



NEWSLETTER

July – August 2009

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Editorial



Welcome!
Although this newsletter covers the holiday

season, you will see that

the months of July and August were full of important initiatives and activities for people with dementia and their carers.

Following the European Parliament elections, we are delighted to be able to welcome back many MEPs who had supported our cause by joining the European Alzheimer's Alliance Members. We look forward to collaborating with them again, as well as with new MEPs.

The findings from the prevalence workgroup of our European Collaboration on Dementia (EuroCoDe) project were published during the 2009 International Conference on Alzheimer's Disease in Vienna in July. There was significant media interest in these new figures which have already been adopted by the European Commission for their own calculations of the number of people with dementia in the European Union. These findings as well as other research news from the ICAD conference are covered in great detail in this newsletter.

July also saw the transfer of the European Presidency

from the Czech Republic to Sweden. We are pleased to note that the new Presidency has highlighted in its priorities the need to address opportunities for healthy and dignified ageing for older people in the EU.

Perhaps the most exciting news we bring in this newsletter is the decision by the European Commission to adopt proposals to tackle Alzheimer's disease and other dementias. This news also gives a clear indication that our campaign to make dementia a European priority continues to bear fruit.

In addition, Wales is developing a national dementia action plan and is currently holding a consultation on its plans.

During the summer, the Alzheimer Europe staff has also been busy with the new website of our organisation which we are hoping to launch in the coming month. We really hope that our new website will provide all dementia-related information in an easier to navigate way.

At the time of sending out this newsletter, I am aware that our members will be busy preparing for World Alzheimer's Day at the end of September. I would like to take this opportunity to wish all of you a successful campaign and look forward to reporting your activities in our next newsletter.

Jean Georges
Executive Director

European Alzheimer's Alliance

June 2009: MEPs who have supported the work of Alzheimer Europe reelected



We are delighted to welcome back the re-elected MEPs below who supported our work in the last Parliamentary session. We look forward to our continued collaboration with them, as well as working with the newly-elected MEPs for the 2009-2014 European Parliamentary session.

Belgium:

Brepoels Frieda (Greens/EFA), Staes Bart (Greens-EFA), Sterckx Dirk (ALDE)

Cyprus:

Triantaphyllides Kyriacos (GUE-NGL)

Czech Republic:

Cabnoch Milan (ECR), Kohlíček Jaromír (GUE/NGL), Roithová Zuzana (EPP), Vlasák Oldřich (ECR)

Denmark:

Jensen Anne E. (ALDE), Schaldemose Christel (S&D)

Finland:

Pietikäinen Sirpa (EPP)

France

Audy Jean-Pierre (EPP), Daul Joseph (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Grossetête Françoise (EPP), Henin Jacky (GUE/NGL), Lamassoure Alain (EPP), Morin Chartier Elisabeth (EPP)

Germany

Niebler Angelika (EPP), Ulmer Thomas (EPP), Weisgerber Anja (EPP)

Greece

Koppa Maria Eleni (S&D), Kratsa-Tsagaropoulou Rodi (EPP)

Hungary

Surján László (EPP)

Ireland

Aylward Liam (ALDE), Crowley Brian (ALDE), McGuinness Mairead (EPP), Mitchell Gay (EPP)

Italy

Panzeri Pier Antonio (S&D), Toia Patrizia (S&D)

Luxembourg

Goebbels Robert (S&D), Lulling Astrid (EPP)

Netherlands

De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP)

Portugal

Coelho Carlos (EPP), Estrela Edite (S&D), Figueiredo Ilda (GUE/NGL), Gomes Ana Maria (S&D)

Romania

Winkler Iuliu (EPP)

Slovakia

Mikolasik Miroslav (EPP), Zaborska Anna (EPP)

United Kingdom

Hall Fiona (ALDE), McAvan Linda (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Stihler Catherine (S&D), Watson Graham (ALDE), Willmott Glenis (S&D).

Alzheimer Europe

13 July 2009: Numbers of people with dementia in Europe higher than previously reported

According to research reported at the Alzheimer's Association 2009 International Conference on Alzheimer's Disease (ICAD 2009) in Vienna, the number of people with Alzheimer's disease and dementia in Europe may be higher than previously reported since both the number of new cases and the total number of people affected continue to rise among the very oldest segments of the population.

The goal of the EuroCoDe (European Collaboration on Dementia) project, financed by the European Commission and coordinated by Alzheimer Europe, was to determine the prevalence of dementia in Europe based on up-to-date research findings. Dr Emma Reynish, a consultant geriatrician from the Victoria Hospital, Kirkcaldy, United Kingdom and her EuroCoDe colleagues conducted an extensive literature search using Cochrane review methodologies and compiled a database of all European epidemiological studies in the field up to the present date. 194 articles were identified by the review and 26 studies met inclusion criteria to participate with raw data in the collaborative analysis.

According to Dr Emma Reynish, while dementia prevalence rates for all men and for women up to age 85 largely confirmed previous findings, age-specific prevalence rates were higher than previously documented in the female "oldest old" age groups, rising to over 50% in those over 95 years.

“Our key findings confirmed that age remains as the single most important risk factor for dementia,” Reynish said. “Nevertheless, due to the lack of data in the oldest old in previous prevalence studies, the prevalence of dementia of women over the age of 85 had been underreported.”

Jean Georges, Executive Director of Alzheimer Europe welcomed the findings: “These results are important for two reasons. Firstly, they confirm what we already knew about the prevalence of dementia in Europe for people up to the age of 85. At the same time, the reported prevalence in the oldest old shows that we have previously underreported the total number of people with dementia in Europe. In the European Union alone, we now estimate the total number of people with dementia to be 7.3 million, rather than 6.5 million. This poses important challenges for all European health care systems, since the oldest old is one of the fastest growing sectors of our European societies.”

The prevalence of dementia in Europe:

The findings of the EuroCoDe working group on prevalence found the following age-related prevalence rates for **men**:

| Age range | EuroCoDe | EURODEM |
|-----------|----------|---------|
| 30-59 | | 0.16% |
| 60-64 | 0.2% | 1.58% |
| 65-69 | 1.8% | 2.17% |
| 70-74 | 3.2% | 4.61% |
| 75-79 | 7.0% | 5.04% |
| 80-84 | 14.5% | 12.12% |
| 85-89 | 20.9% | 18.45% |
| 90-94 | 29.2% | 32.1% |
| >95 | 32.4% | 31.58% |

The findings of the EuroCoDe working group on prevalence found the following age-related prevalence rates for **women**:

| Age range | EuroCoDe | EURODEM |
|-----------|----------|---------|
| 30-59 | | 0.09% |
| 60-64 | 0.9% | 0.47% |
| 65-69 | 1.4% | 1.10% |
| 70-74 | 3.8% | 3.86% |
| 75-79 | 7.6% | 6.67% |
| 80-84 | 16.4% | 13.50% |
| 85-89 | 28.5% | 22.76% |
| 90-94 | 44.4% | 32.25% |
| >95 | 48.8% | 36.00% |

Alzheimer Europe calculated the numbers of people with dementia in Europe based on the EuroCoDe figures and UN statistics:

| | EuroCoDe (2009) | EURODEM (1991) |
|-----------------------------|------------------|------------------|
| Austria | 126,296 | 111,294 |
| Belgium | 163,511 | 144,594 |
| Bulgaria | 99,291 | 90,584 |
| Cyprus | 8,024 | 7,285 |
| Czech Republic | 123,194 | 111,141 |
| Denmark | 78,744 | 70,108 |
| Estonia | 17,825 | 15,831 |
| Finland | 77,516 | 68,738 |
| France | 974,391 | 854,219 |
| Germany | 1,368,330 | 1,214,085 |
| Greece | 159,275 | 144,745 |
| Hungary | 131,995 | 118,169 |
| Ireland | 37,417 | 33,719 |
| Italy | 1,012,819 | 896,688 |
| Latvia | 29,846 | 26,583 |
| Lithuania | 40,619 | 36,423 |
| Luxembourg | 5,814 | 5,178 |
| Malta | 4,524 | 4,122 |
| Netherlands | 210,666 | 187,912 |
| Poland | 391,344 | 354,160 |
| Portugal | 153,386 | 137,403 |
| Romania | 227,036 | 207,789 |
| Slovakia | 51,622 | 46,607 |
| Slovenia | 25,380 | 22,822 |
| Spain | 690,992 | 611,734 |
| Sweden | 161,327 | 141,948 |
| UK | 931,134 | 822,679 |
| Total European Union | 7,299,318 | 6,486,560 |
| Iceland | 3,319 | 2,967 |
| Norway | 71,447 | 62,679 |
| Switzerland | 125,614 | 110,654 |
| Turkey | 253,367 | 242,771 |
| | 7,753,065 | 6,905,631 |

