



# NEWSLETTER

October - December 2008

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## Editorial



Welcome! This quarter has been exceptionally busy and productive and I am delighted by the exposure Alzheimer's disease is currently being given at both national and European level. In particular, three events indicate that policy makers are truly hearing the call for action against dementia.

Firstly, no less than the President of France, Nicolas Sarkozy, as well as national health ministers from around Europe, pledged their support to helping people with dementia and their carers at the "The fight against Alzheimer's disease and related disorders" conference, hosted by Roselyne Bachelot in Paris from 30 to 31 October. Delegates were delighted to hear the President talk of his personal commitment and call for European action.

Secondly, in December, the Council of European Health Ministers adopted far-reaching conclusions on public health strategies to combat neurodegenerative diseases associated with ageing, in particular Alzheimer's disease. The Council also called upon the European Commission to adopt an initiative in 2009 which would strengthen European collaboration in the field of Alzheimer's disease.

Thirdly, I am greatly encouraged that 247 Members of the European Parliament have already signed the Written Declaration 80/2008 on priorities in the fight against Alzheimer's disease which was launched by five European Alzheimer's Alliance members, including its Chairperson, Françoise Grossetete. MEPs have until 22 January 2009 to pledge their support and I sincerely hope that the remaining MEPs grasp this opportunity to pledge their support.

Two of our long-term projects (European Collaboration on Dementia – EuroCoDe and our end-of-life care project) were completed during October and we were able to produce the final report of both projects in for our lunch debate in the European Parliament at the beginning of December. We report on this meeting at which Anders Wimo of the Karolinska Institute in Sweden presented the findings of the socio-economic group of the EuroCoDe project.

Finally, I would like to apologise: Our busy time table and unexpected staff shortages unfortunately resulted in the newsletter being delayed.

I hope you enjoy this edition of our newsletter and take this opportunity to wish you all the best for the festive season and the New Year.

**Jean Georges**  
Executive Director

## Making dementia a European priority

Our campaign enjoys increasing support from MEPs with the following pledging their support in October, November and December 2008:



**Adamou Adamos**  
Cyprus, GUE-NGL



**Aylward Liam**  
Ireland, UEN



**Demetriou Panayiotis**  
Cyprus, EPP-ED



**Evans Robert**  
United Kingdom, PES



**Jørgensen Karin-Riis**  
Denmark, ALDE



**Simpson Brian**  
United Kingdom, PES



**Toia Patrizia**  
Italy, ALDE



**Triantaphyllides Kyriacos**  
Cyprus, GUE-NGL

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 88. 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:

### Austria

1. Ettl Harald (PES)

### Belgium

2. Brepoels Frieda (EPP-ED)
3. Busquin Philippe (PES)
4. Hutchinson Alain (PES)
5. Langendries Raymond (EPP-ED)
6. Staes Bart (Greens –EFA)
7. Sterckx Dirk (ALDE)

### Bulgaria

8. Zdravkova Dushana (EPP-ED)

### Cyprus

9. Adamos Adamou (GUE-NGL)
10. Demetriou Panayiotis (EPP-ED)
11. Triantaphyllides Kyriacos (GUE-NGL)

### Czech Republic

12. Cabrnock Milan (EPP-ED)
13. Kohlicek Jaromir (GUE/NGL)
14. Roithova Zuzana (EPP-ED)
15. Vlasak Oldrich (EPP-ED)

### Denmark

16. Busk Neils (ALDE)
17. Dahl Hanne (IND/DEM)
18. Jensen Anne E. (ALDE)
19. Jørgensen Karin-Riis (ALDE)
20. Schaldemose Christel (PES)

### Finland

21. Myller Riitta (PES)
22. Pietikäinen Sirpa (EPP-ED)
23. Virrankoski Kyösti (ALDE)

### France

24. Audy Jean-Pierre (EPP-ED)
25. Daul Joseph (EPP-ED)
26. De Veyrac Christine (EPP-ED)
27. Fouré Brigitte (EPP-ED)
28. Griesbeck Nathalie (ALDE)
29. Grossetête Françoise (EPP-ED)
30. Henin Jacky (GUE/NGL)
31. Lamassoure Alain (EPP-ED)
32. Morin Elisabeth (EPP-ED)
33. Onesta Gérard (Greens-EFA)

