



# NEWSLETTER

April – June 2009

## Highlights in this issue

<b>2 April 2009:</b> EP supports derogation for MRI from EMF directive	7
<b>25 May 2009:</b> Malta launches dementia strategy group	12
<b>28 May 2009:</b> Scottish government announces national dementia strategy	10
<b>28 May 2009:</b> Alzheimer Europe organises successful conference in Brussels	3



## Table of contents

Editorial.....	1
European Alzheimer's Alliance .....	2
Alzheimer Europe .....	3
Alzheimer Europe Networking .....	4
European developments.....	5
Other European developments .....	9
Policy Watch.....	10
Members' News.....	11
Science Watch .....	15
Dementia in Society .....	19
New resources and publications .....	19
AE Calendar .....	22
Future Conferences.....	22

## Editorial



Our 19<sup>th</sup> annual conference "Stars for Help" ,at the end of May, highlighted the advances that the European Union has made in its efforts to address Alzheimer's disease. Participants were reminded of the unprecedented exposure Alzheimer's disease has received during the last 12 months. The feedback I received was that delegates were encouraged and inspired that interest was shown by the attendance and/or participation of national ministers, European delegates and her Royal Highness, Princess Maltilde of Belgium.

Since our last newsletter, a number of our publications have been completed. The third issue of the Dementia in Europe magazine (which included a special section dedicated to the European elections) and Alzheimer Europe's new conference publication concept were all finalised. We were particularly happy to be able to launch all of these at the Brussels conference.

Our new website is also progressing and we believe the new design to be more accessible, understandable and comprehensive. The developers are now at work and we eagerly anticipate

the new website launch during the summer.

For me, one of the highlights of our annual conferences is that I get the opportunity to see members in person and share experiences and ideas. I think this exchange is invaluable. In this issue of the newsletter, we are able to share members' news and campaigns from several countries, including Bulgaria, the Czech Republic, Finland, France, Germany, Greece, Malta, Portugal, Switzerland and the UK.

This issue also reports on several drug trials being carried out, all at different stages of the drug testing process. I am cautiously encouraged by this, being only too aware of the attrition rate when drugs are developed.

We are also reminded of the growing importance that technology can play for people with dementia and their carers, as we bring news about investment in the UK into research centres to develop digital technology which will assist the elderly.

Once again, I extend my apologies as our "monthly" newsletter has been delayed, resulting in a quarterly edition due to the enormous workload all the team have recently carried out. However, I hope you enjoy reading this issue as much as we enjoyed preparing it!

**Jean Georges**  
Executive Director

## European Alzheimer's Alliance

In April, two additional Members of the European Parliament joined the European Alzheimer's Alliance



**Zaborska Anna**

Slovakia, EPP-ED



**Van Nistelrooij Lambert**

Netherlands, EPP-ED

With their support, the number of Members of the European Parliament who have pledged their support to Alzheimer Europe by either signing the Paris Declaration or joining the European Alzheimer's Alliance has been increased to 90. Alzheimer Europe can now count on the support of Members of the European Parliament from all seven political groups and from 22 of the 27 Member States of the European Union.

Prior to the elections to the new European Parliament in June 2009, the supporters of Alzheimer Europe were the following:

### Austria:

Ettl Harald (PES)

### Belgium:

Brepoels Frieda (EPP-ED), Busquin Philippe (PES), Hutchinson Alain (PES), Langendries Raymond (EPP-ED), Staes Bart (Greens -EFA), Sterckx Dirk (ALDE)

### Bulgaria:

Zdravkova Dushana (EPP-ED)

### Cyprus:

Adamos Adamou (GUE-NGL), Demetriou Panayiotis (EPP-ED), Triantaphyllides Kyriacos (GUE-NGL)

### Czech Republic:

Cabnoch Milan (EPP-ED), Kohlicek Jaromir (GUE/NGL), Roithova Zuzana (EPP-ED), Vlasak Oldrich (EPP-ED)

### Denmark:

Busk Neils (ALDE), Dahl Hanne (IND/DEM), Jensen Anne E. (ALDE), Jørgensen Karin-Riis (ALDE), Schaldemose Christel (PES)

### Finland:

Myller Riitta (PES), Pietikäinen Sirpa (EPP-ED), Virrankoski Kyösti (ALDE)

### France

Audy Jean-Pierre (EPP-ED), Daul Joseph (EPP-ED), De Veyrac Christine (EPP-ED), Fouré Brigitte (EPP-ED), Griesbeck Nathalie (ALDE), Grossetête Françoise (EPP-ED), Henin Jacky (GUE/NGL), Lamassoure Alain (EPP-ED), Morin Elisabeth (EPP-ED), Onesta Gérard (Greens-EFA), Toubon Jacques (EPP-ED)

### Germany

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

### Greece

Koppa Maria Eleni (PES), Kratsa-Tsagaropoulou Rodi (EPP-ED), Matsouka Maria (PES), Panayotopoulos Marie (EPP-ED), Papadimoulis Dimitrios (GUE/NGL), Schinas Margaritis (EPP-ED), Trakatellis Antonios (EPP-ED), Vakalis Nikolaos (EPP-ED)

### Hungary

Levai Katalin (PES), Surján László (EPP-ED)

### Ireland

Aylward Liam (UEN), Crowley Brian (UEN), McDonald Mary Lou (GUE/NGL), McGuinness Mairead (EPP-ED), Mitchell Gay (EPP-ED), Ryan Eoin (UEN), Sinnott Kathy (IND/DEM)

### Italy

Battilocchio Alessandro (PES), Panzeri Pier Antonio (PES), Podestà Guido (EPP-ED), Toia Patrizia (ALDE)

### Lithuania

Dickute Jolanta (ALDE)

### Luxembourg

Goebbels Robert (PES), Lulling Astrid (EPP-ED), Spautz Jean (EPP-ED)

### Netherlands

Corbey Dorette (PES), De Lange Esther (EPP-ED), van Nistelrooij Lambert (EPP-ED), Wortmann Corien (EPP-ED)

### Poland

Masiel Jan Tadeusz (UEN), Rogalski Boguslaw (UEN)

### Portugal

Coelho Carlos (EPP-ED), Esteves Maria do Assunção (EPP-ED), Estrela Edite (PES), Figueiredo Ilda (GUE/NGL), Gomes Ana Maria (PES), Pinheiro João de Deus (EPP-ED), Queiró Luis (EPP-ED), Ribeiro José (EPP-ED), Silva Peneda José Albino (EPP-ED)

**Romania**

Winkler Iuliu (EPP-ED)

**Slovakia**

Mikolasik Miroslav (EPP-ED), Zaborska Anna (EPP-ED)

**Sweden**

Cederschiold Charlotte (EPP-ED)

**United Kingdom**

Bowis John (EPP-ED), Evans Robert (PES), Hall Fiona (ALDE), McAvan Linda (PES), Moraes Claude (PES), Simpson Brian (PES), Stihler Catherine (PES), Watson Graham (ALDE), Willmott Glenis (PES)

**Alzheimer Europe**

**28 May 2009: Alzheimer Europe holds its Board meeting and Annual General meeting**

The Board of Alzheimer Europe met in Brussels, Belgium. The Executive Director presented the audited annual accounts as of 31 December 2008, the 2009 finances (risk assessment), an overview of the 2010 workplan and the 2010 budget.

The Alzheimer Europe 2010 workplan includes:

- the dementia ethics network
- the legal rights project
- work on including people with dementia
- the European dementia observatory
- the 2010 Alzheimer Europe Conference
- a membership survey
- membership development
- possible statutory review and fundraising
- European Public Affairs work (to include the European Alzheimer Alliance and the possible setting up of a Dementia Intergroup, policy watch and the Dementia in Europe magazine, as well as the clinical trials database).

The Board then discussed funding opportunities, in particular, the possibility of obtaining core funding from the European Commission as well as the German Ministry's

pledge to provide funding to start a Dementia Ethics Network.

Current membership development was considered. The Board decided to propose to the Annual General Meeting that the status of provisional membership be extended to the Bulgarian associations and offer provisional status to Slovenia, Estonia and Croatia. Finally, the Board discussed the European Medicines Agency's code of practice for the collaboration with pharmaceutical companies and unanimously decided to adopt it.

The Board meeting was followed by the Annual General Meeting where representatives from Alzheimer Europe's member associations from 18 different countries attended. The Annual General Meeting:

- Unanimously adopted the Annual and Financial Report for 2008
- Unanimously reappointed Mazars as the external auditors of Alzheimer Europe for the 2009 accounts
- Approved the increase of 20% in membership fees for 2010
- Unanimously agreed to have Alzheimer Bulgaria and Foundation Compassion Bulgaria continue as provisional members and grant provisional membership to the Slovenian Alzheimer Association "forget-me-not", the Estonia Association of Alzheimer's Disease and the Alzheimer's Disease Societies Croatia
- Unanimously approved the 2010 workplan and budget.

