

# NEWSLETTER

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MARCH Update 2008

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## **Editorial**

March was yet another busy period for Alzheimer Europe and our



campaign to make dementia
a European priority
continues to gather pace.

Françoise Grossetête, the Chairperson of the European Alzheimer's Alliance, put the finishing Written touches to а Declaration on Alzheimer's This will be Disease. submitted to the European Parliament and will be open signatures for two months. We hope, of course, that half of all Members of the European Parliament will sign the Declaration to ensure it is adopted as an official European action plan on Alzheimer's disease.

We were also busy with the organisation of a lunch debate in the European Parliament and we chose to ask Professor Lutz Frölich, from the Central Institute for Health Mental from Mannheim and leader of the workpackage on prevention of the Alzheimer Europe project, EuroCoDe to present the findings of his working group and to an overview of provide possible prevention strategies in the field of dementia.

Already, we are heartened by the great interest this

meeting has generated amongst Members of the European Parliament and we look forward to an interesting exchange of information with them on 1 April.

Considerable progress on two of our key projects was made at the end of March. Firstly, experts met to discuss the Commissionfunded EuroCoDe project and we are pleased to report that the results should be delivered to the Commission as planned, at the end of this year.

Similarly, the Alzheimer Europe expert group on end-of-life care for people with dementia met in Brussels to discuss a first draft of possible recommendations on this important subject. Verv positive feedback was given by the experts on the work carried out by Dianne Gove, the Information Officer of Alzheimer Europe.

As mentioned in our last newsletter, we decided to opt to increase its frequency by publishing it on a monthly basis. I believe that the very fact we are able to produce a monthly newsletter with such depth of news items is evidence of how many different actors are collaborating and working towards finding solutions for people with dementia and their carers.

> Jean Georges Executive Director



## Making dementia a European priority

Our campaign enjoys increasing support from MEPs with the following pledging their support in March 2008:



Brigitte Fouré France, EPP-ED



Alain Lamassoure France, 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 58. Alzheimer Europe can now count on the support of Members of the European Parliament from all seven political groups and from 19 of the 27 Member States of the European Union:

#### **Austria**

Ettl Harald (PES)

#### **Belgium**

- 2. Busquin Philippe (PES)
- 3. Hutchinson Alain (PES)
- 4. Langendries Raymond (EPP-ED)
- 5. Sterckx Dirk (ALDE)

## **Czech Republic**

- 6. Cabrnoch Milan (EPP-ED)
- 7. Kohlicek Jaromir (GUE/NGL)
- 8. Roithova Zuzana (EPP-ED)
- 9. Vlasak Oldrich (EPP-ED)

#### **Finland**

- 10. Myller Riitta (PES)
- 11. Virrankoski Kyösti (ALDE)

### France

- 12. Bourzai Bernadette (France, PES)
- 13. Daul Joseph (EPP-ED)
- 14. De Veyrac Christine (EPP-ED)
- 15. Fouré Brigitte (EPP-ED)
- 16. Griesbeck Nathalie (ALDE)
- 17. Grossetête Françoise (EPP-ED)
- 18. Henin Jacky (GUE/NGL)
- 19. Lamassoure Alain (EPP-ED)
- 20. Morin Elisabeth (EPP-ED)
- 21. Onesta Gérard (Greens-EFA)
- 22. Toubon Jacques (EPP-ED)

### Germany

- 23. Niebler Angelika (EPP-ED)
- 24. Ulmer Thomas (EPP-ED)
- 25. Weisgerber Anja (EPP-ED)

#### Greece

- 26. Koppa Maria Eleni (PES)
- 27. Kratsa-Tsagaropoulou Rodi (EPP-ED)
- 28. Matsouka Maria (PES)
- 29. Panayotopoulos Marie (EPP-ED)
- 30. Papadimoulis Dimitrios (GUE/NGL)
- 31. Schinas Margaritis (EPP-ED)
- 32. Vakalis Nikolaos (EPP-ED)

## Hungary

- 33. Levai Katalin (PES)
- 34. Surján László (EPP-ED)

## Ireland

- 35. Crowley Brian (UEN)
- 36. McDonald Mary Lou (GUE/NGL)
- 37. McGuiness Mairead (EPP-ED)
- 38. Mitchell Gay (EPP-ED)
- 39. Sinnott Kathy (IND/DEM)