The working group on the prevalence of dementia was comprised of:

- Reynish Emma, Centre Hospitalier Universitaire, Toulouse, France/Victoria Hospital, Kirkcaldy, United Kingdom
- Bickel Horst, Technische Universität München, Munich, Germany
- Fratiglioni Laura, Caracciolo Barbara, Von Strauss Eva, Karolinska Institutet, Stockholm, Sweden
- Georges Jean, Alzheimer Europe, Luxembourg, Luxembourg
- Kiejna Andrzej, Frydecka Dorota, Wrocław Medical University, Wrocław, Poland
- Prince Martin, Institute of Psychiatry, London, United Kingdom

Alzheimer Europe Networking

From 2-3 July (Toulouse, France) Dianne participated in **European summer school on health law and bioethics** held at the University of Toulouse.

From 5-7 July (Paris, France), Jean attended the **Conference of the International Association of Gerontology** and presented the findings of the carers' survey at a Lundbeck symposium.

On 8 July (Paris, France), Dianne attended the **INTERDEM** meeting where future project possibilities were discussed.

On 9 July (Luxembourg, Luxembourg), Jean met with Nick Fahy and Antoni Montserrat from the **European Commission** to present the final results of the “European Collaboration on Dementia – EuroCoDe” project.

On 18 August (Brussels, Belgium), Annette and Jean met with Andrew Ketteringham, Director of External Affairs of the **Alzheimer’s Society** for an exchange on possible areas of collaboration in European affairs.

On 20 August (London, United Kingdom), Jean met with Ruth Bosworth, Associate Director, Alliance Development of **Pfizer** for an exchange on the initiatives of the two organisations in the dementia field.

European developments

June 2009: European Commission calls for proposals for pilot projects on preventing elderly abuse

The European Commission’s call for proposals (VP/2009/014) will offer grant funding to two applicants which may involve not-for-profit organisations including public authorities, universities and research centres and civil society/stakeholder organisations.

One grant will be awarded for each of the following two types of project:

(1) Monitoring elder abuse across the European Union through public health and long-term care systems.

(2) Mapping existing policy approaches and policy frameworks in the European Union, to identify good practices and present a reference framework comprising measures and instruments needed for an effective prevention of elder abuse.

The deadline for the submission of applications is 27 September 2009.

We provide full references to articles on our website

www.alzheimer-europe.org

23 June 2009: European Medicines Agency publishes report on the information on the benefit and risk of medicines

Following a survey to find out ways in which the European Medicines Agency (EMA) could improve the information it provides on the benefits and risks of medicines, a report entitled “Information on benefit-risk of medicines: patients’, consumers’ and healthcare professionals’ expectations” has been published by the EMA.

The survey included contributions from eleven patients’ and consumers’ organisations, twelve healthcare professionals’ organisations in the EU and representatives of the EMA. The survey showed:

1. Patients’ and healthcare professionals’ expectations to be very similar
2. that it is important to distinguish benefit-risk at both an individual and population level
3. a necessity to communicate high information on medicines
4. that the “full picture” for all individual situations is not always available
5. the information on medicines should
 - a. always communicate benefit and risk together
 - b. give clear information to help choose the most appropriate treatment
 - c. give a clear description of benefits and risk, both qualitative and quantitative
 - d. describe those factors which may influence a benefit or a risk in an individual
6. that we do not always have the full picture for all individual situations and new technologies may help to give an improved prediction on benefit-risk for individuals
7. A need to facilitate access to information

The report lists the following proposals:

1. Further explore how to optimise content and access to information on benefits and risk in summary of product characteristics, package leaflet and public assessment report
2. Foster dissemination of information from regulators
3. Prepare recommendations on the quantitative descriptions of benefits and risks
4. Prepare recommendations on risk communication in areas of uncertainty
5. Further explore how best to communicate on safety issues and
6. Continue interaction between the three parties

1 July 2009: Swedish Presidency of the EU commences

After the Czech Republic, Sweden is now holding the Presidency of the EU.

The Swedish Presidency's vision is a strong and effective Europe where focus is on the common responsibility to meet the challenges of today and tomorrow, including preparedness to manage crises. The Swedish priorities are based on Presidency trio cooperation with France and the Czech Republic, as well as the 18-month programme approved in June 2008.



The Presidency major priorities will be to address the economy challenges, employment and climate. At the same time, the EU will strengthen its competitiveness, create new jobs and contribute to a better environment. The Presidency will develop cooperation between different policy areas so that positive economic growth can be combined with reduced burden on the climate and environment.

Among other things, the Presidency will aim to increase the opportunities for healthy and dignified ageing for older people in the EU. The focus will be placed on the older person and better cooperation between those working with health and social issues. The Presidency wants to find coordination and cooperation solutions and highlight good practices in different EU Member States.

Other priorities will include the Stockholm Programme that will aim to safeguard the security and rights of individuals (free movement of people, combat crime, asylum and migration).

The Presidency will set up a EU Strategy for the Baltic Sea to ensure a cleaner marine environment and a more competitive region.

The Presidency will continue to work to strengthen the EU as a global actor with a clear agenda for peace, development, democracy and human rights.

The Presidency work will be affected by a new European Parliament, a new Commission and the ratification of the Lisbon Treaty. The Presidency intends to act so that the Treaty is launched in a positive spirit.

On the agenda : Healthy and Dignified Ageing Conference, Solna/Stockholm, 15–16 September 2009.

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

22 July 2009: European Commission adopts proposals to tackle Alzheimer's disease, dementias and other neurodegenerative conditions

Two initiatives (i) a Communication from the Commission (COM(2009) 380/4) to the European Parliament and the Council on European initiative on Alzheimer's disease and other dementias, and (ii) a proposal for a Council Recommendation on measures to combat neurodegenerative diseases, in particular Alzheimer's, through joint programming of research activities, have been adopted by the European Commission.

The Commission proposes four main areas of action:

- Acting early to diagnose dementia and reduce the risk of dementia in the first place;
- Improving research coordination between EU countries;
- Sharing of best practices and
- Providing a forum to reflect on rights, autonomy and dignity of patients.

The EU Health Commissioner, Androulla Vassiliou, said "Losing mental capacity to dementia is not just a normal part of getting older. As the European population ages, we must work together to better understand and prevent these conditions. We must show our solidarity to people with dementia by sharing best practice in caring for them and respecting their rights and dignity."



The Recommendation on Joint programming of research invites Member States to pool their resources and better coordinate their research efforts in the field of neurodegenerative diseases, in particular Alzheimer's disease. EU Science and Research Commissioner Janez Potočnik said "We will see a major step ahead if Member States now start coordinating their national programmes around a common agenda... This is an opportunity for European science and a response to a challenge of our modern society."

Jean Georges, Executive Director of Alzheimer Europe, welcomed the adoption of these initiatives stating that “This is exactly the kind of result we had hoped for. It indicates that our campaign to make dementia a European priority is bearing fruit and will lead to concrete results in the years to come.”

