



NEWSLETTER

December 2010-January 2011

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Editorial



At the end of 2010 Alzheimer Europe was exceptionally busy with the publication of two major pieces of work: The Alzheimer Europe Report 'The ethical issues linked to the use of assistive technology in dementia care' and also the 2010 Dementia in Europe Yearbook which was dedicated to proxy decision making and forms of legal capacity for people with dementia. Both of these publications were launched during our lunch debate in the European Parliament and were very warmly received.

Nessa Childers, MEP (Ireland) hosted our 8th lunch debate in the European Parliament focusing on the Joint Programming of research in Neurodegenerative diseases. It was a lively debate and provided useful insights into the process, aims and status of the Joint Programming.

We have also been busy with our Alzheimer Europe conferences. If you have missed our conference in Luxembourg, then visit our website to see the videos of all the keynote speakers of our conference. I hope this will encourage you to submit an abstract to our Annual Conference which will take place in Warsaw from 6 to 8 October 2011.

I am absolutely thrilled that in January, the European Parliament overwhelmingly voted to adopt a resolution on a European initiative to combat Alzheimer's disease and neurodegenerative diseases.

On January 1st, the EU Presidency rotated to Hungary and we sincerely hope that the momentum built up by previous presidencies to keep dementia a political priority is continued.

In the US, the importance of a national Alzheimer plan has been recognised as President Obama signed the national Alzheimer's Project Act into law on January 4th.

It is also reassuring to report that in the UK, the National Institute for Health and Clinical Excellence has now extended its recommendation for the use of Alzheimer's drugs.

National Alzheimer's associations have been busy and we report on the annual conference in Portugal, a report highlighting insufficient support and care at home for people with dementia and their carers in the UK as well as training on dementia for graduates in Italy. It is also encouraging that Alzheimer Scotland has received significant funding for its Dementia Nurse Programme.

Raising awareness of dementia can be effectively achieved by people with dementia speaking out about their experiences. We are therefore very happy to report that both Peter Ashley and James McKillop have been recognised officially for their extensive work in this regard.

Lastly, it is with great sadness that we report on the passing of Jim Jackson, who, as former Chief Executive of Alzheimer Scotland was a long-standing campaigner and advocate for people with dementia and a great supporter of the International and European dementia movement. He will be greatly missed.

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

6 December 2010: Alzheimer Europe Board meeting held in Brussels

An Alzheimer Europe Board meeting was held in Brussels on 6 December 2010. The Board discussed:

- The various meetings which had been attended by the staff of Alzheimer Europe
- The 2010 work plan: The Board reviewed the 2010 conference in Luxembourg, the current status of the project 'the value of diagnosis' and finished project 'the ethical use of assistive technology in dementia care', the Dementia in Europe magazine, the Dementia in Europe Yearbook and an update was given on the status of the European Alzheimer's Initiative
- The 2010 finances
- The draft strategic plan (2011-2015)
- The work plan and budget for 2011: This will include the ongoing project 'value of diagnosis', publication of an article on the assistive technology work carried out in 2010, a project on the ethical issues linked to dementia research, the publication of three Dementia in Europe magazines and ten newsletters and the 2011 Dementia in Europe Yearbook. The Board also discussed the status of the application for a

grant from the European Commission for 2011. (Since the meeting on 6 December, the Commission has awarded Alzheimer Europe core funding for 2011)

- The 2011 Alzheimer Europe Conference in Warsaw.

The next Board meeting will be held in Brussels on 13 March 2011.

7 December 2010: Alzheimer Europe Report: "The ethical issues linked to the use of assistive technology in dementia care" launched



During the European lunch debate hosted by Nessa Childers, MEP (Ireland), the Alzheimer Europe Report entitled "The ethical issues linked to the use of assistive technology in dementia care" was launched.

This publication examines the ethical issues linked to the use of assistive technology (AT) for/by people with dementia. A brief overview is provided of the three main issues of importance, namely dementia, assistive technology and ethics. This is followed by a discussion of the various ethical issues linked to the use of AT (based on an extensive review of literature) which addresses not only possible disadvantages but also looks at the positive implications of the use of AT and how it can contribute towards respecting certain ethical principles with regard to people with dementia. Alzheimer Europe presents its position and guidelines on the ethical use of AT for/by people with dementia and proposes an ethical framework for decision making. This publication is targeted at a wide audience including people with dementia, carers, health and social care professionals, service providers, AT designers, researchers and policy makers.

7 December 2010: Alzheimer Europe launches the 2010 Dementia in Europe Yearbook which focuses on proxy decision making and forms of legal capacity for people with dementia



The 2010 Dementia in Europe Yearbook presents Alzheimer Europe's work on the ongoing Lawnet project which explores and provides an inventory of the provisions relating to the rights and protection of people with dementia within member states of the European Union (as well as in Iceland, Norway, Switzerland and Turkey). The topic in the 2010 yearbook is proxy decision making (e.g. guardianship measures and continuing powers of attorney) and various forms of legal capacity e.g. relating to marriage, making a will, making a contract, voting, civil liability and criminal responsibility). The Yearbook also contains the Alzheimer Europe Annual Report for 2009.

