August-September 2011

Welcome to the

NEWSLETTER

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Highlights in this issue

23-24 August: AE organises **2** meeting on ethics of dementia research.

19-20 September: United **8** Nations recognise Alzheimer's disease as major disease areas

21 September: Members of
European**4**Alzheimer's
Alliance show their support
during World
Alzheimer's
Day**4**

21 September: AE member
organisations6-8World Alzheimer's Day



Table of contents			
Editorial1			
Alzheimer Europe2			
Alzheimer Europe Networking3			
DECIDE4			
PharmaCog4			
European Alzheimer's Alliance4			
EU Developments5			
Policy Watch7			
Members' News8			
Science Watch11			
Living with Dementia14			
Dementia in Society14			
New Resources and Publications			
AE Calendar 16			
Future Conferences16			

Editorial

FUROPE

This edition of our newsletter covers the months of August and September.



During that time, our small team has undergone some changes and I am delighted to announce that Alex Teligadas has joined our small team as our new Communications Officer. He has been off to a flying start and has contributed articles to this newsletter, represented Alzheimer Europe at a recent DECIDE project meeting in Rome and helped us proof-read the two publications we published in September.

As part of his role in representing AE on different EU projects, he reports on recent developments from both the DECIDE and the PharmaCog projects in this newsletter.

I am equally happy that Julie Fraser, our previous Communications Officer, will continue to work with Alzheimer Europe as Editor of the Dementia in Europe Magazine. This magazine has become an essential part of our campaign to make dementia a European priority and we published issue 9 at the end of September.

As with previous editions, we were able to obtain interviews with key policy makers, such as Máire Geoghegan-Quinn, the EU Commissioner for Research and Innovation, Elzbieta Katarzyna Lukacijewska, MEP (Poland) and Nicola Sturgeon, Scotland's Deputy First Minister.

We dedicated a special section of our magazine to Poland, as publication coincided with our Annual Conference in Warsaw. As you can imagine, we have been busy with the final preparations of our Annual Conference which will be organised under the theme: "European solidarity without borders". With over 400 registered delegates so far, it promises to become one of our most successful conferences to date.

An important development this month was the UN Summit on non-communicable diseases in New York. Although the report focused initially only on the prevention and control of cardiovascular diseases. respiratory diseases, cancer and diabetes, it was possible to have Alzheimer's disease recognised as a major disease area thanks to the lobbying of the Alzheimer movement. From a European perspective, we were delighted that the European Parliament gave its clear backing to our campaign of having dementia included as a priority.

September is also the month of World Alzheimer's Day and, as in previous years, 21 September was used to raise by our national member organisations the awareness of Alzheimer's disease and other forms of dementia. The ingenuity of members on how to involve society is truly amazing. We only cover some of our members' activities, but will report additional ones in next month's newsletter.

We also report how Françoise Grossetête, MEP (France) and Frédérique Ries, MEP (Belgium), two members of the European Alzheimer's Alliance supported World Alzheimer's Day.

I hope you enjoy this newsletter and hope to see you at our Warsaw Conference.

> Jean Georges Executive Director



Alzheimer Europe

23-24 August: Ethics of Dementia Research working group meets in Brussels

The working group on the ethics of dementia research met in Brussels for its second meeting. Two members of the Steering Committee of the European Dementia Ethics Network, namely Prof. Iva Holmerova (CZ) and Sabine Jansen (DE) also sat in on the meeting. Chaired by Dianne Gove, Information Officer of Alzheimer Europe, the working group discussed the issues raised in an extensive literature review on the ethics of dementia research including:

- involving people with dementia
- protecting the wellbeing of participants with dementia
- participation in clinical trials
- research linked to prodromal or pre-symptomatic diagnosis
- psycho-social and social sciences dementia research
- selecting, monitoring and disseminating research
- end-of-life research
- research on the brain and other tissue.

Future recommendations were also considered which will be in the report due to be published in early 2012.



The ethics of dementia research working group consists of representatives from:

- Austria Dr Thomas Frühwald, Chief Doctor of the Department of Acute Geriatry of the Hietzing Hospital, Vienna
- Belgium Prof. Dr Lieve Van den Block, senior founding member of the End-of-life care Research Group of Ghent University and Vrije Universiteit Brussel, and professor of communication and education in Family Medicine at Vrije Universiteit Brussels
- France Dr Fabrice Gzil, Head of Social Studies Department, Fondation Médéric Alzheimer in Paris
- Italy Dr Carlo Petrini, Head of the Bioethics Unit of National Institute, Rome and Prof. Sandro Sorbi, Professor of Neurology, Department of Neurological Science and Psychiatry at the University of Florence;
- Lithuania Dr Rasa Ruseckiene, Consultant in adult and old age psychiatry and therapist
- Sweden Dr Peter Annas, PhD, Senior Research Scientist and AstraZeneca's representative in the PharmaCog project

- United Kingdom (England) Angela Clayton-Turner, volunteer, carer and member of the Alzheimer Society, lay member of her local Research Ethics Committee
- United Kingdom (Scotland) James McKillop OBE, who lives with dementia and is a founding member of the Scottish Working Group on Dementia, and his wife, Maureen McKillop, carer.

1 September: Alzheimer Europe welcomes Alex Teligadas as new Communications Officer



Alex Teligadas joined Alzheimer Europe as the Communications Officer on 1 September 2011. In addition to his communications duties, he will be representing the organisation in EU projects such as DECIDE and Pharma-Cog and supporting the

dissemination activities of these projects.

Before joining AE, Alex had worked for 14 years in marketing and communications with the satellite and communications company SES ASTRA.

The previous Communications Officer, Julie Fraser, will continue to work with Alzheimer Europe as the editor of the Dementia in Europe Magazine.

9 September: Alzheimer Europe organises "Value of Knowing" symposium during IPA Conference

On 9 September 2011, Iva Holmerova chaired the symposium on the "Value of Knowing" at the International Psychogeriatric Association (IPA) conference.

James and Maureen McKillop spoke about their personal experience of the period prior to diagnosis and the positive impact that knowing the diagnosis has had on their lives.

Dianne Gove then presented the results of this study carried out by the Harvard School of Public Health and Alzheimer Europe.

Beth Kallmyer from the US Alzheimer's Association then highlighted the implications of the findings of this study which involved the general public in France, Germany, Poland, Spain and the United States.

9 September: Dianne Gove discusses ethical use of assistive technology at the IPA conference

On 9 September, Dianne Gove (Information Officer, Alzheimer Europe) gave a presentation on the importance of meaning when assessing the ethical use of assistive technology (AT) during the International Psychogeriatric Association (IPA) conference in The Hague.

Ms Gove focused on the factors influencing the choice and the ethical use of assistive technology devices and systems. Two case studies showed the variety of ethical issues which may arise from the use of AT.



The panel session was chaired by Cees Hertogh, Professor in Geriatric Ethics (Department of Nursing Home Medicine, Amsterdam, the Netherlands) and member of the steering committee of the European Dementia Ethics Network. The other speakers were:

- Dr Inger Hagen (Forget-me-not AS, Norway), who also presented case studies highlighting ethical issues linked to the use of assistive technology. Dr Hagen was a member of Alzheimer Europe's recent working group on AT.
- Louise Robinson (Professor of Primary Care and Ageing, Newcastle University, the United Kingdom), who wishes to extend access to assistive technology "from health to supermarkets to amazon.com".

