



# NEWSLETTER

January 2009

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## Editorial



Welcome to 2009! It will be a challenge to build upon the unprecedented exposure Alzheimer's disease was given by the French Presidency and the Council of Ministers in 2008. This challenge will be even greater as the effects of the economic downturn take hold. We sincerely hope that the momentum continues with the new EU Presidency, held by the Czech Republic.

Our main focus this month has been the Written Declaration 80/2008 on the priorities in the fight against Alzheimer's disease. It is with absolute delight that we can report that over half of the Members of the European Parliament have given their support to this initiative, thus ensuring that the Declaration has been adopted by the European Parliament. Our heartfelt thanks go to Françoise Grossetête (France), John Bowis (United Kingdom), Katalin Lévai (Hungary), Jan Tadeusz Masiel (Poland) and Antonios Trakatellis (Greece) for having initiated this Declaration and for their dedication in ensuring that their colleagues support the declaration. I am particularly proud of the efforts made by all European Alzheimer associations in lobbying their national MEPs.

At the time of writing, the long-awaited English dementia strategy is being launched. This news is most welcome and shows that a growing number of countries give dementia the priority it deserves. England now joins with France, Norway and Scotland in having a national dementia strategy in place. In Belgium, the Walloon Parliament adopted a resolution calling for the development of an Alzheimer's Plan and we all hope that other countries will soon follow their example despite the current economic problems. It is worth recalling here the statements made by President Sarkozy at the EU Conference on Alzheimer's disease: "If we were dealing with people's health only where there is global growth it would be unacceptable (...) I want to say that whatever the context we are in, the fight of all Europeans against Alzheimer's disease is a priority".

In the office, aside from securing support for the Written Declaration we have been busy helping to plan the forthcoming Alzheimer Europe Conference in Brussels as well as re-developing our website which will see an entirely new area dedicated to clinical trials.

**Jean Georges**  
**Executive Director**  
**Alzheimer Europe**

## European Alzheimer's Alliance makes dementia a European priority

**5 February 2009: MEPs call for European Action Plan on Alzheimer's disease**



The European Parliament has adopted Written Declaration 80/2008 on the priorities in the fight against Alzheimer's disease, in which MEPs call on the European

Commission and the Member States to recognise Alzheimer's disease as a European public health priority and to develop a European Action Plan. According to this important call, the European Union should promote pan-European research and collaborate in order to improve early diagnosis and the quality of life of people with dementia and their carers. Furthermore, the Declaration explicitly recognises the important role of Alzheimer associations and asks for their activities to be supported.

The Written Declaration was launched by MEPs Françoise Grossetête (France), John Bowis (United Kingdom), Katalin Levai (Hungary), Jan Tadeusz Masiel (Poland) and Antonios Trakatellis (Greece), all of whom are members of the European Alzheimer's Alliance. They gathered the support of 465 Members of the European Parliament from all 27 countries of the European Union and all political groups. Speaking on behalf of her colleagues, Françoise Grossetête stated, "As Chairperson of the European Alzheimer's Alliance, I am greatly encouraged that my colleagues in the European Parliament share my conviction that the European Union cannot ignore the lives of the 6.1 million Europeans who currently have Alzheimer's disease or another form of dementia. Our Alliance was created with the aim of making dementia a European priority and I am truly delighted that our campaign has resulted in this great success. I am convinced that this initiative will result in greater European

collaboration on Alzheimer's disease and concrete measures which will improve the quality of life of people with dementia and carers alike".

Jean Georges, Executive Director of Alzheimer Europe welcomed the European Parliament initiative and stated, "Alzheimer Europe would like to thank the authors of the Written Declaration for their incredible support in passing this important initiative and in convincing their colleagues that the time for European action on dementia is now. The European Parliament has clearly demonstrated that Alzheimer's disease does not recognise any geographical borders or political differences. To have support from all 27 European countries and all political groups in the European Parliament for our campaign has been truly awe-inspiring. We promise to give our continued support to the European Parliament, the European Commission and the Member States for the development of a European Action Plan".

