



# NEWSLETTER

November 2010

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## Editorial

This month we are a step closer to the European Parliament adopting their own initiative report on the Commission's Communication on a European initiative on Alzheimer's disease and other dementias as the Environment and Health committee (ENVI) convincingly voted to adopt the report. I am particularly optimistic as many of Alzheimer Europe's suggestions were taken on board. We now eagerly await the EP plenary session in January.



Dementia has been the topic at many European meetings this month: A Conference of the Belgian EU Presidency was dedicated to the societal aspects of dementia and led to an exchange of information, pilot projects and best practices between Member States, experts and associations.

The European Medicines Agency also convened a meeting dedicated to dementia research and the experts looked into the very specific needs of people with familial Alzheimer's disease. We can only hope that the meeting will provide incentives for the pharmaceutical industry to research possible new treatments for this neglected patient population.

Alzheimer Europe members have continued to raise awareness and understanding of Alzheimer disease during November. The Alzheimer Society's new Chief Executive, Jeremy Hughes, has now taken up his post and I would like to extend a warm welcome to him on behalf of all of us at Alzheimer Europe. We look forward to continuing the strong

collaboration we have enjoyed with the Society.

In the challenging economic climate I am only too aware that funding for research can be endangered and yet indications continue to suggest that now, more than ever, we need to continue to increase funding. This month is no exception. We report on a Finnish study which has found prevalence rates to be higher in Finland than previously thought, with their predictions that the number of people with dementia will increase by 90% by 2030. It is therefore encouraging to also be able to bring news of a new, EUR 10.4 million, six-year project known as DIPPAL which is dedicated to research in Alzheimer's disease.

You will see that we have introduced a 'job opportunities' news section. We hope that members will keep us informed of any jobs which they would like to share in this way.

The staff of Alzheimer Europe has been involved in many different meetings this month. In addition, we have been preparing for December's lunch debate and meeting the publishing deadlines for the 2010 Alzheimer in Europe Yearbook (which focuses on legal capacity and proxy decision making in dementia) and also the Alzheimer Europe report on the ethical issues linked to the use of assistive technology in dementia care. Both will be published in early December.

The next newsletter will be a combined edition for December and January and I therefore take this opportunity to wish you all the best for this upcoming festive period.

See you all in 2011

**Jean Georges**  
Executive Director

## European Alzheimer's Alliance

Currently, the total number of MEPs in the Alliance stands at 50, 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), Sterckx Dirk (ALDE), **Bulgaria:** Parvanova Antonia (ALDE), **Cyprus:** Triantaphyllides Kyriacos (GUE-NGL), **Czech Republic:** Cabrnock Milan (ECR), Kohlíček Jaromír (GUE/NGL), Roithova Zuzana (EPP), **Denmark:** Schaldemose Christel (S&D), **Finland:** Jaakonsaari Liisa (S&D), Jääteemäki 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), McGuinness Mairead (EPP), Mitchell Gay (EPP), **Italy:** Panzeri Pier Antonio (S&D), Toia Patrizia (S&D), **Luxembourg:** Lulling Astrid (EPP), **Netherlands:** De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP), **Portugal:** Coelho Carlos (EPP), Matias Marisa (GUE/NGL), **Romania:** Antonescu Elena Oana (EPP), **Slovakia:** Mikolasik Miroslav (EPP), Zaborska Anna (EPP), **United Kingdom:** Hall Fiona (ALDE), Lynne Liz (ALDE), McAvan Linda (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Taylor Keith (Greens/EFA), Watson Graham (ALDE), Willmott Glenis (S&D), Yannakoudakis Marina (ECR).

## Alzheimer Europe

### 3-4 November 2010: Alzheimer Europe organises meeting for "Value of Knowing" Project

Alzheimer Europe organised a meeting for the Steering Committee of the Value of Knowing project in London, UK. The meeting was attended by representatives of the US, Polish and Spanish Alzheimer associations as well as invited experts, including Florence Lustman (the coordinator of the French Alzheimer Plan). The aim of the meeting was to identify the key areas for the survey to be conducted in France, Germany, Poland, Spain and the US. Alzheimer Europe was represented by Jean Georges.

The work of the Value of Knowing project is supported by a grant of Bayer Healthcare and started in July 2010 with the aim of carrying out a survey to investigate the differences in public perception and awareness of Alzheimer's disease in a number of European countries and the US and to identify the views of the general public on the value of a diagnosis of Alzheimer's disease.

### 24 November 2010: Alzheimer Europe presents its policy activities to AGE Platform

Annette Dumas presented Alzheimer Europe's policy activities at the AGE Platform Europe Health and Social Services Expert Group meeting, which was held in Brussels, Belgium on 24 November. AGE Platform and Alzheimer Europe discussed possible ways in which they might work more closely together.