7 December 2010: Alzheimer Europe organises lunch debate in European Parliament dedicated to the Joint Programming of research

Alzheimer Europe organised its 8th lunch debate in the European Parliament on 7 December. It was

hosted by Nessa Childers, MEP (Ireland), and entitled "The Joint Programming of research in Neurodegenerative Diseases (JPND). What progress so far?" Answering this were Pieter Jelle Visser, a member of the JPND Management Board and Elmar Nimmesgern of the European Commission, Research and Innovation Directorate General, Medical Research Unit.



Opening the debate, Ms Childers gave a brief introduction regarding action on Alzheimer's disease at European level, highlighting how neurodegenerative diseases require specific action. She said that EU initiatives in Alzheimer's disease should eventually help secure earlier diagnosis, enabling appropriate treatment and support to be given, but also hoped that we could work towards finding a cure for Alzheimer's disease. Recognising that it is not possible to give predictions on how long this process may take, she believed that the JPND should accelerate the process.



Pieter Jelle Visser explained how the JPND works and said that it was instigated to help address the fact that in Europe research on Alzheimer's disease is fragmented and budgets are not as effectively used as they might be. It is hoped, he said, that by increasing the collaboration between Member States on key research topics, such as Alzheimer's disease, joint programming can result in great benefits such as harmonising national strategic research approaches, achieving a synergistic use of shrinking research budgets, reinforcing the potential for scientific collaboration in Europe by grouping calls for grants, offering greater accountability to stakeholders in pooling research efforts addressing common social

issues in Europe and a simplification of European procedures governing scientific collaboration and its administration.

Mr Visser also gave an overview of the management structure, workflow of the JPND and research priorities.

Elmar Nimmesgern clarified the role which the Commission plays in terms of the JPND. Currently, the Commission is actively supporting the Joint Programming by having organised a workshop, developing the Strategic Research Agenda (SRA), preparing a report for the European Parliament (due in 2011) and supporting the mapping of ongoing research. Evidence of concrete progress was given by highlighting the discussions which have occurred about early priorities for joint action which expanded to include several countries.

The Chairperson of Alzheimer Europe, Heike von Lützu-Hohlbein reinforced how important research can be to the quality of life of people with dementia in that it can lead to earlier diagnosis and better treatment.

20 January 2010: Video of plenary presentations from Alzheimer Europe's 20th Annual Conference available on website

Videos of the presentations in the plenary sessions during Alzheimer Europe's 20th Annual Conference, 'Facing Dementia Together', which was held in Luxembourg, are now available on the Alzheimer Europe website. They can be found on the conference (previous conferences – Luxembourg) section of Alzheimer Europe's website under the heading 'conference videos'.

Alzheimer Europe Networking

On 6 December 2010 (Brussels, Belgium) the Alzheimer Europe Board met.

On 7 December 2010 (Brussels, Belgium) Alzheimer Europe organised a lunch debate on the Joint Programming initiative hosted by Nessa Childers, MEP (Ireland).

On 8 December 2010 (Brussels, Belgium) Annette met with Antoni Gelonch from Sanofi-Aventis.

On 8-11 December 2010 (Lisbon, Portugal) Annette attended the Alzheimer Conference (Alzheimer's disease: towards an integrated policy) and made a presentation.

On 13 January 2011 (Brussels, Belgium) Annette participated in the Europa! TV interview on dementia with Marisa Matias (MEP) and attended the S&D public debate in the EP on the "Innovation Union" (debate 1: non-technological innovation and social innovation).

On 14 January (Brussels, Belgium) Jean and Annette met with Sue Silk from Janssen.

On 19 January (Brussels, Belgium) Annette had a teleconference with Pfizer to discuss the AHAIP (Active and Healthy Ageing Initiative Partnership) public consultation.

On 26 January (Brussels, Belgium) Annette made a presentation at the Health and Science Briefing on AD organised by Pfizer and hosted by MEPs Nessa Childers (Ireland), Eleana Oana Antonescu (Romania) and Marisa Matias (Portugal).

On 27 January (Brussels, Belgium) Annette met Kaisa Immonen Charalambos (EPF) to discuss the AHAIP public consultation and met the Age Intergroup in the EP on the AHAIP.

European developments

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

1 January 2011: Hungary holds Presidency of the EU

 Hungary took over the EU Presidency from Belgium on 1 January 2011. Under the motto "Strong Europe", this Presidency is also marked by the need to address the unprecedented economic crisis and the need to lay the foundations for future development. The aim of this new Presidency is thus to create an economically, socially, politically and institutionally stronger and more attractive Europe.

The Presidency priorities

The Hungarian Presidency will revolve around 4 main priorities: 1) promote economic growth by strengthening economic governance and concentrating on job creation and social inclusion; 2) strengthen the EU common policies by making them more efficient and competitive while preserving social cohesion; 3) bring Europe closer to its citizens; 4) move forward with the enlargement process.

Jobs, growth and social inclusion

Economic growth and economic governance will need to be stimulated. Based on the principle that Europe cannot be competitive without creating new jobs or having a more efficient employment policy, employment will be a priority of the Presidency.