On behalf of the 6.1 million Europeans who are living with dementia, as well as their carers, Alzheimer Europe and its national member organisations would like to thank all 465 Members of the European Parliament who have thus given a clear signal of their commitment to Alzheimer Europe's campaign to make dementia a European priority.

## Alzheimer Europe

**22 January 2009: Lundbeck approves silver sponsorship for Alzheimer Europe**

Lundbeck has approved silver sponsorship (EUR 20,000) for Alzheimer Europe, with the possibility of gold sponsorship at a later date. The company has also approved silver sponsorship (5,000) for Alzheimer Europe's 19<sup>th</sup> Conference which will be held in Brussels this coming May.

**28 January 2009: Fondation Médéric Alzheimer approves silver sponsorship for the 19th Alzheimer Europe Conference**

Fondation Médéric Alzheimer has approved silver sponsorship (EUR 5,000) for Alzheimer Europe's 19<sup>th</sup> Conference which will be held in Brussels this coming May.

## Alzheimer Europe Networking

On 14 January (Luxembourg, Luxembourg), Julie Fraser and Jean Georges met with **Visual Online** to discuss the redesign of the Alzheimer Europe website.

On 14 January (Brussels, Belgium), Annette Dumas attended the **EPF meeting** with patient organisations representatives to discuss the European Commission pharmaceutical package.

On 16 January (Luxembourg, Luxembourg), Julie Fraser and Jean Georges met with **Binsfeld Live** to discuss a possible collaboration on the 2010 AE Conference in Luxembourg.

On 20 January (Brussels, Belgium), Annette Dumas attended the **EFPIA meeting** to discuss the European Commission's proposal on Information to Patients.

On 20 January (Brussels, Belgium), Annette Dumas attended the opening of **the exhibition "the Mound of Remembrance and Reconciliation"** which was organised by MEP Jan T. Masiel.

On 21 January (Brussels, Belgium), Annette Dumas visited **MEPs' assistants** to discuss various on-going common activities.

On 26 January (Luxembourg, Luxembourg), Julie Fraser and Jean Georges met with **Visual Online** to discuss the redesign of the Alzheimer Europe website.

On 29 January (Brussels, Belgium), Annette Dumas attended the **European Commission** meeting with NGOs to discuss the Pact for Mental Health.

On 30 January (London, United Kingdom), Jean Georges met with representatives of **Pfizer and Eisai** for a meeting on earlier recognition of Alzheimer's disease.

## European developments

### 5 January 2009: Party of European Socialists presents its priorities for 2009



Prior to the European elections that will take place in June this year, and following a wide-ranging public consultation on the party priorities, the PES has presented its manifesto.

Under the title 'People first – a new direction for Europe', the manifesto lists the party's priorities: 1) relaunch the economy and prevent new financial crises, 2) New social Europe - giving people a fairer deal, 3) transform Europe into the leading global force against climate change, 4) champion gender equality in Europe, 5) develop an effective European migration policy and 6) enhance Europe's role as a partner for peace, security and development.

Measures proposed include: better policies to protect the most vulnerable people during the economic recession and beyond; goals and standards for national social, health and education policy to contribute to the fight against poverty and inequalities as well as the social and economic development of the EU; needs-based social welfare benefits for all those who are retired, unemployed or unable to work in all European countries to guarantee a life of dignity; strengthening of the anti-

discrimination legislation to ensure equal treatment on grounds of gender, race, disability, age, sexual orientation and religion or belief.

### 6 January 2009: Czech Prime Minister and Deputy Prime Minister present Czech EU presidency priorities



The presidency key priorities are economy, energy and Europe in the world (the three 'Es') and the motto is 'Europe without barriers'.

#### Social Services

Given the current demographic trends, the presidency will focus on services as a tool for preventing social exclusion and for active inclusion of the most vulnerable persons and, at the same time, as an area of growing employment opportunities. The presidency will address the availability of social services in terms of location, financing and type. It will – inter alia - support high quality, accessible and efficient social services. The conference to discuss social inclusion issues will propose the

adoption of the Council conclusions. Attention will also be paid to the improvement of quality, availability and financing of long-term care, protection of the dignity and rights of persons dependent on care, and support for an active, healthy ageing and ageing well.