A lively debate followed this well-attended session. Several audience members presented arguments concerning the ethical use of assistive technology, including Mr Alistair Niemeijer, who was also an expert in Alzheimer Europe's working group on AT.

Alzheimer Europe Networking

- On 23 August (Brussels, Belgium), Annette met with representatives of Merck for an exchange of views on health literacy.
- From 23 to 24 August (Brussels, Belgium), Alzheimer Europe organised a meeting of its working group on the ethics of dementia research and of the Steering Committee of the European Dementia Ethics Network.
- From 5 to 9 September (The Hague, Netherlands) Dianne attended the International Psychogeriatrics Association's (IPA) 15th International Conference, where she also participated in the INTERDEM meeting and the EADC workshop on nonpharmacological interventions.
- On 6 September (Brussels, Belgium), Annette attended the Parliament Magazine reception for the Polish EU Presidency.
- On 8 September (The Hague, Netherlands), Alzheimer Europe organised a "Value of Knowing" symposium during the IPA Conference.
- On 8 September (Vienna, Austria) Gwladys went to Vienna to discuss the 2012 AE Conference.
- From 12-13 September (Warsaw, Poland) Gwladys went to Poland for preparations of the 2011 AE Conference.
- On 13 September (Rome, Italy) Alex attended a DECIDE review meeting.
- On 14 September (Luxembourg, Luxembourg), Jean met with Antoni Montserrat, Michael Hübel and Albrecht Werner from the Public Health Directorate of the European Commission.
- On 19 September (Paris, France) Annette attended the France Alzheimer event to celebrate World Alzheimer's Day.
- On 21 September (Brussels, Belgium) Annette attended a breakfast meeting on diagnostic technology organised by GE Healthcare.
- On 21 September (Brussels, Belgium) Annette attended the EPF/EFPIA/PGEU lunch seminar on "Adherence to treatment".
- On 21 September (Brussels, Belgium), Annette and Jean attended the Parliament Magazine event "Facing the Future" on World Alzheimer's Day.
- On 22 September (Brussels, Belgium) Annette attended the EFPIA Think Tank.
- From 26-28 September (Lecce, Italy) Dianne attended the Ambient Assisted Living (AAL) Forum 2011.



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www.alzheimer-europe.org/Publications/E-shop

This issue Includes:

- highlights from President Sarkozy's address to the 2011 Alzheimer Association International Conference in Paris
- interviews with Máire Geoghegan-Quinn, EU Commissioner for Research and Innovation and Nicola Sturgeon, Scotland's Deputy First Minister
- a report on Alzheimer Europe's latest lunch debate in the European Parliament dedicated to ALCOVE, the European Joint Action on Dementia
- highlights from the findings of the "Value of knowing" survey of AE and the Harvard School of Public Health
- an overview of national dementia strategies in Europe
- a special section dedicated to Poland.

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DECIDE

13 September: DECIDE holds preparatory meeting ahead of review



On 13 September, the DECIDE project team held a preparatory meeting in Rome, ahead

of the first annual review by the European Commission.

DECIDE stands for Diagnostic Enhancement of Confidence by an International Distributed Environment. This twoyear project aims to design, implement and validate einfrastructure which will provide clinicians with a secure, user-friendly service for the early diagnosis of Alzheimer's disease.

The review will take place on 6 October on the premises of the 21st Alzheimer Europe Conference in Warsaw.

PharmaCog

6 September: Alexandra Auffret is the new PharmaCog Academic Coordinator



Alexandra Auffret was named as the new Academic Coordinator for the PharmaCog project. Ms Auffret, previously European Project Manager, replaces Olivier Blin.

PharmaCog, short for "Prediction of cognitive properties of new drug candidates for neurodegenerative

diseases in early clinical development", is a project coordinated by GlaxoSmithKline R&D and the Université de la Méditerranée, Marseille, France and started its activities on 1 January 2010 thanks to significant funding (EUR 20.2 million) from the Innovative Medicines Initiative.

26 September: University of Genoa joins PharmaCog



The University of Genoa has joined PharmaCog as a new

beneficiary. The university will recruit patients for the clinical trial in Work Package 5: Identification of biomarkers sensitive to disease progression (clinical trials).

European Alzheimer's Alliance

21 September: Frédérique Ries hosts Parliament Magazine conference on Alzheimer's disease

On 22 September, Parliament Magazine and Sanofi organised a conference called "Facing the Future" which addressed current and future Alzheimer's disease topics.

The conference was hosted in Brussels by Frédérique Ries, MEP (Belgium), who is also a member of the European Alzheimer's Alliance. Notable speakers included:

• Christine Barr, Project Manager, ALCOVE

- Enda Connolly, Irish Health Research Board
- Filip Domanski, representative of the Polish EU Council Presidency and Health Attaché of the Permanent Representation of Poland in Brussels
- Jean Georges, Executive Director, Alzheimer Europe
- Thomas Rooney, Head of Translational Research Neurodegenerative Diseases Group, TSU Aging, Sanofi
- Martin Seychell, Deputy Director General for Health and Consumers, European Commission.



The delegates concentrated

on current European collaboration on dementia research and on funding a future where dementia cases are expected to double within 20 years.

21 September: Françoise Grossetête co-authors article on EU efforts to combat Alzheimer's disease



Françoise Grossetête, MEP (France) and Chairperson of the European Alzheimer's Alliance, commemorated World Alzheimer's Day by publishing a joint article outlining the progress made by various EU initiatives to combat Alzheimer's disease.

The co-author is Philippe Amouyel, Professor of Epidemiology at CHRU (Lille, France), Director of the Fondation Plan Alzheimer and President of the coordination committee of JPND (EU Joint Programming - Neurodegenerative Disease Research).

The authors argue that joint, international public/private research initiatives are – and will remain – the most effective way to make progress towards an eventual cure for Alzheimer's disease.

The article shows the steady rise in Alzheimer's disease cases (which may reach 65.7 million worldwide by 2030) and describes the main programmes operating in Europe today, including details of the JPND, ALCOVE and IMI initiatives. There is an increasing number of people with Alzheimer's disease today, and that number will continue to grow: in Europe, among people aged 85+, one of four women and one of five men are currently affected by Alzheimer's disease or other forms of dementia. The number of afflicted people will reportedly double over the next 20 years.

Worldwide, there are now an estimated 35.6 million people with Alzheimer's disease. This number will nearly double after 20 years, meaning that there could be up to 65.7 million people with Alzheimer's disease by 2030.These are the lowest estimates. The authors note that the number of people with Alzheimer's disease is



generally underestimated, due to the difficulty of diagnosis.

The European Parliament and Commission, sovereign EU Member States and private organisations are all involved in funding and conducting Alzheimer's disease research. The authors chose the following initiatives to illustrate the scope and extent of Alzheimer's disease research:

EU Joint Programming - Neurodegenerative Disease Research (JPND)

The JPND initiative, which began in 2008, pools resources from all EU countries to address challenges which cannot be resolved by any country individually. The area of neurodegenerative diseases, especially Alzheimer's disease, was the first to be selected as a Joint Programming initiative. JPND currently includes 23 countries which collaborate on the following pilot project: "Optimization of biomarkers and harmonisation of their use among the clinical centers." This project was launched in May 2011. To date, over EUR 17 million have been raised and distributed to researchers in 21 countries.

The ALCOVE project (Alzheimer's Cooperative Valuation in Europe)

ALCOVE is a joint action between European Member States which aims to improve knowledge on dementia and its consequences. Research is focused on four key areas: prevalence, early diagnosis, care & services and ethics & dignity. ALCOVE is funded by the European Commission and currently involves 30 partners from 19 Member States.