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

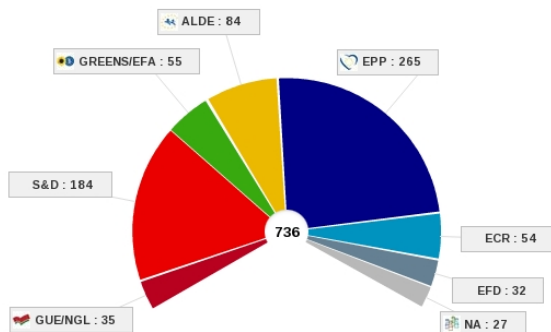
Special report - A look at the new European Parliament (2009-2014)

Between 4 and 7 June 2009, 375 million EU citizens were invited to elect their Members of the European Parliament (MEP). This time, only 736 MEPs were elected. The MEPs have now elected their President, Vice-Presidents and Quaestors. The 20 Committees have also decided on their Chairs and Vice-Chairs. The European Parliament resumed work on 24 August, following the summer break.

The political groups

The EPP/ED (European People’s Party/European Democrats) remains the major group in the EP, followed by the Progressive Alliance of Socialists and Democrats (former Party of the European Socialists). The ALDE (Liberal) group remains the third group while the Green Group has gained a position, moving from the 5th place to the 4th place. A new group has emerged, the European Conservatives and Reformists Group.

Repartition of seats in the EP



EPP : Group of the European People's Party (Christian Democrats)

S&D : Group of the Progressive Alliance of Socialists and Democrats in the European Parliament

ALDE : Group of the Alliance of Liberals and Democrats for Europe

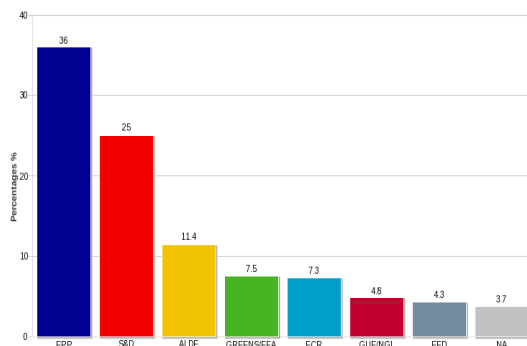
GREENS/ EFA : Group of the Greens/European Free Alliance

ECR : European Conservatives and Reformists Group

GUE/ NGL : Confederal Group of the European United Left - Nordic Green Left

EFD : Europe of Freedom and Democracy Group

NA : Non-attached



Although the EPP is the largest group, it will have to secure the support of other political groups to reach qualified majority. Equally, it will be difficult for the Socialist Group to rally other groups to reach qualified majority.

Political group leaders

| | | |
|------------------------------------|--|------------|
| Joseph Daul | European People's Party - EPP | France |
| Martin Schulz | Progressive Alliance of Socialists and Democrats - S&D | Germany |
| Guy Verhofstadt | Alliance of Liberals and Democrats for Europe - ALDE | Belgium |
| Rebecca Harms & Daniel Cohn-Bendit | Greens/ European Free Alliance – Greens/EFA | Germany |
| Michał Kamiński | European Conservatives and Reformists Group - ECR | Poland |
| Lothar Bisky | Confederal Group of the European United Left - Nordic Green Left – GUE/NLG | Germany |
| Nigel Farage & Enrico Speroni | Europe of Freedom and Democracy Group - EFD | UK & Italy |

EP President and Vice-Presidents

Jerzy Buzek (EPP, Poland) was elected President of the EP at the sitting on 14 July. He will preside over the EP for two and a half years, when an MEP from the S&D group takes over for the rest of the mandate.

The Vice-Presidents to be elected are : Giovanni Pittella (S&D, Italy), Rodi Kratsa-Tsagaropoulou (EPP, Greece), Stavros Lambridinis (S&R, Greece), Miguel Angel Martinez Martinez (S&D, Spain), Alejo Vidal-Quadras (EPP, Spain), Dagmar Roth-Behrendt (S&D, Germany), Libor Roucek (S&D, Czech Republic), Isabelle Durant (EFA/Greens, Belgium), Roberta Angelini (EPP, Italy), Dianna Wallis (ALDE, UK), Pal Schmitt (EPP, Hungary), Edward Millan-Scott (ECR, UK), Rainer Wieland (EPP, Germany) and Silvana Koch-Mehrin (ALDE, Germany).

Parliamentary Committees of interest to Alzheimer Europe

| Committee | Chair | Vice-Chairs |
|-----------------------------|--------------------------------------|---|
| Environment and Health | Jo Leinen (S&D, UK) | Corinne Lepage (ALDE, France), Karl Schlyter (EFA/Greens, Sweden), Boguslaw Sonik (EPP, Poland), Dan Jorgensen (S&D, Denmark) |
| Employment & Social Affairs | Pervenche Beres (S&D, France) | Liz Lynne (ALDE, UK), Ilda Figueiredo (GUE/NLG, Portugal), Elisabeth Schroedter (EFA/Greens, Germany), Thomas Mann (EPP, Germany) |
| Industry and Research | Herbert Reul (EPP, Germany) | Patrizia Toia (S&D, Italy), Jens Rohde (ALDE, Denmark), Anni Podimata (S&D, Greece), vžen Tosenovsky (ECR, Czech Republic) |
| Women's Committee | Eva-Britt Svensson (GUE/NLG, Sweden) | Livia Jokora (EPP, Hungary), Edite Estrella (S&D, Portugal), Barbara Matera (EPP, Italy) |
| Budget | Alain Lamassoure (EPP-France) | Jutta Haug (S&D, Germany), Alexander Alvaro (ALDE, Germany), Jean-Luc Dehaene (EPP, Belgium), Ivaylo Kalfin (S&D, Bulgaria) |
| Legal Affairs | Klaus-Heiner Lehne (EPP, Germany) | Luigi Berlinguer (S&D, Italy), Evelyne Regner (S&D, Austria), Sebastian Bodu (EPP, Romania) |

Policy Watch

15 June 2009: Consultation period open for the National Dementia Action Plan for Wales

The National Dementia Action Plan for Wales is now open for consultation until 11 September 2009. The Plan has been developed by a group of experts, led by Ian Thomas, the Director of the Alzheimer's Society in Wales. It centres around four levels of action (Strengthening individuals, strengthening communities, improving infrastructure and access to services for all, and, lastly, making structural changes to economic, cultural and environmental conditions) and has 21 objectives, all of which aim at improving the lives for people living with dementia.

9 July 2009: "Dementia Advisors" start work in England

Following the launch of the English National Dementia Strategy in February, the role of Dementia Advisor has been created. These Advisors will "act as a guide to help people with dementia and their families navigate the care and support system throughout their illness. They will provide easy access to care, support and advice." Initially 22 locations have been selected to have a dementia adviser but Phil Hope, the Care Services Minister, said "I want to see dementia advisors start taking up post all around the country. They will be crucial in making sure people with dementia and their families get the help and support they need."

14 July 2009: The UK Government launches "big care debate"

The UK Government has published for consultation a Green Paper entitled "Shaping the Future of Care Together". The Paper outlines proposals for changing the current system of social care in England and has a strong emphasis on older people and people with dementia. In order to create a system that is "fair, simple, delivers personalised care and is affordable to everyone, the Government proposes the creation of a National Care Service with a universal minimum entitled to care as well as a national assessment of care needs programme.

Three funding models are mooted and open to consultation:

1. Partnership, whereby the state would pay up to a third of the care costs of any individual, ensuring that everyone receives some free support
2. Insurance, whereby the state would pay for a proportion of the care costs of any individual, and

3. Comprehensive, whereby everyone over retirement age would be required to pay into an insurance scheme and all care would be free once this requirement is met.

The consultation period is open until 13 November 2009.

21 July 2009: Over 30 scientists back call for a three-fold increase in funding for research in the UK, claiming that the "key weakness is lack of funding, not lack of talent"

An initiative from the Government's National Dementia Strategy, a government-hosted summit was held at the Royal Society on 21 July which examined "research into cause, cure and care, highlighting gaps in knowledge and new opportunities for the future".