**28-30 May 2009: Alzheimer Europe's 19th Annual Conference takes place in Brussels, Belgium**



Some 300 delegates (including, amongst others, people with dementia, carers, local, national and European policy makers and medical personnel) from over 20 countries participated in Alzheimer Europe's 19th Annual Conference. It was supported by the attendance of Her Royal Highness Princess Mathilde of Belgium (pictured left with Marian Thijssens) and hosted by the Belgian Alzheimer Association (Ligue Nationale/Alzheimer Liga) together with Alzheimer Europe.

The Conference motto “Stars for Help” sought to highlight the European Union’s (EU) significant advances in making Alzheimer’s disease and other forms of dementia a public health priority.



Opening the conference, Maurice O Connell, (pictured below) Chair of Alzheimer Europe, highlighted European advances that have been achieved, such as the EU French Presidency Conference dedicated to Alzheimer’s disease as well as the Council of Ministers’ recommendations at the end of 2008 which called upon the European Commission to promote European research into dementia and propose an EU initiative on Alzheimer’s disease. Belgian policy makers also participated at the opening ceremony, calling for intensive collaboration (Emir Kir, Minister for Social Policy and Family Affairs for Brussels), a national dementia action plan (Isabelle Paul, representing Didier Donfut, Minister for Social Affairs, Health and Equal opportunities for Wallonia) and a raising of public awareness (Laurette Onkelinx, Deputy Prime Minister and Minister for Social Affairs and Public Health, Belgium).

The focus of the first day’s plenary session was to improve the lives of people with dementia and their carers. Commencing with the writer and poet, Marleen Declercq (pictured left), who has dementia, and Marian Thijssens, whose husband has Alzheimer’s disease, both offered thought-provoking and memorable insights into their experiences living with dementia. Presentations on Alzheimer Europe’s recommendations for quality care at the end of life and the assessment of quality of life in dementia followed. The second day’s plenary session was dedicated to the findings of Alzheimer Europe’s recent European Collaboration on Dementia (EuroCoDe) in the areas of prevalence, prevention, diagnosis and



treatment, non-pharmacological interventions, socio-economic cost and social support systems for dementia.

Throughout the two days delegates had a wide range of parallel sessions from which to choose. The final session “prioritising dementia” considered how the different stakeholders were acting to improve the situation of people with dementia and their carers and included Professor Joël Ménard, the author of the French Alzheimer Plan, who explained that the Plan is novel in that its governance is based on transparency and a direct reporting line to the French President. Mike Splaine from the US Alzheimer’s Association, spoke of how the US is addressing dementia and Peter Ashley, who has dementia, presented with pride the English Dementia Strategy and the role of people with dementia in its development. Bringing great encouragement that the work to make dementia a priority continues, was Nick Fahy from the European Commission. Mr Fahy emphasised the role of the Commission in coordinating action among Member States to avoid duplication, assist early intervention and facilitate best practice as well as exercise leadership to support and raise the level of health throughout Member States.

For the first time ever, Alzheimer Europe was delighted to be able to offer some complimentary tickets to people with dementia. One of the recipients, Stewart Cooper, who has dementia, said of the conference that he “was amazed at the number of people attending, representing so many institutions throughout Europe, including the UK” finding “the depth of research by all these dedicated people (to be) amazing.”

Feedback on the two days was positive, with delegates saying that they found the programme to offer informative, interesting and comprehensive presentations; Indeed, some delegates found they were spoilt for choice with the parallel sessions as they said they would have liked to have been able to attend all of them! The bar for next year’s conference in Luxembourg is set!

## Alzheimer Europe Networking

On 1, 6 and 14 April (Luxembourg, Luxembourg) Jean and Julie met with publishers **Binsfeld** to discuss issue 3 of the Dementia in Europe magazine and conference publications.

On 2 April (Brussels, Belgium), Annette attended the **meeting organised by Christopher Fjellner**, MEP, with representatives of patient organisations to discuss the Commission’s legislative proposal on information to patients.

On 3 April (Luxembourg, Luxembourg) Jean attended the **Dementia Ethics Network Steering Committee** meeting.

On 3 April (Luxembourg, Luxembourg) the Steering Committee of the Dementia Ethics Network met in Luxembourg.

On 15 April (Brussels, Belgium), Annette attended the **Carers Interest Group meeting** in the European Parliament to discuss the Commission’s Green Paper on the healthcare workforce.

On 16 April (Luxembourg, Luxembourg) Petra Wilson from **Cisco** visited the Alzheimer Europe offices in Luxembourg.

- On 20-21 April (Barcelona, Spain) Jean attended the **Recognition Programme** organised by Eisai/Pfizer.
- On 24 April (Brussels, Belgium) Jean met with Lukas Pfister and Ann Peeters from Merck Sharp & Dohme.
- On 27 April (Luxembourg, Luxembourg) Jean and Julie met with **Visual on line** to finalise new website design.
- On 28 April (Stockholm, Sweden) Jean attended a preparatory meeting for the **Swedish Presidency Conference on Dignity of the Elderly**
- On 30 April (Brussels, Belgium) the **organising Committee of the 19th Alzheimer Europe Conference met in Brussels.**
- On 5 and 6 May (Paris, France) Jean attended the peer review organised by the European Commission. The peer review was dedicated to a comparison and analysis of Member States' initiatives with regard to behavioural problems at home.
- On 7 May (Luxembourg, Luxembourg) Jean and Julie met with publishers **Binsfeld** to sign off issue 3 of the Dementia in Europe magazine and conference publications.
- On 7 May (Luxembourg, Luxembourg) Jean and Julie met with publishers **Binsfeld** to sign off issue 3 of the Dementia in Europe magazine and conference publications
- On 17 May (Luxembourg, Luxembourg) Jean and Julie met with **Visual on line** to see a preview of how the website will work.
- On 18 May (Brussels, Belgium) Jean and Annette met **with A. Montserrat**. At the meeting Mr. Montserrat gave an overview of the Commission's plans for an upcoming Alzheimer's initiative.
- On 19 May (Brussels, Belgium) Annette had a meeting with A. Chidgey and V. Combe (UK Alzheimer Society).
- On 25 May (Brussels, Belgium) Annette met F. Macchia (Eurordis) to **discuss Commission's proposal on information to patients.**
- On 28 May (Brussels, Belgium) the staff of Alzheimer Europe attended the **AE Board meeting and General Assembly meeting.**
- On 29-30 May (Brussels, Belgium) the staff of AE attended the **Annual Conference.**
- On 2 June (Vienna, Austria) Jean met with representatives from Baxter.
- On 24-26 June (Barcelona, Spain) Jean attended a meeting on caregiver interventions organised by Lilly.

## European developments

### 25 March 2009: Pharmaceutical Forum meeting: delivering for patients

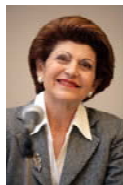
The European Commission organised a meeting to move forward the principles agreed during the Pharmaceutical Forum. Under the title *'Pharmaceutical Forum: delivering for patients'*, the Commission and the stakeholders involved in the 3 themes (information to patients, health technology assessment, pricing and reimbursement) presented recommendations and the deliverables of the process.

The first deliverable was the process itself that gathered various parties having potentially diverging interests. The second deliverable was the adoption of conclusions and recommendations for direct implementation and/or further improvements. The last deliverable has provided directions for future work.

It is now the role and responsibility of the Member States to actively take forward the agreed recommendations and report on their

efforts. An evaluation of the process will be made in two years time.

### 26 March 2009: Health Commission speech on ageing and population at the 7<sup>th</sup> European Business Summit



Health Commissioner, Androulla Vassiliou, addressed the 7<sup>th</sup> European Business Summit with a speech 'Ageing and health: who will pay for the grey?'

In her speech, the Commissioner highlighted the impact of an ageing population on Europe's health systems.

The Commissioner stressed the need for the health systems to provide a greater focus on the prevention and treatment of chronic diseases. She also advocated the importance to pool and use resources more efficiently.

She presented how EU action could provide economies of scale, pool expertise and resources, avoid duplication of Member States efforts. This can improve cost-efficiency in health spending.

In relation to the economic crisis, the Commissioner insisted that there is sufficient



investment in public health now as part of a broader economic stimulus agenda.

### 31 March 2009: EP Health and Environment Committee votes on patients' rights in cross border healthcare

MEPs voted on John Bowis' (EPP-ED, UK), pictured below, report on the rights of patients in cross border healthcare.