The Europe 2020 Strategy will be the instrument for boosting employment, enhancing competitiveness and social inclusion. The Innovation flagship in particular will be drawn up and implementation will begin during the Presidency. 'New Skills, New Jobs' will be discussed with a specific focus on job creation. Specific attention will be paid to the demographic trends and family policy measures. Sharing of best practices will be an part of the process.

Stronger Europe: building on the foundations and protecting the future

The Presidency will review the future of the EU common policies. This priority will cover the Common Agricultural Policy, energy supply, environment sustainability and climate change. The EU economic, social and territorial cohesion pillars will remain at the core of the cohesion policy.

A Union close to its citizens

This priority will cover measures that will guarantee the citizens' freedoms and rights. This will include the implementation of the Stockholm programme, the fair trial of victims of crime, protection of personal data, easier access to justice (e-Justice), the citizens' initiative, the abolition of controls in the Schengen area, specific attention to 2011 as the Year of Volunteering.

Enlargement

The Presidency will take the enlargement process forward (Croatia, Turkey and the Western Balkans), renew the neighbouring policy.

The Presidency work programme

In the field of **health**, the agenda will be governed by the EU 2020 Strategy. The Presidency will adopt flagship initiatives related to employment and social issues identified by the Strategy with a specific emphasis on job creation, child poverty and Roma integration. The Presidency will also try to find answers to the challenges of the demographic change and the need for sustainable healthcare systems.

Another specific emphasis will be on the reduction of the unemployment of young people by improving job opportunities with different levels of knowledge and skills and by creating attractive jobs for the younger generations.

In the field of **social policy**, the objective of the Presidency is to address the challenges of an ageing population so that the elderly people can enjoy a good quality of life and continue to be valued members of society. The Presidency will highlight the reconciliation of work and family life with regard to the demographic trends. It will propose dedicating a European Year to Families.

Another social priority will be the launch of the implementation of the European Disability Strategy for the 2010-2020 period.

As a response to the common healthcare challenges faced by the Member States (economic crisis, demographic changes, gaps in health status, shortages in health professionals, better use of modern technologies), the Presidency will focus on issues related to the imbalances in workforce availability. It will also pay specific attention to e-health.

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

19 January 2011: European Parliament adopts Resolution on a European initiative to combat Alzheimer's disease and other dementias



At its plenary sitting of 19 January 2011, the European Parliament adopted Marisa Matias' (MEP, Portugal, GUE/NLG) motion for a resolution on a European initiative to combat Alzheimer's disease and neurodegenerative disease.

The report calls on European governments to:

- make Alzheimer's disease and other dementias a priority
- raise public awareness about dementia in the EU, facilitating recognition of the early

symptoms of dementia, improving access to early diagnosis and treatments

- increase cooperation between countries in research, care and prevention of Alzheimer's disease
- set up specialist centres and the provision of satisfactory medical equipment and improvements to the skills of professional carers
- develop action plans aimed at improving the well-being and quality of life of people with dementia and their families.

This own-initiative report improves the European Communication to the European Parliament and the Council on a European initiative on Alzheimer's disease and other dementias (COM (2009) 380). It will reinforce the work of the Joint Action between the European Commission and the Member States who will be implementing the actions of this Communication. In 2013 the Commission will produce an implementation report on this Communication.

The report was adopted by 646 votes in favour, 6 against and 6 abstentions.

19 January 2011: European Parliament adopts resolution on the rights for patients who seek healthcare in another EU country

At its plenary sitting of 19 January 2011, the European Parliament adopted, in second reading, a Resolution on new legislation setting out clear rights for the patients who seek healthcare in another EU country (Directive of the European Parliament and of the Council on the application of patients' rights in cross-border healthcare). This new text now clarifies that the EU citizens can be reimbursed for the healthcare they will receive in another Member State as long as the type of treatment and costs are normally covered in their own country.

Nevertheless, authorities may require that patients seek 'prior authorisation' for treatments requiring overnight hospital stays or specialised healthcare. Any refusal will have to be justified according to a restricted list of possible reasons.

Each Member State will have to establish a 'contact point' that will provide relevant information to the patients seeking treatment abroad. These 'contact points' will also provide assistance should any problem arise.

This new law will also enhance provisions for cooperation in the field of rare diseases.

The text now needs to be formally approved by the Council. It is the result of extensive discussions between the European Commission, the Council and the European Parliament. The Rapporteur in first reading was John Bowis, UK MEP and member of the European Alzheimer's Alliance and, in second reading, Françoise Grossetête, French MEP and Chair of the European Alzheimer's Alliance.

Once signed into law, the Member States will have 30 months to change their national legislation to accommodate this new piece of legislation.

Policy Watch

31 December 2010: Inquiry in the UK launched into how to save money in dementia care and deliver better outcomes

The Chairperson of the UK All-Party Parliamentary Group on Dementia (APPG), Baroness Greengross, has announced an inquiry into how to save money in dementia care and deliver better outcomes for people with dementia. The inquiry aims to identify good practice examples that providers and commissioners of dementia care in the UK can draw on. The APPG has called for written evidence of ways in which money can be saved and existing resources be used more efficiently, whilst ensuring quality of life for people with dementia. On the Alzheimer's Society website there are questionnaires aimed at different interested parties (people with dementia and their carers, commissioners and providers and/or other stakeholders) which can be downloaded and submitted on-line.