Innovative Medicines Initiative (IMI)

IMI is another European Union initiative which brings together pharmaceutical companies, academic institutions, private firms, regulatory agencies and patient organisations. The aim is to speed up the development of better and safer medicines. A current IMI project is called PharmaCog, or "Prediction of cognitive properties of new drugs for neurodegenerative diseases in early clinical development." PharmaCog focuses on developing new tools for testing drug candidates more effectively and is funded by a contribution of some EUR 20 million from the European Commission and pharmaceutical companies.

Members of the European Alzheimer's Alliance

Currently, the total number of MEPs in the Alliance stands at 53, 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: Brepoels Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA) Bulgaria: Parvanova Antonyia (ALDE), Cyprus: Triantaphyllides Kyriacos (GUE-NGL), Czech Republic: Cabrnoch Milan (ECR), Kohlicek Jaromir (GUE/NGL), Roithova Zuzana (EPP), Denmark: Schaldemose Christel (S&D), Finland: Jaakonsaari Liisa (S&D), Jäätteenmäki Anneli (ALDE), Pietikäinen Sirpa (EPP), France: Audy Jean-Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Grossetête Françoise (EPP), Morin-Chartier Elisabeth (EPP), 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), McGuiness Mairead (EPP), 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), 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).

EU Developments

19 July: European Commission announces an investment of nearly EUR 7 billion for research and innovation



Within the framework of the EU's Seventh Framework Programme for Research (FP7), Commissioner Máire Geoghegan-Quinn announced an investment of

nearly EUR 7 billion for innovation through research. Over the next 15 years, it is hoped that this investment will result in the creation of around 450,000 jobs and nearly EUR 80 billion in GDP growth.

The European Commission's press release states that "[g]rants will promote research to tackle the biggest societal challenges facing Europe and the world. Universities, research organisations and industry will be among more than 16,000 funding recipients.

"The main focus of the calls is the integration of research with innovation to tackle societal challenges and create sustainable jobs and growth by giving Europe a lead in the key technology markets of the future.

"This will be achieved by providing more support than ever before for activities that help bridge the gap between research and the market, for example by demonstrating that new technologies have commercial potential or can work on a sufficiently large scale to be industrially viable. This market-linked approach is also central to the European Innovation Partnerships (EIPs), set up under the Innovation Union action plan. Each EIP, including the pilot on Active and Healthy Ageing will be supported by FP7 projects.

"In all, EUR 220 million of the EUR 656 million available for health research and EUR 240 million of the EUR 1.3 billion in funding for information and communication technology (ICT) will be allocated to work aimed at tackling the challenge of providing for an ageing population."



11 August: European Commission proposes 2013 as the "European Year of Citizens"

On 11 August, Viviane Reding, European Commissioner for Justice and Citizens proposed to make 2013 the 'European Year of Citizens'.

2013 will be the 20th anniversary of the 'citizenship of the European Union' concept. This concept and its related rights first appeared in the Maastricht Treaty.

Since then, tangible progress affecting the lives of European citizens has been made. However, the Commission's EU Citizenship report of 2010 has evidenced some remaining barriers and hurdles that need to be overcome so the European citizens can fully exercise their rights abroad. The initiative also answers the European Parliament's call for such a year.

Several events, conferences and seminars will be organised at EU, national, regional and local level.

The Commission's decision will need to be approved by the European Parliament and the Council of Ministers.

The proposed budget for the activities to take place during the 2013 European Year of Citizens is EUR 1 million.

25 August: European Commission publishes Men's Health Report

On 25 August, the European Commission published a report on "The State of Men's Health in Europe". This report presents the state of men's health across Europe. Patterns emerging from data taken from 34 European countries show marked differences in health outcomes among men both between and within countries.

In the field of dementia, the report highlights that excess of weight constitutes an increased risk of dementia in men.

15 September: European Parliament recognises importance of Alzheimer's disease in UN fight against non-communicable diseases

The European Parliament adopted a resolution on 15 September in which it calls for EU support and leadership in the prevention and control of non-communicable diseases which will be addressed at a United Nations High Level Meeting in New York on 18 and 19 September.

In particular, the Parliament asks for the adoption of a European Action Plan on non-communicable diseases and for the establishment of national plans by Member States.

In its resolution, Members of the European Parliament also asked for mental and neurological disorders, including Alzheimer's disease not to be neglected.

21 September: CORDIS website highlights EU dementia research

On 21 September, CORDIS, the European Commission research website, presented the European research projects on dementia funded under the Seventh Framework Programme (FP7). Research on neurodegenerative diseases under FP7 has gone much further than in previous framework programmes. Since

2007, over EUR 100 million have been dedicated to research on Alzheimer's disease.

Most of the funding into Alzheimer's disease under FP7 has been carried out under its 'Health' theme (around EUR 60 million). The projects focus primarily on gaining a better understanding of the pathophysiology of Alzheimer's disease and the development of new diagnostic and therapeutic targets.

Because of the cross-disciplinary approach to EU research funding, Alzheimer's disease has also been a focus of other FP7 themes such as 'Nanosciences, nanotechnologies, materials and new production technologies' and 'Information and communication technologies'.

Research into Alzheimer's disease is also being carried out as part of the Joint Programming on Neurodegenerative Diseases (JPND) initiative, funded by the EU as part of the JUMPAHEAD ('Coordination Action in support of the implementation of a Joint Programming Initiative for Combating Neurodegenerative Diseases, in particular Alzheimer s disease') project.

The JPND was the first Joint Programming Initiative to be set up and involves 23 countries. It is currently implementing a call for proposals focusing on neurodegenerative diseases and the optimisation of biomarkers and harmonisation of their use between clinical centres. Approximately EUR 14 million has been set aside for this specific call.

Research on neurodegenerative diseases has also been addressed as part of the Innovative Medicines Initiative Joint Undertaking (IMI JU), a public-private partnership between the European Commission and the pharmaceutical industry EFPIA). The IMI JU activities includes support for the discovery of new tools to improve the efficacy of drugs against Alzheimer's disease.

22 September: European Parliament organises seminar on information and communication technology

On 22 September 2011, Niccolò Rinaldi, MEP (Italy) and Antonyia Parvanova, MEP (Bulgaria) organised a seminar in the European Parliament to evaluate the use of Information and Communication Technology (ICT) for improving the quality of life and healthy ageing of the population. By applying user-friendly tools, ICT has the potential to contribute to socio-economic competitiveness while improving the quality of life of the population.

The recent studies and experiences presented by the panellists showed the strong link between quality of life and the use of ICT:

- health ("e-health" system maintaining physical and mental health, prevention and early diagnosis)
- citizens life-long education ("e-learning" system opening on-line access to information and programmes, school facilities)
- security and social welfare (maintaining human dignity, intergenerational fairness)



- freedom movement of persons (independent mobility, socially developed transport and traffic control systems)
- open-society communication (people leading people, culture lifestyle, respect for the environment, participation of citizens).

To answer the challenges faced by the healthcare systems and the economic situation, the MEPs stressed the need to strengthen the dialogue with the academic world and focus on research and innovation. ICT has to be seen as a long-term investment to answer these challenges. Political willingness and awareness of public opinion are key elements to consider as well.

Policy Watch

1 August: New studies on the attitude and opinion of patients and carers published on website of French Alzheimer Plan

Measure 37 of the French Alzheimer Plan (Studying disease knowledge and attitudes) seeks to study what impact the French Alzheimer Plan has on patients and carers. A series of surveys were carried out between 2008 and 2009.