The MEPs agree the proposal is about patients and their mobility within the EU, not about the free movement of service providers and that it fully respects the national competences in organising and delivering healthcare. It does not oblige

health care providers in a Member State to provide health care to a person from another Member State. The new directive will not affect current patient rights, which are already codified under another EU regulation, or the regulations on the co-ordination of social security systems.

MEPs agree that patients have the right to seek health care abroad, but that Member States may nonetheless choose to introduce – under certain conditions - a system of a prior authorisation for the reimbursement of the costs of hospital care. The Committee wants Member States (instead of the Commission) to define what is hospital care. The prior authorisation requirement must not create an obstacle to the freedom of movement of patients.

MEPs agree with the general rule that patients are to be reimbursed up to the level they would have received in their home country. The Member States may decide to cover other related costs, such as therapeutic treatment and accommodation and travel costs.

The MEPs also added a provision that Member States may offer their patients a system of voluntary prior notification. In return, reimbursement would be made directly by the Member State to the hospital of treatment. The Commission is to examine whether a clearing house should be established to facilitate the reimbursement of costs.

We provide full references to articles on our website  
[www.alzheimer-europe.org](http://www.alzheimer-europe.org)

The committee added special rules for patients with rare diseases and disabilities that might need special treatment. Patients affected by

rare diseases should have the right to reimbursement even if the treatment in question is not provided for by the legislation of their Member State. Special costs for persons with disabilities must also be reimbursed under certain conditions.

To improve patient's confidence in cross-border health care, they must receive appropriate information on all important aspects of cross border health care (level of reimbursement, right of redress in the event of harm caused). The MEPs agreed that national contact points shall be established. They also proposed the establishment of a European Patients Ombudsman, to deal with patients' complaints with regard to prior authorisation, reimbursement of costs or harm once all complaint options within the relevant Member State have been explored.

Long term care and organ transplantation are excluded from the directive. The vote in plenary will take place in May.

### 1 April 2009: EP Health and Environment Committee backs A. Trakatellis report on the Council recommendations in the field of rare diseases



Antonios Trakatellis (EPP-ED, Greece) report on the Council recommendations in the field of rare diseases received an overwhelming backing of his colleagues.

The European Commission is now called to submit an implementation report by the end of 2012, covering a number of specific points.

The Member States are called to encourage, possibly with European Union funding or co-funding, centres and hospitals of expertise to create specific training for professionals, declare whether they have any specialised centres and compile a catalogue of experts, include provisions aimed at fostering research in the national plan for rare diseases.

### 1 April 2009: EP Agriculture Committee votes on Directive on the use of animals in clinical research

The Agriculture Committee adopted Neil Parish's (EPP-ED, UK) report on the use of animals in clinical research.



The MEPs amended the Directive to make it more balanced and enable medical research in Europe to go ahead.

The report bans the use of great apes (chimpanzees, bonobos, gorillas and orangutans) except for experiments intended to conserve these species who are threatened by extinction.

The report promotes the use of fewer primates without compromising the fight against serious diseases. Although the report supports the use of second-generation specimens born in laboratories to end the capture of wild animals, it has concerns over the possibility to set up such colonies and the sufficient supply of these animals. The report therefore asks the Commission to carry out feasibility studies. In the meantime, a 10-year transition period is requested.

The report also defined and classified the three categories of pain inflicted to the animals during a test. Animals undergoing 'moderate pain' tests would be re-used.

More efforts must be made to devise alternative methods to reduce the number of test on animals and the MEPs ask for the expansion of the role of the European Centre for the Validation of Alternative Methods.

The MEPs call for more transparency of the test performed and prevention of red tape.

Larval forms and embryonic or foetal forms other than mammals will not be covered by the Directive.

Drcar Murko report in the Health and Environment Committee was voted against in February. The vote in plenary will take place during the week of 4-7 May.

### 2 April 2009: EP backs anti-discrimination Directive

MEPs voted in Plenary on Kathalijne Buitenweg's (Greens/EFA, NL, pictured below) report on the anti-discrimination Directive. The Directive is intended to reduce discrimination on grounds of religion or belief, age, disability or sexual orientation, whether direct or indirect, and whether based on real or presumed criteria.

The directive will apply to social protection and health care, social benefits, education and access to goods and services, including housing.

The Directive has no impact on matrimonial law or the secular state. Member States retain responsibility for the organisation and content of education. They are not precluded from taking steps to prevent or compensate for disadvantages (such as positive action or quotas) or



from allowing such measures to be taken by the public, private or voluntary sectors. Advertising and media sectors are to be excluded from the scope of the directive.

The Directive equals harassment to discrimination. However, the concept of harassment must be defined in accordance with national law and the practices of Member States.

MEPs want the Directive to cover transport, telecommunications, information, financial services, culture and leisure. Efforts at "reasonable accommodation" of the needs of people with disabilities (for example: wheelchair, access to buildings) must be made or alternative solutions found where appropriate. Such measures must not impose a "disproportionate burden" nor require a fundamental change in the nature of the goods and services.

Risk factors related to disability and age used in the insurance and banking industries should not be regarded as discrimination as they are a determining factor for the assessment of risk. However, MEPs call for service providers to demonstrate the risks precisely.

Differences of treatment on grounds of age may be accepted if legitimate (sale of alcohol, weapons or granting of driving licences). But young people with disabilities must also have access to favourable terms and conditions such as free or reduced tariffs for the use of public transport, museums or sport facilities.

This Directive completes three other directives: one on discrimination based on racial or ethnic origin, both within and outside the labour market; one on discrimination on the labour market; and one on equal treatment between men and women. All these goals were reaffirmed in the Buitenweg report.

### 2 April 2009: European Parliament supports derogation for MRI from scope of EMF Directive

Frédérique Ries' (ALDE – Belgium) own-initiative report on health concerns associated with electromagnetic fields which calls for a derogation for Magnetic Resonance Imaging (MRI) from the scope of Physical Agents 2004/40/EC Directive on electromagnetic fields was adopted.



#### Notes

FICETTI Consortium is currently carrying out a stakeholder consultation to inform the European Commission's impact assessment

prior to determining if and how to propose an amendment to Directive 2004/40/EC (EMF).

The Swedish EU Presidency will hold a conference on the future of Directive on 6-8 October.

### June 2009: European Commission calls for proposals for transnational actions on social experimentation

The European Commission's call for proposals (VP/2009/005) will support innovative social projects in the areas of social inclusion and social protection.

The call is part of the PROGRESS funding programme. It seeks to promote social experimentation as a source of innovation in the field of social policies falling within the Open Method of Coordination applied to social protection and social inclusion in the EU.

The projects will need to contribute to developing innovative social policies in key areas of the European strategy for social protection and social inclusion. These could include, inter alia, quality and viability of health care and long-term care.

The call should intensify mutual learning and facilitate the adaptation of public policies to evolving social needs and improving their governance.

Particular attention should be given to the issues of governance, evaluation and dissemination.

The deadline for the submission of applications is 1 September 2009.

### 9 June 2009: Council Recommendation on patient safety, including the prevention and control of healthcare associated infections

At its Employment, Social Policy, Health and Consumer Affairs meeting, the Council produced recommendations in the field patient safety, including the prevention and control of healthcare associated infections.

The Council issued general patient safety recommendations:

- 1) the establishment and development of national policies and programmes on patient safety
- 2) the empowerment and information of citizens and patients
- 3) the establishment or strengthening of blame-free reporting and learning systems on adverse events

- 4) the promotion, at the appropriate level, of education and training of healthcare workers on patient safety
- 5) the classification and measurement of patient safety at Community level, by working with each other and with the Commission
- 6) the sharing of knowledge, experience and best practice by working with each other and with the Commission and relevant European and international bodies
- 7) the development and promotion of research on patient safety.

The Council also issued additional recommendations on the prevention and control of healthcare associated infections:

- 1) the adoption and implementation of a strategy at the appropriate level for the prevention and control of healthcare associated infections
- 2) consider the establishment of an inter-sectoral mechanism or equivalent systems corresponding to the infrastructure in each Member State, collaborating with, or integrated into, the existing inter-sectoral mechanism on the prudent use of antimicrobial agents in human medicine.

Finally, the Council recommends to:

- 1) disseminate the content of this Recommendation to healthcare organisations, professional bodies and educational institutions and encourage them to follow the approaches suggested therein so that its key elements can be put into everyday practice
- 2) report to the Commission on the progress of the implementation of this Recommendation and subsequently on request by the Commission with a view to contributing to the follow-up of this Recommendation at Community level.

We provide full references to articles on our website  
[www.alzheimer-europe.org](http://www.alzheimer-europe.org)

### 9 June 2009: Council Recommendation on action in the field of rare diseases

At its Employment, Social Policy, Health and Consumer Affairs meeting, the Council produced recommendations in the field of rare diseases.