The evidence is to be submitted by 26 February 2011 and the APPG will produce their report by the summer of 2011.

4 January 2011: US passes Alzheimer Act

President Obama signed the National Alzheimer's Project Act (NAPA) into law on 4 January. This Act, which was first introduced to Congress in July 2009, will create 'a coordinated national plan to overcome the Alzheimer crisis and will ensure the coordination and evaluation of all national efforts in Alzheimer research, clinical care, institutional, and home- and community-based programs and their outcomes.'

The Alzheimer's Association has played a key role in the preparations and advocating the Plan. The history of the Act's progress can be found on the Alzheimer's Association website.

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

18 January 2011: UK Government regulatory body extends recommendation for the use of Alzheimer's drugs

The National Institute for Health and Clinical Excellence (NICE) in the UK has updated its draft guidance for the use of donepezil, galantamine and rivastigmine to include mild, as well as moderate dementia. It also recommends the use of memantine for severe dementia and for some people with moderate disease.

Ruth Sutherland, Interim Chief Executive, Alzheimer's Society, said: "This decision stands to benefit hundreds of thousands of people. The drugs aren't a miracle cure but they can make important differences to people's lives. For the price of a cup of coffee they can mean the difference between recognising your loved ones and playing with your grandchildren. It is critical that this draft decision

becomes a reality and that all people with Alzheimer's are given the opportunity to benefit from these treatments. It will be important to ensure any new guidance is monitored closely to end postcode prescribing and ensure these drugs are available across the country."

Members' News

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

9-10 December 2010: Alzheimer Portugal hosts conference on Alzheimer's disease



The Alzheimer Portugal Conference, "Alzheimer Disease – towards an integrated politic" took place on 9-10 December 2010. Marisa Matias, MEP (Portugal) and European Alzheimer Alliance member, who was unable to attend the conference, sent a video with her presentation about the European Parliament's own initiative report on the European initiative on Alzheimer's disease. Ms Matias is the Rapporteur for the report.

Five Portuguese Members of Parliament, representing five different political parties, participated in a debate on dementia. Topics discussed included:

- The recognition of dementia as a priority
- The urgent need for a dementia plan
- The need to adapt existing services and facilities for people with dementia and
- The importance of specific dementia training.

Annette Dumas represented Alzheimer Europe and gave a presentation on the work of Alzheimer Europe since the launch of its political priorities in the Paris Declaration in 2006.



Maria do Rosário Zincke dos Reis, the Chairperson of Alzheimer Portugal and also Honorary Secretary of Alzheimer Europe gave a presentation about the

European framework relating to legal rights, guardianship and advance directives. Other topics discussed by the same panel, included the management of the property of people with incapacity and also advance directives in Portugal.

The conference ended with a play about dementia (a dialogue between a son and his mother who had Alzheimer's). It was performed by professional and well known actors. Maria do Rosário Zincke dos Reis said it had a great impact and really showed the dark side of dementia, but ended happily.



Panel discussion: Paulo Fidalgo, Maria José nogueira Pinto, Luisa Salgueiro, Teresa Caeiro, Paula Santos, João Semedo

4 January 2011: Norwegian Alzheimer association appoints new representatives



Maija Juva and Sigurd Sparr have retired from their roles within the dementia section of the National Organisation for Public Health (Nasjonalforeningen), Norway, as section leader and chairperson respectively.



Alzheimer Europe would like to thank Maija for her support and collaboration over the years. In particular we would like to thank Maija for her outstanding work during Alzheimer Europe's 18th annual conference in Oslo, Norway in 2008. Alzheimer Europe is delighted to continue working with Sigurd as he continues in his role as Honorary Secretary on the Board of Alzheimer Europe.

May-Hilde Garden has taken on the role of section leader of dementia and the new chairperson is Wenche Frogn Sellæg.

21 January 2011: Alzheimer Society report finds insufficient support and care at home for people with dementia and their carers



The Alzheimer's Society has published its report entitled "Support, Stay, Save. Care and support of people with dementia" which is part of the Society's "Putting care right" campaign. The report contains input from over 2,000 carers, people with dementia and home care workers on the aspirations, experiences and outcomes of providing dementia care in the community in England, Wales and Northern Ireland. The report revealed that many people with dementia and their carers receive insufficient support and care at home.

The Society makes six recommendations:

1. There must be an urgent and concerted effort to support people with dementia to live independently in their own homes and avoid early and unnecessary admission to long-term care.
2. Commissioners should recognise the considerable resources already being spent on health and social care on dementia and the opportunity to use them more effectively.
3. Carers must be supported to carry out their caring role.
4. Joined-up working across health and social care must become the norm if people with dementia are to be supported to remain independent in their own homes.

5. Variable experiences of care and support should be tackled through expanded sharing of good practice.
6. Home care workers must be supported to provide good care to people with dementia in their own homes.

27 January 2011: Scottish Government invests GBP 300,000 in Alzheimer Scotland's Dementia Nurse Programme



The Dementia Nurse programme in Scotland aims to greatly improve the standard of acute hospital care received by people with dementia. The Scottish Government has announced it will invest GBP 300,000 into this programme.