First, the INPES Study (Institut National de Prévention et d'Éducation pour la Santé - National Institute for Prevention and Health Education) reviewed the literature on the social representation of Alzheimer's disease published over 15 years. The results show that the perception of Alzheimer's disease throughout the world is extremely negative, with only slight differences between general public and those more concerned with the disease.

INPES asked IPSOS to carry a qualitative survey on 100 persons from the public, family carers and health professionals in order to review the public awareness, knowledge and attitudes about Alzheimer's disease. The study showed that fear and shame are associated with Alzheimer's disease. The study also revealed rather fragmented knowledge on Alzheimer's disease between the category of people being surveyed, including family carers and health professionals. Great expectations related to research, institutions and training were evidenced in the general population.

In 2011, another series of surveys will be carried out under Measure 37 to assess the evolution of attitudes toward Alzheimer's disease and opinions on some measures of the Alzheimer's Plan.

A module of questions will be added to the INPES health survey addressed to general practitioners. The objective of this new survey is to:

- explore social representations of Alzheimer's disease among public, patients, family carers, general practitioners, health and care professionals in general
- evaluate the opinion and expectations related to the Alzheimer's plan.

A series of quantitative studies will be carried out on different populations: the general public, GPs, family carers and patients, health and care professionals.

The French Alzheimer Plan website now shows the results of the studies carried out to date under this measure and presents the next studies.

Other measures of the Plan will be considered under the remit of Measure 37 of the Plan.

18 August: UK invests GBP 18 million in dementia research

In the UK the government has announced a total investment of GBP 800 million in health research, GBP 18 million of which is allocated to dementia research. The GBP 18 million will be divided between four new biomedical research which specialise in dementia research units (University of Cambridge, Newcastle University, Kings College London and University College London).

Andrew Chidgey, Head of Policy and Public Affairs, Alzheimer's Society, said "[i]t is fabulous news that dementia research is finally being taken seriously and beginning to be treated as the priority it should be. The funding is a very significant first step on the road to bringing dementia in line with other conditions such as cancer, which receives eight times more government funding. There is a great opportunity here to make a real and lasting difference for people with dementia and their carers. We look forward to seeing the results transform lives."

25 August: Advisory Council on Alzheimer's disease formed in the USA

An Advisory Council on Alzheimer's disease research, care and services has been announced in the USA. The Council is formed under the framework of the National Alzheimer's Project Act (2011). The Advisory Council is charged with "developing recommendations to improve the health outcomes for people with Alzheimer's and other dementias, and their families and to reduce the financial impact of Alzheimer's disease on individuals, families and the nation. The council will provide an annual assessment of all federally funded efforts in Alzheimer's research, care and services along with their outcomes."

26 August: France Alzheimer regrets further delay to reform of loss of independence in France

AS the French Government failed to act on a promise to reform the financing of long-term care, the eighth such delay in five years, Ms Marie-Odile Desana, President of France Alzheimer, expressed her disappointment at the low priority given to a reform which could affect up to 1.2 million people with dementia and their caregivers.

France Alzheimer also doubts whether any progress will be made in 2012, as this will be a presidential election year in France.

14 September: UK Care Services Minister announces additional funding for memory services

The UK Department of Health published the results of an audit of memory services which showed that:

• 94% of primary care trusts had a dedicated memory service for dementia.



- Spending on memory services had increased by 23% from 2008-9 to 2009-10.
- The number of people using a memory service had increased by 57% from 2008-09 to 2010-11.



In order to improve early diagnosis and early interventions, Paul Burstow, the Care Services Minister announced that an extra GBP 10 million would be

made available to primary care trusts to improve memory services in the community.

19-20 September: United Nations recognises Alzheimer's disease as a major disease area

On 19-20 September, at the sixty-sixth session of the General Assembly of the United Nations, the Political Declaration of the High-Level Meeting of the General Assembly on the Prevention and Control of non-communicable diseases (NCD) was adopted. This meeting marked only the second in the history of the UN on global health issues. Paragraph 18 of the final political declaration of the summit states that the Heads of State and Governments "recognise that mental and neurological disorders, including Alzheimer's disease, are an important cause of morbidity and contribute to the global non-communicable disease burden, for which there is a need to provide equitable access to effective programmes and health-care interventions".

Listed in the Declaration are areas which should be addressed by a "whole-of-government and a whole-of-society effort". The General Assembly calls for action to:

- reduce risk factors and create health-promoting environments
- strengthen national policies and health systems
- strengthen international cooperation, including collaborative partnerships
- promote research and development
- strengthen monitoring and evaluation.

Options for strengthening and facilitating multi-sectorial action for the prevention and control of NCDs through effective partnership are due to be submitted at the sixty-seventh session of the General Assembly at the end of 2012. In addition, a report on the progress achieved in realising the commitments made in the Political Declaration of 20 September is to be presented at the sixty-eight session of General Assembly.

20 September: Scottish Government announces training scheme for dementia champions

In a bid to drive up care standards for people with dementia, the Scottish Government has announced a training programme for hundreds of dementia champions over the next two years.

As an initial step, a contract has been awarded to Alzheimer Scotland and the University of the West of Scotland to train the first 100 dementia champions in acute general hospitals to ensure the needs of patients with dementia are met.

The move was welcomed by Henry Simmons, Chief Executive of Alzheimer Scotland: "We have long campaigned to highlight the difficulties faced by people with dementia in our acute general hospitals."



Members' News

24 August: Alzheimer Coalition set up in Poland



An Alzheimer's Coalition has been formed in Poland with 11 founding members (5 professors of neurology and/or psychiatry from the Polish Alzheimer's Society and 6

representatives of the Polish Alzheimer Organisation's Forum).

The Coalition's first task is to organise a public debate on the development of a national Alzheimer's plan for Poland.

24 August: Alzheimer's Society (UK) announces winners of photographic competition

As part of its "Remember the Person" campaign, the Alzheimer's Society announced the winners of its photographic competition on 24 August. The competition called for photographs of "people with dementia living their lives with their family, enjoying their hobbies or simply being themselves." The Society received nearly 200 entries. The winners were:

- <u>First place</u>: Photograph by Lesley Duggleby with the accompanying text stating: "This is me and my beautiful Mum, looking so peaceful and relaxed as if not a care in the world. Love you Mum xxx"
- <u>Second place</u>: Photograph by Wendy Sawyer with the accompanying text: "This is when my Dad was in the early stages of dementia when he still knew he had a daughter and granddaughter. Whenever I see this picture I can still hear their laughter as they played 'Peek-a-Boo'. It shows him as I remember him, a kind person who adored us both. He was finally released from this cruel illness on 11th February 2010."
- <u>Third place</u>: Photograph by Matt Timbers with the accompanying text, "This is a shot of Carrie Jahn, the Community Relations Director of Sunrise Tettenhall, dancing with Florence, who is a resident at Sunrise. Sunrise were holding a 1940's Music afternoon, for the residents and their friends and families, so that they could share in the mood of the music. Florence now suffers with dementia, and to see her dancing and smiling, lifted my heart. It was almost magical to see many of the residents, who must at times feel so isolated, brought together through the stimulus of



music and dance, to relive memories of their younger days."

29 August: Swiss Federal Office of Public Health organises national "Impulsday"

The Swiss Federal Office of Public Health organised a national "Impulsday" on 29 August to highlight the challenges of dementia to health and society. Switzerland does not yet have a national Alzheimer's disease plan.