#### **Patients' Rights in Cross-Border Healthcare**

The Presidency will endeavour to set out an overall framework for the provision of cross-border healthcare. It considers this EU measure to be a benefit for patients and healthcare systems alike, especially with regard to increasing patient mobility. The future system of cross-border care provision must also take into account the quality and safety of healthcare, regardless of which Member State it is provided in.

#### **Financial Sustainability of Healthcare Systems**

The key factors influencing healthcare expenditures are an ageing population, medical progress and innovation, and the growing expectations and demands of patients. The Presidency will focus primarily on the definition of financial sustainability and its objectives, and on the analysis of the resources available for healthcare funding. In terms of long-term care funding, it will be necessary to draw attention to the pressure it faces as a result of the growing demand for long-term care services, in relation to the negative demographic trends and the lack of providers of this type of care. The May 2009 high-level conference is to provide a forum for Member States to share experience and exchange information and best practices concerning healthcare systems and their financial sustainability.

#### **The Pharmaceutical Package**

The presidency will debate the legislative proposals of the *Pharmaceutical Package*. The proposals will focus on three issues: improve the functioning of the pharmacovigilance system at European level; strengthen the legal distribution chain for pharmaceuticals against illegal or counterfeit products; provide the general public with information on prescription pharmaceuticals. The presidency also supports the improvement and guarantee of a high quality and safety of pharmaceuticals, while maintaining cost-effectiveness.

#### **22 January 2009: European parliament launches website dedicated to the European elections**

The European Parliament has dedicated a website

(<http://www.europarl.europa.eu/elections2009/default.htm>) to the forthcoming European elections, which will take place in June this year.

## Policy Watch

#### **12 December 2008: Portuguese Parliament approves law that will offer greater social protection to people with Alzheimer's disease.**

Two Law Projects, (Projecto de Lei n° 502/X and n° 504/X) which afford greater social protection to people with Alzheimer's and/or Parkinson's disease, have been approved unanimously by the Portuguese Parliament. This decision has been welcomed by Alzheimer Portugal.

#### **22 December 2008: Belgian MP calls for Alzheimer Plan in Wallonia**



Chantal Bertouille, (pictured left), Belgian MP, has tabled a resolution on Alzheimer's disease in the Walloon region. The resolution calls on the next Walloon government to make Alzheimer's disease a priority.

In particular, Ms Bertouille advocates early diagnosis, information to the public through a single entry-point and the setting up of a Walloon centre of expertise for disoriented people. This centre will cover issues related to the environment of the person with Alzheimer's disease, ethics, regular and tailored training of the carers, quality of life in day care centres, pooling of epidemiologic data and planification of short, medium and long-term needs.

Increased support to carers will include the development and diversification of respite structures, consolidation of their rights and training and reinforcement of the coordination between all actors with a special attention paid to the family doctor.

An unprecedented effort into the financing of research and support of a transnational research network is also called for.

#### **22 December 2008: UK General Practitioners to be trained to diagnose dementia**

The English Dementia Strategy, which was due to be published this month, contains an initiative ensuring that all general practitioners (GPs) be trained to diagnose dementia. Phil Hope, UK Care Services Minister, explained that "We need to be diagnosing people with dementia much earlier so we can have earlier intervention in their lives and support carers – this is what everyone tells us they want and need. It's also a more cost-efficient way of

caring for people. If we can get this right over the next ten years we could save nearly GBP 1 billion while providing better care”.

### January 2009: Call for tender for respite structures issued in framework of French Alzheimer's Plan

A call for tender was issued by the Ministries of Labour, Social Relations, Family and Solidarity, in association with CNSA (national solidarity and autonomy body) towards the experimentation of respite care platforms and new support schemes for family carers of persons with Alzheimer's disease and dementias.

This call falls within Measure 1 of the French Alzheimer Plan 2008-2012. This measure aims to grant carers of persons with dementia a greater support by developing a diversified and nation-wide care support structure. The deadline for submission is 13 March 2009.