#### Italy

- 40. Battilocchio Alessandro (NI)
- 41. Podestá Guido (EPP-ED)

## Lithuania

42. Dickute Jolanta (ALDE)

#### Luxembourg

43. Lulling Astrid (EPP-ED)

## Malta

44. Muscat Joseph (PES)

## The Netherlands

- 45. Corbey Dorette (PES)
- 46. Wortmann Corien (Netherlands



#### **Poland**

- 47. Masiel Jan Tadeusz (Poland, UEN)
- 48. Rogalski Boguslaw (Poland, UEN)

## **Portugal**

- 49. Coelho Carlos (EPP-ED)
- 50. Figueiredo Ilda (GUE/NGL)

#### Slovakia

51. Mikolasik Miroslav (EPP-ED)

#### Sweden

52. Cederschiold Charlotte (EPP-ED)

### **United Kingdom**

- 53. Bowis John (EPP-ED)
- 54. Hall Fiona (ALDE)
- 55. McAvan Linda (PES)
- 56. Moraes Claude (PES)
- 57. Stihler Catherine (PES)
- 58. Willmott Glenis (PES)

Similarly, our campaign continues to gather support from individuals and at the end of March 2008, 2779 individuals had signed our call to make dementia a European priority.

Alzheimer Europe also gratefully reports on the activities of the following Member of the European Alzheimer's Alliance.

## 13 March 2008: Françoise Grossetête, MEP, highlights needs of people with Alzheimer's disease in the European Parliament

On 13 March 2008, the European Parliament discussed and adopted a report on the proposal for a decision of the European Parliament and of the Council on the participation by the Community in a research and development programme aimed at enhancing the quality of life of older people through the use of new Information and Communication Technologies (ICT). The European Union will contribute 150 million euro to the programme.

In a press release, Françoise Grossetête, Chair of the European Alzheimer's Alliance

welcomed the adoption of the report and highlighted the need for the European Union to address the challenge of the ageing of European populations.

She recognised the growing use of technologies to enhance the quality of life of older people by alleviating and supporting people with memory, visual, auditive and mobility deficiencies.

She expressed the hope that such services would also contribute to help people live longer and better at home, paying special attention to the use of such services for people with Alzheimer's disease.

# Alzheimer Europe news

19 March 2008: Alzheimer Europe discusses dementia ethics with representatives of German Health Ministry



Representatives of the German Health Ministry, the German Alzheimer's association,

Alzheimer Europe and the Swiss based centre Sonnenweid met in Berlin to discuss the range of ethical challenges experienced by family and professional carers. The participants agreed to explore the possibility of developing a European project providing support to carers in addressing these challenging situations.

27-29 March 2008: Alzheimer Europe presents EuroCoDe findings at 5<sup>th</sup> International Pharmaco-Economic Conference on Alzheimer's disease

Close to 100 researchers and representatives of pharmaceutical



companies met in Newark, USA for the 5<sup>th</sup> International Pharmaco-Economic Conference on Alzheimer's disease. Organised by the Karolinska Institutet and the Alzheimer's Drug Discovery Foundation, the conference covered such important subjects as the economics of dementia, a worldwide perspective of regulators and payers, pharmacoeconomics in clinical trials as well as cost effectiveness of diagnostics and biomarkers.

Jean Georges, the Executive Director of Alzheimer Europe, presented data on the impact of dementia on family carers, as well as an overview of some of the differences



between European countries as to the social support provided by governments to people with dementia and their carers. The presented data was collected by Alzheimer Europe in the framework of its Commission funded project "European Collaboration on dementia – EuroCoDe".

## 30 March 2008: Alzheimer Europe expert group discusses first draft of Alzheimer Europe position on end-oflife care

The multidisciplinary and multinational expert group on end-of-life care met in Brussels for a discussion of the draft recommendations prepared by Dianne Gove, the Information Officer of Alzheimer Europe.

The group, chaired by Sigurd Sparr (Norway) and consisting of Ana Bernardo (Portugal), Mary Cosgrave (Ireland), Iva Holmerová (Czech Republic), Sabine Jansen (Germany), Birgitta Martensson (Switzerland) Barbara Pointon (United Kingdom) and Catalina Tudose (Romania) congratulated Dianne on the high quality of the first draft of the Alzheimer Europe position.