34. Toubon Jacques (EPP-ED)

**Germany**

- 35. Niebler Angelika (EPP-ED)
- 36. Ulmer Thomas (EPP-ED)
- 37. Weisgerber Anja (EPP-ED)

**Greece**

- 38. Koppa Maria Eleni (PES)
- 39. Kratsa-Tsagaropoulou Rodi (EPP-ED)
- 40. Matsouka Maria (PES)
- 41. Panayotopoulos Marie (EPP-ED)
- 42. Papadimoulis Dimitrios (GUE/NGL)
- 43. Schinas Margaritis (EPP-ED)
- 44. Trakatellis Antonios (EPP-ED)
- 45. Vakalis Nikolaos (EPP-ED)

**Hungary**

- 46. Levai Katalin (PES)
- 47. Surján László (EPP-ED)

**Ireland**

- 48. Aylward Liam (UEN)
- 49. Crowley Brian (UEN)
- 50. McDonald Mary Lou (GUE/NGL)
- 51. McGuinness Mairead (EPP-ED)
- 52. Mitchell Gay (EPP-ED)
- 53. Ryan Eoin (UEN)
- 54. Sinnott Kathy (IND/DEM)

**Italy**

- 55. Battilocchio Alessandro (PES)
- 56. Panzeri Pier Antonio (PES)
- 57. Podestà Guido (EPP-ED)
- 58. Toia Patrizia (ALDE)

**Lithuania**

- 59. Dickute Jolanta (ALDE)

**Luxembourg**

- 60. Goebbels Robert (PES)
- 61. Lulling Astrid (EPP-ED)

62. Spautz Jean (EPP-ED)

**Netherlands**

- 63. Corbey Dorette (PES)
- 64. De Lange Esther (EPP-ED)
- 65. Wortmann Corien (EPP-ED)

**Poland**

- 66. Masiel Jan Tadeusz (UEN)
- 67. Rogalski Boguslaw (UEN)

**Portugal**

- 68. Coelho Carlos (EPP-ED)
- 69. Esteves Maria do Assunção (EPP-ED)
- 70. Estrela Edite (PES)
- 71. Figueiredo Ilda (GUE/NGL)
- 72. Gomes Ana Maria (PES)
- 73. Pinheiro João de Deus (EPP-ED)
- 74. Queiró Luis (EPP-ED)
- 75. Ribeiro José (EPP-ED)
- 76. Silva Peneda José Albino (EPP-ED)

**Romania**

- 77. Winkler Luliu (EPP-ED)

**Slovakia**

- 78. Mikolasik Miroslav (EPP-ED)

**Sweden**

- 79. Cederschiold Charlotte (EPP-ED)

**United Kingdom**

- 80. Bowis John (EPP-ED)
- 81. Evans Robert (PES)
- 82. Hall Fiona (ALDE)
- 83. McAvan Linda (PES)
- 84. Moraes Claude (PES)
- 85. Simpson Brian (PES)
- 86. Stihler Catherine (PES)
- 87. Watson Graham (ALDE)
- 88. Willmott Glenis (PES)

## European Alzheimer's Alliance

### 8 October 2008: Members of European Parliament call for development of European Action Plan on Alzheimer's disease

Françoise Grossetête (France), John Bowis (United Kingdom), Katalin Levai (Hungary), Jan Tadeusz Masiel (Poland) and Antonios Trakatellis (Greece) joined forces to issue a call to the European Commission and the Council

of Ministers to recognise Alzheimer's disease as a European public health priority and to develop a European Action Plan on Alzheimer's disease.