### January 2009: The Government of Northern Ireland launches policy consultation document on proposed mental capacity and mental health legislation

A public consultation document on mental capacity and mental health legislation has been launched by the Government of Northern Ireland. The feedback received will be used during the detailed drafting of legislation. A questionnaire (which is at the end of the document) contains five areas on which feedback is sought:

- Do you agree that the Principles, as outlined in this document, should be embedded in both mental capacity and mental health legislation?
- The document outlines the policy intentions underpinning the significant Powers proposed for both the Mental Capacity Bill and the Mental Health Bill. Is there any other major power which you would wish the Department to give consideration to?
- In the context of policy proposals for both the Mental Capacity Bill and the Mental Health Bill, are there any other Protections which the Department needs to consider to further protect service users, carers, staff or members of society?
- Do you agree with the Department's view that the central thrust of embedding these principles within mental capacity and mental health legislation is to safeguard dignity and

improve protection of human rights and equality of opportunity and consequently a full Equality Impact Assessment is not needed?

- Do you have any further comments on the Department's proposals set out in this document?

The closing date for feedback is 31 March 2009.

### 20 January 2008: Economic downturn delays the launch of the English national dementia strategy

Prof. Sube Banerjee, who was charged with developing the English national dementia strategy, stated that the current economic downturn is further delaying the launch of the national strategy. Originally scheduled to be launched in October 2008, Andrew Chidgey, head of policy and campaigns at the Alzheimer's Society, explained that there is now “much more scrutiny for departments on new announcements and projects aren't necessarily getting through as quickly given the work that's going on to deal with the financial crisis.”

We provide full references to articles on our website

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

### 2 February 2009: National Dementia Strategy for England launched

The English Health Secretary, Alan Johnson and Care Services Minister, Phil Hope launched the first-ever National Dementia Strategy for England. In support of the Strategy, the government has pledged an extra GBP 150 million.

The 17 recommendations contained in the Strategy are based on the three key themes of (i) raising awareness and understanding, (ii) early diagnosis and support and (iii) living well with dementia. Having worked closely alongside the government to develop the Strategy, the Alzheimer's Society believes that the strategy “will make an incredible difference to the lives of people with dementia and their carers”.

Welcoming the launch of the Strategy, Maurice O'Connell, Chairman of Alzheimer Europe, said, “I am delighted for the 570,000 people living with dementia in England, as well as their carers, that this long-awaited Strategy will now be implemented and that England joins Norway, France and Scotland in giving dementia the priority it deserves. I hope that other national European policy-makers take

heed and implement their own national dementia strategies.”

## Members' News

**18 December 2008: Arlette Meyrieux, President of France Alzheimer receives the Legion of Honour for services to Alzheimer's disease**



The French President, Nicolas Sarkozy, bestowed the highest decoration in France, the “Chevalier of the Legion of Honour” upon Arlette Meyrieux, the President of France Alzheimer at a ceremony held at the Elysée Palace, Paris on 18

December. Accepting the award, Ms Meyrieux thanked the volunteers who work for the association for their dedication on a daily basis.

Arlette Meyrieux started working with France Alzheimer in 1995 and was elected President of France Alzheimer Savoie in 1998. Becoming the first elected member of the Board of Directors of France Alzheimer in 2000, in 2003 she was elected as its Vice President and its President in 2005.

**December 2008: Alzheimer Portugal pledges efforts to ensure that people with Alzheimer's disease are reimbursed for their medication**

A proposed law (Projecto de Lei n° 501/X) which would have raised the reimbursement level of medication for people with Alzheimer's disease has been rejected by the Portuguese Parliament.

Following the adoption of two law projects which offer greater social protection to people with Alzheimer's and/or Parkinson's disease, Alzheimer Portugal hope that Parliament will eventually also approve the law regarding the reimbursement of medication for people with Alzheimer's disease and the association has committed itself to ensuring that reimbursement by the National Health System occurs.

**January 2009: Federazione Alzheimer Italia publishes Annual Report**



Federazione Alzheimer Italia has presented its annual report in a new comprehensive way. The new format includes information on:

- Alzheimer's disease

- The organisation (its mission; values and principles; how it is governed; its relationship with other stakeholders and its strategies and priorities)
- The culture of transparency (financial accounts, balance sheet, income and expenditure)
- The activities of the organisation (the raising of awareness and information; help and support; representation and participation; promotion of research; the development of a network of help within the country)
- The future objectives of the organisation.