The recommendations cover a variety of subject and include:

- Advance planning,
- · Carers' needs
- Interaction between carers and healthcare professionals,
- · Dignity,
- Communication,
- Spiritual care,
- · Cultural issues and minority groups,

As well as specific care issues such as

- Pain management,
- · Feeding and swallowing problems,
- Constipation, diarrhoea and incontinence,
- Pneumonia and infections,
- · Dehydration and mouth care,
- Skin care
- Sedation and the use of restraint.

## 31 March 2008: Experts meet to discuss final steps of Alzheimer Europe's EuroCoDe project

The working groups of the EuroCoDe project met in Brussels to discuss the progress achieved so far and to discuss the final stages necessary till the completion of the project at the end of 2008 which will result in:

- A meta-analyis of European prevalence data,
- Recommendations on the social support of people with dementia and their carers,
- Guidelines on the diagnosis and treatment of dementia.
- A report on the socio-economic cost of dementia in Europe,
- Guidelines on psycho-social interventions,
- A report on prevention strategiues in dementia.



The EuroCoDe expert group: from left to right: Charras Kevin (France), Palermiti Federico (France), Kárpáti Krisztián (Hungary). Kenigsberg Paul Ariel (France), Dobranici Letitia (Romania), Cantegreil Inge (France), Heimonen Sirkaliisa (Finland), Fraser Julie (Luxembourg), Sadowska Alicja (Poland), Guillory Gwladys (Luxembourg), Gove Dianne (Luxembourg), von Lützau-Hohlbein Heike (Germany), Dumas Annette (Belgium), O'Connell Maurice (Ireland), McDaid David (United Kingdom), Kivipelto Miia (Sweden), Tanco Manuel (Spain), Wimo Anders (Sweden), Verhey Frans (Netherlands), Caracciolo Barbara (Sweden), Woods Bob (United Kingdom), Moniz-Cook Esme (United Kingdom), Vernooij-Dassen Myrra (Netherlands), Gulacsi Laszlo (Hungary), Frölich Lutz (Germany), Laine Pekka (Finland), Jackson Jim (United Kingdom), Vasse Emmelyne (Netherlands), Freter Hans-Jürgen (Germany)



## **AE Networking**

The following meetings were attended by representatives of Alzheimer Europe:

Date	Meeting	AE Representative
5-6 March	Management Board of the European Medicines Agency in London, United Kingdom	Georges Jean
12 March	INFODAY on the Public Health Programme of the European Commission in Luxembourg, Luxembourg	Georges Jean
12 March	Meeting with FEFAF (European Federation of Unpaid Parents and Carers at Home) in Brussels, Belgium	Dumas Annette
17 March	European Commission Conference on Elder Abuse in Brussels, Belgium	Henry Sabine & Dumas Annette
17 March	Meeting of Patient organisations of the Patients' and Consumers' Working Party of the European Medicines Agency in London, United Kingdom	Georges Jean
25 March	Meeting with Multimount Visual Communications	Georges Jean & Dumas Annette
25 March	Meeting with Baxter	Georges Jean & Dumas Annette
27-29 March	5th International Pharmaco-Economic Conference on Alzheimer's Disease in Newark, USA	Georges Jean
30 March	Alzheimer Europe Palliative Care Expert Group in Brussels, Belgium	
31 March	FuroCode Working Group Meetings in Brussels, Relation	

# **European** developments

28 February 2008: Cyprus nominates Androula Vassiliou to succeed Marcos Kyprianou as new EU Health Commissioner



The Republic of Cyprus has nominated Ms Androula Vassiliou to succeed Health Commissioner Markos Kyprianou who has

resigned to become Cyprus' new Foreign Minister. In full compliance with the prerogatives of the institutions, Ms Vassiliou will appear before the European Parliament for a hearing on 1 April 2008.

Ms Vassiliou started her career as a lawyer. She was an elected Member of the House of Representatives of Cyprus between 1996 and 2006. She served on the European Affairs Committee and on the Joint Parliamentary Committee of Cyprus and the EU. She was an Alternate Representative of the Cyprus parliament to the Convention for the Future of Europe (2001-2003) and also Vice-President of the European Liberal Democrats and Reform Party (2001-2006).