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## Alzheimer Europe Networking

On 3-4 November (London, UK) Jean attended the Steering Committee of the Alzheimer Europe "Value of Diagnosis" Project.  
On 8 November (London, UK) Jean attended the Expert meeting in familial neuro-degenerative disorders at the European Medicines Agency.  
On 15 November (Brussels, Belgium) Jean had a meeting with Pfizer.  
On 16 November (Brussels, Belgium) Jean and Annette met the ILC Expert Working Group meeting on dementia in the European Parliament.  
On 17 November (Brussels, Belgium) Annette attended the AGE conference on Elderly abuse in the European Parliament.  
On 18 November (Brussels, Belgium) Annette met the EFPIA Think Tank.  
On 24 November (Brussels, Belgium) Annette had a meeting with AGE and presentation of AE's work.  
On 25-26 November (Brussels, Belgium) representatives of the AE Board and staff attended the Belgian EU presidency conference "Improving the quality of life of people with dementia: A challenge for European society".  
On 29-30 November (London, UK) Julie attended the training session on the review of product information as well as the plenary meeting at the European Medicines Agency.  
On 30 November (Brussels, Belgium) Annette attended the ENVI vote on M. Matias report on a European initiative on dementia.  
On 30 November-1 December (Strasbourg, France) Jean attended the Council of Europe Seminar on decision making process regarding medical treatment in end-of-life situations.

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## European developments

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

### 27 October 2010: European Commission publishes its 2011 Work Programme

The European Commission has published its 2011 Work Programme which is built on the five main

political priorities for the EU as set out by President Barroso in the first State of the Union Address (September 2010). These are:

1. Dealing with the economic crisis and building the momentum of the recovery
2. Restoring growth for jobs by accelerating the Europe 2020 reform agenda
3. Building an area of freedom, justice and security
4. Launching negotiations for a modern EU budget

5. Pulling the EU's weight on the global stage.

Recognition is given the fact that the Programme is being presented "at a particularly challenging time for the EU" and that there is an "urgent need to complete the EU's work on key proposals including economic governance and financial regulation". The Commission will now work "closely with the European Parliament and the Council, as well as stakeholders, including national parliaments, to ensure that the initiatives it will promote in the coming year will rest on a sound consensus about how the EU should meet the expectations of its citizens for an ambitious and effective Europe."

**28 October 2010: Seminar held on human rights of person in institutional care**



An international seminar on human rights of persons in institutional care (Forgotten Europeans – Forgotten rights) was held in Brussels which was organised by the United Nations Human Rights Office of the High Commissioner, Europe Regional Office. Discussions and presentations focused on issues relating to the human rights of children, elderly people and people with disabilities in need of care and support in settings other than their home environment, of the need to develop clear standards and of the need for governments to develop community-based alternatives to institutional care. Several NGOs were present (e.g. linked to family carers, independent living, mental health, disability and survivors of psychiatry). One of the overall aims of the seminar was to raise awareness of policy makers in the EU to the human rights of vulnerable and often invisible groups who are either in residential institutional care or risk going into it. Alzheimer Europe was represented by Dianne Gove and Annette Dumas.

**8 November 2010 – EMA organises workshop on dementia research**

The European Medicines Agency (EMA) organised an expert meeting in familial neurodegenerative disorders which took place in London, UK, on 8 November. The aim of the meeting was to discuss the involvement of people with familial Alzheimer's disease in clinical trials (currently people with familial Alzheimer's disease are excluded from trials) and the criteria that regulatory authorities should use for such trials. The EMA would like to encourage companies to carry out trials for people with familial Alzheimer as there is a significant "unmet medical need" for this population. During the meeting, Bruno Dubois also presented his new criteria for the definition of Alzheimer's disease. Alzheimer Europe was represented at this meeting by Jean Georges.

**10 November 2010: Results of European project on management of residential care for older people discussed**

A conference on the project "Quality management by result-oriented indicators – Towards benchmarking in residential care for older people" was held in Brussels. The main objective of the project was to develop "an international framework of standards, including a conceptual analysis for quality of life and

a set of result-oriented indicators to define, measure and assess quality in residential care for older people." At the conference the results were disseminated and discussed. The handbook "Measuring Progress: Indicators for Care homes" has been made available in English, German and Dutch. It provides tools and recommendations on how to apply the validated list of result-oriented indicators.

The European Centre for Social Welfare Policy and Research has been the Coordinator of the project, in cooperation with the Ministry of Health, Equalities, Care and Ageing of the State of North Rhine-Westphalia, the University of Dortmund (Germany), Vilans (Netherlands), City University London and E-Qalin GmbH. The project is co-funded under the Progress programme of the European Commission's DG Employment, Social Affairs and Equal Opportunities and runs from December 2008 until December 2010.

The conference, which enjoyed the participation of some 130 experts, was organised by the European Centre for Social Welfare Policy and Research in cooperation with The North Rhine-Westphalia Government Offices in Düsseldorf and Brussels.

**11 November 2010: EPSO Social Questions Working Party agrees to declare 2012 Year of Active and Healthy Ageing**

At its meeting of 11 November, the Social Questions Working Party of EPSO (Employment and Social Affairs Council) reached an agreement on the draft proposal to declare 2012 Year of Active and Healthy Ageing and Solidarity between Generations.

This development follows a series of recommendations that have been produced over the past few years.

The European Parliament is currently producing an opinion on the draft proposal.

**24 November 2010: European Parliament calls for stricter information on prescription medicines**



Members of the European Parliament (MEPs) endorsed the report of Mr Christofer Fjellner, MEP, (Sweden), on Information to the General Public on Prescription Medicines. Changes made to the draft legislation require that patients must have better access to high quality information (including a drug's characteristics and the treated disease or condition) on prescription medicines in the future. These changes were based on the fundamental principle that patients should have the right to obtain accurate and unbiased information on medicines. In addition, the changes clarify pharmaceutical companies' obligations and possibilities to inform, as well as the role to be played by Member States. The adopted draft directive and regulation will now go before the Council for consideration.