Henry Simmons, Chief Executive of Alzheimer Scotland, said: "This is a very positive and extremely welcome contribution from the Scottish Government and works towards our aim to have a specialist Dementia Nurse in every acute hospital. Frontline NHS staff need our support to help them to better understand the needs of people with dementia, and their families, and to care for them more effectively. We must build on this and ensure that people with dementia and their families receive consistent and high quality support from the point of diagnosis to the very difficult end-of-life stages of the illness."

31 January 2011: Alzheimer Uniti (Italy) organises dementia module for graduates



Certificates were given out in January 2011 to thirteen graduates who had completed a master's course given by Alzheimer Uniti in their head office in Rome in collaboration with the University of Rome, La Sapienza. The course was entitled "Professional Competence and Responsibility in the Assistance of Patients with Dementia" for graduates studying for their master's degrees. The programme was given, one week-end every month, from January 2010 to December 2010.

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.

1 December 2010: Pharmaceutical companies combine efforts to develop diagnostic tools for Alzheimer's disease

Janssen Pharmaceutica NV announced a research agreement to collaborate with GE Healthcare in order to develop 'non-invasive or minimally invasive diagnostic bio-signatures to detect Alzheimer's disease prior to the onset of clinical symptoms'. It is hoped that by developing such a bio-signature that earlier diagnosis could be achieved which may, in turn, enable earlier intervention.

2 December 2010: Study examines the relationship between pesticide use and mental decline

A study on nearly 1,000 French vineyard workers suggests that the mental function of those people who had mixed or sprayed the pesticides had slightly more mental decline than those who were not exposed to the pesticides.

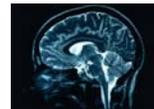
The participants' mental function was tested between 1997 and 2003 and all had spent at least two decades working directly with pesticides, or with treated plants, or in buildings nearby.

The study was conducted by researchers from the Université Victor-Segalen and the Université de Caen in France and published in the medical journal Occupational and Environmental Medicine.

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

www.alzheimer-europe.org

8 December 2010: Study examines blood flow in the brain



A study in which researchers investigated blood flow in the brain found the activity of an enzyme, which helps to control blood flow and the leakiness of blood vessel walls, to be increased in the brains of people with Alzheimer's disease. The scientists have called for further investigations to be carried out.

The research was carried out by the Dementia Research Group, Bristol University and published in the journals Brain Research and Neurology of Aging.

8 December 2010: Study examines higher dosage patch for people with Alzheimer's disease

Researchers at the Saint Louis University, USA are testing a new, higher dose (15 cm) Exelon patch. It is hoped the medication will improve cognition in daily life for those with moderate to severe Alzheimer's disease-related dementia. The study will consist of 15 people, half of whom will receive 5 cm dosage and the other half 15 cm dosage.

22 December 2010: Study examines role a gene in the development of fronto-temporal lobar degeneration

A study has found that people with a mutated progranulin gene (which has been associated with dementia) who 'also inherited two copies of a specific variant of the TMEM106B gene are significantly less likely to develop fronto-temporal lobar degeneration (FTLD) or they have their disease onset delayed'. The researchers hope that by a getting a greater understanding of the TMEM106B gene that new ways of protecting against FTLD could be explored.

The study was led by Rosa Rademakers and colleagues from the Mayo Clinic, Florida, USA and published in the journal Neurology.

22 December 2010: Study suggests new method for detecting people at risk from dementia

A study suggests that by using spinal fluid testing alongside MRI scans may provide an early indication of a person's risk of developing Alzheimer's disease. Over 100 cognitively normal individuals were divided into two groups: a) those with high levels of cerebrospinal fluid (CSF) amyloid, and b) those with a low level of CSF amyloid. MRI scan measurements over 12 months were used to calculate the brain shrinkage rates. The researchers found that the brains shrank twice as quickly in those normal individuals who had low CSF levels of amyloid.

The study was led by Jonathan Schott from the Dementia Research Centre, UCL. It was part-funded by the Alzheimer Research Trust and published in the Annals of Neurology.

Rebecca Wood, Chief Executive of the Alzheimer's Research Trust, the leading UK dementia research charity, said, "We are hamstrung by our inability to accurately detect Alzheimer's, but these findings could prove to be pivotal. Spotting Alzheimer's early is essential to the global research effort to beat the disease. We know that treatments for many diseases can be more successful if given early and this is likely to be true for Alzheimer's. It will be crucial to keep following the study group to see how many develop Alzheimer's, and to expand the research to test the approach further."

31 December 2010: Study examines the relationship between dementia and depression



A study on over 350 people aged 85 years and older found that: 1) the prevalence of depression was significantly higher among people with dementia than without dementia, 2) a large proportion of people (with and without dementia)

were under-diagnosed for depression and untreated, and 3) many of the factors associated with depression among people without dementia were not associated with depression among those with dementia and this supported the theory that the spectrum of associated factors for depression in dementia seems to be different from that for depression in people without dementia.

The study was conducted by researchers from the Umeå University, Umeå, Sweden and published on line on the International Psychogeriatrics website.

31 December 2010: Study examines the use of hospice care for people with end stage dementia and the associated outcomes

A study on over three hundred people with advanced dementia into the use of hospice care for end stage dementia and the associated outcomes has found that "a minority of NH residents with advanced dementia received hospice care. Hospice recipients were more likely to received scheduled opioids for pain and symptomatic treatment for dyspnea and had fewer unmet needs at the end of life."