## 4 March 2008: European Commission announces delays of directive on cross-border health care

At a meeting on patients' rights organised by the Ludwig van Mises Institute in the European Parliament, Philippe Brunet, Head of Cabinet of the EU Health Commissioner announced that the directive on cross-border healthcare initially planned for April 2008 would be delayed. We provide full references to articles on our website

www.alzheimer-europe.org

## 11 March 2008: European Commission launches public consultation in preparation for a legal proposal to combat counterfeit medicines for human use

Counterfeiting of medicinal products has become an increasing threat for patients, healthcare professionals and industry and a concern for EU and national policy-makers. The Directorate-General Enterprise and Industry is consulting all stakeholders and interested parties on key ideas for amending the regulatory framework for medicinal products in an effort to combat the counterfeiting of medicinal products.

For the purpose of this public consultation, which concentrates on sectoral pharmaceutical EU-legislation, the Commission has identified three areas of regulation of medicinal products where improvements to the regulatory framework could make a real contribution to protecting against counterfeit medicinal products.

These measures relate to:

- Manufacture, placing on the market of medicinal products and related inspections
- Import, export, transit (transhipment) of medicinal products
- Manufacture, placing on the market of active substances and related inspections



Contributions should be sent by e-mail to entrpharmaceuticals-counterfeit@ec.europa.eu by 9 May 2008.

## 12 March 2008: Public Health Executive Agency organises Infoday on 2008 call for proposals of the Commission health programme

At the Infoday on the call for proposals of the Commission health programme, the European Commission provided detailed information on the three strands of the call which aim at:

- Improving citizens' health security,
- Promoting health and reducing health inequalities,
- Generating and disseminating health information and knowledge.

Unlike previous calls, the Commission included new financing mechanisms. Apart from project funding, the Commission will now also provide funding for operating grants and conferences.

Jean Georges attended the meeting on behalf of Alzheimer Europe.

## 17 March 2008: EU Conference discusses issue of elder abuse

The EU conference on abuse of the elderly brought together experts and policy makers to raise awareness and trigger an open debate on this issue.

The conference noted that in some cases, abuse is deliberate – adults extorting money from their elderly parents or homes overusing tranquilisers. But most abuse takes the form of neglect, when carers don't have the resources to do their job properly or simply can't cope.

With forecasts putting 12% of the population in the 80+ age bracket by 2050, more and more people will depend on relatives or professionals to meet their care needs.



"Member states are starting to support carers and relatives better through training and guidance", explained social affairs

commissioner, Vladimír Špidla who participated in the conference. He argued that care for the elderly should be covered by human rights legislation, and welcomed the support groups and telephone hotlines set up to curb abuse.

Sabine Henry, Vice-Chairperson of Alzheimer Europe and Annette Dumas, EU Public Affairs Officer participated in the conference on behalf of Alzheimer Europe.

## 25 March 2008: European Commission launches public consultation on patient safety

The European Commission launched on 25 March 2008 an 8 week public consultation on patient safety. The results of this will help in the development of the Commission's proposal on general patient safety issues planned for the end of 2008.

The two primary objectives of the Commission's general patient safety proposal will be:

- to support Member States in their efforts to minimise harm to patients from adverse events in their health systems, through appropriate policies and actions to improve safety and, therefore, quality of care.
- to improve EU citizens' confidence that they will receive sufficient and comprehensible information available on levels of safety and available redress in EU health systems, including healthcare providers in their own country and in other Member States.

The Commission would like to have the views of all those involved in this field, including patients and consumers.

Deadline for contributions is 20 May 2008.

## **Policy Watch**

## 2 March 2008: UK minister sets out plans to enable elderly couples to stay together in care homes

The UK Health Secretary, Alan Johnson, disclosed plans for older people and their carers at the Labour Spring Conference in Birmingham. Focusing on adult social care he announced plans to ensure couples remain together when they are forced into care. Alan Johnson said, "when a couple have lived all their lives together they should not be forced apart at the end of their lives."

# 14 March 2008: Reform of German long-term care insurance results in some improvements for people with dementia

After months of discussion, the law reforming the German long-term care insurance has finally been passed. It includes several improvements for people with dementia.

 Those who do not yet fall into one of the official care categories will soon be able to receive up to a maximum of





EUR 200 per month for services such as support groups, helper circles and day care.

- In addition to improved out-patient services, it will soon be possible for people in group living facilities to combine their services and use them for the purpose of supervision/care.
- Last minute changes were agreed which will result in the possibility of additional staff for people with dementia receiving in-patient care.