**16 January 2009: Alzheimer's Society calls upon the National Institute for Health and Clinical Excellence to review its decision on anti-dementia drugs**

Following the Alzheimer's Society's own review of the calculations used by the National Institute for Health and Clinical Excellence (NICE) to determine the cost-effectiveness of anti-dementia drugs, the Society has appealed to NICE to review its earlier decision which had the result of denying people with dementia access to drugs. Neil Hunt, Chief Executive of the Alzheimer's Society, said, “Now that we have examined NICE's calculations first hand and taken expert advice, Alzheimer's Society remains convinced that denying people with Alzheimer's effective drugs makes no sense.”

**19-25 January 2009: Phone-in raises more than EUR 50,000 for Federazione Alzheimer Italia**

Appeals broadcast on television to help to raise money to help people with dementia and their carers resulted in nearly 40,000 SMS and phone calls being made, raising more than EUR 50,000 for the Alzheimer Federation, Italy (Federazione Alzheimer Italia).

Seventeen broadcasts were aired from 19-25 January. The Federation thanked all those who supported this initiative for their collaboration and sensitivity, including RAI Italy, TIM, Vodafone, Wind, 3 Italia and Telecom Italia as well as Pippo Baudo, Michele Mirabella, Marco Mazzocchi, Federica Sciarelli, Carlo Conti, Ada D'Eusanio, Fabio Fazio, Bruno Vespa and Andrea Vianello.



## Members' Forthcoming Events

### 19-22 February 2009: 6<sup>th</sup> Panhellenic Conference on Alzheimer's Disease and Related Disorders

The 6<sup>th</sup> Panellenic Conference on Alzheimer's Disease, organised by the Greek Association of Alzheimer's Disease and Related Disorders, has its main objective as "investigating ways of improving the quality of life of both people with Alzheimer's disease and their caregivers". The issues to be covered are:

- Diagnosis
- Epidemiology and risk factors
- Pharmacological therapies
- Ethical issues
- Genetics
- Neuropsychological examination
- Neuropathology and neuroimaging
- Mild Cognitive Impairment, dementia and normal ageing
- Non-pharmalogical therapies
- Other types of dementia
- Nutrition and dementia
- Psychosocial interventions
- Quality of life in ageing
- Vascular dementia
- Caregivers and family
- Day centres for people with Alzheimer's disease
- Neuroplasticity
- Primary nursing
- Communication, mass media and dementia

### 18 February 2009: Concert proceeds to be donated to Federazione Alzheimer Italia

The "Happy Birthday Faber" concert, which will be held on 18 February 2009 in Milan, Italy, will see its profits donated to Federazione Alzheimer Italia. 35 singers and groups will celebrate the birthday of Fabrizio De André (1940-1999). Fabrizio was a famous Italian singer-composer and the first in Italy to interpret the songs of Jacques Brel, Leonard Cohen and Bob Dylan.

After the recording by Mina of "La canzone di Marinella" in 1968, Fabrizio De André, the song's author, was hailed as the most important Italian "cantautore" or singer-songwriter.

### 9 May 2009: Fundación Alzheimer España (FAE) to hold its IV European Conference


"Behavioural disorders in Alzheimer's disease. Perspectives from caregivers" is the title given to the Spanish Alzheimer association "Fundación Alzheimer España's" (FAE) IV<sup>th</sup> European Conference on Alzheimer's disease. FAE will present the results from their own survey, which was conducted on over 1,200 family carers in Spain.

The topics to be covered include:

- The definition of behavioural disorders
- How do carers cope with behavioural problems?
- Alzheimer associations and the experience of behavioural problems
- Apathy: Characteristics and impact strategy
- Pharmacological treatment of behavioural disorders
- Non-pharmacological therapeutic approaches
- Hormonal treatment of behavioural disorders
- Behavioural disorders and competence.

## Science Watch

### 27 November 2008: European Medicines Agency delivers opinion on antipsychotics



The European Medicines Agency's (EMA) Committee for Medicinal Products for Human Use (CHMP) has concluded that "conventional (typical) antipsychotics are likely to be associated with increased mortality when used in elderly people with dementia... No conclusion could be drawn as to whether the risk differs between individual antipsychotics within the class of conventional antipsychotics. Therefore, until and unless better evidence becomes available, it cannot be excluded that the increased risk applies to all products of the class".