### 25-26 November 2010: Belgian Presidency Conference on dementia takes place



The Belgian Presidency organised a conference entitled "Improving the quality of life of people with dementia: A challenge for European society" in Brussels, Belgium on 25-26 November. The overall aim of the conference was to facilitate exchange between Member States, experts and associations in order to identify promising initiatives and good practices and to transform the results of the conference into conclusions which can be presented by the Belgian Presidency to the Council of Ministers.

The first day of the meeting was a mixture of sharing information and discussion (e.g. about progress with the French Alzheimer Plan, dementia-friendly communities, studies and initiatives about perceptions of dementia and measures to support carers).

On the second day, participants had the opportunity to attend one of three working groups, either on ethical aspects and rights, increasing the quality of life of the person with dementia and the carer or image and public awareness of dementia. The aim of these workshops was to stimulate discussion about these issues and to improve or adapt the recommendations which had been written in advance.

The meeting was attended by a number of AE Board and staff members and Jean Georges was invited to comment on the conference outcomes.

### 26 November 2010: European Commission 'Active and Healthy Ageing European Innovation Partnership' stakeholder conference takes place

The European Commission (DG SANCO and DG INFSO) stakeholder conference on the 'Active and Healthy Ageing European Innovation Partnership' took place in Brussels, Belgium on 26 November. This new innovation strategy is a pilot which will address one societal challenge, the ageing of the population, with a new approach to EU research and innovation. The initiative will be launched at the beginning of 2011. The idea is to identify the challenges, share and integrate evidence-based ideas and best practices to address these challenges and reinforce the EU competitiveness. Annette Dumas represented Alzheimer Europe.

### 29-30 November 2010: European Medicines Agency holds training session on product information and hosts meeting for its human Scientific Committees' Working Party (patients and consumers group)

The European Medicines Agency (EMA) held a training session on the review of product information in London, UK, on 29 November 2010 which encompassed: documents which the EMA addresses to the public, patients' perspective, detailed information on the European Public Assessment Reports (EPAR) (including an analysis of experience gained during 2010 and practical exercises for

participants) and on the package leaflet (PL) (including information on the new template and an analysis of experience gained during 2010), use of the electronic mailing system (EudraLink) and safety in communications. Training manuals together with a CD-ROM were distributed to participants.

On 30 November, the EMA Human Scientific Committees' Working Party with Patients' and Consumers' organisations (PCWP) met with eligible organisations. At this meeting the involvement of patients and consumers organisations (PCOs) in EMA activities was presented and then discussed by participants. Areas focused on included information on the benefit/risk communication (highlighting a study of stakeholders expectations and attitudes), the revision of eligibility criteria, the patient perspective of the use of Interactive voice response system, the role of PCOs in scientific committees, a review of the revised EMA website and the new EMA policy on conflicts of interest. There was considerable discussion around the need for transparency by participating organisations and how that can be best achieved. Alzheimer Europe was represented at both meetings by Julie Fraser.

### 30 November–1 December 2010: Meeting discusses decision-making process in end-of-life situations

The Steering Committee on Bioethics (CDBI) of the Council of Europe organised the symposium on the decision-making process in the field of medical treatment in end-of-life situations, which took place in Strasbourg, France on 30 November – 1 December. Dianne Gove represented Alzheimer Europe and presented the perspective of Alzheimer Europe on the use of advance directives based on our previous work on this topic. The meeting covered a wide range of ethical, medical, legal and social issues and participants included specialists in palliative care, lawyers, ethicists and a few representatives from associations. It focused on patients with capacity to consent as well as those lacking capacity or with limited capacity.

### 30 November 2010: European Parliament outlines practicalities for future European Citizens' Initiatives

The European Citizens' Initiative aims to increase the participatory democracy of the European Union by enabling EU citizens to 'call directly on the European Commission to bring forward an initiative of interest to them in an area of EU competence.' The initiative was set up by the Lisbon Treaty and requires 1 million signatures to become valid.

On 30 November the European Parliament's Constitutional Affairs Committee (AFCO) unanimously adopted an outline of how the Citizen's Initiative will work in practice. Amongst other things the AFCO agreed that signatures should come from a quarter of Member States and that the scheme should be made as user friendly as possible.

The report is due to be voted on at the European Parliament's December sitting. If it is accepted by the Parliament and the Council and subsequently by the Council, EU members will have 12 months to implement the necessary measures to make it work.

The legal basis of the citizens' initiative is set out in Article 11, Paragraph 4 of the Treaty of the European Unions (TEU) and Article 24, paragraph 1 of the Treaty on the Functioning of the European Union (TFEU) as amended by the Treaty of Lisbon.

**30 November 2010: European Parliamentary committee adopts report on a European Initiative on Alzheimer's disease and other dementias**

The Environment and Health Committee (ENVI) voted on the European Parliament own initiative report, which has suggestions for improvements to the European Commission Communication on a European initiative on Alzheimer's disease and other dementias [COM(2009) 380 final].



The Rapporteur for the own initiative report is Maris Mattias (Portugal, GUE/NLG group) who is a member of the European Alzheimer's Alliance. Alzheimer Europe had been involved in the consultation process submitted amendments to EP own initiative report, a number of which were incorporated into the final document.

The report was convincingly adopted by ENVI (48 votes in favour, 0 against and 1 abstention) and it will now go before the plenary session of the European Parliament in January 2011.