However, the definition of "care needs" is still very much orientated towards physical needs and therefore puts people with dementia and other mental illnesses at a distinct disadvantage. The results of discussions on this issue, led by the advisory council of the Ministry of Health, will be revealed at the end of



Whilst welcoming the positive changes, Heike von Lützau-Hohlbein, Chairperson of the German Alzheimer Society, commented, "We hope that the extremely complicated new rules will be quickly implemented without

unnecessary bureaucracy and without creating new confusion [...] Even after the reform we need to campaign. We don't want to wait for years until the issue [the definition of care needs] gets on the agenda. We owe it to people who are in need of care."

We provide full references to articles on our website

www.alzheimer-europe.org

## From our Member Organisations

1 March 2008: Alicja Sadowska is reelected as Chairperson of the Polish Alzheimer's Association



At the General Meeting of the Polish Alzheimer's Association, Alicja Sadowska, a Board member of Alzheimer Europe, was re-elected as Chairperson of the organisation.

Other members of the Board

are:

- Aldona Ekiert Vice-Chairperson
- Elzbieta Bletek Secretary General
- Marianna Michalak Treasurer

- · Andrzej Rodys Member
- Mirka Wojciechowska Member.

6 March 2008: German association updates manual on "Residential care of people with dementia"



The German Alzheimer's Society (Deutsche Alzheimer Gesellschaft), has updated and fully revised its manual

entitled, "Stationäre Versorgung von Demenzkranken. Leitfaden für den Umgang mit demenzdranken Menschen" (Residential care of people with dementia). The book targets both professional carers in care homes and informal carers.

Topics covered include:

- New care home concepts
- · Care of people with dementia
- Architectonic design and milieu therapy
- Organisation and personnel development
- Medical care in the home
- Legal issues
- Finance
- Communication between formal and informal carers
- Care home selection

## Other European Organisations

20 March 2008: AGE calls for leave to allow people to care for dependant relatives



In response to the European Commission's

consultation on the reconciliation of work and family life, AGE (the European Older People's Platform) has stated that more should be done to facilitate a life-work balance for older workers and to accommodate their needs as employees with their caring obligations for dependent family members of any age i.e. not just for children. This should involve comprehensive and flexible employment arrangements as well as time off to care for dependents. According to AGE, this would be particularly helpful to women in late middle age in paid employment who often take on responsibility for the care of their elderly parents or grand-children.

AGE makes several other recommendations including one to develop EU legislation with





specific measures for elder care in view of the progressive ageing of European populations.

## Science Watch

## 1 March 2008: Study suggests a decline in the rate of dementia

A study published in the Journal of the Alzheimer's Association, "Alzheimer and Dementia" conducted by the Department of Medicine, University of Michigan, USA, suggests that between 1993 and 2004, there is evidence of a compression of cognitive morbidity. The researchers concluded that "societal investment in building and maintaining cognitive reserve through formal education in childhood and continued cognitive stimulation during work and leisure in adulthood might help limit the burden of dementia among the growing number of older adults worldwide."

# 3 March 2008: Study examines the risk of Alzheimer's disease in children who have two parents with the disease

A study carried out in the USA suggests that children of parents who both have Alzheimer's disease are more likely to get the disease themselves.

The research was carried out on a 111 families where both parents had a clinical diagnosis of Alzheimer's disease). It was led by Suman Jayadev, MD from the Department of Neurology, University Washington, with researchers from the Department of Epidemiology and Health Policy Research, University of Florida and the VA Puget Sound Health Care System, USA

## 10 March 2008: Study highlights key problems faced by dementia carers

A study to examine the experience of being a carer has found that many carers of people with dementia feel overwhelmed by grief. Responses from more than 400 dementia carers on over 100 issues were analysed, however the problem of grief was evident when carers were asked "What would you say is the biggest barrier you have faced as a caregiver?" Their responses fall under five main areas:

- Personal grief and loss experienced
- The patient's difficult behaviour and need for hands-on-care
- Shortfalls in community and financial support
- Difficulties in communicating with the patient, other relatives and medical professionals

 The caregiver's loss of personal time and freedom

The study was led by Associate Professor Jacquelyn Frank of the University of Indianapolis Centre for Aging and Community, USA.

## 11 March 2008: Cannabidiol found to slow memory decline in mice



Talking at a symposium hosted by the Royal Pharmaceutical Society of Great Britain, researchers at the Hebrew University of Jerusalem

presented their findings that cannabidiol, a compound found in cannabis, may slow down memory problems in mice.