In a Written Declaration, the Members of the European Parliament from five different European countries and three different political groups call in particular for increased European collaboration on research into the causes, prevention and treatment of Alzheimer's disease, as well as earlier diagnosis, improved support for people with dementia and their

carers and better recognition of the role of Alzheimer associations.



Françoise Grossetête, Chairperson of the European Alzheimer's Alliance stressed: "As Members of the European Parliament, we cannot remain indifferent to the 6.1 million European citizens who live with Alzheimer's disease or a different form of dementia today. We give our full support to the French Presidency initiative to improve the collaboration between Member States on research and the exchange of best practices."

**31 October 2008: Françoise Grossetête calls for European action on dementia**

Speaking at the French Presidency Conference on Alzheimer's disease in Paris, Françoise Grossetête welcomed the clear priority given by the French Presidency to the fight against Alzheimer's disease and other forms of dementia and expressed her hope that the conference would lead to the adoption of a European Action Plan on Alzheimer's disease.

She welcomed the work carried out by Alzheimer Europe and praised the "Dementia in Europe Magazine" focusing on national and European policy initiatives, as well as other Alzheimer Europe publication which provide policy makers with much needed comparative information on the state of dementia care and treatment in the different European countries.

**9 December 2008: Jan Tadeusz Masiel, MEP, hosts lunch debate on Alzheimer's disease in the European Parliament**

Jan Tadeusz Masiel (MEP, Poland), shown back right below) hosted Alzheimer Europe's fourth lunch debate in European Parliament on the socio-economic cost of Alzheimer's disease, which was presented by Anders Wimo of the Karolinska Institute Stockholm. He began the proceedings by explaining that the lunch debates had become something of a tradition between Alzheimer Europe and the European Alzheimer's Alliance, enabling a platform for discussion about Alzheimer's disease within the European Parliament.

Highlighting additional ways in which MEPs have the opportunity to be kept informed about Alzheimer's disease, Mr Masiel spoke of the 80 MEPs who had already pledged their support to fight Alzheimer's disease by signing the Paris Declaration, which lists Alzheimer Europe's political priorities, or/and becoming a member of the European Alzheimer's Alliance. Finally Mr Masiel called on all MEPs to give their support to Written Declaration no 80/2008 on the priorities in the fight against Alzheimer's disease, saying that he "sincerely hopes that this Declaration meets the number of required signatures in order that it becomes a reality and strengthens our joint action, both of Alzheimer Europe and its members, and within the European Parliament".



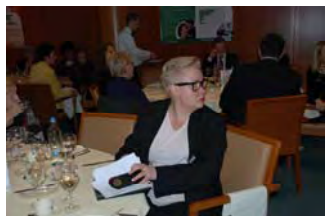
Jan Tadeusz Masiel, MEP (Poland) welcomes the participants



Professor Wimo talks about the socio-economic impact



Representatives of the Greek Alzheimer's Association in discussion with Marie Panayotopoulos, MEP (Greece)



Sirpa Pietikäinen, MEP (Finland) listens attentively



Zdzislaw Podkanski, MEP (Poland) in conversation with the speaker



Agnieszka Szczesniak, Jean Georges and Jan Tadeusz Masiel after a successful meeting

## Written Declaration Update

By the end of December, 247 Members of the European Parliament had given their support to the Written Declaration initiated by MEPs Françoise Grossetête (France), John Bowis (United Kingdom), Katalin Levai (Hungary), Jan Tadeusz Masiel (Poland) and Antonios Trakatellis (Greece).

The Written Declaration will be open for signature until 22 January 2009 and will become official if more than half of all Members of the European Parliament sign the document.

Alzheimer Europe and its national member organisations would like to thank all 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.