**Other European organisations**

**17 November 2010: Conference on elderly abuse and quality care for older people takes place**

The AGE Platform Europe conference on 'How can the EU face elderly abuse and improve quality care for older people?' took place in Brussels, Belgium on 17 November and was chaired by Liz Lynne (MEP, UK ALDE), a member of the European Alzheimer's Alliance.



This was the final conference of the EU-funded and AGE Platform Europe-run EUSTaCEA project against elderly abuse. The 'European Charter on the rights and responsibilities of older people in need of long-term care' was presented at the conference.

The Charter aims to become a reference document setting out the fundamental principles and rights that are needed for the well-being of those who are dependent on others for support and care due to age, illness or disability. The Charter is targeted at policy makers, care-givers and older people's organisations. Annette Dumas attended on behalf of Alzheimer Europe.

**18 November 2010: EFPIA Think Tank meeting takes place**

The European Federation Pharmaceutical Industry and Associations (EFPIA) Think Tank meeting took place in Brussels, Belgium. Discussions focused on the relationship between patient organisations and pharmaceutical companies in areas such as:

- written agreements - a model template for written agreements between the pharmaceutical companies and patient organisation was discussed and endorsed by the patient organisations,
- funding of patient groups – a guidance on working with patient organisations was presented at the meeting. The EFPIA code on transparency and their 'leadership statement on ethical procedures' produced by EFPIA in June this year were presented. In addition, the level of industry funding received by a patient organisation as core funding and the European Commission' level of industry funding acceptable for a patient organisation to receive EU funding was considered. EuropaColon made a presentation on the opportunities offered by a centralised accreditation. This model could offer a possibly easier way to get core funding.

**Members' News**

In this section we report on our members' latest initiatives and work.

**1 November 2010: Alzheimer Uniti (Italy) assists in the preparation of a film about Alzheimer's disease**



"Una sconfinata giovinezza" (Endless Youth) is a film about Alzheimer's disease which has been released in Italy.

Pupi Avati, who wrote and directed the film, approached Professor Luisa Bartorelli, Chairperson of Alzheimer Uniti, for help to understand both the science of the disease and it's impact on family members. The leading actor, Fabrizio Bentivoglio, prepared, in part, by studying photographs of the facial expressions of people with dementia from a book published by Alzheimer Uniti.

The film centres around a husband and wife, who have been happily married for many years when the first signs of Alzheimer's disease appear in the husband. As the disease progresses, the husband remembers his childhood. As his personality slowly changes and he becomes a stranger to his wife, it is her love that ultimately protects him.

A spokesperson from Alzheimer Uniti said: "The film is quite unusual within the genre of contemporary Italian cinema and has received a lot of publicity (starting with its unexpected exclusion from the Venice Film Festival!). There have been special presentations of the film in Rome and in other cities such as Ancona, with open discussions between the public and cast members and the director and with the participation of Alzheimer Uniti. The film has led to numerous letters to the editors of newspapers questioning aspects of the film and its portrayal of Alzheimer's, helping to raise awareness of the disease."

**9-16 November 2010: Alzheimer Uniti (Italy) organised training for pharmacists**

Alzheimer Uniti (Italy) organised two specialised training sessions for pharmacists. The objective of

these sessions was to build awareness of the disease and issues which surround it. Alzheimer Uniti has now signed an agreement with FEDERFARMA, the Italian Pharmacists Organisation, to inform it regularly regarding available activities for people with dementia and their families.

**18 November 2010: Alzheimer Portugal organises fundraising concert, supported by guitarist Pedro J6ia**

Alzheimer Portugal organised a fundraising concert in order to raise enough funds to construct and equip their nursing home and day care centre in Cascais, known as "casa do Alecrim" ("Rosemary House"). This home has been specifically designed for people with dementia to enable the residents to retain as much autonomy and freedom as possible in both the indoor and outdoor space provided.



The organisation was supported by the participation of internationally renowned flamenco guitarist, Pedro J6ia and they gave particular thanks to him for his support which ensured that awareness was raised of Alzheimer Portugal's work.

Alzheimer Portugal also thanked everyone who participated and contributed to make the "Rosemary House" Nursing Home and Day Care Centre a reality.

**29 November 2010: (UK) Alzheimer's Society welcomes new Chief Executive**



Alzheimer's Society welcomed new Chief Executive, Jeremy Hughes, on Monday 29

November. Jeremy joins the Society from Breakthrough Breast Cancer and has also worked for the International Federation of Red Cross & Red Crescent Societies, the British Red Cross and disability care charity Leonard Cheshire. In addition, he is Chair of National Voices, the umbrella body for more than 200 health and social care charities.

Commenting on his first day, Jeremy said "I am tremendously excited to be joining Alzheimer's



Society at such an important time for people living with dementia in England, Wales and Northern Ireland. Recent weeks have seen a draft decision from NICE on widening access to drugs, a commitment from the government to reduce the use of antipsychotics by two thirds and the launch of the Dementia Action Alliance. Each of these is a significant step forward and, taken together, they demonstrate just what can be achieved when passionate and hard-working people join together in support of others."

The former interim Chief Executive and Chief Operating Officer for Alzheimer's Society, Ruth Sutherland, has left to become Executive Director of Services for disability charity Scope. During her time with the Society, Ruth played an important part in restructuring the organisation and worked closely with the Department of Health on the development and delivery of the National Dementia Strategy for

England. Commenting on her departure, Society Chair, Alastair Balls said "Ruth has shown great strength of leadership in the transformation of the Society, particularly with regard to the *Fit for the future* programme. We will miss her but wish her every success in the future."