There were about 60 participants, from federal and cantonal authorities, service providers and private organisations. They were presented with medical and therapeutic information, results of a study on the cost of dementia, as well as the needs of people with dementia and their caregivers. According to research commissioned by Alzheimer Switzerland:

- There were some 107,000 people with dementia in Switzerland in 2009.
- 42% of these people are in nursing homes while 58% live at home.
- The total cost of dementia in 2009 was CHF 6.9 billion (EUR 5.6 billion).
- Together, institutional and informal care accounted for over 90% of the cost.

The research report concluded that dementia imposes a considerable economic burden on Swiss society. The cost of dementia is dominated by the costs of care, while diagnosis and treatment costs are minor. The contribution of informal caregivers is substantial since they account for 44% of the total cost of dementia (based on market cost valuation).

6 September: Alzheimer Germany promotes "learning from each other" in multi-generational homes

On 6 September, the German Alzheimer association organised a conference which brought together representatives from 60 Alzheimer associations and multigenerational homes. Their aim was to exchange new ideas and cooperate to create support services for people with dementia and their families.

Sabine Jansen (Executive Director, Alzheimer Germany) praised the many benefits of multi-generational homes and the efforts of the volunteers who work within them. She also pointed out that there are still only few such homes which promote togetherness and social harmony.

12 September: Alzheimer's Society research highlights public lack of awareness on dementia prevention

According to research carried out by the Alzheimer's Society and BUPA, only one in ten people realised that regular exercise was one of the best way to reduce the risk of developing dementia, while over a quarter believed brain training and crosswords to be the best way.

Dr Anne Corbett, the Research manager of the Alzheimer's Society commented on these findings: "This research shows that many people don't realise physical activity can have a real impact in determining whether you develop dementia."

14 September: Spanish Lottery issues special lottery tickets for World Alzheimer's Day



The Spanish National Lottery produced special tickets featuring the CEAFA logo and mentioning World Alzheimer's Day.

CEAFA is the Spanish Association of relatives of people with Alzheimer's disease and other forms of dementia, and also a full member of Alzheimer Europe. The lottery tickets were used for the draw of 17 September to raise awareness of World Alzheimer's Day.

17 September: Association Luxembourg Alzheimer organises 10th edition of its successful Memory Walk

For the 10th time, the Luxembourg Alzheimer's Association organised its memory walk to commemorate World Alzheimer's Day.



The association was present for the whole day with information stands in the town of Rumelange and organised a number of visits to the main

attractions of the town.

In addition, two concerts were organised with the well known group "Les Gavroches" and Géraldine Tebbe paying tribute to such famous singers as Marlene Dietrich, Hildegard Knef and Zarah Leander.



www.alzheimer-europe.org/Donation

18 September: Alzheimer Portugal organises Memory Walk 2011

Alzheimer Portugal organised a Memory Walk in Lisbon on 18 September as part of the celebrations of World Alzheimer's Day. Memory Walk 2011 was the first of its kind in Portugal. Participants followed a course of some six kilometres, reflecting scientific evidence that walking

about six km per week can help keep the memory active in old age.

The central message of the Memory Walk was the importance of physical exercise for people of all ages. It also helped to raise awareness of Alzheimer's disease, which is not yet recognised as a chronic disease in Portugal.





Newsletter: August-September 2011

21 September: Romanian Alzheimer Society celebrates World Alzheimer's Day with a flurry of activities

On 21 September, the Romanian Alzheimer Society held radio interviews, met with volunteers, launched a memory evaluation campaign and led a seminar for families of people with Alzheimer's disease.

These were only some of the activities that took place during World Alzheimer's Day in seven Romanian cities.

Many more events and activities will take place until 21 October, ensuring many opportunities to increase awareness of Alzheimer's disease in Romania.

21 September: Greece celebrates World Alzheimer's Day during an eventful month



The Greek Association of Alzheimer's Disease and Related Disorders organised numerous activities in September to celebrate World Alzheimer's Day. Events included a week-long Alzheimer's disease awareness campaign, a

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rapid chess tournament for senior citizens and a Memory Walk in Thessaloniki which attracted some 300 people.

Throughout the month, TV and radio spots specially made for World Alzheimer's Day were broadcast on national and local stations, while members of the Association participated in numerous media interviews. The Greek Association also provided information about Alzheimer's disease and other forms of dementia, including a short memory test for elderly people.

21 September: Alzheimer Scotland opens new Dementia Research Centre on World Alzheimer's Day

Alzheimer Scotland has opened a new centre for dementia research in partnership with the University of Edinburgh. The Centre will develop and maintain a brain tissue bank and also intends to attract new funding for clinical and scientific research.

Henry Simmons, Chief Executive of Alzheimer Scotland, said: "There are over 82,000 people with dementia in Scotland and that figure is set to double within a generation. It is one of the biggest health and social care problems that Scotland faces. There are currently very few drugs available to people with dementia and not everyone benefits from them. It is vital that we invest in clinical and scientific research, to help people live well with the illness and ultimately to work towards prevention or a cure."

The Alzheimer Scotland Dementia Research Centre was officially opened in Edinburgh on 21 September by Nicola

Sturgeon, Deputy First Minister and Cabinet Secretary for Health, Wellbeing and Cities Strategy in the Scottish Parliament.

21 September: Alzheimer Italia conducts high-tech campaign on World Alzheimer's Day

Alzheimer Italia created mobile phone applications and activated Facebook users during an

electronic commemoration of World Alzheimer's Day.

The association presented new applications for both the iPhone and Android mobile phones. These free apps provide a mobile Alzheimer's disease handbook for caregivers. On the web, Facebook users were asked to remove their profile pictures for the day, as a symbol of loss of identity.



Alzheimer Italia also launched a new journalism award, which will reward writers of articles which contain accurate, sensitive and complete information about Alzheimer's disease.

21 September: France Alzheimer promotes nondrug therapies on World Alzheimer's Day



The French Alzheimer society campaigned to raise awareness of non-drug therapies for Alzheimer's disease as part of their activities to commemorate World Alzheimer's Day.

The campaign reminded families and caregivers that people with dementia can gain great benefit from activities like art and music therapy, therapeutic

gardens and dementia holidays.

24 September: 800 kites fly over the Côte d'Azur on World Alzheimer's Day

Alzheimer Monaco (Association Monégasque pour la recherche sur la maladie d'Alzheimer), along with France Alzheimer and other associations, organised a campaign to fill the skies over Monaco and neighbouring French communities with 800 kites. These kites were hand painted by people with dementia and children at a previous event during the summer.

The kite campaign helped to raise awareness of non-drug

therapies and also showed that people with Alzheimer's disease can still be active creatively and socially.





26 September 2011: Cyprus Alzheimer's Association presents an art exhibition dedicated to Alzheimer's disease

The Cyprus Alzheimer's Association presented "Mother Memory", an exhibition featuring painting, photography and video by local artist Nicholas Panayi. The exhibition is part of the campaign for raising public awareness for Alzheimer disease and is under the auspices of the Cypriot Ministry of Health.

Mr Panayi's mother was diagnosed with Alzheimer's disease 10 years ago. The process of gradual loss of memory and coordination of body functions has deeply influenced the way the artist sees life and has a direct impact on his work.

"Mother Memory" ran from 26 September to 3 October in Nicosia.