**Austria:** Ettl Harald, Pirker Hubert, Rübiger Paul, Swoboda Hannes

**Belgium:** Brepoels Frieda, Busquin Philippe, Corda Giovanna, Deprez Gérard, De Vits Mia, Langendries Raymond, Ries Frédérique, Staes Bart, Sterckx Dirk, Thyssen Marianne, Van Lancker Anne

**Bulgaria:** Baeva Mariela Velichkova, Binev Slavi, Lyubcheva Marusya Ivanova, Paparizov Atanas, Raeva Bilyana Ilieva, Stavreva Petya, Stoyanov Dimitar, Urutchev Vladimir, Vigenin Kristian, Zdravkova Dushana

**Cyprus:** Adamou Adamos, Demetriou Panayiotis, Kasoulides Ioannis, Matsakis Mario, Matsis Yiannakis, Triantaphyllides Kyriacos

**Czech Republic:** Cabrnock Milan, Kohlíček Jaromír, Maštálka Jiří, Ransdorf Miloslav, Remek Vladimír, Rouček Libor, Škottová Nina, Vlasák Oldřich, Zvěřina Jaroslav

**Denmark:** Busk Niels, Christensen Ole, Jensen Anne E., Lebech Johannes, Riis-Jørgensen Karin, Thomsen Britta

**Estonia:** Oviir Siiri

**Finland:** Pietikäinen Sirpa, Seppänen Esko, Takkula Hannu

**France:** Arif Kader, Audy Jean-Pierre, Bennahmias Jean-Luc, Cornillet Thierry, De Sarnez Marielle, Descamps Marie-Hélène, Douay Brigitte, Fontaine Nicole, Fouré Brigitte, Fournou Janelly, Gaubert Patrick, Gibault Claire, Griesbeck Nathalie, Grossetête Françoise, Lamassoure Alain, Lefrançois Roselyne, Lehideux Bernard, Lipietz Alain, Louis Patrick, Mathieu Véronique, Onesta

Gérard, Sudre Margie, Toubon Jacques, Vergnaud Bernadette, Vlasto Dominique, Weber Henri

**Germany:** Beer Angelika, Cramer Michael, Kallenbach Gisela, Kaufmann Sylvia-Yvonne, Özdemir Cem, Roth-Behrendt Dagmar

**Greece:** Angelakas Emmanouil, Arnaoutakis Stavros, Botopoulos Costas, Dimitrakopoulos Giorgos, Georgiou Georgios, Gklavakis Ioannis, Koppa Maria Eleni, Kratsa-Tsagaropoulou Rodi, Lambrinidis Stavros, Matsouka Maria, Panayotopoulos-Cassiotou Marie, Papadimoulis Dimitrios, Papastamkos Georgios, Podimata Anni, Schinas Margaritis, Trakatellis Antonios, Tzampazi Evangelia, Vakalis Nikolaos, Varvitsiotis Ioannis

**Hungary:** Lévai Katalin, Szájer József

**Ireland:** Aylward Liam, Burke Colm, Crowley Brian, Harkin Marian, McGuinness Mairead, Mitchell Gay, Ó Neachtain Seán, Ryan Eoin, Sinnott Kathy

**Italy:** Agnoletto Vittorio, Bartolozzi Paolo, Bonsignore Vito, Braghetto Iles, Gardini Elisabetta, Kusstatscher Sepp, Lo Curto Eleonora, Morgantini Luisa, Muscardini Cristiana, Patriciello Aldo, Robusti Giovanni, Romagnoli Luca

**Latvia:** Andrejevs Georgs, Kristovskis Ģirts Valdis

**Lithuania:** Budreikaitė Danutė, Dičkutė Jolanta, Maldeikis Eugenijus, Paleckis Justas Vincas

**Luxembourg:** Lulling Astrid, Spautz Jean

**Malta:**

**Netherlands:** Jacobs Lily, de Lange Esther, Liotard Kartika Tamara, Manders Toine, Wortmann-Kool Corien

**Poland:** Czarnecki Marek Aleksander, Golik Bogdan, Janowski Mieczysław Edmund, Kaczmarek Filip, Masiel Jan Tadeusz, Olbrycht Jan, Podkański Zdzisław Zbigniew, Protasiewicz Jacek, Rutowicz Leopold Józef, Staniszevska Grażyna, Tomaszewska Ewa, Tomczak Witold, Wojciechowski Janusz, Zaleski Zbigniew, Zwiefka Tadeusz