**30 November 2010: German Alzheimer Society publishes guide on assistance in home care for people with dementia**



The German Alzheimer Society has published the booklet "Volunteer helpers in home care for people with dementia". These helpers are organized in circles of carers. The booklet provides information on the structure, organisation, financing, and the practical work of circles of volunteer helpers.

Heike von Lützu-Hohlbein, Chairperson of the German Alzheimer Society and of Alzheimer Europe, said, "Volunteers become helpers in many places and make a valuable contribution to the social care of people with dementia as well as relieving family caregivers. With this brochure, we want to support the dissemination of circles of carers especially in rural areas."

The brochure "Voluntary helpers in home care for people with dementia" by Christel Schulz is published by the German Alzheimer Society, has 64 pages and costs EUR 4.

"The conference builds on our efforts for a better quality of life for people with dementia and will focus on the latest developments in medical treatments, non-pharmacological interventions and prevention, aiming at sharing best practices among stakeholders."

**Science Watch**

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

**We provide full references to articles on our website. Please visit the Alzheimer Europe website on:**

[www.alzheimer-europe.org](http://www.alzheimer-europe.org)

**3 November 2010: Study examines the effect of omega-3 acid on symptoms of Alzheimer's disease**

A study suggests that supplementation with the omega-3 fatty acid docosahexaenoic acid (DHA) does not slow the rate of cognitive and functional decline in people with mild to moderate Alzheimer disease. In previous animal studies, it had been suggested that oral intake of DHA reduced Alzheimer-like brain pathology.

The study, which was funded by the National Institute on Aging, was led by Dr. Joseph F. Quinn, from the Oregon Health and Science University, Portland. It was published in the Journal of the American Medical Association.

**11 November 2010: Study examines the relationship between cholesterol levels in middle age and the risk of dementia in later life**

A study suggests that “women whose cholesterol levels decline from middle age to old age are at 2.5 times greater risk of developing the memory-wasting diseases than those whose cholesterol stayed the same or increased over the years.” This led researchers to conclude that there was no link between middle-age cholesterol levels and dementia risk.

The lead author of the study was Michelle M Mielke, assistant professor of psychiatry at the Johns Hopkins University School of Medicine. It was published in the journal *Neurology*.

**13 November 2010: Paper published on prevalence of dementia in Finland**

The research paper “Prevalence of dementia – a rising challenge among ageing populations” has been published in the journal *European Geriatric Medicine* (EGM). The aim of the Finnish study was to “determine the prevalence of dementia syndrome in an ageing rural population” and to then discuss the prevalence. The researchers found the prevalence of dementia to be 8.8% in a total population aged 60+ (43.8% aged 90+) and that prevalence rates were higher than those found in earlier Finnish or European studies. They concluded that “active measures are needed in order to improve the access to diagnostics and care for [people with dementia]. Assuming no changes in mortality, and that no effective prevention strategies or curative treatment take place, the number of [people with dementia] in the study area will increase due to the population development by 39% by the year 2020, and by 90% by the year 2030.”

The study was conducted by researchers from the University of Oulu and the Oulu Deaconess Institute, Finland.

**15 November 2010: Study compares association between risk of developing Alzheimer’s disease and parents having Alzheimer’s disease**

A study suggests that adult children of mothers with Alzheimer’s disease may be at an increased risk of developing the disease. Researchers examined levels of the protein amyloid (associated with Alzheimer’s disease) and compared individuals with a maternal or paternal history of Alzheimer’s disease to those with no family history of the disease. They found that “only individuals whose mothers had Alzheimer’s showed altered levels of amyloid, as well as proteins involved with oxidative stress. In contrast, individuals whose fathers had Alzheimer’s and those with no family history had protein levels within normal range.” The authors have called for further research to be conducted.

The first author of the research was Dr. Lisa Mosconi, NYU Langone and published in the journal of *Biological Psychiatry*.

**15 November 2010: Study identifies role which protein may play in Alzheimer’s disease**

A study suggests that amyloid beta peptide, the build up of which is associated with Alzheimer’s disease, is made up of three forms of amyloid precursor protein (APP), the main form being APP695.

The research also suggests that the protein (known as amyloid precursor protein intracellular domain, or AICD,) which forms from the breakdown of APP695 “is a contributing factor in the deterioration in nerve and brain cells which leads to Alzheimer’s disease”.

The researchers hope that this will enable research to focus more clearly on the exact mechanism by which amyloid beta peptide accumulates in the brain.

Published in the *Journal of Biological Chemistry*, the study was co led by Professor Tony Turner, Leeds’ Faculty of Biological Sciences, together with colleagues from the University of Leeds, UK.

**15 November 2010: Study suggests possibility of early identification of signs of Alzheimer’s disease**

A study has shown that:

- white matter lesions in the areas of the brain similar to those found in people with dementia in later life are present in some adults aged in their 40s,
- ‘attention tests’ may be useful to highlight those people with lesions (previously this was only thought possible by using MRI scans).

The researchers wish that their findings be confirmed in further tests.

The study was led by Professor David Bunce of the Centre for Mental Health Research at The Australian National University and Brunel University and published in the journal *PLoS One*.