The CHMP arrived at this conclusion after considering the assessment report on convention antipsychotics (see below) and reviewing all available evidence.

### **22 December 2008: Study examines the effect food intake can have on cognitive performance**

Researchers from Oxford University, UK, and the Universities of Oslo and Bergen, Norway, who studied the effect food intake may have on cognitive performance amongst elderly people, found that those participants who had consumed chocolate, wine or tea (all of which contain flavonoids) had significantly better mean cognitive test scores and lower prevalence of poor cognitive performance than those who did not.

The findings have been published in the *Journal of Nutrition*, and the researchers call for further investigation to establish whether the findings were due to the presence of flavonoids or some other aspect of the foods studied. They also highlighted that whilst moderate alcohol consumption is associated with better cognitive function and a reduced risk of Alzheimer's disease, heavy alcohol consumption is associated with being a risk factor for dementia.

### **26 December 2009: Study identifies molecule important for memory function**



Researchers at the University of Bristol, UK, have identified a molecule known as "neuronal calcium sensor-1" (NCS-1) as probably playing an important role in the memory function, allowing for the recognition of people. Led by Professor Kei Cho from the Department of Medicine, the research has been published in the journal *Neuron*.

### **9 January 2009: Research identifies new genes which may increase susceptibility for Alzheimer's disease**

A genome-wide association study carried out by researchers at the University of the Miami Miller School of Medicine and the Vanderbilt University Medical Centre, identifies nine genes that may increase susceptibility for Alzheimer's disease. The amyloid precursor protein which is recognised as a risk gene for early-onset Alzheimer's disease was also found to be involved in late-onset Alzheimer's disease. Further, chromosome 12q was found to have an area associated with an increased risk of Alzheimer's disease: this area was found to be close to the vitamin D3 receptor zone. Low levels of vitamin D have been found in people

with Alzheimer's disease and it may be that a "variation in the vitamin D3 receptor gene that causes low vitamin D levels may also increase the risk for Alzheimer's disease".

The research was led by Margaret A Pericak-Vance, PhD, together with Jonathan L Haines, PhD and has been published in the *American Journal of Human Genetics*.

### **9 January 2009: Study examines the effects of antipsychotic drugs**

Research over a three-year period into the use of antipsychotics on people with Alzheimer's disease in care homes found a "significant increase risk of death" for those people taking antipsychotics. Led by Professor Clive Ballard of King's College, London, the study monitored 165 people with Alzheimer's disease who were being prescribed psychotics: 83 continued treatment and 82 had it withdrawn and replaced with placebos.

The study found that survival rates between the two groups were different and this difference increased over time. After 36 months the survival rate for the group receiving the antipsychotics was 30% against 59% of the placebo group rate.

### **9 January 2009: Examination of amyloid formation reveals possible benefit of laser treatment**

A study, which set out to better understand how amyloid plaques form, has revealed a potential benefit in the use of laser treatment to prevent fibre growth. In order to view amyloid formation, researchers made real-time observations of the growth of individual fibrils, adding a dye (thioflavin T (ThT)) to tangles and a laser beam, which seemed to inhibit the fibril growth and destroy existing fibrils.

The research, which was carried out by Yuji Goto of the Institute for Protein Research, Osaka University and colleagues, has been published in the *Journal of Biological Chemistry*.

### **11 January 2009: Study examines link between gene and Alzheimer's disease**



The findings of research published in *Nature Genetics* suggest a variant in the gene *PCDH11X* significantly correlated with the increased risk of late-onset Alzheimer's disease and that this correlation was "almost entirely confined to women (as) *PCDH11X* lies on the female X chromosome".

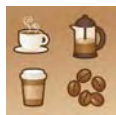
The research was led by Dr Steven Younkin of the Mayo Clinic College of Medicine in Jacksonville, Florida, USA.