The study was conducted by Dan K. Kiely , Hebrew Senior Life, and 1 200 Center Street, Boston, MA, USA and colleagues and published in the Journal of the American Geriatrics Society.

1 January 2011: Study suggests that dementia in later life is an independent risk factor for death

A study which set out to compare the mortality rates of elderly people with dementia to those who don't have dementia found that 'dementia was associated with more than double the risk of mortality, but this increased risk did not reflect exacerbation by midlife socio-demographic and cardiovascular risk factors.' Researchers said that the findings suggest that the process of dementia itself or its consequences may go beyond well-established midlife risk factors for mortality.'

The research was conducted Michal Schnaider Beerl, Mount Sinai School of Medicine, USA together with Uri Goldbourt and published in the American Journal of Geriatric Psychiatry.

7 January 2011: Study identifies potential biomarker for Alzheimer's disease



A new study suggests that the blood may contain markers which can identify dementia before the symptoms of memory loss occur.

The researchers manufactured molecules in different shapes which were designed to react with antibodies and found that these molecules reacted with antibodies in the blood from people with Alzheimer's disease but there was no reaction with antibodies in the blood from people without Alzheimer's disease. Researchers have called for further investigations to be carried out to test these results.

Led by professor Thomas Kodadek from the Scripps Research Institute in Florida, USA, the study was published in the journal Cell.

10 January 2011: Study examines expenditure for nursing home residents with dementia

A US study found that a 'large proportion of Medicare (a social insurance program administered by the US government) expenditure for nursing home residents with advanced dementia is spent on aggressive treatments that may be avoidable and of limited clinical benefit'. The study also found, amongst other things, that acute costs were lower for those residents who had either a Do No Hospitalise (DNH) order, lived on special care dementia unit or did not have a feeding tube.

The Medicare expenditures were examined for 323 nursing home residents with advanced dementia and the study was part of the Choices, Attitudes, and Strategies for Care of Advanced Dementia (CASCADE) study. Conducted by the Institute for Aging Research, an affiliate of Harvard Medical School, the research was published in the Archives of Internal Medicine.

12 January 2011: Study identifies link between Alzheimer's disease and Down Syndrome

A study has revealed that the 'genetic mechanism which destroys brain cells is responsible for early development of Alzheimer's disease in people with Down Syndrome and for development of Alzheimer's disease in general population.' The researchers discovered that the excessive production the protein Regulator of Calcineurin 1 (RCAC1) results in a chain reaction which kills neurons in the hippocampus and cortex in people with Down Syndrome and Alzheimer's disease. The researchers called for further investigations.

The research, led by Dr Weihong Song, Canada Research Chair in Alzheimer's disease and professor of psychiatry at the University of British Columbia Faculty of Medicine was reported in the Journal of Biological Chemistry.

18 January 2011: Study examines the relationship between ADHD and the risk of later on set of dementia

A study on over 500 people (360 with dementia and 149 healthy controls) found a "higher risk of Lewy body dementia patients with preceding adult ADHD" (attention-deficit and hyperactivity disorder) and the researchers have called for additional investigations to be conducted.

The study was conducted by A Golimstok, Neurology Department, Hospital Italiano Buenos Aires, Argentina and colleagues and published in the European Journal of Neurology.

18 January 2011: Study examines the relationship between the ration of beta amyloid in plasma and cognitive decline

A study on over 3,000 older adults without dementia suggests that those participants 'who had a low ratio of beta-amyloid (42:40) in plasma showed faster cognitive decline in a 9-year study than did those with a higher ratio of the two beta-amyloid peptides. In addition the study revealed that the 'association between plasma beta-amyloid 42:40 ration and cognitive decline was strongest among people with a low cognitive reserve'. The researchers hope that this finding may help to identify those at risk of dementia.

The research was carried out by Dr Kristine Yaffe, University of California, San Francisco and colleagues. It received support by the National Institute of Aging and reported in the Journal of the American Medical Association (JAMA).

20 January 2011: Beta-amyloid imaging agent fails to secure US government agency approval

The Peripheral and Central nervous System Drugs Advisory Committee of the US Food and Drug Administration (FDA) voted against (13:3) the immediate approval of the beta-amyloid imaging agent, florbetapir. Beta-amyloid plaques are associated with Alzheimer's disease. However, the Advisory Committee voted to approve florbetapir at a later date on the proviso that the company (Radiopharmaceuticals Inc) developing the compound agreed to certain conditions.

21 January 2011: Study examines benefits of shunt insertion for people with dementia

A study on 14 people over a period of three and half years suggests that mental functions and ability to walk improved in people with dementia after the insertion of a shunt (a narrow plastic tube which is surgically inserted into the brain, enabling excessive fluid to be drained). All participants had a shunt inserted, half of whom were given an open shunt from the start and the other half a closed shunt. The latter group only showed improvements after three months, when the shunt was opened. The researchers have called for further studies to be conducted.

Researchers from the Sahlgrenska Academy and Sahlgrenska University Hospital, Sweden, carried out the study, which was reported in the American Journal of Neurosurgery.