**Portugal:** Casaca Paulo, Coelho, Carlos, Esteves Maria da Assunção, Estrela Edite, Fernandes Emanuel Jardim, Ferreira Elisa, Figueiredo Ilda, França Armando, Gomes Ana Maria, Guerreiro Pedro, Madeira Jamila, Marques Sérgio, Ribeiro e Castro José, Silva Peneda José Albino

**Romania:** Bulzesc Nicodim, Buşoi Cristian Silviu, Csibi Magor Imre, David Dragoş Florin, Dumitriu Constantin, Filip Petru, Marinescu

Marian-Jean, Oprea Dumitru, Petre Maria, Sógor Csaba

**Slovakia:** Belohorská Irena, Duka-Zólyomi Árpád, Gaľa Milan, Šťastný Peter, Záborská Anna

**Slovenia:** Juri Aurelio, Kacin Jelko, Peterle Alojz

**Spain:** Ayuso Pilar, Díaz de Mera García Consuegra Agustín, Fraile Cantón Juan, Galeote Gerardo, Garcés Ramón Vicente Miguel, García-Margallo y Marfil José Manuel, Grau i Segú Martí, Guardans Cambó Ignasi, Gutiérrez-Cortines Cristina, Herranz García Esther, Luque Aguilar Florencio, Martínez Martínez Miguel Angel, Menéndez del Valle Emilio, Miguélez Ramos Rosa, Naranjo Escobar Juan Andrés, Riera Madurell Teresa, Romeva i Rueda Raül, Salafranca Sánchez-Neyra José Ignacio, Salinas García María Isabel, Sánchez Presedo Antolín, Sanz Palacio Salvador Domingo, Sornosa Martínez María, Varela Suanzes-Carpegna Daniel, Vidal-Quadras Alejo

**Sweden:** Ek Lena, Schmidt Olle, Wijkman Anders

**United Kingdom:** Ashworth Richard James, Attwooll Elspeth, Beazley Christopher, Bowis John, Bushill-Matthews Philip, Callanan Martin, Chichester Giles, Corbett Richard, Elles James, Evans Jill, Evans Robert, Ford Glyn, Hall Fiona, Harbour Malcolm, Honeyball Mary, Hughes Stephen, Jackson Caroline, Kinnock Glenys, Kirkhope Timothy, Lambert Jean, Lynne Elizabeth, Martin David, McAvan Linda, McCarthy Arlene, Morgan Eluned, Newton Dunn Bill, Nicholson James, Purvis John, Simpson Brian, Stevenson Struan, Stihler Catherine, Sumberg David, Tannock Charles, Tittley Gary, Van Orden Geoffrey, Watson Graham

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## Alzheimer Europe news

### 2 October 2008: Novartis approves Gold sponsorship for Alzheimer Europe in 2009

Novartis informed Alzheimer Europe of its decision to provide Gold sponsorship to the activities of the organisation in 2009 for the amount of EUR 40,000.

### 10 October 2008: Wyeth approves Silver sponsorship for Alzheimer Europe in 2009

Wyeth informed Alzheimer Europe of its decision to provide Silver sponsorship to the activities of the organisation in 2009 for the

amount of EUR 20,000, as well as Bronze sponsorship for the 19<sup>th</sup> Annual Conference in Brussels.

### 17 October 2008: Pfizer approves Gold sponsorship for Alzheimer Europe in 2009

Pfizer informed Alzheimer Europe of its decision to provide Gold sponsorship to the activities of the organisation in 2009 for the amount of EUR 40,000, as well as Gold sponsorship for the 19<sup>th</sup> Annual Conference in Brussels.

### 2 December 2008: GSK approves Silver sponsorship for Alzheimer Europe in 2009

GSK informed Alzheimer Europe of its decision to provide Silver sponsorship to the activities of the organisation in 2009 for the amount of EUR 30,000.