### **13 January 2009: Survey reveals the effects behavioural symptoms associated with Alzheimer's disease can have on caregivers**

A survey conducted on behalf of the Alzheimer's Foundation for caregiving in Canada (AFCC) found that among caregivers of people with Alzheimer's disease "behavioural symptoms such as agitation and aggression are common in their loved ones and take a significant toll on primary caregivers, especially those who feel scared or threatened by these behaviours."

The survey also found that the caregivers' willingness to be open about the symptoms of the disease varied according to the symptom in question. For example many were happy to discuss disorientation but were not comfortable to openly discuss aggression. The physical changes experienced by the caregiver since starting to care for someone with Alzheimer's disease were reported as firstly, fatigue, followed by difficulty in sleeping, headaches, back pain, weight gain and a worsening of existing conditions.

### **14 January 2009: Study examines the effect of caffeine consumption at mid-life on cognitive ability**



Research which chartered nearly 1,500 people's consumption of caffeine over a 21-year period found that those participants who had been moderate coffee drinkers in middle-age were less likely to develop dementia in later life.

### **20 January 2009: Study examines link between personality and lifestyle in relation to the incidence of dementia**

Research published in the journal *Neurology*, examined the relationship between personality, lifestyle and the incidence of dementia. The researchers found that people who were easily stressed, less outgoing and socially isolated may have an increased risk of dementia.

Led by Dr. Hui-Xin Wang of the Ageing Research Centre of the Karolinska Institutet, Sweden, the team monitored 506 older people for a period of 6 years.

### **22 January 2009: Study examines the relationship between vitamin D and cognitive impairment**

A study carried out by Dr Iain Lang of the Peninsula Medical School, Exeter, UK, and colleagues from the University of Cambridge and the University of Michigan, seems to identify a link between a lack of vitamin D and cognitive function in later life.

Nearly 2000 people aged 65 and over were assessed. People with low levels of vitamin D displayed more problems with memory and attention than those with higher levels of vitamin D. The study will be published in the *Journal of Geriatric Psychology and Neurology*.

### **22 January 2009: Survey reveals abusive behaviour by carers of people with dementia**

In order to determine the prevalence of abusive behaviours by family carers of people with dementia a survey was carried out on 220 family carers, by community mental health teams in Essex and London. Whilst few cases of physical or frequent abuse were reported, the most common abuse was found to be verbal and third of participants reported "important" levels of abuse.

The survey was led by Claudia Cooper, Department of Mental Health Sciences of the University College London and published in the *British Medical Journal* on line.

### **26 January 2009: Study examines the relationship between calorie intake and memory function**



A study carried out by researchers at the University of Münster, Germany, suggests that a reduced calorie intake in healthy elderly people may benefit memory performance.

The study monitored 50 healthy, normal to overweight elderly people who had been divided into three groups: Group 1 worked with a dietician who cut their daily calories; group 2 was given a diet which contained higher levels of unsaturated fatty acids; group 3 was the control group. The research, conducted by A Flöel et al, showed no significant changes in memory performance for groups 2 and 3, but that there was a beneficial effect for group 1. A larger study has now commenced to test the above findings.

### **January 2009: Study examines the efficacy of galantamine on people with severe Alzheimer's disease**

Research carried out on people with severe Alzheimer's disease found the use of the drug

galantamine was safe and that cognitive function improved. However, no improvement was found for activities of daily living.

407 people with Alzheimer's disease participated between 2003 and 2007 - of which 207 received galantamine and 200 a placebo. Registered with ClinicalTrials.gov (NCT00216593), the trial was funded by Janssen-Cilag EMEA.

We provide full references to articles on our website

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

## Dementia in Society

### January 2009: Documentary on Alzheimer's disease released

"Facing the facts" is a one-hour, documentary that "examines the personal and societal implication of the illness, and the latest research", which was aired in January 2009 in the US. It won the 2008 Golden Eagle award for best independent short documentary and is available on DVD.

### 30 January 2009: Terry Pratchett reflects on perceptions people have about people with Alzheimer's disease



Author Sir Terry Pratchett, explains in the Times newspaper why he has allowed a film crew accompany him whilst he finds out about his prognosis (with Posterior Cortical Atrophy (PCA), a form of Alzheimer's disease), "Well why be bashful about it? It's not as if I'd

done something wrong. In too many people's minds Alzheimer's is considered madness. It is a physical disease that affects the brain." He also said that he must keep writing, stating, "otherwise, I'm just Terry Pratchett, "the sufferer". It's all part of our modern culture. We like people to be sufferers because then we can pity them."