Over 30 scientists from the UK took the opportunity to sign an open letter in the hope that they would end "years of underfunding" for research into dementia. It read:

"Today (21 July) the government will hold a ministerial dementia research summit at the Royal Society. After years of under-funding, it is encouraging that dementia research is receiving serious attention.

"Within a generation, 1.4 million people in the UK will live with dementia, costing our economy £50 billion per year.

"Yet for every pound spent on dementia care, a fraction of a penny is spent on research into defeating the condition.

"Our key weakness is lack of funding, not lack of talent.

"The Government must use this summit to initiate a national dementia research strategy. Most importantly, it must commit to tripling its annual support for dementia research to £96 million within five years.

"If the government squanders this opportunity, we will all pay the price."

29 July 2009: US Proposal to create an Office of the National Alzheimer's Project in the White House

In order to "meet the needs of the growing number of Alzheimer's patients", two U.S. senators (Mel Martinez and Evan Bayh) introduced a proposal to create an Office of the National Alzheimer's Project in the White House. The aim of this would be to coordinate "all research, clinical care and service toward the prevention, care and cure of Alzheimer's. This office will produce a national strategic plan to help assure that the millions of Americans

who now have Alzheimer's and the millions of potentially at-risk Americans will have a coordinated effort to target the 6th leading cause of death in the United States."

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

Members' News

28 June 2009: Chairperson of the German Alzheimer Association participates in televised debate on Alzheimer's disease

Heike von Lützu-Hohlbein, Chairperson of the German Alzheimer Association (Deutsche Alzheimer Gesellschaft e.V.) and Treasurer of Alzheimer Europe, took part in a one-hour televised discussion entitled "Campaign against forgetfulness – Alzheimer's Disease" (Kampf gegen das Vergessen – Volkskrankheit Alzheimer). Some 200 guests were invited, consisting of people with an interest in dementia such as researchers, pharmaceutical industry representatives, politicians and advocates of people with dementia and their carers. In addition to Ms von Lützu-Hohlbein, the panel included Prof. Christian Haas, researcher, Dr Karl-Theodor Schröder, State Secretary of the Ministry of Health and Dr Martin Zügel, Chief Executive of Merz Pharmaceuticals.



The debate was moderated by Nina Ruge and aired by the channel PHOENIX as part of its series "Scientific Forum Petersberg" (Wissenschafts FORUM Petersberg).



July 2009: The Alzheimer Society of Ireland opens a new Respite Centre

The Alzheimer Society of Ireland (ASI) has opened its new short term respite centre in its new flagship facility - The Orchard Centre - in Temple Road, Blackrock, Co. Dublin. Situated within a walled orchard and garden, the integrated dementia-specific Orchard Centre is built on land kindly donated to ASI by The Daughters of Charity and comprises an 11 bed National Respite Centre, a 24 place Day Care Centre for South Dublin, the Alzheimer Society's National



Offices and the Alzheimer National Training Helpline.

Opened on a phased basis since October 2008, the centre currently provides day care service to 24 clients Monday to Friday and overnight respite to six clients, four nights per week. At full capacity, The Orchard Centre will operate 24 hours a day, seven days a week and will be able to accommodate up to 6,800 day care places and 3,600 respite stays per year while at the same time providing carers and families the opportunity to have a much needed break.

The Orchard Centre provides a specifically designed and appropriate care environment for those with Alzheimer's disease or a related dementia. "The design of the building allows clients the freedom to walk around – it comprises an airy setting and a specially designed enclosed garden," said Maurice O'Connell, Chief Executive of the ASI. "There is a very soothing and calm atmosphere for clients and one in which family members can have every confidence that the best possible care is being provided to their loved one," he added.



The Orchard Centre is a €5.5 million project which was funded by a €2.2 million grant from the Dormant Accounts Fund with contributions of a further €2 million from the Royal City of Dublin Hospital Trust and the Health Service Executive (HSE). The Alzheimer Society of Ireland has raised more than €1.1 million in charitable donations.

The Orchard Centre has three main functions: to provide a state-of-the-art Day Care and Respite Care facility, to provide the Alzheimer National Helpline to provide information and support to people concerned about or living with dementia and to provide national administrative office space for the staff of the Alzheimer Society of Ireland.



4 July 2009: The first stone of Alzheimer Portugal's nursing home laid

Alzheimer Portugal is very pleased to announce that the first stone of the "Alapraia Project", a nursing home aimed specifically at people with dementia, was laid on July 4th.



With this new Project, Alzheimer Portugal wants to contribute to

improve the quality of life of people with Alzheimer's disease and other dementias.

The unit, which has the financial support of the Municipal County of Cascais will have a Day Care Centre and a Residential Home Service, responding to 77 people in total.

The ceremony was attended by, inter alia, The President of the Municipality of Cascais, Dr. António d'Orey Capucho, and Members from the Board of Alzheimer Portugal.

Alzheimer's Society Leading the fight against dementia **6 July 2009: Alzheimer's Society reveals**

"shocking lack of dementia awareness in UK"

During the Dementia Awareness Week (5-11 July in England and Wales and 14-20 June in Northern Ireland) the Alzheimer's Society released results from a survey of over 2,000 people which revealed common misconceptions about dementia, such as:

- 72% of those surveyed believing family history would put people at greater risk despite that this is true in relatively few cases
- Only 52% realising that there is no cure for dementia
- 45% thinking that a history of mental illness increased risk even though there is no evidence to support this
- 32% mistakenly agreeing that dementia was a "natural part of ageing" and
- 26% believing that there was no way to reduce the risk.

Sarah Day, Head of Public Health at the Alzheimer's Society said "Clearly there is still a shocking lack of understanding when it comes to dementia. The truth is dementia is not a natural part of ageing; it is caused by diseases of the brain and robs people of their lives."

The Alzheimer's Society top tips for reducing risk are:

- Stay active
- Eat healthily
- Don't smoke
- Keep a health weight
- Get regular blood pressure and cholesterol checks.

21 July 2009: New director appointed at the Association Luxembourg Alzheimer

Romain Schmit has begun work in his role as Director of the Association Luxembourg Alzheimer (ALA). Mr Schmit has studied



Economics at the University of Toulouse, France. Prior to his appointment, he held senior positions within the financial sector, latterly as a Member of the Board of Ephidos Holdings S.A.

In Luxembourg Mr. Schmit is an Official IFBL (Institut de Formation Bancaire Luxembourg) Senior Expert, Member of IFBL Private Banking Quality Circle and a Member of the Jury of Certified Private Bankers.

Nasjonalforeningen for folkehelsen **August 2009: Norwegian Alzheimer Association campaigns for better dementia care**

In the run up to the Norwegian Parliamentary elections (due to take place on 14 September), the Norwegian Alzheimer Association (Nasjonalforeningen Demesforbundet) have raised awareness of what it is like to live with dementia by running a postcard campaign, targeted at parliamentary candidates. Prior to the election, local Alzheimer's member associations will send these postcards to the top candidates in their region and the hope is that the candidates, by having a greater understanding, will vote for better quality dementia care during their term in office.

Focusing on the need for adapted day care programmes and nursing homes for people with dementia (which are financed by the authorities), the Norwegian Alzheimer Association hopes to highlight that currently the needs of people with dementia and their carers are not being met. This is due to the fact that more than 90 % of the people with dementia who are living at home do not have access to an adequate day care programme, and that only 20 % of the beds in nursing homes are adapted for people with dementia.

The Norwegian Alzheimer's Association believes that better legislation and ear marked public financing are needed in order to provide people with dementia with the same quality care independent where in the country they live.

Alzheimer's Society Leading the fight against dementia **22 August 2009: Chief Executive of the Alzheimer's Society calls for a debate on funding for the care of people with dementia**

In an open letter to the editor of the Telegraph newspaper, Neil Hunt, Chief Executive of the Alzheimer's Society, UK, said:

"SIR – Your leading article (August 20) rightly highlights the cruelty of the care system for people with dementia.