The Council recommends:



- 1) the establishment and implementation of plans or strategies for rare diseases
- 2) an adequate definition, codification and inventorying of rare diseases
- 3) research in rare disease
- 4) centres of expertise and European reference networks for rare diseases
- 5) the gathering the expertise on rare diseases at European level
- 6) the empowerment of the patient organisations
- 7) the sustainability of infrastructures developed in the field of information, research and healthcare for rare diseases.

### 22 June 2009: A new political group in the European Parliament: the European Conservatives and Reformist

The British Conservatives have fulfilled their pledge not to join the EPP group but to form a new "anti-federalist" political group in the EP: the European Conservatives and Reformists. This group is now likely to be the fourth largest group in the EP.

The UK Tory faction will be its biggest single national element (26 MEPs). It also includes Poland's opposition Law and Justice party (15 MEPs) and the Czech Republic Civic Democratic party (ODS) with 9 MEPs. It will also comprise one member from Belgium's Lijst Dedecker, the Centre party (Keskusta) in Finland, the Hungarian Democratic Forum (MDF) and Latvia's For Fatherland and Freedom/LNNK party.

The new Tory group is bound by a declaration of 10 principles based on "Euro realism" and the sovereignty of nations.

### 23 June 2009: Schulz re-elected Socialist leader in EU Parliament

Martin Schulz, MEP for Germany, was re-elected leader of the socialist group in the European Parliament by 144 of the 160 members.

The group has also agreed on an interim name for the group: the Progressive Alliance of Socialists.

At the same meeting, group announced it had formally integrated the Italian Partito Democratico into its ranks.

### 23 June 2009: EPP Group in the European Parliament elects its Chairman and Vice Chairmen

Joseph Daul has been re-elected Chair of the EPP (European People's Party) Group by 225 of the 228 Group members voting. Joseph

Daul, MEP for France, has chaired the Group since January 2007.

On the same day, the following MEPs were elected as Group Vice Chairmen: Vito Bonsignore (Italy), Rumiana Jeleva (Bulgaria), Othmar Karas (Austria), Ioannis Kasoulides (Cyprus), Marian Jean Marinescu (Romania), Jaime Mayor Oreja (Spain), Paulo Rangel (Portugal), József Szajer (Hungary), Manfred Weber (Germany), Corien Wortmann-Kool (Netherlands).

The EPP Group is the largest political group in the European Parliament with 264 Members from 26 Member States.

## Other European developments

### 19 March 2009: Mental Health Europe welcomes the Written Declaration on the Protection of Human Rights in Closed Institutions

The NGO, Mental Health Europe (MHE), has sent an open letter to the Members of the European Parliament in support of the Written Declaration on the Protection of Human Rights in Closed Institutions. MHE draws attention to the fact that "every day, being closed doors and beyond any control, people with mental health problems are deprived of even their basic human rights". The Declaration calls for the systematic inspection of closed institutions not only by official bodies, but also by groups of citizens and MHE calls upon MEPs for their "commitment and support to promote a coordinated EU policy for human rights in closed institutions".

### May 2009: Health equity website launched

EuroHealthNet has launched [www.equitychannel.net](http://www.equitychannel.net), a website which aims to:

1. bring about the changes to ensure health equity for all,
2. stimulate and support changes in policies at international, national and local levels, and
3. bring together involvement from people from all backgrounds and communities.

### 18 May 2009: European Pact on Mental Health and Well-being newsletter launched

The EC has launched a newsletter on the progress to date and implementation of the European Pact on Mental Health and Well-

being. It has been prepared by the technical of MH Basis at Gencat (Government of Catalonia, Spain), in collaboration with the European Commission's DG Health and Consumers. The first newsletter contains:

1. Introduction and background: Launch of the European Pact on Mental Health and Well-being.
2. Implementation of the pact, after the high level conference.
3. Mental health in youth and education priority area thematic conference.
4. Call for action: How you can get involved in the process ...
5. Latest news and events.

## Policy Watch

### 6 March 2009: Warning issued for people using transdermal drug patches who undergo MRI scans

The US Food and Drug Administration (FDA) has warned of the risk of skin burns in people wearing transdermal drug patches who undergo MRI scans. Amongst other things, patches may be used to administer medication, including medication for people with dementia. The problem lies in the fact that around a quarter of all patches on the market contain metal and these can overheat during the MRI scan, resulting in some people suffering burns. The FDA are currently reviewing product labels to check that they carry a warning and are considering how it might be possible to have a MRI warning actually on the patch itself. In addition, they advise people who have a patch when they undergo a MRI to inform their doctor at the point of referral, when they actually make their MRI appointment as well as informing the facility when they arrive for the scan.

### 18 March 2009: Trial launched for use of tracking devices with people with dementia

To help people with dementia to have more freedom to go out safely, a National Health Service (NHS) trust is to fit Global Positioning Systems (GPS) to 20 people with dementia. This is the first trial of its kind in Britain, with the tracking device monitoring movements on a map.

### 28 May 2009: Scottish government announces a national dementia strategy

The Scottish Government has announced that their dementia strategy will "build" on the recommendations in the recently published Mental Welfare Commission and Care Commission report for the improvement of care in care homes for people with dementia.

Although the Government announced that Dementia was to be a national priority in 1997, the recent report has highlighted serious shortfalls in the care of people with dementia. Public Health Minister, Shona Robison said: "This is a deeply shocking report. That's why we will accept all the recommendations... Our dementia strategy will build on this, recognising that there is much more that can be done. The strategy will ensure we deliver the dementia care that people need and deserve."

A wide-ranging consultation process has already begun to ensure the Strategy will be "Comprehensive, with the necessary investment to make it truly successful in meeting the needs of the many people affected by dementia across Scotland" said Henry Simmons, the Chief Executive of Alzheimer Scotland.

### 17 June 2009: UK report on dementia care finds that high quality dementia care is not yet provided

The All-Party Parliamentary Group (APPG) on Dementia has published its findings from its inquiry into the dementia care skills of care home staff and staff supporting people with dementia living in their own homes in the report "Prepared to care: Challenging the dementia skills gap".

The Group examined "the readiness of the social care workforce to deliver personalised care to people with dementia" and found that on the whole, the social care workforce is not yet ready to provide high quality dementia care as the workforce has a very limited knowledge of dementia. Whilst the Group found some examples of excellent practice, they also found examples of poor practice, with the proportion of staff receiving dementia care training being low. Barriers to workforce development were found to be negative attitudes toward dementia, a significant under-recognition of dementia (and hence inaccurate assessment of training needs), poor employment terms and conditions and a lack of career opportunities.

The APPG made 7 recommendations, calling for the

- Prioritising of objective 13 of the National Dementia Strategy for England, namely, an informed and effective workforce for people with dementia
- Shift to a situation where the workforce as a whole demonstrates effective knowledge and skills in caring for people with dementia
- Careful design of workforce development programmes so that the

needs of care staff are met and the lives of people with dementia are improved

- Regulation of dementia care trainers to combat current inequalities in quality
- Greater recognition of the level of skill required to provide good quality dementia care as well as the importance of maximising the quality of life of individuals who develop dementia
- The development of effective working relationships between commissioners and service providers, based on good knowledge of what good dementia care is and what is required to provide it
- Well-integrated working between social care and healthcare.

## Members' News

### 7 April 2009: Alzheimer Society's campaign encourages people to seek help

Aiming to address the under-diagnosis of dementia, the Alzheimer Society launched their "Worried about your memory?" campaign in 2008. Follow-up research as shown that of the respondents who requested the "Worried about your memory?" booklet, nearly 40% said that they sought help earlier than they would have otherwise done and that "1 in 5 received a diagnosis as a result of taking action. In addition, 1 in 7 GPs have noticed more people asking about memory problems since the launch of the campaign."

Neil Hunt, Chief Executive of the Alzheimer's Society said of the campaign that "the fact that the "Worried about your memory?" campaign is making an impact is hugely encouraging and shows how providing information can help change lives."

**We provide full references to articles on our website**

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

### 14 April 2009: Alzheimer's Society launches free guidance on delivering the National Dementia Strategy for England

"Dementia: What every commissioner needs to know" has been published by the Alzheimer's Society with the aim to "help commissioners of health and social care services who need to

understand how to effectively commission services for people with dementia and their carers in line with the National Dementia Strategy for England." The booklet covers:

- A description of dementia
- The prevalence and projections of the numbers of people with dementia
- The costs and quality of dementia care
- The National Dementia Strategy for England
- Implementation of the Strategy "against broader commissioning goals"
- Steps to help local commissioners respond to the Strategy
- How the Alzheimer's Society be of assistance.