### 3 December 2008: Alzheimer Europe and affiliates submit collaborative project proposal to the European Commission

Following the European Commission's call "Health-2009-3.2.1: Organisation of dementia care" Alzheimer Europe and its partners have responded by putting forward a project proposal entitled "EU-DemCare – Experience of users of dementia care", which focuses on the experiences and expectations of both people with dementia and their carers about the organization of dementia care and dementia services.

By working in close collaboration with representatives of national governments and policy makers, Alzheimer Europe and some 30 partners hope to ensure that synergies with existing national initiatives can be achieved. It is also anticipated that the involvement of policy makers in the development stages of the project will contribute to a greater impact on current and future reforms of the organization of dementia care in European countries.

The outcome of the project application is due in May 2009.

### 5 December 2008: Janssen Pharmaceutical approves Gold sponsorship for Alzheimer Europe in 2009

Janssen Pharmaceutical informed Alzheimer Europe of its decision to provide Gold sponsorship to the activities of the organisation in 2009 for the amount of EUR 40,000 and silver sponsorship for the 19<sup>th</sup> Annual Conference in Brussels.

**8 December 2008: Board assesses work of Alzheimer Europe during 2008**

Meeting in Brussels on 8 December, the Alzheimer Europe Board reflected on the activities of the organisation during 2008 and discussed future work plans. These included:

- Participation in the French presidency conference and follow up
- The launch and dissemination of the Dementia in Europe magazine, now on its second issue
- The progress of the Written Declaration and ways in which Alzheimer Europe and its members could encourage support
- The possibility of drafting a dementia election manifesto for use in the upcoming European elections
- The completion of the End-of-life care report
- The publication and dissemination of the 2008 Dementia in Europe Yearbook
- The financial forecasts, risk assessment and cash flow situation of the organisation
- The forthcoming Alzheimer Europe Conference in Brussels
- The EUDemCare recent project application
- The 2009 work plan
- The revision of the draft document on involving people with dementia within the organisations activities

The next Board meeting will be held on 2 March 2009.

**9 December 2008: Issue 2 of Alzheimer Europe’s Dementia in Europe magazine published**



The second edition of the Dementia in Europe magazine was launched during Alzheimer Europe’s lunch debate in the European Parliament on 9 December 2008. Dedicated to European policy, this edition has substantial coverage of the French Presidency Conference on Alzheimer’s disease as well as articles on the recently completed European Collaboration on Dementia project and the European Ethics Network workshop. The situation of dementia in Poland is considered as well as a roundup of whether European countries have national dementia strategies in place. The work of the Alzheimer Associations is shown, inter alia, by

the coverage of World Alzheimer’s Day. Stigmatisation of dementia is also discussed.

**9 December 2008: Alzheimer Europe’s 2008 Dementia in Europe Yearbook launched at the European Parliament**



Alzheimer Europe launched its 3<sup>rd</sup> Dementia in Europe Yearbook during a lunch debate at the European Parliament. With forewords from Androulla Vassiliou, European Commissioner for Health and Françoise Grossetête, MEP (France) and Chairperson of the European Alzheimer’s Alliance, the Yearbook contains the outcome of the European Collaboration on Dementia (EuroCoDe) project from four of the six workgroups on:

- (a) Social support. Led by Dianne Gove from Alzheimer Europe, the group found huge inequalities of access to diagnosis, services and treatment throughout Europe.
- (b) Socio-economic costs. Anders Wimo from the Karolinska Institute, Sweden, and his team calculated the current cost of dementia in Europe to be EUR 130 bn, which will rise alongside the predicted prevalence rates.
- (c) Non-pharmacological interventions. The group, which found that guidelines exist in only five countries, was led by Myrra Vernooij-Dassen of the University Medical Centre St. Radboard, the Netherlands,
- (d) Risk factors and prevention. Led by Lutz Frölich of the Central Institute for Mental Health, Mannheim, the group highlighted some promising possibilities for the development of prevention strategies.