25 January 2011: Study examines effect of fatty acids on mild cognitive impairment

A study has found that the prevalence of mild cognitive impairment decreased with an increase in the consumption of monounsaturated (eg. Found in olive oil) and polyunsaturated fatty acids (eg found in omega 3).

The research was conducted as part of the Mayo Clinic Study of Aging (USA) and published in the Journal of Alzheimer's disease.

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

26 January 2011: Rat study examines the effect of protein on memory

A study on rats suggests that memory could be enhanced injecting into the hippocampus the protein insulin-like growth factor II (IGF-II).

The study was led by Cristina Alberini, a neuroscientist at the Mount Sinai School of Medicine in New York, USA and published on-line in the journal Nature.

27 January 2011: Study examines the effect of cognitive impairment on the accuracy of instructions and understanding in the Emergency Department

A study conducted at an academic emergency department (ED) on over 200 patients found that people with delirium superimposed on dementia (DSD) had 'lower odds of agreeing with their surrogates with regard to why they were in the ED' compared with patients without cognitive impairment. People with DSD also had 'significantly lower odds of comprehending their discharge diagnosis, return to the ED instructions and follow-up instructions.



Carried out by Jin H Jan, Department of Emergency Medicine, Vanderbilt University Medical Center, Nashville, USA and colleagues, the study was published in the journal *Annals of Emergency Medicine*.

Living with dementia

5 November 2010: Honorary Degree awarded to Peter Ashley in recognition of services to dementia



In November 2010, the University of Worcester, UK, presented ex-business man, Peter Ashley with an Honorary Masters degree in recognition of Mr Ashley's services in the field of dementia. Peter Ashley, an Alzheimer's Society ambassador, was diagnosed with Lewy body dementia in 2001 and has since worked tirelessly to inform and raise awareness of the disease, taking on many different roles and speaking at a number of Alzheimer Europe conferences.

Professor Dawn Brooker, Director of the University of Worcester' Association for Dementia Studies, said: "Peter is a truly remarkable man and has pioneered the movement in Europe for people living with dementia to speak out on their own behalf."

1 January 2011: James McKillop to become a Member of the British Empire (MBE)



James McKillop, who has dementia, has been awarded an MBE for voluntary service to people with dementia in Scotland.

James McKillop is a former chairperson and founding member of the Scottish Dementia Working Group (SDWG) which campaigns to improve services for people with dementia and to improve attitudes towards people with dementia. He has also raised awareness of the disease by participating in various European and International conferences on dementia, including Alzheimer Europe's recent 20th Annual conference in Luxembourg.

A spokesperson for Alzheimer Scotland said, 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."

The award will be presented in the summer by a member of the royal family.

Dementia in society

1 December 2010: 'Dementia and sight loss conference' takes place

The Dementia and sight loss conference took place in London on 1 December with the aim of improving awareness, policy and practice for people with

dementia and sight loss (in the UK 2% of people over 75 will have both conditions). The Chairperson for the Conference, Baroness Sally Greengross, highlighted the fact that people with both conditions 'face double the burden when performing simple tasks like going to the toilet or moving around, and with perception.'

The conference is one of the initiatives of the Dementia and Sight Loss Interest Group is an alliance of charities (which includes the Alzheimer's Society).

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.

16 December 2010: Interim report published into the care of people with dementia in hospital in England and Wales

The National Audit of Dementia interim report was published on 16 December. Some key findings include the fact that:

- 95% of hospitals do not have mandatory training in dementia awareness for all staff whose work is likely to bring them into contact with patients with dementia.
- About one-third of patients did not have a nutritional assessment recorded during their admission.
- Fewer than one-half of patients received a formal mental status test upon admission to hospital.
- One-third of patients referred to in-hospital psychiatry liaison services not seen within 96 hours.
- Fewer than one in ten hospital executive boards regularly review readmission data for patients with dementia and only one in five regularly review information on delayed patient transfers.

The full report is to be published in December 2011.

31 January 2011: Book published on dementia aimed at children



'Grandpa remembers love' is an illustrated story written for children who may have a relative with dementia. Elaine and Teddy, the grandchildren in the story, learn to focus on what their grandpa (who has dementia) can do, rather than what he is unable to do. The book also has a resource section which includes:

- Tips for talking to someone who has memory loss
- Memory/activity scale for children

- List of activity and story books
- List of website for children and teenagers.

Written by Theresa Matocha and illustrated by Lilli Stein, *Grandpa remembers love* (ISBN: 9781449086954) is available from Authorhouse publications.

Job Opportunities

21 January 2011: PhD-level positions in the University of Eastern Finland

The following vacancies have been announced by the University of Eastern Finland:

3 PhD-level positions (for 36 months, salary level 6/4) are available in the Translational Identification of Biomarkers and Therapeutic Strategies for Neurodegenerative Diseases Consortium in the University of Eastern Finland (UEF):

- Position 1: Data mining in clinical, biomarker and imaging data. A post-doctoral researcher with background in, e.g., biology, medicine, information technology, or physics and knowledge in managing of large data sets will be hired for setting up a platform to manage and analyse data. Applicant should have a PhD degree in Biomedical Sciences or equivalent. Contact person: Professor Hilikka Soininen: E-mail hilikka.soininen@uef.fi.
- Position 2: Functional genetics, which integrates genetic, epigenetic, and bioinformatics for identification of disease-associating risk genes and molecular pathways. A post-doctoral researcher with knowledge on genetic, epigenetic, molecular, and cellular studies will be hired to set-up and coordinate the project. Special emphasis is laid on epigenetic expertise. Applicant should have a PhD degree in Biomedical Sciences or equivalent. Contact

person: Research Director Mikko Hiltunen, E-mail: mikko.hiltunen@uef.fi.