At present, 46,000 people receive funding for NHS continuing care because their needs are judged to be "health needs" rather than "care needs"; yet we know there are over 200,000 people with late-stage dementia. Dementia is caused by diseases of the brain such as Alzheimer's disease. It should never be classified as a "social" condition, as in the case of Judith Roe. Individuals have significant health needs that go beyond social care.

You refer to a "reckless unwillingness" on the part of the Government to confront the issue. However, the Alzheimer's Society welcomes the Green Paper on social care. We do need a debate on who pays for care for those with dementia, focused on deciding a fair, sustainable model with the needs of people with dementia at its heart."

Member's Forthcoming Events



16 September 2009: Spanish Alzheimer association (CEAFA) to give awards for dementia work

The Spanish Alzheimer association, La Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias (CEAFA), will organize their third annual award ceremony which is due to take place on 16 September. These awards give recognition to different work in the field of dementia. The categories are:

INVESTIGATION/RESEARCH. This year, the Award is for the researcher Mr. Manuel Sarasa, whose work has been devoted for many years to find bio-markers for early diagnosis.

INFORMATION. "Entre Mayores Hablamos de ti" is a newspaper which offers complete information about health. Alzheimer's disease has been one of the main focuses of this publication.

CAREER. The European Parliament for the adoption of Written Declaration about Alzheimer Disease.

19 September 2009: Luxembourg Alzheimer's Association to hold memory walk for World Alzheimer's Day



Association Luxembourg Alzheimer (ALA) will celebrate World Alzheimer's Day by holding a memory walk for "people who live in oblivion" (pensons à ceux qui vivent dans l'oubli) in Esch Alzette, Luxembourg.



29-30 October 2009: Alzheimer Portugal to host its annual conference

Alzheimer Portugal will organise a conference entitled "Alzheimer Disease and other Forms of Dementia: Which politics?" at the Fundação Calouste Gulbenkian

According to the latest studies released, there are in Portugal about 90,000 people with Alzheimer's disease. In Europe, they are now over 7.3 million. These figures are predicted to double by 2040.

Several countries have already designed, and are currently implementing, a national Alzheimer's plan. The European Commission and the Parliament have both acknowledged Alzheimer's disease as a public health priority, thus contributing to the improvement of the quality of life for those with dementia and those surrounding them.

What about in Portugal? Which services are needed and how to provide them? Which models to follow? Which support?

These are some of the questions we seek to answer through active participation, as we strive together to identify the available resources and the needs which must be fulfilled.

The aim of this Conference is to make political decision makers, and the public in general, aware of these issues, and make Alzheimer's disease a National Public Health priority.

The Conference will address the need for a comprehensive "National Dementia Plan", discussing some existing National Dementia Plans already in the European Community. Participants including specialists, journalists and members of political parties will help ensure we have a more aware, responsible, and cohesive society which seeks to address the needs of people with dementia and their carers.

Science Watch

2 July 2009: Johnson & Johnson and Elan Corporation plc announces agreement for Alzheimer's Immunotherapy Programme and Equity Investment

Johnson & Johnson "will acquire substantially all of the assets and rights of Elan related to its Alzheimer's Immunotherapy Programme (AIP) in addition, Johnson & Johnson will invest \$1 billion in Elan in exchange for newly issued American Depositary Receipts (ADRs) which will represent 18.4% of Elan's outstanding ordinary shares."

3 July 2009: Study examines the relationship between mid-life status and cognitive function in later life

Findings in a study published in the British Medical Journal (BMJ) suggests that people living without a partner during middle age had a much higher risk of developing cognitive impairment in late life compared to those living with a partner. The study also concluded that people who are widowed at middle age are three times more likely to develop dementia.

Researchers led by Miia Kivipelto of the Karolinska Institute, Stockholm, Sweden, interviewed some 2,000 people from Eastern Finland, dividing them according to their status (married/cohabitant, single, divorced or widowed). Participants were interviewed at around 50 years of age and again around 21 years later. The researchers also examined the relationship between the apolipoprotein E e4 gene (a known risk factor for Alzheimer's disease) and living alone. They found that the highest risk for developing Alzheimer's disease was for those people who carried the variant gene and who were widowed during middle age.

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5 July 2009: Study on mice examines relationship between caffeine and Alzheimer's disease

A study found that cognitively impaired transgenic mice who were given caffeine showed "superior working memory" and reduced A β deposits in the brain compared to the continuing impairment of control transgenic mice.



The research was led by Gary Arendash, PhD from the Florida Alzheimer's Disease Research Center and published in the Journal of Alzheimer's Disease. The researchers plan to commence human trials to establish whether caffeine can benefit people with mild cognitive impairment or early Alzheimer's disease.

8 July 2009: Study suggests relationship between linguistic skills in early life and later cognitive impairment

A study suggests that superior language ability in early life may be linked to later life cognitive ability. Researchers, who studied the brains of 38 nuns after death carried out an analysis of 14 of the nuns' old essays. These had been written during the nuns' late teenage years or early twenties. The findings suggest that those nuns who in later life showed signs of memory impairment had displayed lower language abilities in their earlier essays than those nuns who did not have memory impairment in later life.



The study was led by Dr Juan Troncoso of the John Hopkins University, USA and published in Neurology.

9 July 2009: Study examines cognitive functioning in Alzheimer's disease and Vascular Dementia

By analysing 81 studies, researchers were able to compare the cognitive abilities of people diagnosed with Alzheimer's disease and with vascular dementia. They found that only two tests administered were able to reliably distinguish between Alzheimer's disease and vascular dementia: The Emotional Recognition Task (the ability to identify facial expressions in photographs and match emotional expressions to situations, at which people with Alzheimer's disease were better) and Delayed Story Recall (at which people with vascular dementia were better). Tests such as Digit Span (repeating a set of numbers forward and backward), verbal fluency (generating words by first letter or category, such as animals) and drawing tasks were unable to differentiate between the two types of dementia.

In order that a correct diagnosis be made and hence appropriate treatment given, the researchers concluded that doctors should base their diagnoses on many different types of information, including medical history and brain imaging.

The research was conducted by Jane Mathias PhD and Jennifer Burke M Psych from the University of Adelaide, Australia.

12 July 2009: Study examines the relationship between DHA and cognitive decline in people with Alzheimer's disease

A study found that there may be some benefit for some people with Alzheimer's disease in taking DHA (docosahexaenoic acid), an omega 3 fatty acid. Participants were given either a 2g dose of DHA or a placebo over an 18 month period. Initial findings showed that despite blood levels of DHA and brain DHA levels increasing the treatment did not slow down the rate of change on tests of mental function (ADAS-cog), global dementia severity status (CDR-SOB), activities of daily living (ADL) or behavioural symptoms (NPI) in the population as a whole.

However, during data analysis the results indicated that for those people with Alzheimer's disease, who do not carry the ApoE-e4 gene, DHA had a beneficial effect in that the cognitive tests revealed a slower rate of cognitive decline, whereas for people who carry the ApoE-e4 gene no benefit was apparent.

The study, led by Joseph Quinn, MD from the Oregon Health and Sciences University, was conducted on 402 people with mild to moderate Alzheimer's disease.

12 July 2009: Diabetes drug fails as potential Alzheimer's treatment

A six-month study on the potential benefit of administering the diabetes drug, rosiglitazone, for the treatment of Alzheimer's disease has failed to yield positive results. Researchers observed that in over 500 people with mild to moderate Alzheimer's disease, who took rosiglitazone, cognitive function, behaviour and daily activities were not improved.

The research was presented by Michael Gold, Glaxo's vice-president of neurosciences at the International Conference on Alzheimer's Disease, Vienna, Austria.

13 July 2009: Data from phase I drug trials for the treatment of mild to moderate Alzheimer's disease presented

Elan Corporation plc and Transition Therapeutics Inc presented their phase 1 data for the drug ELND005 (scyllo-inositol formerly known as AZD-103). The trial suggests that treatment with ELND005 results in "desired concentrations in human brain tissue and cerebrospinal fluid when given orally. Preclinical data shows that ELND005 administration is associated with preservation of choline acetyltransferase (ChAT), reflecting preservation of nerve cells that are critical to

memory function of the brain." Phase II trials are ongoing.