**15 November 2010: Mouse study investigates the relationship between the drug diazoxide and symptoms of Alzheimer’s disease**

A mouse study has found a relationship between use of the drug diazoxide (which has been used to treat high blood pressure and is used to treat hypoglycemia) and an improvement of learning and memory function. Mice, which had been genetically altered to display symptoms of Alzheimer’s disease, received either a placebo or water with diazoxide in it. Findings suggest that diazoxide “stabilized nerve cells in the brain and prevented a biological cascade in the mice that can result in the destruction of these cells. The drug also improved blood flow in the brain and prevented the harmful accumulation of two proteins, beta-amyloid and tau”.

The study was conducted by researchers from the National Institute on Aging (NIA), USA in collaboration with colleagues from Konkuk University college of Veterinary Medicine, Seoul, South Korea and the Indiana University School of Medicine, Indianapolis.

**16 November 2010: Study reveals specific brain tissue loss in People with Alzheimer's disease**

A study has found that, compared to healthy individuals, the brain structure known as the caudate nucleus is smaller in people with Alzheimer's disease, people with mild cognitive impairment and also in older and overweight individuals. The findings suggest "a gradual progression of brain tissue loss in the caudate nucleus as dementia becomes more severe."

The study was conducted on 400 elderly people (100 healthy, 100 with a diagnosis of Alzheimer's disease and 200 with mild cognitive impairment) and carried out by Sarah Madsen and colleagues from the University of California, Los Angeles, USA. It was presented at the 2010 meeting of the Society for Neuroscience in San Diego.

**17 November 2010: Study reveals changes in the brain in people at risk for Alzheimer's disease**

Researchers found that cortical areas of the brain thin in the brains in people with amnesic mild cognitive impairment who later develop Alzheimer's disease. They used magnetic resonance imaging (MRI) screenings which revealed a "thinning of the cortical areas that receive strong input from the substantia innominata (a region deep within the brain that sends chemical signals to the cerebral cortex, which in turn is largely responsible for the reasoning, memory and other functions) in those who went on to develop Alzheimer's disease." The researchers hope that this findings may offer a potential early marker for dementia.

The study was conducted on 52 people with amnesic mild cognitive impairment over a six-year period. Of these, 23 people progressed to Alzheimer's disease. The study was conducted by researchers at Rush University Medical Center, USA and presented at the 2010 meeting for the Society of Neuroscience in San Diego, California, USA.

**18 November 2010: Funding awarded of EUR 10.4 million for project in the field of Alzheimer's disease**

A six-year project known as DIPPAL (Diagnostic Précoce et Pléothérapie de la maladie d'Alzheimer) has been announced with three main objectives to:

- develop and validate a prototype multiparameter blood test for the early, reliable diagnosis of Alzheimer's Disease,
- discover a Pleodrug™ for the effective treatment of AD and take it through to the end of Phase II clinical trials,
- develop a companion test to monitor the effectiveness of the Pleodrug™ in humans and/or to determine the sub-population of "responder" patients.

The project will be led by the biopharmaceutical company Pharnext and financed by the French state innovation agency, OSEO. A total of funding package has been announced amounting to EUR 10.4 million (EUR 2.7 million as a grant and EUR 7.7 million being repayable if the project is a success).

**29 November 2010: Study examines the availability of hospice care to people with dementia in the US**

According to a survey of the directors of 426 hospice and palliative care programmes, hospice care is 'much more widely available to patients with dementia than it was 15 years ago.'

The study found that:

- hospice care to people with dementia had risen from 21% in 1995 to 94% in 2010
- nearly two-thirds of palliative care programme directors said they cared for people with dementia
- inadequate insurance coverage is a barrier to people with dementia receiving in-home palliative care services before coming eligible for hospice care.

The study, led by Alexia M Torke, assistant professor of medicine and geriatrics at the Indiana University School of Medicine, USA, was published in the Journal of the American Geriatrics Society.

**29 November 2010: Mouse study examines the role enzyme plays in cognitive function**

A study on genetically modified mice suggests that gene therapy used to improve the levels of enzyme Ephrin type-B receptor 2 (EphB2) may be beneficial in treating the symptoms of Alzheimer's disease. The levels of EphB2 decrease in humans with Alzheimer's disease and also in mice genetically engineered to simulate the disease. The researchers wanted to establish whether the low levels of EphB2 contributed to the development of memory problems. They found that a reduction of EphB2 levels in normal healthy mice disrupted neurotransmission and they also found that when they normalised low EphB2 levels that this process appeared to reduce memory problems and behavioural abnormalities. The researchers have called for additional studies to be conducted.

The research was led by Lennart Mucke, with colleagues from the Gladstone Institute of Neurological Disease in San Francisco. The study was published in the journal Nature.

## Correction

Alzheimer Europe would like to correct a spelling mistake in the last newsletter regarding "Galantamine". The news should have read:

**4 October 2010: Alzheimer drug fails to receive marketing authorisation by the European Medicines Agency**

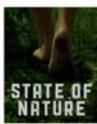
The European Medicines Agency (EMA) declined authorisation for the drug Galantamine Stada. A statement was released on the EMA website which reads "The European Medicines Agency has completed an arbitration procedure following a disagreement among Member States of the European Union (EU) regarding the authorisation of the medicine Galantamine Stada. The Agency's Committee for Medicinal Products for Human Use

(CHMP) has concluded that the benefits of Galantamine Stada do not outweigh its risks, and the marketing authorisation cannot be granted in Austria or in other Member States of the EU: Czech Republic, Denmark, Finland, Ireland, Portugal, Slovakia and Spain.”