### 29 April 2009: Heike von Lützu-Hohlbein awarded the Cross of Merit on ribbon of the Order of Merit of the Federal Republic of Germany

Heike von Lützu-Hohlbein, chair of the German Alzheimer Association (Deutsche



Alzheimer Gesellschaft) was presented with the Cross of Merit by Social Minister of Bavaria, Christine Haderthauer in Munich. The Minister stated, "With over 20 years of service to people with dementia, you have certainly earned it. For your outstanding performance the Federal President has awarded you the Cross of Merit on ribbon."

Heike von Lützu-Hohlbein has been on the board of the Deutsche Alzheimer Gesellschaft since 1990, was a founder of the German Alzheimer Foundation, was treasurer of the Deutsche Alzheimer Gesellschaft for many years and is currently honorary treasurer of Alzheimer Europe. On presentation of the award, Ms von Lützu-Hohlbein declared that she was very pleased to receive this honour and that she accepted on behalf of the many volunteers who through self-help groups and Alzheimer societies help improve the situation of more than a million people with dementia and their relatives. She pointed out that 20 years ago there was practically no support for people with dementia and their carers, that much has been done but that there is still a lot to do. She concluded by saying that the award gave her the strength to carry on.

### 4<sup>th</sup> May 2009: Alzheimer Portugal opens Documentation Centre

Alzheimer Portugal is offering a new service open to both its members and also the general

public: The Alzheimer Portugal Documentation Centre. The Centre is open five days a week (10h00 – 16h30), facilitating the research of Alzheimer's disease and other types of dementia by way of documentation, books and magazines. It is also possible to watch movies and search other materials related to Dementia. The Centre also hosts a historical archive of the Association and offers free access to the internet.



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**11 May 2009: Alzheimer's Society welcomes a new Vice-President and Ambassador**



The Alzheimer's Society has welcomed David Blunkett (Member of Parliament) as their new Vice-President and Graham Browne (who lives with Pick's disease) as a new Ambassador. Former Home Secretary, Mr Blunkett has been a long-time support of the Society.



Mr Browne has spoken of his experience of living with Pick's disease at the launch of the Alzheimer Society's "Dementia Out of the Shadows" report. He also attends the Living with dementia volunteer meetings and is on the committee of the Towner Club for younger people with dementia in Brighton.

**15 May 2009: The Swiss Alzheimer Association hold a media conference on the need for a Swiss dementia strategy**



The Association Alzheimer Suisse highlighted the need for a Swiss dementia strategy at their press conference. They presented their Manifesto "Priority Alzheimer" which had been signed by 15,000 people, to the Federal Counsellor, Couchepin. Switzerland has 104,000 people with dementia and this is expected to increase to 300,000 by 2050 and the Manifesto includes calls for the promotion of early detection as well as the widening of the range of, and the availability of, care and support for all people with dementia and emphasises the need to help people with dementia to remain in their homes.

National Counsellors, Jean-Françoise Steirert, and Reto Wohrli, will present two motions during the summer session with the aim of forcing the Federal Council to act and to raise awareness that Switzerland needs a national Alzheimer policy.

**18<sup>th</sup> May 2009: Alzheimer Portugal's Day Care Centre extends its services**

The Alzheimer Portugal Day Care Centre now offers an additional service, that of Home Care Support. This service is offered from late afternoon until mid-evening (16h00 to 21h00) and enables Alzheimer Portugal to help people with dementia and their carers. Services offered include the provision of meals, hygiene assistance as well as company and support for daily life activities, which are carried out by occupational therapists and physiotherapists.

This new service is of great benefit for carers who are unable to be with their relatives with dementia during that schedule as well as for those who are unable to pay the high prices of private home care companies.

**22 May 2009: Alzheimer Scotland launches TV advert for its Dementia Helpline**

Alzheimer Scotland launched its first-ever TV advert in the Glasgow Film Theatre, Scotland. The advert will be shown on TV from Monday 25 May until late June 2009 in order to raise awareness of Alzheimer Scotland's 24 hour, free-phone Dementia Helpline (0808 808 3000). One caller said, "It's invaluable to people like myself. I am caring for my husband who has dementia and I am also working full-time. We have not family, so I have no-one to talk to or share the caring. Sometimes it all gets too much and then, it is then that I call the helpline."

**25 May 2009: The Maltese Dementia Strategy Group launched**



Mr Mario Galea, (pictured left) Parliamentary Secretary for the Elderly and Community Care, Malta, launched the Maltese Dementia Strategy Working Group. The aim of the Group is to develop a national strategy on dementia which would consist of a strategy plan for improving the planning and development of future dementia care services in the Maltese islands.

**30 May 2009: Czech Alzheimer Society relaunches their newsletter**

The Czech Alzheimer Society has relaunched "Dragonfly", their quarterly newsletter. It covers



Czech, European and Worldwide news on dementia. The first (relaunched) edition carries news about the wife of the Czech Prime Minister, who has declared her interest in the work done for senior citizens. The newsletter is disseminated by e mail but will also be available on their website.



**1 June 2009: Alzheimer Scotland launches Dementia Awareness Week 2009**

With the aim “to change attitudes, both in service provision and in the world at large” (Kate Fearnley, Alzheimer Scotland’s Director of Personalisation), Alzheimer Scotland’s 2009 conference challenged participants to “think about dementia services in new ways, from support after diagnosis through to improving end of life care.” Attended by some 400 delegates, the conference addressed “best practice in dementia services and how to put people with dementia and their carers in control, so that those services fit better with their lives.”

We provide full references to articles on our website  
[www.alzheimer-europe.org](http://www.alzheimer-europe.org)

**June 2009: Programme to promote the prevention and early diagnosis of dementia completed by the Athens Association of Alzheimer’s Disease and Related Disorders in collaboration with the Athens Municipality**

The “Help My Memory” project was launched two years ago by the Athens Association of Alzheimer’s Disease and Related Disorders in collaboration with the Athens Municipality.



With a support team of 30 people made up of health professionals, neurologists, psychiatrists, psychologists, social workers, staff and volunteers the programme was able to include on site:

- Presentations on memory and its disorders
- Expert-performed memory screening tests and doctors available for consultation
- Regular, cognitive-enhancement sessions in fixed groups for normal elderly, MCI or early-stage dementia patients

- Support groups for carers.

These services were offered free for members of the 20 Municipal Recreation Elderly Clubs of the City of Athens.

By the end of the programme, 4000 elderly people had been screened for memory problems and ten groups (each made up of ten people) received cognitive training/memory exercises for normal elderly, people with MCI or early-stage dementia.

**11-13 June: The Alzheimer Society of Finland participates in the 5th Kuopio Alzheimer Symposium**



The 5th Kuopio Alzheimer Symposium, which was organised by The Finnish Alzheimer’s Disease Research Society, gathered 250 scientists and clinicians from 14 countries. The programme consisted of new exciting data concerning frontal dementias, early diagnosis, symptomatic treatment and emerging disease modifying treatment options including dietary interventions and rehabilitation of dementia. In the poster session the Alzheimer Society of Finland presented its work and role as an intermediary between the scientific world and everyday practice in the prevention process (see photo above – Pekka Laine talks about the work of the Society). New data about caregiver depression was also presented in the Symposium by researcher Tarja Välimäki from Kuopio University. The data has been gathered as a part of the multidisciplinary intervention project “Alsova”, in which the Alzheimer Society of Finland also participated.

**17 June 2009: French Court of Auditors pleased by the “professionalism and management” of France Alzheimer’s accounts**

The French Court of Auditors has published the results of its new audit of the Association France Alzheimer. The Court noted that its earlier recommendations to the French Alzheimer Association had been taken into account and the Court was pleased with the professionalism and management of the association. Further, the Court noted that France Alzheimer “in particular made the best of its role as a Union and mobilised to bring about ambitious plans”. The 5<sup>th</sup> President of the Chamber of the Court, Mr Jean-Pierre Bayle, said that the Court was “generally satisfied and that donors should be too”.

**June 2009: New edition of Alzheimer Portugal Newsletter launched**





Alzheimer Portugal have updated and enhanced their newsletter, increasing the publication from eight to twenty eight pages. This allows for the inclusion of new themes, more illustrations and as well as ensuring the presentation is

reader-friendly by, amongst other things, increasing the font size.

Pedro Neves of Alzheimer Portugal explained the importance of the newsletter to the organization when he said "The use of communication tools (printed and online) is very important in order to raise awareness and spread the message of our Association to people with Alzheimer's Disease, their carers, doctors and students of the disease. The newsletter is also an efficient and fast way to get more support for our cause"

#### **24 June 2009: France Alzheimer launches television campaign**

In order to raise awareness about Alzheimer's disease and related diseases, the Association France Alzheimer have launched 30-second information slots. These depict situations in which people with Alzheimer's disease may find themselves in, and the difficulties faced, including behavioural disorders and disorientation. It also highlights the difficulties carers face.