The Yearbook can be obtained from Alzheimer Europe for EUR 15.00.

**9 December 2008: “The socio-economic cost of Alzheimer’s disease” presented at Alzheimer Europe’s lunch debate in the European Parliament**

Alzheimer Europe’s fourth lunch debate in the European Parliament focused on the socio-economic cost of Alzheimer’s disease, with Anders Wimo of the Karolinska Institute presenting his workgroups’ findings from the European Collaboration on Dementia project. Great interest was shown by some 45 participants, including 13 MEPs and /or their assistants attending as well as national

Alzheimer Associations, representatives of permanent representations and pharmaceutical companies.

The debate was hosted by Jan Tadeusz Masiel, MEP (Poland), and European Alzheimer Alliance member who spoke of the EuroCoDe project, as well as how MEPs can show their support for people with dementia. Mr Wimo was introduced by Jean Georges, Executive Director of Alzheimer Europe, who took the opportunity to highlight the role of Alzheimer Europe and member organisations in the fight against dementia.



Mr Wimo explained that the working group looked at two types of cost, direct medical and non-medical costs (such as hospital care and drugs) and informal costs (such as production losses of patients and of unpaid informal carers).

These costs were compared for three geographical groups: (i) EU27, (ii) EU27 plus candidate countries and (iii) the whole of Europe (including Russia) and four care patterns emerged (a) Northern (Denmark, Ireland, Scandinavia, Sweden and the UK), (b) Western (Belgium, France, Germany and the Netherlands), (c) Southern (Italy, Spain and Turkey) and (d) Eastern (Hungary).

The conclusions of the working group were:

- a. The societal costs of dementia in the EU are enormous. If treatment remains the same, with predicted prevalence rates the cost will rise from EUR 130 billion to EUR 200 billion by 2030.
- b. More data is needed from Eastern Europe to make the figures more meaningful
- c. Informal care is a substantial part of the total cost of dementia and the quantification of informal cost is crucial for any cost estimates.

Thanking Mr Wimo for his presentation, and Mr Masiel for hosting the debate, Jean Georges wished all MEPs luck in their forthcoming elections. Mr Masiel closed the debate and gave his heartfelt thanks to Mr Wimo. He stressed the importance of working with the European Commission to find solutions for people with dementia and their carers. Mr Masiel also reminded MEPs of the importance of their signing the Written Declaration 80/2008 against Alzheimer's disease before 22 January 2009 to show support for the 6.1 million Europeans living with the disease.

The next Alzheimer Europe lunch debate in the European Parliament will be on 3 March 2009.

### **17 December 2008: Alzheimer Europe gives full backing to EU Health Ministers' call for European initiative on Alzheimer's disease**

Following the decision by the Council of European Health Ministers to adopt far-reaching conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer's disease, Jean Georges, Executive Director of Alzheimer Europe welcomed the EU initiative: "Alzheimer Europe would like to congratulate the French Presidency on the significant achievement of reaching a consensus amongst all Member States and the European Commission to make Alzheimer's disease and other forms of dementia a European priority. Together with our member organisations, we have actively campaigned for the development of national action plans and improved European collaboration and we are truly delighted that the Council of Ministers has given such a resounding backing to our call. We hope that the initiative will lead to improvements for the lives of the 6.1 million Europeans currently living with a form of dementia in the European Union, as well as those of their carers and families and promise our full support to the European Commission for the development of a comprehensive strategy addressing the medical, care-related, social and ethical issues faced by people with dementia and their carers."

