical Practice in Alzheimer Disease (CPAD), www.paragon-conventions.com	Budapest, Hungary
5-7 December 2012	Nursing Ethics: intensive course on foundational approaches, contemporary and educational issues in the field of nursing ethics, http://www.masterbioethics.org	Leuven, Belgium
25-27 January 2013	5th European Neurological Conference on Clinical Practices: Neurovascular and Neurodegenerative Diseases, www.enccp.net	Krakow, Poland
6-10 March 2013	11th International Conference on Alzheimer’s and Parkinson’s Diseases, www.kenes.com/adpd	Florence, Italy
21-23 March 2013	57. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), www.dgkn-kongress.de	Leipzig, Germany
23-27 June 2013	The 20th IAGG Congress of gerontology and geriatrics, www.iagg2013.org	Seoul, Korea
3-5 October 2013	23 rd Alzheimer Europe Conference: “Living well in a dementia-friendly society”, www.alzheimer-europe.org/EN/Conferences	Valletta, Malta
20-23 March 2014	58. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), www.dgkn-kongress.de	Berlin, Germany
21-24 March 2014	30. International Congress of Clinical Neurophysiology (ICCN), www.iccn2014.de	Berlin, Germany

22nd Alzheimer Europe Conference

Changing perceptions, practice and policy

Vienna / 4-6 October 2012

Mark the dates!

www.alzheimer-europe.org/conferences



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