The Association would like to thank all who worked on this clip, including comedians, actors, technicians of the agency Saatchi & Saatchi and the director, Nacho Gayan, all of whom gave their time free of charge.

#### **June 2009: Two new consulting centres for people with dementia and their carers to open in Bulgaria**

Foundation Compassion Alzheimer Bulgaria and Alzheimer Bulgaria are delighted to announce plans to open two consulting centres, one in Sofia and the other Varna. The teams at the centres will include a psychologist, social worker and legal adviser who will support people with dementia and their carers and it is the first time in Bulgaria that such centres exist. The centres will be part-funded by the Ministry for Labour and Social Policy, (following a successful application by the two Bulgarian associations) for a six-month period (from June until the end of 2009).

#### **22 June 2009: The impact of the national Dutch dementia care programme assessed**

According to new results from Alzheimer Nederland, informal carers remain heavily burdened and do not feel the effect of the

national Dutch dementia care programme, which was launched last year and should be implemented nationwide by 2011. The lack of impact felt by carers has received coverage on the television, national newspapers and radio, creating much debate in Holland. The Parliament will also discuss this problem.

#### **24 June 2009: France Alzheimer dedicates area on website to people with dementia**

France Alzheimer's has launched an area on their website (<http://www.francealzheimer.org>) which is dedicated to people with dementia and offers four sections:

- "Listening to you"
- "helping you to have a better life" gives general advice and tips for communicating with friends, activities and organising their surroundings
- "get help" provides an overview of the medical, social and legal aid available and
- "you have the floor" enables people with dementia to share their experience of dementia in the form of stories, poems, etc in the hope that the feeling some have of isolation is prevented.

#### **25 June 2009: New tissue and brain bank supported by France Alzheimer**

The official opening of the Platform of Biological Resources took place in the Hospital "Pitié Salpêtrière", Paris, France on 25 June. Tissue and brain banks enable research into the human brain which are essential to better understand neurodegenerative diseases. Samples are needed from people with disease as well as those without.

France Alzheimer, together with France Parkinson, initiated this project in 2006 when they decided to unite their efforts to build a common structure and share costs. This resulted in the formation of an economic interest group – GIE Neuro-CEB, which the Association for Research on Multiple Sclerosis and the Association for Knowing Cerebral Syndromes have since joined. France Alzheimer alone has already committed EUR 100,000 to the development of this bank. The Platform has received financial support from the Foundation IFRAD and the Federation of Brain Research through resources from the Rotary International.

## Science Watch

### April 2009: Phase III highest dose testing of bapineuzumab halted

A risk of developing vasogenic oedema has resulted in Wyeth and Elan's Phase III testing of the highest dose of bapineuzumab being stopped but participants taking the lower doses are not considered at risk. The trial is expected to continue just for the lower dosage groups subject to amendment of the study protocol. New participants will be enrolled for the lower doses and those who were previously on the higher dosage may be able to switch to a lower dose.

We provide full references to articles on our website

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

### 9 April 2009: Heightened activity in the hippocampus may be early warning sign for dementia

A study carried out at the University of Oxford (UK) using brain scans has found that healthy young people carrying the APOE  $\epsilon$ 4 allele had increased activity in the hippocampus (the part of the brain that deals with memory) even when at rest. APOE  $\epsilon$ 4 has been associated with increased risk of developing Alzheimer's disease although not everyone with this rogue gene will do so. Whilst this finding may eventually lead to a predictive test, Dr Peter Nestor from the University of Cambridge points out that the results should not be over-interpreted as signifying that the young, health volunteers were already starting to develop Alzheimer's disease.

### 13 April 2009: New technique devised which allows for observation of nerve cell death

Researchers in Germany have developed an animal model in which it is possible to trace the death of neurons. By inserting a gene which leads to a severe form of Alzheimer's disease (in humans) into zebrafish, (which are optically transparent), researchers were able to observe changes in the cells using imaging techniques. They say that they are hopeful this will enhance the understanding of the disease and consequently better target the development of drugs.

### 14 April 2009: Eye test for mild cognitive impairment developed

Researchers from Emory University, USA, find that people with mild cognitive impairment (MCI) reacted differently to images than people

without MCI. By showing people an image, then after a delay, another image and repeating this process several minutes later, researchers found that "people with MCI spent less time looking at the new picture than control subjects." The researchers believe that this is similar to people with Alzheimer's disease, "who look at both images equally because they cannot remember seeing the first image." Tracking and observational studies on the participants are planned to see if they develop dementia.

### 14 April 2009: Review looks at the use of feeding tubes for people with advanced dementia

A Cochrane review which looked at the benefits of using feeding tubes (either by using nasogastric tubes or via a percutaneous endoscopic gastrostomy) with people with advanced dementia found a lack of evidence to suggest that they are beneficial. Effectiveness was said to be inconclusive in terms of "prolonging survival, improving quality of life, or leading to better nourishment or decreasing the risk of pressure sores." The authors noted that such conclusions do not mean that tube feeding is unsuitable for every person with advanced dementia, rather that there is lack of evidence to show the benefits and insufficient data on the adverse effects of intervention.

### 14 April 2009: Potential Alzheimer drug completes phase I trial

The drug SUVN-502 has successfully completed its phase I trial with, according to the developing drug company (Suven Life Sciences) "no serious adverse events, no clinically significant changes or study medication related abnormalities observed". It is hoped that the drug will be able to help people with, amongst other things, Alzheimer's disease. Phase IIa trials are planned for the end of 2009.

### 14 April 2009: First clinical trial ends for potential drug to prevent plaque formation

A new drug "CPHPC" which was tried on five people for three months, seemingly without side effects, was found to remove SAP, a blood protein thought to be involved in the formation of plaques associated with Alzheimer's disease. A larger trial is now planned. The research was published on-line in the Proceedings of the National Academy of Sciences and carried out by scientists from Italy and the UK.

**15 April 2009: Phase 3 trial of Alzheimer's drug planned**

Drug companies Pfizer and Medivation have announced a 12-month, phase 3 clinical trial aimed to "evaluate the safety and efficacy of Dimebon, when added to ongoing treatment with donepezil HCl tablets" (which are used for people with mild to moderate Alzheimer's disease). Entitled "CONCERT", the study will include over 1000 people from the US, Australia, New Zealand and Western Europe who have mild-to moderate Alzheimer's disease.

**15 April 2009: Study examines the variation in blood sugar levels of diabetics and the risk of dementia**

By analysing data for a twenty year period from more than 16,600 people with type 2 diabetes, researchers from Kaiser Permanente, Oakland, California, found that severe episodes of low blood sugar levels in older people with type 2 diabetes may increase the risk of dementia. The study is published in Journal of the American Medical Association.

**22 April 2009: Study examines the effects of non-steroidal anti-inflammatory drugs on Alzheimer's disease**

Contrary to previous studies, new research suggests that the non-steroidal anti-inflammatory drugs (NSAIDs) may increase the risk of Alzheimer's disease. The study which looked at nearly 3000 people over a 12 year-period was carried out in Seattle and has been published in the journal Neurology.

We provide full references to articles on our website  
[www.alzheimer-europe.org](http://www.alzheimer-europe.org)

**22 April 2009: Painkillers may delay, rather than prevent Alzheimer's disease**



A study carried out by the University of Washington, USA, suggests that ibuprofen and naproxen (non-steroidal anti-inflammatory drugs (NSAIDs)) may delay the onset of Alzheimer's disease, but not prevent it. It also found that the risk of developing dementia was higher for people who were heavy NSAIDs users. The research, conducted over a 12 year period, monitored over 2500 people, aged 75 and over, who did not have dementia at the start of the study. As these findings oppose early ones, the researchers have called for earlier studies to be

reinterpreted. The study can be found in American Academy of Neurology.

**22 April 2009: Phase II clinical trial to commence for potential Alzheimer's drug**

Originally used as an anti-cancer chemotherapy, it is now thought that the drug "Byrostatin" may be useful to treat people with Alzheimer's disease. Phase II clinical trials are due to commence following the approval received from the Food and Drug Administration (FDA).

**27 April 2009: Study investigates the effect of fatty acid on memory function in rats**

Oleoylethanolamide (OEA) is a compound which is formed in the small intestine from oleic acids. Research published in the Proceedings of the National Academy of Sciences, found that the memory of rats was improved when a compound known as oleoylethanolamide (OEA) was administered to them and that the effects decreased when "cell receptors activated by OEA were blocked". Further research is required to establish whether OEA could assist people with memory problems.

Researchers from the University of California, University of Rome and the Italian Institute of Technology carried out this study.