Science Watch

1 August: Review of current treatments for sleep disturbance in people with Alzheimer's disease carried out

A review of 38 studies was carried out of the "evidencebase behind current treatment options for sleep disturbance in Alzheimer's dementia" which found most current treatments to be ineffective. Of the nonpharmacological treatments, bright light therapy (BLT) had the best results. The researchers called for further investigation of interventions for treating sleep disturbance in Alzheimer's dementia.

The study was carried out by Vani Rao, Department of Psychiatry and Behavioral Sciences, School of Medicine, Johns Hopkins University, Baltimore, MD, USA and colleagues. It was published in the journal of Geriatric Psychiatry.

1 August: Study suggests structural brain changes occur in cases of subjective memory impairment

A study suggests that even in cases where subjective memory impairment is experienced, deterioration may be visible in some brain structures. The researchers used functional magnetic resonance imaging to illustrate that elderly people with subjective memory impairment show functional alterations in the region of the hippocampus.

The study was conducted by Susanne Erk, Department of Psychiatry and Psychotherapy, Division of Mind and Brain Research, Charité–Universitätsmedizin Berlin, Campus Mitte, Berlin, Germany and colleagues from the University of Bonn and the German Center for Neurodegenerative Diseases, Bonn, Germany. It was published in the journal Archives of General Psychiatry.

1 August: Study examines the role of atrial fibrillation and its association with the risk of incident dementia

A study on a population-based sample of 3,045 community-dwelling adults aged 65 and older without dementia or clinical stroke who were followed from 1994 to 2008 found that "atrial fibrillation (AF) is associated with higher risk of developing Alzheimer's disease and dementia. Future studies should examine whether specific treatments, including optimal anticoagulation, can decrease this risk."

Researchers from the University of Washington and colleagues carried out the study which was published, ahead of print, online in the Journal of American Geriatrics Society.

We provide full references to articles on our website: www.alzheimer-europe.org

2 August: Study examines the relationship of lifestyle on brain shrinkage and cognitive impairment

A study on over 1,300 people without dementia suggests that "smoking, high blood pressure, diabetes and being overweight in middle age may cause brain shrinkage and lead to cognitive problems up to a decade later."

The study was supported by the National Heart, Lung and Blood Institute, the National Neurological Disorders and Stroke and the National Institute on Aging. It was published in the journal Neurology.

2 August: Study examines method for early detection of Alzheimer's disease

A study suggests that in "people with mild cognitive impairment (MCI), PET scans taken at the start of the study showed greater impairment in those who went on to develop Alzheimer's disease than in those who didn't." Researchers also found "the scans were better for predicting who would develop Alzheimer's disease than Alzheimer's than cognitive tests, and could detect changes in brain function over a shorter time period."

The study was conducted by Karl Herholz, from the Wolfson Molecular Imaging Centre and colleagues from Manchester University and it received funding from Alzheimer's Research UK and the Alzheimer's Disease Neuroimaging Initiative. It was published in the Journal of Nuclear Medicine.

3 August: Study identifies blood test as potential biomarker of Alzheimer's disease

A study suggests that "autoantibody expression profiles, determined using protein microarray technology, can be used to select a relatively small panel of useful autoantibody biomarkers that can detect the presence of specific diseases such as AD with great accuracy using only a small sample of blood."

The study was conducted by researchers from the University of Medicine and Dentistry of New Jersey, USA and Durin Technologies, USA. It was published in the journal PloS One.



9 August: Study examines the relationship between sleep-disordered breathing and cognitive impairment

A study on 298 women with a mean age of 82 which examined sleep-disordered breathing found that "compared with the 193 women without sleep-disordered breathing, the 105 women (35.2%) with sleep-disordered breathing were more likely to develop mild cognitive impairment or dementia."

The study was carried out by Kristine Yaffe, Departments of Psychiatry, Neurology, and Epidemiology, University of California, San Francisco and colleagues from the California Pacific Medical Center, San Francisco, Harvard Medical School, Boston, Johns Hopkins Bloomberg School of Public Health, Baltimore, the University of Minnesota and the Veterans Affairs Medical Center, Minneapolis and the Department of Psychiatry, University of California, San Diego. It was published in the Journal of the American Medical Association.

10 August: Study suggests Alzheimer's disease symptoms may be less noticeable in people over 80

A study on people with and without Alzheimer's disease, were divided into groups by age. The researchers found that whilst both groups had similar levels of cognitive impairment that "the pattern of changes associated with Alzheimer's disease appeared to be less noticeable in people over the age of 80 (very-old) compared to those between the ages of 69 and 75 (young-old). When compared to their healthy counterparts, executive function, immediate memory and attention/processing speed were less abnormal in those considered very old compared to those considered young-old. The very-old also showed less severe thinning of portions of cerebral cortex and the overall cerebrum than the young-old, as compared to their healthy counterparts." Researchers concluded that the study illustrated the effect age can have on the profile of brain atrophy and cognitive changes in Alzheimer's disease.

The study author was Mark Bondi, PhD, University of California San Diego School of Medicine and VA San Diego Healthcare System, USA and the research was published in Neurology, the medical journal of the American Academy of Neurology.

We provide full references to articles on our website: www.alzheimer-europe.org

11 August: Rat study examines the relationship between physical exercise and memory

A study on ageing rats suggests that a small amount of physical exercise (the rats ran half a kilometer per week) resulted the protection against infection-induced memory loss. The scientists hope to next study the role of stress plays in older rats.

The study was carried out by Ruth Barrientos, Colorado University Boulder Research Associate, Psychology and Neuroscience department, USA and colleagues, and funded by the National Institute on Aging. It was published in the Journal of Neuroscience.

18 August: Review examines the risk of dementia and drinking

A review of 143 studies dating back to 1977, which included more than 365,000 participants, suggests that "moderate drinkers were less likely to develop cognitive impairment or Alzheimer's disease and other forms of dementia."

The review was conducted by Edward J Neafsey and Michael A Collins, professors in the Department of Molecular Pharmacology and Therapeutics, Loyola University, Chicago, USA. It was published in the journal Neuropsychiatric Disease and Treatment.

18 August: Mouse study examines effect of vitamin C on Alzheimer's disease

A study found that treatment with vitamin C on genetically modified mice dissolved amyloid plaques in the brain (which are associated with Alzheimer's disease). Researchers also found that the vitamin did not need to come from fresh fruit.

The study was conducted by Katrin Mani and colleagues at Lund University, Sweden and published in the Journal of Biological Chemistry.

19 August: Study examines the relationship between salt intake, exercise and mental decline

Researchers who monitored over three years the salt consumption and levels of physical activity of over 1,200 healthy elderly men and women suggests that a "diet high in sodium (more than 3,090 mg of sodium a day), combined with little exercise, was detrimental to the cognitive performance of older adults." The researchers concluded that the study may have "significant public health implications, emphasising the importance of addressing multiple lifestyle factors rather than a single domain effect on brain health."

The study was carried out by Alexandra Fiocco, the University of Toronto, Canada and colleagues and published in the journal Neurobiology of Aging reports.

22 August: Study examines the relationship between antidepressant drug and protein associated with Alzheimer's disease

A mouse study suggests that an antidepressant drug may result in a drop of amyloid beta (which is associated with Alzheimer's disease) in the brain,. Researchers found that after genetically engineered mice were given one of three selective serotonin reuptake inhibitors that amyloid beta levels dropped after just one treatment. The reduction in amyloid beta was greater in those mice which received the drug for a four month period.