## 14 March 2008: Researchers explore possible use of gene therapy for neurodegenerative diseases



Scientists from Gunma University (Japan), led by Hirokazu Hirai, have tested on mice a potential genetic therapy for spinocerebellar ataxia, a severe inherited brain-wasting disease of the

same family as Huntington's disease.

The treatment involves injecting the HIV virus into the brain in a modified form so that it is harmless. An extra gene which makes a protein called CRAG is added to the virus. This fixes the genetic fault that causes the symptoms of the disease.

It will, however, be some time before this and other forms of gene therapy become viable forms of treatment for humans as it is difficult to find a safe way to deliver the genes. Also, as pointed out by Professor Patrick Chinnery, an expert in neurogenetics at Newcastle University (UK), "There are concerns that the gene gets inserted in different parts of the human genome and could potentially disrupt normal healthy genes and cause problems. The biggest concern is that it might disrupt and switch off a gene that suppresses cancer."

We provide full references to articles on our website

www.alzheimer-europe.org

## 18 March 2008: 10 million US baby boomers are predicted to develop Alzheimer's disease by 2050

The Alzheimer's Association (USA) estimates that 10 million baby boomers (i.e. people who



are now aged between 44 and 62) will develop Alzheimer's disease at some point in their lives. There are currently 5.2 million people with dementia in the USA and the direct and indirect costs of dementia to Medicaid, Medicare and business are said to amount to over USD 148 billion per year. However, much of the cost of dementia care is borne by informal carers. The economic value of the care they provide in the USA was estimated at USD 89 billion in 2007.

The Alzheimer's Association further states, "By 2050, the number of individuals age 65 and over with Alzheimer's could range from 11 million to 16 million unless science finds a way to prevent or effectively treat the disease. By that date, more than 60 percent of people with Alzheimer's disease will be age 85 or older."

These and other interesting facts about the impact of dementia can be found in the Alzheimer's Association's report entitled "Alzheimer's disease facts and figures" which is a comprehensive statistical abstract of US data on Alzheimer's disease. It contains information on prevalence, mortality, lifetime risk, the costs of care and family caregiving.

# 25 March 2008: Researchers examine links between oestrogen levels and verbal memory impairment

British researchers at the Institute of Psychiatry in London (UK), led by Michael Craig (a trained psychiatrist and gynaecologist), discovered that pre-menopausal women's performance on word recognition tasks improved when given a gonadotropin hormone releasing hormone agonist (GnRHa) - a drug which shuts down the ovaries and induces a temporary menopause. The women were given this drug in preparation for surgery to treat fibroids. When their ovaries were not working their performance on the memory task dropped from 75% to 65% accuracy, returning to 75% when their oestrogen level was restored.

Decreased activity in an area of the brain called the pre-frontal cortex was also detected during treatment. This area of the brain is linked to learning and memory. It plays a role in the deep processing of "to-be-learned" words. Consequently, the difficulties occur at the encoding rather than the retrieval stage.

Although this study was carried out on premenopausal women, the possible link to hormone replacement therapy (HRT) cannot be overlooked as HRT also involves restoring decreasing levels of oestrogen. However, the 2002 Women's Health Initiative trial found that HRT may increase the risk of breast cancer and cardiovascular disease. Whilst, Dr. Craig suggests that there may be a critical window of

time around the menopause during which HRT might protect against Alzheimer's disease, there is no conclusive evidence for this and women are therefore not advised to start HRT as a preventive measure against Alzheimer's disease.

# 27 March 2008: Research finds limited benefits but also increased risk of stroke for elderly people taking ginkgo biloba extract



An American pilot study involving 118 cognitively intact people over 84 found no significant

difference in the development of dementia between those who were given 240mg of ginkgo biloba extract (GBE) per day and those who were given a placebo (dummy pill).

However, when the researchers looked at the data again, once the results were known, and took into account actual adherence to the medication, they detected a significant reduction in the time taken to develop very mild dementia. This slight benefit might of course be limited to elderly healthy subjects and not extend to those under the age of 85.

Of particular concern was the finding that 7 people in the GBE group developed a stroke or TIA (a warning stroke not lasting more than 24 hours). The researchers state that this finding requires further study.