The British Broadcasting Corporation (BBC) is running a two-year mental health project, part of which "Terry Pratchett: Living with Alzheimer's" will be aired on BBC2 on February 4.

## New resources and publications

### 5 January 2009: Genetics website updated

The EuroGenguide website (which gives information to European patients about genetic testing and research) has been updated to include new information, an automatic translation tool and additional links.

### 6 January 2009: International Medicine Price Survey published

A report written by the Mental Health Economics Task Force of the International Psychogeriatric Association entitled "Medicine Prices and Affordability for mental health of older people 2008" has been published. Reporting on a medicine price survey of 20 countries in 2007, the report lists, inter-alia, comparative prices for Alzheimer's drugs, antipsychotic drugs and antidepressants.

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#### Alzheimer Europe Board

**Chairperson:** Maurice O'Connell (Ireland)

**Vice-Chairperson:** Sabine Henry (Belgium)

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Alicja Sadowska (Poland)

Charles Scerri (Malta)

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
6 February	Health Editorial Board of the European Commission (Luxembourg, Luxembourg)	Jean Georges
9 February	EFPIA Think Tank (Brussels, Belgium)	Annette Dumas
9-11 February	Meeting with Polish Organisation (Brussels, Belgium)	Jean Georges
12 February	19 <sup>th</sup> AE Conference Organising Committee (Brussels, Belgium)	Jean Georges
17 February	European Voice Health Check Debate (Brussels, Belgium)	Annette Dumas
17-18 February	Consent in Dementia Conference (Belfast, United Kingdom)	Jean Georges
19/23 February	Greek Alzheimer Conference (Thessaloniki, Greece)	Annette Dumas

## Future Conferences

Dates	Meeting	Place
25 March 2009	24 <sup>th</sup> Conference of Alzheimer's Disease International <a href="http://www.adi2009.org">http://www.adi2009.org</a>	Singapore
26 May 2009	9e Colloque de la Société des Neurosciences <a href="http://www.neurosciences.asso.fr">www.neurosciences.asso.fr</a>	Bordeaux, France
28-30 May 2009	The 19 <sup>th</sup> Alzheimer Europe Conference <a href="http://www.alzheimer2009.eu">www.alzheimer2009.eu</a>	Brussels, Belgium
11 June 2009	The 5 <sup>th</sup> Kuopio Alzheimer Symposium <a href="http://www.uku.fi/alz2009">www.uku.fi/alz2009</a>	Kuopio, Finland
5 July 2009	19 <sup>th</sup> World Congress of Gerontology <a href="http://www.gerontologyparis2009.com/site/view8.php">http://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
24 October 2009	19 <sup>th</sup> World Congress of Neurology <a href="http://www.wcn2009bangkok.com/index.cfm">http://www.wcn2009bangkok.com/index.cfm</a>	Bangkok, Thailand



www.alzheimer.be  
Ligue Nationale Alzheimer Liga ASBL/vzw/VoG



# 19<sup>th</sup> Alzheimer Europe Conference

28-30 May 2009

Brussels  
[www.alzheimer2009.eu](http://www.alzheimer2009.eu)



Françoise  
Grossetête  
(France)



John Bowis  
(UK)



Katalin Lévai  
(Hungary)



Jan Tadeusz  
Masiel  
(Poland)



Antonios  
Trakatellis  
(Greece)

## WHOLE-HEARTEDLY THANK ALL MEPs

who supported

### **Written Declaration n° 80/2008**

**on priorities in the fight against Alzheimer's disease**

YOU have helped to ensure that Alzheimer's disease is given recognition as a European health priority and to develop a European action plan with a view to:

- Promoting pan-European research on the causes, prevention and treatment of Alzheimer's disease
- Improving early diagnosis
- Simplifying procedures for patients and carers and improving their quality of life
- Promoting the role of Alzheimer's associations and giving them regular support

The Declaration was officially adopted by the European Parliament on 5 February 2009