In order to examine the effect serotonin signalling may have on amyloid beta in humans, the researchers carried out a retrospective comparison of brains, comparing the brain amyloid load in cognitively normal elderly participants who were exposed to antidepressant drugs within the past five years to those who were not. The results suggest that "serotonin signalling was associated with less A β accumulation in cognitively normal individuals."



The research was conducted by John Cirrito of the Washington University School of Medicine, St Louis, USA and colleagues and published in the Proceedings of the National Academy of Sciences.

24 August: Study highlights two potential biomarkers for Alzheimer's disease

A study in which the brains of over 300 elderly people with no cognitive problems were analysed suggests that brain scans may reveal those people at risk of Alzheimer's disease before symptoms are experienced. Using PET scans the researchers found that one in three participants had high levels of amyloid plaques (associated with Alzheimer's disease) and further research using MRI scans showed that these people were more likely to have abnormal levels of certain metabolites that are known to be altered in Alzheimer's disease.

The study was published ahead of print in the journal of Neurology (editorial) and a summary can be found on the Alzheimer's Society website.

26 August: Cost-effective method to create compound used for Alzheimer's disease developed

Researchers have developed a cost-effective method to create the compound known as "huperzine A" (found on moss) – an enzyme inhibitor which can be used in China to treat people with Alzheimer's disease and is sold in the US as a supplement to help memory.

The research was carried out by Seth Herzon, Yale University and colleagues and published in the journal Chemical Science.

1 September: New study shows lower levels of a key protein in brains of people with Alzheimer's disease

Researchers at the University of Texas Medical Branch at Galveston (UTMB) have found that the level of the ubiquilin-1 protein is consistently lower in the brains of people with Alzheimer's disease. According to UTMB, ubiquilin-1 acts as a "chaperone" during the formation of the amyloid precursor protein known as APP.

APP is the source of toxic protein plaques which are nearly always found in the brains of people with Alzheimer's disease. These plaques are aggregations of malformed proteins, and the UTMB team has shown that ubiquilin-1 reduces this aggregation.

"Ubiquilin-1 prevents the APP molecule from falling into a conformation it's not supposed to be in," said UTMB Associate Professor Darren Boehning. "This fits with a theme we're seeing across the neurodegenerative disorders and the disorders of aging - the idea that many of these disorders are associated with decreased quality control by chaperones."

Professor Boehning and UTMB Assistant Professor José Barral are co-authors of a paper which is available online in the Journal of Biological Chemistry.

6 September: Short-term memory loss may be predictor for Alzheimer's disease

Spanish researchers have found that short-term memory loss may be a better predictor of Alzheimer's disease than many biomarkers.

Scientists collected cerebrospinal fluid samples, analysed blood samples for genes associated with Alzheimer's disease and used MRI to determine brain volume and cortical thickness.

Results showed that two measures of delayed memory and the cortical thickness of the left middle temporal lobe were both associated with a higher risk of MCI developing into Alzheimer's disease.

The test group consisted of:

- 116 people with MCI who developed Alzheimer's disease within two years
- 204 people with MCI who did not develop Alzheimer's disease
- 97 healthy controls

The study was carried out by a team from the Alzheimer's Disease Neuroimaging Initiative.

7 September: European Medicines Agency publishes its opinion on the use of biomarkers for Alzheimer's disease

The European Medicines Agency (EMA) has published an opinion on the use of novel methodologies in the predementia stage of Alzheimer's disease. According to the abstract, "the qualification of biomarkers in the predementia stage of Alzheimer's disease will allow better inclusion criteria of patients in pre-dementia trials in which the benefit/risk is higher for treatment with these novel compounds."

10 September: Study shows that high density of blood vessels in the brain may point to Alzheimer's disease

Scientists at the University of British Columbia showed that mouse brains altered to show symptoms of Alzheimer's disease had a much higher density of capillaries than the brains of normal mice. They also found a similar high density of blood vessels in brain samples of people who had died of Alzheimer's disease.

Dr Susanne Sorensen, Head of Research for Alzheimer's Society (UK), commented that "[m]ore research is now needed to confirm this link and also to answer the proverbial chicken and egg question of whether these changes are a cause or a symptom of the disease."

This study was led by Professor W. Jeffries, University of British Columbia, and the paper is available on the website of www.plosone.org

12 September: Study examines role of nitrated Aß in seeding plaques

A new study reports that human A β modified by nitration has a greater tendency to aggregate. Aggregated A β is the basis of amyloid plaques. Researchers found nitrated A β



in plaques in the brains of both humans with Alzheimer's disease and AD model mice.

Nitrated A β was also seen to seed plaques in AD mice (whereas the non-nitrated form did not) and synaptic function and memory were also affected. When nitration was blocked, the plaque load dropped and learning ability returned to normal.

Furthermore, amyloid plaques are known to stimulate production of more nitrates. Professor Michael Heneka, a University of Bonn researcher, suggests that this may be a vicious cycle which spreads Alzheimer's disease through the brain.

This research also sheds new light on inflammation, which is known to initiate the process leading to nitration. Apparently, inflammation is not a side effect of Alzheimer's disease, but can "accelerate and drive the degenerative pathology," said Prof Heneka.

The research project on nitrated A β was carried out by a team led by Professor Michael T. Heneka, Department of Neurology, University of Bonn, Germany.15 September: Study investigates use of electromagnetic brain stimulation

23 September: Preclinical trials examine role of hawAD14 drug

CoPlex Therapeutics and Hawthorn Pharmaceuticals have agreed to develop and commercialise preclinical drug hawAD14. This drug is a small molecule candidate for the treatment of Alzheimer's and other neurodegenerative diseases.

Research shows that hawAD14 decreases production of amyloid beta (A β , the main component of brain plaque) and also alters proteins associated with the neurofibrillary tangles present in Alzheimer's disease.

Living with Dementia

6 July: James McKillop receives MBE



James McKillop, founding member of the Scottish Dementia Working Group (SDWG), received an MBE from the Queen on 6 July 2011 in recognition of his work to improve the rights of people with dementia and raising

awareness of the disease. The SDWG is an independent group run by people with dementia with the aim of improving services for, and improve attitudes towards, people with dementia.

Henry Simmons, Chief Executive of Alzheimer Scotland, said "Alzheimer Scotland are greatly pleased that James' achievements and those of the Scottish Dementia Working Group have been publicly recognised in this way. James is a true inspiration to us all: using his own experiences of dementia to make a huge difference to the lives of countless others who have the illness.

"James and the SDWG have brought a vital new perspective of dementia to health & social care

professionals, politicians and the media - their impact cannot be underestimated."

10 August: Actor Larry Hagman talks of his experience of living with his wife who has Alzheimer's disease

Actor Larry Hagman, who stared in the TV series Dallas, has spoken about the effects Alzheimer's disease has had on his wife, Maj. He said, "Alzheimer's hasn't robbed her of the



knowledge of who I am, but I dread that day. She can remember things that happened 50 years ago but she can't remember what she had for breakfast."

After caring for her, Mr Hagman eventually found it necessary to move her to a flat where she has constant care. He said: "It is hers and she feels safe and she has 24hour care. I still go and see her every day for lunch and more if I can." He added: "I miss her every day. We were a good team."

26 August: Singer Glen Campbell speaks about living with Alzheimer's disease



In an interview singer Glen Campbell, who announced he has Alzheimer's disease in June 2011, and his wife, Kim, spoke about his final album and about

living with the disease. Kim Campbell described why the decision was taken to be public about her husband having Alzheimer's disease, she said "It was becoming obvious on stage. He always delivered flawless performances, and now he will flub a lyric here and there. He's always been totally open and honest about his life, and it felt like the natural thing for us to do; let everybody know." She also said that when he performs she is convinced that there is a change in his brain, she said "It's like a light switches on. When he walks out on stage, it's just BING! Wow!"