**29 April 2009: UK Universities to establish research centres for digital technology**

In order to develop digital technology which will assist the elderly, disabled and people in rural communities, Lord Drayson (Minister for Science and Innovation) has announced an investment into three new research centres (based at Newcastle, Nottingham and Aberdeen universities).



The Newcastle centre's work will include the "ambient kitchen" which includes electronic tags and sensors built into the floors, utensils, appliances, cupboards and work surfaces. Such technology can be used to assist with, for example, preparing a recipe, by detecting a sudden departure from the correct process and projecting helpful advice onto a facing wall.

It is hoped that the development of a wide range of assistive technology will benefit, amongst others, people with dementia by affording a better quality of life, resulting in less pressure on friends and family and a reduced strain on health care resources.

#### **4 May 2009: Study examines the relationship of delirium on Alzheimer's disease**

A study found there to be a "significant acceleration in the slope of cognitive decline following an episode of delirium." The researchers have called for further investigation to determine whether prevention of delirium might delay cognitive decline in people with Alzheimer's disease.

The research was led by Dr Tamara Fong, Beth Israel Deaconess Medical Center, Harvard Medical School, USA.

#### **5 May 2009: Spinal fluid may be potential biomarker of Alzheimer's disease**

A study suggests that cerebrospinal fluid (CSF) levels of A $\beta$  peptide 1-42 (A $\beta$  42), tau and phosphorylated tau (ptau) are potential biomarkers for Alzheimer's disease. Participants had a clinical diagnosis of very mild dementia of the Alzheimer type (DAT) at the time of lumbar puncture. A relationship between the rate of dementia progression and CSF levels was found to exist. Researchers said that "biomarkers of CSF may be useful prognostically and to identify individuals who are more likely to progress for participation in therapeutic clinical trials."

For further information please see "Cerebrospinal fluid biomarkers and rate of cognitive decline in very mild dementia of the Alzheimer type in the Archives of Neurology, (Vol 66, No 5 may 2009) by following the link at: <http://archneur.ama-assn.org/>

#### **7 May 2009: Study examines cancer and Huntington's disease drug on memory function in mice**

Researchers from the Massachusetts Institute of Technology, USA investigated whether the drugs, histone deacetylase (HDAC) inhibitors, affected the brains, behaviour and/or learning of mice. Although the drugs have been used in the treatment of Huntington's disease and some forms of cancer, they have not been used to treat dementia.

The study suggests that the genetically modified mice regained their long-term memory and ability to learn new tasks after taking HDAC inhibitors. Further research has been called for.

#### **11 May 2009: Study examines the relationship between certain dementia drugs and their side effects**

Cholinesterase inhibitors are commonly used to treat dementia. A study on over 80,000

participants examined the relationship between these drugs and their side effects. It found that the use of "Cholinesterase inhibitors is associated with increased rates of syncope (fainting), bradycardia (low heart rate), pacemaker insertion, and hip fracture in older adults with dementia." The researchers concluded that this previously underrecognised risk be weighed against the drugs benefits.

The Study, led by Sudeep S. Gill from the Department of Medicine Queen's University, Kingston, Ontario, Canada was carried out over a two-year period (2002-2004), on 19,803 community-dwelling older adults with dementia who were prescribed with cholinesterase inhibitors and 61,499 controls who were not.

#### **12 May 2009: A tool to assist with the prediction of Alzheimer's disease is being developed**

Researchers from the University of California and the University of Pittsburgh, charged with developing a "late-life dementia risk index", have developed a point system which accurately stratified adults into those with low, moderate and high risk of developing dementia.

#### **13 May 2009: Study examines risk factors for falling in older people with mild to moderate dementia**

Researchers monitored 179 people to assess how to optimise the prevention of falls in people with dementia. Of this group, there was a control group of 39 people, the remainder having one form or another of dementia. The study concluded that the "management of dizzy spells (symptomatic orthostatic hypotension), autonomic symptoms and depression, and the encouragement of physical activity might provide the core elements for the most fruitful strategy to reduce falls in people with dementia."

The research was the result of collaboration between scientists from Newcastle General Hospital, UK, King's College London, UK and Trinity College, Dublin, Ireland.

#### **18 May 2009: Research suggests later retirement age may delay the onset of Alzheimer's disease**

Researchers studied the relationship between lifestyle factors and the onset of dementia by analysing the past education, employment and retirement history of over 1300 people with dementia. Their findings suggest that an extra year of work delayed the onset of dementia by an average of six weeks.

The study was carried out by the Institute of Psychiatry, King's College London and



published in the International Journal of Geriatric Psychiatry.

### **19 May 2009: Study examines relationship between late-life body mass index and dementia**

A study on over 1800 Japanese Americans who had a mean age of 71.8 years and were dementia-free at baseline monitored their body mass index (BMI), waist circumference (WC) and waist to hip ratio (WHR). Researchers found that a "higher baseline BMI and slower declining BMI in late life are associated with a reduced risk of dementia, suggesting the law BMI or a faster decline in the BMI in late life may be preclinical indicators of an underlying dementing illness, especially for those who were initially overweight or obese."

The study was published in the journal *Neurology* (2009;72; 1741-1746) and carried out by researchers from the Universities of Pittsburgh, South Florida and Washington.

### **21 May 2009: Study examines the relationship between vitamin D and cognitive performance**

A study which compared the cognitive performance of more than 3000 men aged 40 to 79 years old found that higher levels of vitamin D are associated with improved cognitive function in middle-aged and older men.

The research, led by Dr David Lee of the University of Manchester, was carried out in eight test centres across Europe by scientists from the University of Manchester, in collaboration with colleagues from other European centres.

### **21 May 2009: Drug company commences Alzheimer's drug tests**

Eli Lilly & Company has announced its plans to start two Phase III clinical trials of their potential Alzheimer's drug, Solanezumab. The trials will last 18 months and participants will take 400mg infusion of Solanezumab or a placebo once every four weeks.

### **June 2009: Study examines whether depression is a predictive measure of Alzheimer's disease and the role of donepezil may have in this process**

A study which examined whether depression in people with amnesic mild cognitive impairment (aMCI) can be a predictive tool for the progression to Alzheimer's disease suggests that depression is indeed a predictive tool in this context. The study further examined whether the drug donepezil can be of benefit in this process and found that treatment with

donepezil could delay progression to Alzheimer's disease among people with aMCI who were depressed.

### **10 June 2009: Study suggests that imaging technology may improve accuracy of dementia diagnosis**

A study suggests that molecular imaging technologies, such as positron emission tomography (PET) scans, can help to diagnose the specific type of dementia a person may have, which in turn will assist with the best provision of care.

The study was carried out by Kirk A. Frey, physician, University of Michigan Hospitals' division of Nuclear Medicine and colleagues and consisted of a review of 66 patients data and PET scans.

### **16 June 2009: Study examines potential biomarker for the early detection of Alzheimer's disease**

A study may have found a diagnostic tool which could identify Alzheimer's disease from normal ageing. Using 63 participants, researchers carried out a near-infrared (NIR) biospectroscopy on blood samples to measure the degree of oxidative stress (OS) in the plasma (OS is involved in many neurological diseases, including Alzheimer's disease). The data enabled the researchers to differentiate sporadic Alzheimer's disease from the normal elderly control group.

### **18 June 2009: Study examines the possibility of taking stem cells from fallopian tubes**

Scientists believe that stem cells have the potential to treat a large number of diseases but that there are practical problems in the sourcing of stem cells. This study wanted to assess the practicality and effectiveness of sourcing stem cells from human fallopian tubes (hFTs).

The study found hFTs, which are discarded after some gynaecological procedures, are a rich additional source of mesenchymal type stem cells and therefore offer a potential source for regenerative medicine.

### **22 June 2009: Study suggests that statins can protect against Alzheimer's disease**

Researchers found that the pre-treatment of animals with the statin "Lovastatin" facilitated a neuroprotective action as they prevented nerve cells from dying. They concluded that "treatment with lovastatin may provide protection against neuronal injury in excitotoxic



conditions associated with neurodegenerative diseases including Alzheimer's disease."

The study was carried out by Amalia Dolga PhD, the University of Groningen and colleagues.

We provide full references to articles on our website  
[www.alzheimer-europe.org](http://www.alzheimer-europe.org)

## Dementia in Society

### 1 April 2009: Postgraduate studies in dementia relaunched

The Dementia Services Development Centre (DSDC), which is based at the University of Stirling, Scotland, has relaunched its postgraduate programme in dementia studies. Various options are available including a one-year certificate, two-year diploma, three-MSc as well as stand-alone modules.