- Position 3: Validation of disease mechanisms and biomarkers in clinically relevant animal models. A post-doctoral researcher will work in close collaboration with research groups studying neurobiological mechanisms of major neurological diseases (Alzheimer's disease, epilepsy, stroke) in a multidisciplinary research environment. Expertise in patch-clamp or intracellular recordings from brain slices is required. Additional experience in calcium imaging will be an advantage. Contact person: Professor Heikki Tanila: E-mail heikki.tanila@uef.fi.

In memoriam

It is with great sadness that we report that Jim Jackson OBE, former Chief Executive of Alzheimer Scotland, passed away on 12 January 2011. Mr



Jackson was the first Chief Executive of Alzheimer Scotland (1994-2008) and following his retirement he became a volunteer research adviser for the organisation. He was also very active at

Alzheimer Europe conferences and projects, being a passionate supporter in the European and International dementia movement.

Henry Simmons, Chief Executive of Alzheimer Scotland said, "It is impossible to sum up in just a few words the contribution made by Jim Jackson to improving and developing dementia care. He will be very much missed by all of us at Alzheimer Scotland and by the many other people who were privileged to work with him. Our deepest sympathies go to his wife, Jennie, and to the rest of his family."

AE Calendar 2011

The following meetings will be attended by representatives of Alzheimer Europe

Date	Meeting	AE Representative
1 February	Meeting with the Polish Alzheimer's Association for the organisation of the 2011 AE Conference in Warsaw (Warsaw, Poland)	Jean
3-4 February	International Pharmaco-economic Conference on AD and presentation of the findings of the EuroCoDe project (London, UK)	Jean
18 February	Meeting with Novartis (Basel, Switzerland)	Jean
3-4 March	Steering Committee of PharmaCog project (Paris, France)	Jean
9 March	Innovative Medicines Initiative Workshop at AD/PD Conference (Barcelona, Spain)	Jean
13-14 March	AE Board (Brussels, Belgium)	AE Board and staff
14 March	AE Public Affairs Working Group (Brussels, Belgium)	AE Member representatives and staff
15 March	European Parliament lunch debate (Brussels, Belgium)	AE Board and staff
25-29 March	Alzheimer's Disease International Conference (Toronto, Canada)	Heike and Jean

Call for abstracts

The call for abstracts for the Alzheimer Europe Conference is now online. Abstracts can be submitted via the Alzheimer Europe website on the following topics:

- Avoiding mistakes in care
- Carers' stories
- Day care centres – Innovative solutions
- Effective communication
- Family care versus institutional care
- Fundraising – Success stories
- How to recognise and cope with psychopathological symptoms in Alzheimer's disease
- Legal systems and regulations – a review
- Occupational therapy
- People with dementia speak up
- Policy initiatives and dementia strategies
- Preventing isolation and loneliness of people with dementia and their carers
- Problems and dilemmas in end-of-life dementia
- Raising awareness – successful campaigns
- Sexuality and relationships
- Support groups for carers

Deadline: 30 April 2011



Future Conferences

Date	Meeting	Place
16-20 February 2011	The 7th Pan – Hellenic Conference of Alzheimer Disease and Related Disorders, http://www.alzheimer-hellas.gr	Thessaloniki, Greece
19-20 February 2011	2011 National Alzheimer Conference: New insights into dementia, www.alzcongres.ro	Bucharest, Romania
24 February 2011	Remember me: Dying of dementia in a multiethnic society, www.careconferences.co.uk	London, UK
9-13 March 2011	The 10th International Conference on Alzheimer's & Parkinson's Diseases (AD/PD 2011), www.kenes.com/adpd	Barcelona, Spain
17-18 March 2011	Colloque Le défi de l'intervention auprès des personnes atteintes de la maladie d'Alzheimer, http://www.iugm.qc.ca/iugm/diffusion-de-l-expertise/colloques-et-symposiums	Montréal, Canada
26-29 March 2011	26th International Conference of Alzheimer's Disease International, http://www.adi2011.org/default.aspx?PageID=Home	Toronto Canada
13-14 April 2011	The 7th Annual World Health Care Congress—Europe, http://www.worldcongress.com/events/HR11015/	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", www.iaggbologna2011.com	Bologna, Italy
9-12 May 2012	12th International Stockholm/Springfield Symposium on Advances in Alzheimer Therapy, www.ad-springfield.com	Stockholm, Sweden
20-23 October 2011	7th International Congress on vascular dementia: Facing the challenges of dementia, http://www.cts.vresp.com/c/?KenesInternationalVA/e06f64a56d/5ba2f9d3c6/0d0ca1445f/ref5=db1	Riga, Latvia



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