Dementia in Society

10 August: UK court allows Alzheimer's disease case to be reported

As a legal first, Judge Mr Justice Ryder has allowed the reporting of Court of Protection case (which usually sits in private) whilst it is in progress.

Journalists were allowed into the hearing of a case concerning a family's wish to care for SJ, their 92-year old father who has dementia and who the family believe has been unlawfully deprived of his liberty for nearly six months. In addition, the family claim that SJ has been denied contact with his son. The local authority dispute this, claiming that the father "lacks the mental capacity to make the decision over where he should live and has insisted he is better off in the care home." The case continues.



15 August: Researchers set up improvisation theatre programme for people with Alzheimer's disease

An eight-week theatre programme is being set up for people with early-stage dementia which uses improvisation. Researchers hope that because improvisation focuses on 'being in the moment' rather than the past or future, that it may offer a safe place for people with Alzheimer's disease. The researchers from Northwestern University's Feinberg School of Medicine, Chicago, USA, together with the Lookingglass Theatre company, hope to find out whether unscripted theatre games can affect the well-being of people with Alzheimer's disease.

Participants are asked a set of questions before and after the programme (about their feelings about their physical health, their mood, memory, family, relationships and about the current life as a whole) to see whether the programme changes their perceptions.

15 August: Design Council launches competition for dementia friendly product and service design

In the UK, a competition entitled "Living well with dementia" has been launched by the Design Council, in partnership with the Department of Health, aimed to encourage the development of "new design-led ideas for products and services that make life simpler and more enjoyable for those with dementia and their carers." It is hoped that the challenge will result in the recruitment of teams which consist of a variety of backgrounds (designers, entrepreneurs, service providers, support groups and/or individuals with ideas). Five teams will be offered a share of GBP 360,000 and professional support for their ideas over a five-month period.

Jeremy Hughes, Chief Executive of the Alzheimer's Society said of the challenge "We need to see dramatic innovation in all areas of dementia care. Throwing down the gauntlet to such a wide range of experts has the potential to be the catalyst for real change - small or large - which could help transform the lives of the 750,000 people living with dementia in the UK. Dementia can affect anyone. However, with a timely diagnosis and the right help and support people can live well with the condition"

23 August: UK study shows one in ten suicides is linked to chronic disease

On 23 August 2011, UK Think Tank DEMOS published a study "The Truth about Suicide" that revealed that one in ten suicides is linked to a chronic illness.

The figures presented in the study come from a literature review, primary care trusts data, interviews with serving and recently retired coroners and suicide inquest files in Norwich from May 2006 to December 2010.

The researchers found that at least 10% of suicides in Britain are linked to a terminal or chronic illness, accounting for more than 400 deaths a year. They also found that some people were ending their lives at a younger age in order to avoid severe symptoms and greater pain later in life as well as wide variations in how verdicts of suicide are recorded by coroners and made available to the public and policymakers are.

This study marks the first attempt to estimate the scale of suicides related to illness. It also challenges the notion that taking one's own life is largely about a patient's mental health rather than physical state.

The study calls on the Coalition Government's to consider making local suicide audits compulsory and formalize the coroners' duty to share information. Further research into other potential factors, such as physical illness, remains to be done.

This study mentions Alzheimer's disease as one of the chronic diseases leading to suicide.

26 August: Care homes use retro-decorating scheme

A service provider for people with dementia in the UK (Surrey council) is using the scheme of retro-decorating in its day services and care homes for people with dementia. It is hoped that surrounding people with dementia with objects from their past (posters, old-fashioned scented soaps etc.) may trigger their memories. The effective use of colour and light may also make daily tasks simpler. Surrey Council will be the first council in England to try to integrate retro-decorating techniques into care for people with dementia who also experience learning difficulties.

New Resources and Publications

31 August: New German website launched with information for people with dementia and their carers

The website, Wegweiser Demenz, has been launched in Germany which offers information about therapy, care and help services, statutory benefits and rights and obligations of people with dementia and their relatives. The site www.wegweiser-demenz.de was launched by the German Federal Ministry of Family Affairs, Senior Citizens, Women and Youth.

Contact Alzheimer Europe at:			
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Newsletter: August-September 2011

Vienna, Austria

Stockholm, Sweden

AE Calendar

Date	Meeting	AE Representative	
6 October 2011	Alzheimer Europe Board Meeting	AE Board and staff	
6 October 2011	Alzheimer Europe Annual General Meeting (Warsaw, Poland)	AE Board, members and staff	
6-8 October 2011	Alzheimer Europe's 21 st Annual Conference "European Solidarity without borders (Warsaw, Poland)	AE Board, members and staff	
13 October 2011	Networking event of LuxInnovation (Esch/Alzette, Luxembourg)	Jean	
Future Conferences			
Date	Meeting	Place	
6-8 October 2011	Alzheimer Europe's 21 st Annual Conference "European Solidarity without borders", http://www.alzheimer-europe.org/EN/Conferences/Warsaw-2011	Warsaw, Poland	
14-17 October 2011	5 th World Congress on Controversies in Neurology (CONy), www.comtecmed.com/cony/2011	Beijing, China	
20-23 October 2011	7 th International Congress on vascular dementia: Facing the challenges of dementia, http://www2.kenes.com/Vascular2011/Pages/home.aspx	Riga, Latvia	
2-3 November 2011	Ageing Globally – Ageing Locally: Planning for all our futures	Dublin, Ireland	
2-4 November 2011	38 th Congress of European Association of Geriatric Psychiatry (EAGP), www.apgerontopsiquiatria.com	Porto, Portugal	
3-5 November 2011	4th edition of our Clinical Trials for Alzheimer's Disease CtaD 2011, www.ctad.fr	San Diego, USA	
8-11 November 2011	Thailand dementia 2011 and 14 th Asia-Pacific Regional Conference of ADI, www.azthaimeeting.com	Bangkok. Thailand	
27-29 January 2012	5th European Neurological Conference on Clinical Practices: Neurovascular and Neurodegenerative Diseases, www.enccp.net	Krakow, Poland	
7-10 March 2012	27th ADI Conference "Science Fact Fiction", http://www.adi2012.org/	London, UK	

Therapy, www.ad-springfield.com 16-19 May 2012 7th World Congress for Neurorehabiliation 2012 (WCNR 2012), Melbourne, Australia http://www.dcconferences.net.au/wcnr2012/ 21-23 March 2013 57. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Leipzig, Germany Funktionelle Bildgebung (DGKN), www.dgkn-kongress.de 4-6 October 2013 22nd Alzheimer Europe Conference "Changing perceptions, practice and policy", Vienna, Austria www.alzheimer-europe.org/EN/Conferences 20-23 March 2014 58. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Berlin, Germany Funktionelle Bildgebung (DGKN), www.dgkn-kongress.de 21-24 March 2014 30. International Congress of Clinical Neurophysiology (ICCN), www.iccn2014.de Berlin, Germany

6th World Congress on Controversies in Neurology (CONy), www.comtecmed.com

12th International Stockholm/Springfield Symposium on Advances in Alzheimer





8-11 March 2012

9-12 May 2012

The Alzheimer Europe newsletter arises from the 2011 Work Plan of Alzheimer Europe, which has received funding from the European Union, in the framework of the Health Programme.