13 July 2009: Study finds a lack of awareness regarding risk factors for Alzheimer's disease

An anonymous online American survey of nearly 700 adults revealed more than half of the participants were unaware of some of the risk factors (obesity, high blood pressure and high stress) associated with Alzheimer's disease, although most understood that Alzheimer's disease is not a normal part of ageing.

The survey was carried out by Colleen E Jackson, MS from the University of Connecticut and colleagues.

13 July 2009: Phase II study completed for potential diagnostic tool for Alzheimer's disease

Phase II findings suggest that "florbetaben" (a positron emission tomography (PET) tracer) may be a useful tool for the diagnosis of Alzheimer's disease. In the study positive florbetaben scans (which indicate the presence of beta-amyloid plaques) were found in a large proportion of those participants who had a clinical diagnosis of Alzheimer's disease, whereas those people without a clinical diagnosis of Alzheimer's had a negative result in the florbetaben scan.

The study was presented by representatives of Bayer Schering Pharma AG, Germany, at the International Conference on Alzheimer's Disease (ICAD) held in Vienna, Austria and Phase III trials are planned for the end of 2009.

13 July 2009: Study examines relationship between post-traumatic stress disorder and dementia

Kristine Yaffe, MD from the University of California, USA and colleagues wanted to examine whether post-traumatic stress disorder (PTSD) is associated with the risk of developing dementia in veterans. They studied over 181,093 veterans aged 55 and over without dementia (53,155 diagnosed with PTSD and 127,938 without PTSD) and found that over a seven year follow up, that veterans with PTSD were "nearly twice as likely to develop incident dementia compared to veterans without PTSD".

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13 July 2009: Study suggests moderate alcohol consumption may reduce risk of dementia for certain people

Researchers examined the relationship between alcohol consumption and incident dementia in over 3,069 adults aged 75 and above without dementia. At the start of the study 2,587 of the participants were assessed to be cognitively normal and 482 had mild cognitive impairment (MCI). Participants were monitored every six months for six years and the study suggests that moderate alcohol consumption was associated with a lower risk of dementia for those participants with normal cognition at the beginning of the study but not for those who already had MCI.

The research was led by Kaycee Sink, MD, MAS from the Wake Forest University School of Medicine, Winston-Salem, NC.

14 July 2009: Studies consider caregiver burden and economic costs of Alzheimer's disease

Various studies presented by Elan Corporation and Wyeth at the International Conference on Alzheimer's Disease (ICAD) suggest that there is an exponential relationship between total costs and Alzheimer disease dependency levels, with costs increasing significantly with increasing dependency.

Caregivers experience increased disruption in daily activities, greater lack of family support and more time devoted to being a caregiver as the dependency levels of people with Alzheimer's disease increased.

People with Alzheimer's disease may have a higher prevalence of certain serious conditions compared to people without Alzheimer's disease.

14 July 2009: Study examines association between diet, cognitive decline and dementia



Researchers analysing a 1995 study of food frequency and cognitive assessment on over 3,000 people aged 65 or older, which was followed up with four assessments over 11 years, found higher scores for cognitive functioning in those people who had closely followed the dietary approaches to stop hypertension (DASH) diet. The diet includes the consumption

of vegetables, whole grains, low-fat dairy products and nuts.

The study was conducted by Heidi Wengreen, RD, PhD of Utah State University and colleagues.

14 July 2009: Study examines diagnosis technique for early Alzheimer's disease

By analysing data including (a) cerebrospinal fluid (CSF) concentration and ratios of Alzheimer's related proteins, (b) MRI volume measures of certain sections of the brain and (c) scores on certain standard memory, learning and brain function tests on some 345 participants (81 with Alzheimer's disease, 163 with amnesic mild cognitive impairment and 101 elderly health controls) researchers were able to develop a prediction model which helped them to accurately diagnose Alzheimer's disease at an early stage. They found that when the results of the memory tests were combined and added to these the results of the MRI volume measurements of the left hippocampus, they were able to distinguish, with 94% accuracy, those participants who progressed from MCI to Alzheimer's disease.

The researchers, led by Michael Ewers, PhD of Trinity College, Dublin, Ireland, said that "the model needs to be validated in autopsy-confirmed Alzheimer's cases."

14 July 2009: Study suggests that physical activity may slow the rate of cognitive decline in older adults

A study carried out by Deborah E Barnes, PhD, MPH and colleagues from the San Francisco VA Medical Centre examined changes in levels of both physical activity and cognitive function over seven years in over 3000 participants aged 70-79 years. They found that "older adults who were sedentary throughout the study had the lowest levels of cognitive function at the beginning and experienced the fastest rate of cognitive decline... Cognitive decline was also faster in those whose physical activity levels consistently declined during the study period."



15 July 2009: Alzheimer drug found to increase beta amyloid in mouse models

The drug dimebolin can be used to treat people with mild to moderate Alzheimer's disease. Recent research in which mice models were given dimebolin resulted in an unexpected "acute increase in the mice' brain beta amyloid levels". The protein beta amyloid is a main constituent of the amyloid plaques found in the

brains of people with Alzheimer's disease and considered to be a key factor in the development and progression of Alzheimer's disease.

The study was carried out by Samuel Gandy, MD, PhD, from the Mount Sinai School of Medicine, New York, USA and John Cirrito PhD and David M Holtman, MD from the Washington University in St Louis, MO, USA and they have called for further research to be conducted to investigate this surprising outcome.

16 July 2009: Study examines the relationship between an antibody and Alzheimer's disease

Results from a new study suggest that treatment with the antibodies of intravenous immune globulin (IVIg) may help protect against Alzheimer's disease. Researchers analysed medical records of 847 people who had received at least one treatment of IVIg (for other conditions such as cancer) over four years and 84,700 who had not. They found that people who had received IVIg had a significantly lower risk of developing Alzheimer's disease compared to those who had not received IVIg. A large scale clinical trial is now underway to determine whether IVIg could be an effective treatment for Alzheimer's disease. The research was carried out by the Mount Sinai School of Medicine, New York.

22 July 2009: Study examines the rate of decline for a person with Alzheimer's disease and carer relationship



Research, published in the Journal of Gerontology, has found that a "particularly close relationship with caregivers may give people with Alzheimer's disease a marked edge over those without one in retaining mind and brain function over time."

Led by Constantine Lyketsos MD, MHS of the John Hopkins Memory and Alzheimer's Treatment Center, the researchers examined 167 pairs of caregivers and people with Alzheimer's disease. The pairs were monitored from 2002, every six months for four years. People with Alzheimer's disease had similar scores for cognitive and functional tests at the beginning of the study. However, during the research, differences appeared between those pairs who had described their relationship as close and those who had indicated their relationship as more distant

20 July 2009: Study examines effects of stem cells on memory function in mice

A study found that mice, which were genetically engineered to have Alzheimer's disease symptoms, were able to increase performance on memory tests after being injected with stem cells (mouse neural stem cells). These cells secreted a protein called "brain-derived neurotrophic factor" (BDNF) resulting in new neurites sprouting enabling stronger connections between neurons.

The study was conducted by Mathew Blurton-Jones, La Ferla and colleagues from the University of California, USA.

21 July 2009: Researchers examine the relationship between the BChE-K gene and Alzheimer's disease

A study suggests that mutation of the gene known as butyrylcholinesterase K (BChE-K) damages the end, or tail, of the BChE gene. In Alzheimer's disease, the tail of this gene plays an important role in the protection from Alzheimer disease plaques and the study may explain why it is that people who carry the mutated gene are susceptible to a more rapid development of Alzheimer's disease than those who carry a normal version of the gene.



The research was carried out by Dr Erez Podoly and colleagues of the Wolfson Center for Structural Biology at the Hebrew University in Israel and the research has been featured in the Journal of Biological Chemistry.