# 27 March 2008: Incident dementia may be associated with changes in folate, vitamin B12 and homocysteine concentrations

Researchers form the Chonnam National University Medical School (Korea) and King's College London (UK) recently investigated the possible importance of baseline concentrations or changes in concentrations of folate, vitamin B12 and homocysteine as predictors/correlates of incident dementia. They found that the onset of dementia was more strongly associated with changes in these concentrations, namely an exaggerated decline in folate, a weaker increase in vitamin B12 and an exaggerated increase in homocysteine concentrations over the follow-up period.

## 27 March 2008: Having a large waist increases the risk of Alzheimer's disease irrespective of overall weight

Previous research has already pointed to a link between being overweight and developing dementia but researchers, working on behalf of one of the biggest healthcare providers in the US, have found that having a large waist



increases the risk even more. In fact, even people of normal weight with a large waist when middle-aged were found to be at greater risk of developing Alzheimer's disease.

After measuring abdominal fat levels of 6,583 people aged between 40 and 45 using calipers, the researchers checked the subjects' medical records some 36 years later (on average) in order to see which people had developed Alzheimer's disease or another form of dementia.

The results indicate that being overweight and having a large waist increases the risk by 230%. Being clinically obese and having a large waist resulted in a 360% increased risk compared to normal weight, small-waisted people. Normal weight people with a large waist had an increased risk of 90%, whereas overweight or obese people who didn't have a large waist only had an 80% increased risk.

The importance of this study is that it shows that waist size rather than general weight (e.g. as measured by body mass index) is probably a better way to predict a person's risk of developing dementia in later life.

## **Dementia in Society**

13 March 2008: Best-selling author, Terry Pratchett, pledges £500,000 to research into





Terry Pratchett, the best-selling author who was diagnosed with Alzheimer's disease last year, is pledging £500,000 to the UK Alzheimer's Research Trust. He said, "There's nearly as many of us as there are cancer sufferers, and it looks as if the number of people with dementia will double within a

generation [...] It is a shock to find out that funding for Alzheimer's research is just three per cent of that to find cancer cures."

Speaking at the ninth Annual Network Conference of the Alzheimer's Research Trust in Bristol, Terry Pratchett also spoke out about his anger that medication is not available on the NHS and that he doesn't have a local specialist to turn to.

## 18 March 2008: Awards announced for dementia-friendly design

The 2008 Design Business Association (DBA) Inclusive Design Challenge, entitled "Thanks for the Memory" called for designers to address cognitive decline and enhance the quality of life

for people with dementia and their carers. The challenge was sponsored by Sanctuary Care.

The two joint-winners from a shortlist of six design projects were announced at the Royal College of Art, London on 18 March:

- Adare's "Mind Book" which is a computer software programme designed to allow patient life history to be stored, communicated and updated in the form of a virtual scrapbook.
- "Ormsthwaite House", designed by retail space specialists is a circular model care home which aims to address the confusion suffered by people with dementia.

## 20 March 2008: Hugo Claus, suffering from Alzheimer's disease, dies by euthanasia



Hugo Claus, a famous Belgian writer who had Alzheimer's disease, has died. He was perhaps best known for his 1983 book entitled "The Sorrow of Belgium" but was also a poet, painter, playwright and film director. He was

awarded the Dutch order of letters in 1986 and was nominated several times for the Nobel Prize for Literature.

He died at the age of 78 at a hospital in Antwerp (Belgium) having requested euthanasia.

# 27 March 2008: ABPI survey reveals high public support in the United Kingdom for increased funding for Alzheimer's disease

The British public wants Alzheimer's to be one of the top three research priorities, according to a survey released by the Association of the British Pharmaceutical Industry (ABPI).

The top two diseases of most concern to people throughout the UK were cancer – 72 per cent listed it as a national priority – and heart disease, cited by 33 per cent. Alzheimer's came third, with 11 per cent of the public demanding greater national health spending and 12 per cent more research.

The research was conducted by the ABPI to investigate whether treatments in the Research & Development pipeline matched both public concerns and NHS priorities.



## **New Publications**

January 2008: Person with dementia contributes a chapter to the new edition of the Oxford Textbook on Old Age Psychiatry.

The new edition of the Oxford Textbook of Old Age Psychiatry is a reference book covering topics about old age such as biological aspects, clinical practice, psychiatric services, specific disorders and sexuality, ethics and medico-legal issues. Included in this new edition is the chapter "Clinical Aspects of dementia: Living with dementia" which has been written by Peter Ashley, who has had dementia for nearly eight years.