### April 2009: Pilot project extended for dementia centre in Northern Ireland

The Northern Ireland office of the Dementia Services Development Centre (DSDC) has received grants from the Department of Health, Social Services and Public Safety and the Atlantic Philanthropies. The grants of GBP 1.2m, over a period of three years, will provide a dementia centre which aims to improve the lives of people with dementia, their carers and families, with particular emphasis on service provision within Northern Ireland. The Centre will offer specific services in the areas of education&training, consultancy, library/information and research. This project is an extension of a pilot project funded by the Atlantic Philanthropies from April 2007 to March 2009.

The DSDC has moved to new premises at the Northern Ireland Science Park, and will include a design and technology demonstration area and improved training facilities. The DSDC is led by Professor June Andrews, (Director). Recruited locally, the Northern Ireland team has been increased and will comprise of a Director of Operations, Associate Director, Project Coordinator, Research Assistant and Training Coordinator.

### 22 April 2009: Novel about Alzheimer's disease shortlisted for international award

"The Wilderness" Samantha Harvey's first novel, describes the life of a man called Jake, who has Alzheimer's disease. Reviewed by the Independent as "a brave and intelligent crafting

of narrative around narrative's ruins in the mind of a sufferer from Alzheimer's Disease" the book was shortlisted for the 2009 Orange Price for Fiction.

### 12 May 2009: "Is Anybody There" released in the UK



The film, "Is Anybody There" is set in 1987 and explores the relationship formed between a young boy, Edward, whose parents run a care home, and, Clarence, one of the new residents. Clarence has dementia and the effects of the disease are illustrated when Edward takes him to visit his wife's grave. Initially bitter about ageing, Clarence, a former magician, becomes a surrogate father to Edward and in return, Edward helps Clarence to enjoy life once more.

### 30 May 2009: Documentary about Alzheimer's disease wins Emmy Award

The National Academy of Television Arts and Sciences Boston/New England Chapter has awarded an Emmy Award for Best Documentary Programme to "Alzheimer's disease: Facing the facts."

The film is a one-hour documentary which illustrates the impact of Alzheimer's disease by speaking with the families who live with Alzheimer', researchers and physicians.

## New resources and publications

### 1 March 2009: Still Alice



Author and neuroscientist, Lisa Genova, was inspired to write "Still Alice" after watching her grandmother live with Alzheimer's disease. Lisa wanted to write how it feels to live with the disease and the fictional novel describes 50 year-old Alice's experience of having early onset Alzheimer's disease. It has been selected by numerous book stores as their "favourite read".

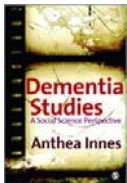
### April 2009: New publication on Cognitive Impairment, Mental Health and Transport



"Cognitive Impairment, Mental health and Transport – Design for Everyone in Mind" is the result of collaboration between the Organisation for Economic and Development (OECD), the European Disability Forum, Inclusion Europe

and Mental health Europe. The book aims to “help those who plan design and run transport systems and infrastructure to understand and find practical solutions to these issues for the benefit of the travelling public as a whole.”

**April 2009: New book on dementia studies published**



“Dementia Studies: A social science perspective” by Dr. Anthea Innes ( who teaches at the Dementia Services Development Centre, University of Stirling), includes chapters such as:

- What is dementia? Unpicking what is “known”
- The context of dementia studies: political, economic and social issues
- Caring for people with dementia: utopian ideals?
- Dementia studies within cultural contexts
- Researching dementia and dementia care: implications of the generation of research
- Knowledge for policy, practice and approaches to research
- A model for dementia studies: knowledge generation and development

Dementia Studies costs GBP 70 (hardback) and GBP 20 (paperback) ISBN: 9781412921633/9781412921640 respectively.

**April 2009: Book published on supporting staff who work in the area of dementia care**

The Alzheimer’s Society new book “Nurturing: our emotions at work in dementia care” looks at the area of staff support and “promotes the need to hear the voices of people working in dementia care. It encourages organisations to be genuinely interested in person-centred care and the effective recruitment, appraisal, support and retention of staff.” The book can be ordered from the Alzheimer’s Society (GBP 20) and is the fourth in the series of “Feelings matter most”.

**May 2009: Suggestions for catering for people with dementia**

The Alzheimer’s Society guide to catering for people with dementia offers practical tips and information on:

- Menu planning
- Eating well, supporting poor appetite and weight loss

- Nutrition, vitamins and minerals
- Taste, flavour and presentation
- Finger foods
- Swallowing difficulties, including the provision of texture modified foods

The 50-page paperback costs GBP 15.00 (exc. P&p) and can be ordered from the Alzheimer’s Society.

**15 May 2009: Alzheimer’s shop launched on-line**

The “Alzheimer’s Store” catalogue is now available on line (<http://www.alzstore.com>) which offers various products aimed at helping people with dementia and/or their carers.

**26 May 2009: Report on the quality of dementia care in Scotland published**

“Remember, I’m still me” is a joint report on the quality of care for people with dementia living in care homes in Scotland, by the Care Commission and Mental Welfare Commission.

The Commissions found that some care homes fell “seriously” short of best practice and people with dementia were not always getting the best possible care to meet their needs and their key findings included:

- Although care was regularly reviewed, the quality of care varied
- Around half of all people never went out of the care home and there was very little planned activity outside of the care home
- A lack of understanding about financial responsibilities and little creative use of funds
- Little evidence that medication was regularly reviewed
- Evidence of inappropriate and multiple prescribing
- Only a third of care home managers had undergone a recognised training course about caring for people with dementia
- The law on medical treatment for people who lack capacity is not being obeyed.

In order to offer care home providers and others involved in the care of people with dementia measure the quality of care they provide, the Commissions developed 10 key messages aimed at:

- Care that respects the individual
- Activities and being part of the community
- Environment in which people live
- Managing money
- Health assessment
- Managing medication
- Managing challenging behaviour and the use of medication
- Legal matters and safeguards
- Consent to treatment
- Staff knowledge and treatment

Responsibility for ensuring these messages are implemented has been placed with the Care Commission and the Mental Welfare Commission.

The report also makes recommendations for the NHS Quality Improvement Scotland, doctors and pharmacists, local authorities, health boards, people who live in care home and their families and carers. In addition, it calls on the Scottish Government to:

- Use the findings to inform the development of a National Dementia Strategy
- Encourage actors to work together to provide best services
- Consider the failure to comply with current legislation regarding Incapacity
- Consider systems to collate and monitor prescribing data at care home level

**27 May 2009: YouTube channel dedicated to dementia launched**

The University of California, San Francisco (UCSF) Memory and Aging Center has a dedicated YouTube channel providing information about dementia. The channel has videos of the doctors and nurses from the Center, talking about the symptoms, causes and current research into dementia.

**28 June 2009: Documentary broadcast about the recent paintings of artist William Utermohlen, who has Alzheimer’s disease**

“The glass eye” is a documentary broadcast by Arte TV, which looks at the work of William Utermohlen, who has Alzheimer’s disease. According to France Alzheimer, the paintings “illustrate the gradual change in perceptions of the world of the artist and are unique testimonial of the experiences of a person with Alzheimer’s disease...”

The artist’s works are a represent a real clinical example permitting the observations of the evolution of the deterioration of the cognitive functions of a person with Alzheimer’s disease. But they are especially valuable, indeed unique, because they reflect the subjective experience of the artist faced with his illness, his painful feeling of incapacity, his fear of death”.



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## AE Calendar

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

Date	Meeting	AE Representative
5-7 July	Conference of the International Association of Gerontology (Paris, France)	Jean Georges

## Future Conferences

Date	Meeting	Place
5 July 2009	19 <sup>th</sup> World Congress of Gerontology <a href="http://www.gerontologyparis2009.com/site/view8.php">www.gerontologyparis2009.com/site/view8.php</a>	Paris, France
27 August 2009	1 <sup>st</sup> international Congress on Clinical Neuro-Epidemiology <a href="http://www.neuro2009.com">www.neuro2009.com</a>	Munich, Germany
15-16 September 2009	Dementia Services Development Centre's 3 <sup>rd</sup> International Conference: Facing the future <a href="http://www.dementia.stir.ac.uk">www.dementia.stir.ac.uk</a>	York, United Kingdom
24 October 2009	19 <sup>th</sup> World Congress of Neurology <a href="http://www.wcn2009bangkok.com/index.cfm">www.wcn2009bangkok.com/index.cfm</a>	Bangkok, Thailand
19-22 November 2009	The 6 <sup>th</sup> International Congress on vascular dementia <a href="http://www.kenes.com/vascular">www.kenes.com/vascular</a>	Barcelona, Spain
2-5 September 2010	Dignity for the Frail Old: From dilemmas to solutions <a href="http://www.dignity.no">www.dignity.no</a>	Bergen, Norway

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