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4 August 2009: Study suggests link between brain activity and delayed onset of memory decline



A study on nearly 500 people found that carrying out frequent cognitive-stimulating activities may delay the onset of cognitive decline. Records were made of how many cognitive activities (including reading, writing, crossword puzzles, board or card games, group discussions, or playing music) participants carried out as well as how many days a week.

Researchers found that those participants who "engaged in the highest level of activity, defined

as 11 activity days per week, delayed accelerated onset of dementia by 15.5 months versus those with the lowest level activity, defined as four activity days per week.”

The research was carried out by the Albert Einstein College of Medicine of Yeshiva University and published in the journal *Neurology*

4 August 2009: Study suggests link between cholesterol levels in mid-life and risk of dementia in later life

A study which monitored cholesterol levels of nearly 10,000 people over a 40-year period found that “elevated cholesterol levels in midlife significantly increase the risk of Alzheimer’s disease and vascular dementia in later life.”

The research was led by Alina Solomon MD from the University of Kuopio, Finland and forms part of ongoing research aimed at better understanding of the risk and protective factors of dementia.

4 August 2009: Study suggests link between face shape and mental decline

Researchers from the University of Edinburgh measured fluctuating asymmetry (FA) on facial photographs of over 200 elderly people and found that “men with higher levels of facial symmetry were less likely to experience a slow down of brain power between the ages of 79-83 years”. Comparable results were not found in women.

5 August 2009: Study examines the effect of oxygen treatment and the rate of cognitive decline in mice

Researchers who exposed 11 transgenic mice (who developed abnormal levels of the protein amyloid beta) to oxygen over several sessions found those which received 100% oxygen to perform much worse than mice exposed to 21% oxygen (similar level of typical room air). The authors concluded that further investigation is required on see

if oxygen treatment (used in surgery) may trigger the symptoms of Alzheimer’s disease in humans.

The study was led by Gary Arendash, University of South Florida, USA and published in *NeuroReport*.

8 August 2009: Study examines the relationship between seizures and Alzheimer’s disease

A study carried out by Nikolaos Scarmeas MD, Columbia University Medical Center, New York,

USA and colleagues found that “unprovoked seizures are uncommon in Alzheimer’s disease, but they do occur more frequently than in the general population. Younger age is a risk factor for seizures in Alzheimer’s disease”.

The research was conducted on over 400 people with probable Alzheimer’s disease at six monthly intervals and published in the *Archives of Neurology*.

12 August 2009: Study investigates role of receptor on amyloid protein in Alzheimer’s disease in mice

In order to test the hypothesis that alpha 7nAChR gene receptors play a role in the development of Alzheimer’s disease, researchers from the Salk Institute for Biological Studies examined the effects of the receptors on transgenic mice over expressing a mutated form of the human amyloid precursor protein (APP) and lacking the alpha 7nAChR gene and then performed a series of memory tests. Those mice with too much APP and no gene for alpha 7nAChR performed as well as normal mice whereas the transgenically modified Alzheimer’s disease mice which had been engineered to over express APP and had the alpha 7nAChR gene performed poorly.

Led by Stephen F Heinemann, the researchers concluded that their findings were “consistent with the hypothesis that the alpha 7nAChR plays a role in Alzheimer’s diseases and suggest that interrupting alpha 7nAChR function could be beneficial in the treatment of Alzheimer’s disease.”

14 August 2009: Study examines the relationship of sleep duration and the risk of dementia

A study carried out by J Benito-León, University Hospital, Madrid, Spain and colleagues found that “prolonged sleep duration (night-time sleep and daytime napping) may be associated with an increased risk of dementia.”

The study consisted of over 3000 participants monitored over a three year period and has been published in the *European Journal of Neurology*.

21 August 2009: Study examines brain activity and different types of dementia

Researchers who monitored the brain activity of people with dementia have found that the brain activity varies according to the type of dementia a person had. People who had



Alzheimer's disease displayed a more random and unstructured brain activity than those people who had fronto-temporal lobar degeneration (FTLD), with the latter developing a more "ordered network organisation".

The study was published in the journal BMC Neuroscience. Led by Willem de Haan from VU University Medical Centre, Amsterdam, the Netherlands, the researchers called for further investigation to establish more insight into the relationship between the disease and neural networks.

25 August 2009: Study examines the relationship between weight and brain tissue

A study has found obese and overweight individuals to have less brain tissue than people of a normal weight. Paul Thompson from the University of California (UCLA) Department of Neurology, who led the study, said that this loss of brain tissue "depletes cognitive reserves, putting (one) at much greater risk of Alzheimer's and other diseases that attack the brain."

The research is published in August's edition of the journal Human Brain.

26 August 2009: Study compares brain function between elderly people considered at risk for Alzheimer's disease and those without genetic and/or family history risk factors

By monitoring the brain activity using a functional magnetic resonance imaging (fMRI) scanner, researchers found an increased activation of certain parts of the brain in at risk (of Alzheimer's disease) individuals compared to those individuals without genetic and/or family history risk factors. The researchers, from the Cleveland Clinic, Lou Ruvo Center for Brain Health, hope that future studies can be developed to help diagnose Alzheimer's disease earlier.

The study was published in August edition of Neurology.

26 August 2009: Study examines relationship between blood pressure and cognitive impairment

Researchers who examined the relationship between blood pressure and cognitive status found that higher diastolic blood pressure (DBP) was associated with impaired cognitive status. (For every increment of 10mm Hg in DBP there was a 7% higher odds of cognitive impairment). No association was found between the systolic blood pressure and cognitive status.

The research was led by G Tsivgoulis MD, University of Alabama at Birmingham and published in the journal Neurology.

27 August 2009: Study confirms the theory that gene mutation causes transmissible prion disease

Prions (which are versions of a protein called PrP) can cause various diseases, including Creutzfeldt-Jakob disease (CJD), a type of dementia. Researchers investigated the theory that "a mutation in a the PrP gene can cause a transmissible prion disease", and their findings suggest that this is indeed the case.

The research was led by Walter Jackson from the White Institute, Cambridge, Massachusetts, USA.

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Dementia in Society

June 2009: Rock stars back scientist recruitment and funding campaign

Rock stars Joe Perry (lead guitarist and co-founder of Aerosmith), Sheryl Crow (singer/songwriter), Will.I.AM (front man, Black Eyed Peas), SEAL (singer/songwriter) and Josh Groban (singer) have joined in the Geoffrey Beene Gives Back "Rock Stars of Science" campaign, which aims to "honour the researchers who are saving our lives, to make science rock as a career choice for the next generation, and to raise the platinum voices in demand for future research funding." The campaign includes posters of the rock stars alongside doctors stating "The musicians you'll know – they're icons. As for the other guys, they're the doctors whose work has brought us closer to cures for Cancer, HIV/AIDS and Alzheimer's disease. These fellows won't set your soul on fire like Sheryl Crow, but they're lighting up the future with something just as powerful. Hope."

11-16 July 2009: International conference on Alzheimer's disease held in Austria

The Alzheimer's Association 2009 International Conference on Alzheimer Disease (ICAD) was held in Vienna, Austria. Participants heard of scientific work being carried out, including studies examining the effect on Alzheimer's disease of exercise, alcohol, stress and various drugs. Presentations were also given on the prevalence of dementia and recruitment strategies for clinical trials. Various poster

presentations were given including those from the Elan Corporation who had presentations about their joint work with Wyeth (which included their clinical programmes for bapineuzumab).

New resources and publications

June 2009: Book published on weekly themed activities for care home residents



“The Activity Year Book” offers ideas for weekly themed activities for care staff who plan activities for elderly people in day or residential care settings. It is written by Anni Bowden and Nancy Lewthwaite. The book costs GBP 24.99 (ISBN: 978-1-84310-963-1).

June 2009: Book on dementia care published

“Excellence in Dementia Care”, edited by Murna Downs and Barbara Bowers, provides an invaluable source of information for all people working with people with dementia. Contributions are from researchers, practitioners and professionals in the care of people with Alzheimer’s disease and other dementias. The focus is on care issues for people with dementia and examples are given from various countries and include, inter alia, the experience of people with dementia and their families.