Galantamine Stada should not be confused with galantamine which is the active ingredient of the drug Reminyl and which is unaffected by this decision.

## Dementia in society

### 17 November 2010: Play launched about dementia



The play, “State of Nature” was performed in November at the Eden Project’s rainforest biome, Cornwall, UK. The play is based on the character Patrick, who has dementia with Lewy bodies. He reminisced about his time in India in the 1960s.

The author, Simon Turley, who has experienced the impact of some of his relatives having dementia with Lewy bodies, said: “Like the majority of people I can point to cases of dementia in my own family, my grandmother, and, much more recently, her son, my uncle. He died of dementia with Lewy Bodies. This condition shares several symptoms with Parkinson’s disease, as well as having the vivid hallucinations and persistent misappropriations of other dementias.”

### 19 November 2010: Care home helps people with Alzheimer’s disease by creating an “Alzheimer’s room”



A care home which has people with dementia has created a ‘time-warp’ room which they claim has been so successful that there has been a drop in the use of anti-psychotic drugs, often used in people with the disease. Manager, Sue Linsley, said: “Our clients can come in and it calms them down. This proves that you don’t need to use anti-psychotics all the time. It’s a working room, the staff use it as an integral part of their care.”

The room, which dates from the 1950s, includes various items such as:

- 1950s furniture.
- A gramophone.
- A Hoover vacuum cleaner.
- A mantel clock with silvered dial contained in an oak arch-shaped case by Smith.
- A manual (Remington) typewriter.
- A phone made of Bakelite.
- A picture of a classic blue Chevrolet.
- A post-war pram.
- A Singer sewing machine - people often made their own clothes using dressmaking patterns.
- A vintage dog on wheels toy.

- A wireless - which would have played the BBC’s Light Programme, Home Service and Third Programme.
- A wooden clothes drying rack.
- An Oval mirror with bevelled edge on chain.
- Black and white photographs.
- Flying ducks.

The care home, Coombe End Court, is in Marlborough, Wiltshire, UK.

### 23 November 2010: US Alzheimer Foundation organises Alzheimer telethon

As part of an Alzheimer’s disease telethon, The Alzheimer’s Foundation of American (AFA) will organise an educational discussion and family profile on Alzheimer’s disease on 4 December 2010. The aim of the telethon is to raise awareness and understanding of Alzheimer’s disease and of the support services and resources available. The “Together for Care” telethon will be hosted by Al Roker, who presents the Today show and aired on NBC as well as telecast online on the AFA website. It is hoped that the discussion will “help parents and children learn how to speak to loved ones with Alzheimer’s disease”.

## New resources and publications

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

### 31 October 2010: National US register opened for people with ALS

In the US there is no national database for the incidence and prevalence rates of Amyotrophic Lateral Sclerosis (ALS). In an attempt to address this, the Agency for Toxic Substances and Disease Registry (ATSDR), Atlanta, USA, opened a new national ALS registry to the public. This registry enables people with ALS to “log on to be counted, entering their health history, family history, and work experience. Then, they can fill out specific surveys - covering topics such as military history or occupation - to help scientists determine whether those factors increase risk of disease.”

The registry has taken four years to develop and will incorporate information from Medicaid, Medicare and Veterans Affairs databases.

### 1 November 2010: Report published on the numbers of deaths attributed to Alzheimer’s disease, dementia and senility in England

The National End of Life Care Intelligence Network (NEoLCIN) has produced the report “Deaths from Alzheimer’s disease, dementia and senility in England”. The report shows the absolute numbers of deaths attributed to Alzheimer’s disease, dementia and senility and also where these are mentioned as the



The National End of Life Care Intelligence Network (NEoLCIN) has

underlying and contributory causes of deaths. The findings suggest that:

1) Approximately 15% of all deaths recorded in England between 2001 and 2009 had one or more of the conditions Alzheimer's disease, dementia or senility mentioned on death certificates.

2) A significant proportion of people who died from an underlying cause of Alzheimer's disease, dementia or senility also had one or more of these conditions coded as a contributory cause:

- 30% of people with an underlying death code of dementia also had a contributory code of senility.
- 20% of people with an underlying code of Alzheimer's disease also had a contributory code of senility, whilst a further 4% also had a contributory code of dementia.
- Approximately 10% of all deaths with an underlying cause of death other than Alzheimer's disease, dementia or senility, had one of these conditions coded as a contributory cause of death.

The authors state that this report "will be an invaluable resource to policy makers, providers and commissioners of care to the elderly and patients with Alzheimer's disease, dementia and senility, and to the non-statutory bodies who support them and their carers."

This report is the first in a series on end of life care for people with Alzheimer's disease, dementia and senility and future analyses will examine the role each condition plays in co-morbidity and also the pattern of admissions and type of care received in hospital during the last year of life.

#### **11 November 2010: UK report highlights the process of care of elderly patients who died shortly after surgery**

Findings from the Elective and Emergency Surgery in the Elderly on National Confidentiality Enquiry into Patient Outcome and Death's (NCEPOD) report "An Age Old Problem – A review of the care received by elderly patients undergoing surgery" have been published. The report highlights "the process of care of elderly patients who died within 30 days of emergency or elective surgery. The report takes a critical look at areas where the care of patients might have been improved, from lack of input from Medicine for the Care of Older People to the level of pain relief provided. Remediable factors have also been identified in the clinical and the organisational care of these patients." Areas considered are:

- Hospital facilities and multidisciplinary care of the elderly
- Patient co-morbidities
- Pre-operative care
- Intra operative care
- Post operative care
- Care of a fractured neck or femur
- Care of the acute abdomen.