The Oxford Textbook of Old Age Psychiatry, ISBN-13: 978-0-19-929810-5 edited by Robin Jacoby, Catherine Oppenheimer, Tom Dening and Alan Thomas costs £59.95 (paperback).

3 March 2008: European Commission publishes fact sheets and booklet on the European Health Programme

The European Commission has published a booklet "Together for health" with fact sheets providing detailed information on their health programme (2008-2013).

7 March 2008: European Commission makes Dementia in Europe Yearbooks available on line

The Alzheimer Europe Dementia in Europe Yearbook 2006 and 2007 are now available on line on the European Commission's website.

## **Contact Alzheimer Europe at:**

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### **Alzheimer Europe Board**

Chairperson: Maurice O'Connell (Alzheimer's Society of Ireland)

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**Vice-Chairperson:** Sabine Henry (Ligue Alzheimer, Belgium)

Honorary Secretary: Sigurd Sparr (Nasjonalforeningen Demensförbundet, Norway)
Honorary Treasurer: Heike von Lützau-Hohlbein (Deutsche Alzheimer Gesellschaft, Germany)

Neil Hunt (Alzheimer's Society UK)
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Pekka Laine (Alzheimer-keskusliitto, Finland)
Ad Adriaansen (Stichting Alzheimer Nederland, The Netherlands)

Patrick Maugard (Association France Alzheimer, France)

Marc Schaefer (Association Luxembourg Alzheimer, Luxembourg)

## **AE** Calendar

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

Date	Meeting	AE Representative
1 April	Alzheimer Europe Board in Brussels, Belgium	
1 April	European Parliament Lunch-debate: "Is Alzheimer's disease preventable?" in Brussels, Belgium	
3 April	Meeting with Roche in Brussels, Belgium	Georges Jean & Dumas Annette
3 April	Meeting with Parliament Magazine in Brussels, Belgium	Georges Jean & Dumas Annette
4-5 April	Lundbeck Symposium in Budapest, Hungary	Georges Jean
7 April	French Senate Hearing on Alzheimer's disease in Paris, France	Dumas Annette
8 April	General Assembly of European Patients' Forum in Brussels, Belgium	Georges Jean & Dumas Annette
8 April	Preparatory meeting for 19 <sup>th</sup> Alzheimer Europe conference in Brussels, Belgium	Georges Jean
8-9 April	Spring conference of European Patients' Forum in Brussels, Belgium	Georges Jean & Dumas Annette
14 April	Steering committee for French Presidency Conference on Alzheimer's disease in Paris, France	Georges Jean
15 April	Carers Intergroup in European Parliament in Brussels, Belgium	Georges Jean & Dumas Annette
16 April	Fondation Médéric Alzheimer in Paris, France	Georges Jean
16 April	NGO Health Grouping Meeting at the Council of Europe, Strasbourg, France	Gove Dianne



## **Future Conferences**

Dates	Meeting	Place
6-8 May	Embracing the challenge: Citizenship and Dementia http://www.dementiacentreni.org/	Belfast, United Kingdom
22-25 May	Breaking Barriers www.alzheimer-conference2008.org	Oslo, Norway
29 May-1 June	36 <sup>th</sup> Congress of the European Association of Geriatric Psychiatry http://www.forumcongress.com/eagp/	Kos, Greece
12-16 July	6 <sup>th</sup> FENS Forum of European Neuroscience http://fens2008.neurosciences.asso.fr/	Geneva, Switzerland
26-31 July	11 <sup>th</sup> International Conference on Alzheimer's disease and related disorders <a href="http://www.alz.org/icad/overview.asp">http://www.alz.org/icad/overview.asp</a>	Chicago, USA
1-2 August	3 <sup>rd</sup> IANA Symposium on Alzheimer's and nutrition http://www.serdi-fr.com/ABQ.htm	Albuquerque, USA
23-26 August	12 <sup>th</sup> Congress of the European Federation of Neurological Societies http://efns2008.efns.org/	Madrid. Spain
3-5 September	6 <sup>th</sup> International Conference on Frontotemporal Dementias <u>www.ftd2008.org</u>	Rotterdam, Netherlands
17-19 September	1st Conference: Clinical Trials on Alzheimer's disease http://www.ctad.fr/	Montpellier, France
9-11 October	5 <sup>th</sup> Congress for the German Alzheimer Association (Alzheimer Gesellschaft) <u>www.ctw-congress.de/alzheimer</u>	Erfurt, Germany