The book hopes to offer valuable insights when making decisions about how to:

- Provide competent and compassionate care for people with Alzheimer’s disease and other dementias
- Build systems to provide effective care
- Encourage collaboration among multi-disciplinary professionals and users and carers
- Support those caring for people with dementia
- Ensure those with dementia maintain dignity, well-being and meaningful participation in life.

Murna Downs is Chair in Dementia Studies and Head of the Bradford Dementia Group, in the

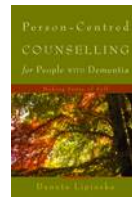
Division of Dementia Studies at Bradford University, UK.

Barbara Bowers is Associate Dean for Research and Helen Denne Schulte Professor in the School of Nursing at the University of Wisconsin-Madison, USA and holds an adjunct position at the Australian Catholic University, Australia.

Excellence in Dementia care costs GBP 65 (hardcover) or GBP 29.99 (paperback). ISBN-13: 978-0335 22375-6; ISBN-10: 0335 22375-3

July 2009: New book published on person centred counselling for people with dementia

Aimed at counsellors, health and social care professionals, carers, people with dementia and their families, “Person-centred counselling for people with dementia: Making sense of self” by Danuta Lipinska “explores the value of counselling for men and women living with this condition and how it enables them to make sense of their lives and their notions of themselves. The book costs GBP 14.99 (ISBN 978-1-84310-978-5).



July 2009: Book published on planning care for people with dementia

“Enriched care planning for people with dementia: A good practice guide to delivering person-centred care”, by Hazel May and Paul Edwards, offers a practical framework to work from for assessment, care planning and review of people with dementia who require or receive health and/or social support. The book costs GBP 25, ISBN 978-1-84310-405-6.



August 2009: Dance therapy for people with dementia

Earlier this year a trial of “Wu Tao” dance therapy was carried by Alzheimer’s Australia WA out on six residents from care homes in Joondalup, Perth Australia. Wu Tao (the dancing way) was developed by former ballerina, Michelle Locke. It is a “series of five dances which aim to balance the body’s life force, or “chi” by stretching the “meridians” which oriental medicine believes channels energy through the body. Each of the dances represents one of the elements – air, water, wood, fire and earth. Once a week a Wu Tao instructor visited to group, which included the residents, their carers, family members, therapy assistants as well as the facility’s

occupational therapist. The instructor taught adapted versions of the dance for them and feedback has been extremely positive.

8 August 2009: Student designs dementia-friendly jigsaw

A design student in the UK has launched a jigsaw puzzle aimed to be used-friendly for people with dementia. Ben Atkinson-Willes (22) from Kingston University became inspired to design an activity puzzle after his granddad, who enjoys puzzles, was diagnosed with Alzheimer's disease.



Ben has adapted the traditional puzzle in a number of ways, incorporating:

- large, chunky pieces, making it easier to handle
 - specially designed contrast background to facilitate matching up pieces
 - finished edges
 - traditional images, rather than younger pictures normally associated with large-pieced puzzles
- foamex which is a long-lasting, durable, flexible and easy to clean material.

14 August 2009: Guide on younger onset dementia released onto web

A 38 page online booklet, entitled "Quality Dementia Care Series: Younger Onset Dementia – A practical guide" has been produced by the Prince of Wales Medical Research Institute (POWMRI), Australia. The objective of the publication is "to draw together information on younger onset dementia and provide practical information for those newly diagnosed as well as their families and carers."

Written by Professor John Hodges and his team from the Fronto-temporal Dementia Research Group (FRONTIER), areas covered in the booklet include:

- Background on younger onset dementia
- Practical approaches to the management of dementia
- The caring role and the family
- Planning for the future
- Research into younger onset dementia: brain donation.

The booklet was commissioned by Alzheimer's Australia and funded by the Federal Government (ABN 79 625 582 771).

17 August 2009: Booklet published on caring and consent

After consultation with Alzheimer Scotland, the Mental Welfare Commission for Scotland and the Office of the Public Guardian, the booklet "Caring and Consent – your right to be involved in decisions about the health care of the adult you care for" has been published. It explains the rights of:



- people who are unable to consent to medical treatment
- their carers to be involved in decisions about their health care and
- rights of a legal proxy

Published by published by Health Rights Information Scotland (HRIS).

Contact Alzheimer Europe at:

Alzheimer Europe, 145 route de Thionville, L-2611, Luxembourg (www.alzheimer-europe.org)
 Jean Georges, Executive Director (jean.georges@alzheimer-europe.org)
 Dianne Gove, Information Officer (dianne.gove@alzheimer-europe.org)
 Annette Dumas, EU Public Affairs Officer (annette.dumas@alzheimer-europe.org)
 Julie Fraser, Communication Officer (julie.fraser@alzheimer-europe.org)
 Gwladys Guillory-Hickey, Administrative Assistant (gwladys.guillory@alzheimer-europe.org)
 Grazia Tomasini, Administrative Assistant (info@alzheimer-europe.org)

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 Marc Schaefer (Luxembourg)
 Maria do Rósario Zincke dos Reis (Portugal)

AE Calendar

The following meetings will be attended by representatives of Alzheimer Europe:

| Date | Meeting | AE Representative |
|-----------------|--|--------------------|
| 1 September | Meeting of the GSK Health Advisory Board (London, United Kingdom) | Jean |
| 1 September | Parliament Magazine Swedish Presidency Reception (Brussels, Belgium) | Annette |
| 2 September | Environment Committee Meeting, European Parliament (Brussels, Belgium) | Annette |
| 2 September | Employment and Social Affairs Committee, European Parliament (Brussels, Belgium) | Annette |
| 3 September | Industry and Research Committee, European Parliament (Brussels, Belgium) | Annette |
| 7 September | AE Staff Meeting (Luxembourg, Luxembourg) | AE Staff |
| 14-16 September | Facing the future, Dementia Services Development Centre (York, United Kingdom) | Dianne |
| 15-16 September | EU Presidency Conference on Healthy and Dignified Ageing (Stockholm, Sweden) | Jean |
| 22 September | EFPIA Think Tank (Brussels, Belgium) | Annette |
| 23 September | European Dementia Ethics Network (Berlin, Germany) | Jean and Dianne |
| 28 September | AE Board Meeting (Brussels, Belgium) | AE Board and Staff |
| 28 September | Meeting with AE sponsors (Brussels, Belgium) | AE Board and Staff |
| 29 September | European Parliament lunch debate "European Action on Dementia" (Brussels, Belgium) | AE Board and Staff |

Future Conferences

| Date | Meeting | Place |
|----------------------|--|--------------------------|
| 15-16 September 2009 | Dementia Services Development Centre's 3 rd International Conference: Facing the future, www.dementia.stir.ac.uk | York, United Kingdom |
| 23 September 2009 | 12. Internationaler Demenzkongress Saar-Lor-Lux, www.demenz-saarlouis.de | Saarlouis-Roden, Germany |
| 24 October 2009 | 19 th World Congress of Neurology, www.wcn2009bangkok.com/index.cfm | Bangkok, Thailand |
| 27 October 2009 | 2 nd Eastern European Psychiatric Congress, http://en.paeeb2009moscow.ru | Moscow, Russia |
| 29 October 2009 | 2 nd Conference "Clinical Trials on Alzheimer's Disease, www.ctad.fr | Las Vegas, USA |
| 3-5 November 2009 | 4 th UK Dementia Congress, www.ukdementiacongress.co.uk | Harrogate, UK |
| 19-22 November 2009 | The 6 th International Congress on vascular dementia, www.kenes.com/vascular | Barcelona, Spain |
| 10 March 2009 | 25 th International Conference of Alzheimer's Disease International, www.adi2010.org | Thessaloniki, Greece |
| 9-11 June 2010 | 7 th International Short Break Conference | Galway, Ireland |
| 2-5 September 2010 | Dignity for the Frail Old: From dilemmas to solutions, www.dignity.no | Bergen, Norway |

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