Details of the report, an executive summary, an elective and emergency tool kit together with useful links can be found on the NCEPOD website.

#### **18 November 2010: European Commission launches updated website to promote Europe for Patients' Campaign**

The European Commission's multilingual (22 languages) and thematic website of the campaign "Europe for patients" has been completely revised and updated. It now has a vibrant new look and includes information from both national and EU level (in the form of fact sheets, news, events, press releases and videos).

This information is presented around the 11 policies of the campaign that put patients first:

- cross border health care
- rare diseases
- organ donation and transplantation
- health workforce
- patient safety
- cancer
- flu vaccination
- childhood vaccination
- use of antibiotics
- mental health
- Alzheimer and other dementias.

The 'Europe for Patients' campaign was originally launched by the European Commission in September 2008. The campaign highlights a series of different healthcare and patient related policy initiatives of the Commission, all of which are bound by the common goal of better healthcare for all in Europe.

## **Job Opportunities**

#### **30 November 2010: Researchers sought for project in the field of palliative and end-of-life care in the European context**

The European Intersectoral and Multi-disciplinary Palliative Care Research Training (EURO IMPACT), coordinated by Prof. Luc Deliens and Prof. Lieve Van den Block, is recruiting 12 full-time early stage or junior researchers for 3 years each, starting in 2011.

EURO IMPACT, a European Union 7th Framework Programme (2010 - 2014) — Marie Curie Initial Training Network, coordinated by the End-of-Life Care Research Group of Ghent University & Vrije Universiteit Brussels in Belgium, is aimed at monitoring and improving the quality of palliative care in Europe. The consortium involves 10 partners at the forefront of palliative care research in Europe. Researchers will be conducting research in the field of palliative and end-of-life care in a European context and preparing a doctoral dissertation. Research projects focus on cancer patients, patients with dementia and patients with other non-cancer diseases. Researchers have obtained an MSc or MA and are in the first 4 years of their research careers and are prepared to be based in another country than their country of residence and to travel across different countries in Europe.

Please visit [www.endoflifecare.be/euroimpact/vaca](http://www.endoflifecare.be/euroimpact/vaca) for more information on the project and how to apply, or contact Lieve Van den Block at [lvdblock@vub.ac.be](mailto:lvdblock@vub.ac.be)

## AE Calendar

The following meetings will be attended by representatives of Alzheimer Europe

Date	Meeting	AE Representative
6 December 2010	Alzheimer Europe Board meeting (Brussels, Belgium)	AE Board and Staff
7 December 2010	European Parliament lunch debate "The Joint Programming of research in Neurodegenerative Diseases (JPND) What progress so far?" (Brussels, Belgium)	AE Board and Staff
9-10 December 2010	Alzheimer Portugal's Annual Conference "Alzheimer Disease – towards an integrated policy" (Lisbon, Portugal)	Annette Dumas

## Future Conferences

Date	Meeting	Place
16-20 February 2011	The 7th Pan – Hellenic Conference of Alzheimer Disease and Related Disorders, <a href="http://www.alzheimer-hellas.gr">http://www.alzheimer-hellas.gr</a>	Thessaloniki, Greece
19-20 February 2011	2011 National Alzheimer Conference: New insights into dementia, <a href="http://www.alzcongres.ro">www.alzcongres.ro</a>	Bucharest, Romania
24 February 2011	Remember me: Dying of dementia in a multiethnic society, <a href="http://www.careconferences.co.uk">www.careconferences.co.uk</a>	London, UK
9-13 March 2011	The 10th International Conference on Alzheimer's & Parkinson's Diseases (AD/PD 2011), <a href="http://www.kenes.com/adpd">www.kenes.com/adpd</a>	Barcelona, Spain
17-18 March 2011	Colloque Le défi de l'intervention auprès des personnes atteintes de la maladie d'Alzheimer, <a href="http://www.iugm.qc.ca/iugm/diffusion-de-l-expertise/colloques-et-symposiums">http://www.iugm.qc.ca/iugm/diffusion-de-l-expertise/colloques-et-symposiums</a>	Montréal, Canada
26-29 March 2011	26th International Conference of Alzheimer's Disease International, <a href="http://www.adi2011.org/default.aspx?PageID=Home">http://www.adi2011.org/default.aspx?PageID=Home</a>	Toronto Canada
13-14 April 2011	The 7th Annual World Health Care Congress—Europe, <a href="http://www.worldcongress.com/events/HR11015/">http://www.worldcongress.com/events/HR11015/</a>	Brussels, Belgium
14-17 April 2011	The VII International Association of Gerontology and Geriatrics (IAGG) – European Region Congress "Healthy and Active Ageing for all Europeans II", <a href="http://www.iaggbologna2011.com">www.iaggbologna2011.com</a>	Bologna, Italy
28-30 January 2011	4 <sup>th</sup> Edition of the European Neurological Conference on Clinical Practices (ENCCP), <a href="http://www.paragon-conventions.net/enccp2011">www.paragon-conventions.net/enccp2011</a>	Lisbon, Portugal
9-12 May 2012	12th International Stockholm/Springfield Symposium on Advances in Alzheimer Therapy, <a href="http://www.ad-springfield.com">www.ad-springfield.com</a>	Stockholm, Sweden



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