### **18 December 2008: Alzheimer Europe's position and recommendations on end-of-life care published**

The Alzheimer Europe position and recommendations on end-of-life care is a practical guide for all those involved in the delicate and demanding stage of dementia. The working group, led by Dr Sigurd Sparr (Head of Geriatrics, University Hospital of Tromsø), consisted of experts in the field of Alzheimer's disease and/or palliative care, representatives from Alzheimer associations and carers from different European countries. The publication provides general guidelines on:

- Dignity and the quality of life
- Mild and moderate dementia
- Advance planning
- Carers' needs
- Interaction between carers and healthcare professionals
- Where care is needed and the kind of support required
- The social and built environment

- Enhancing emotional and personal well-being
- Communication
- Spiritual care and
- Cultural issues and minority groups
- Skin care
- Body temperature
- Sedation
- Restraint and falls
- Difficult breathing and “the death rattle”
- The moments preceding and following death

It also covers specific care issues:

- Pain management
  - Feeding and swallowing problems
  - Constipation, diarrhoea and incontinence
  - Pneumonia and infections
  - Dehydration and mouth care
- Ethical issues and also considered as well as a section on the terminology use

## Alzheimer Europe Networking

From 2 to 4 October (Vigo, Spain), Maurice O’Connell attended the **3rd National Alzheimer’s Conference** of Confederación Española de Asociaciones de Familiares de Alzheimer (CEAFA).

On 8 October (Brussels, Belgium), Jean Georges and Annette Dumas met with Dr. Paul Coleman from **Biogen Idec** for an exchange of information.

On 8 October (Brussels, Belgium), Jean Georges and Annette Dumas met with Shelagh Kerr and Chris Ward from **PhRMA** for an exchange of views on the role of patient representatives in health technology assessment.

On 8 October (Brussels, Belgium), Annette was invited to the goodbye cocktail party organised by **French MEP, Bernadette Bourzai**.

On 10 October (Edinburgh, United Kingdom), Jean Georges met with representatives of **Alzheimer Scotland** including the new Chief Executive Henry Simmons and Jan Killeen.

On 11 October (Edinburgh, United Kingdom), Jean Georges met with **Emma Reynish from the European Alzheimer’s Disease Consortium** for a progress report on the work package of the EuroCoDe project on prevalence.

On 12 October (Edinburgh, United Kingdom), the **working group on prevalence of the EuroCoDe** project met.

From 13 to 14 October (Paris, France), Annette Dumas participated in a **French Presidency Conference entitled “A Europe for patients”**.

On 14 October (Brussels, Belgium), Dianne Gove attended a meeting of the **Intergroup on Ageing on “Mainstreaming Healthy Ageing in the renewed Social Agenda”**.

On 14 October (Brussels, Belgium), Dianne Gove attended a **Eucomed dinner debate on “The Future of Homecare Policy in Europe”**.

On 15 October (Brussels, Belgium), Annette and Dianne met Nelly Le Dévic, the new Executive Director of ESICM (**European Society of Intensive Care Medicine**) to exchange information about our respective organisations.

On 16 October (Brussels, Belgium), Annette Dumas attended the **FEFAP conference on “Women, Families and Society”** and presented a number of recommendations proposed by the Alzheimer Europe members on how better to reconcile work and care.

On 17 October (Marseilles, France), Jean Georges attended the **Epilepsy and Society conference** and gave a presentation on Alzheimer Europe’s campaign to make dementia a European priority.

On 23 October (Brussels, Belgium), Annette met Julie Kjestrup, **EUROPABIO**, to discuss the EUROPABIO Patient Advocacy Group and our respective activities.

On 21 October (Luxembourg, Luxembourg), Jean Georges met with **Antoni Montserrat from the European Commission** for an exchange of views on the French Presidency Conference on Alzheimer’s disease.

On 27 October (Bradford, United Kingdom), Dianne Gove attended a **seminar on the impact of dementia on grandchildren**.

From 30 to 31 October (Paris, France), members of the Alzheimer Europe staff and Board as well as representatives of its member organisations, participated in the **French Presidency Conference on “The fight against Alzheimer’s disease”** with Maurice O’Connell presenting the political priorities of Alzheimer Europe and Jean Georges the preliminary results of the Alzheimer Europe EuroCoDe project.

On 3 November (Brussels, Belgium) Annette had lunch with **Erica Poot, EFPIA**, to discuss on-going EU developments and patient issues.

On 3 November (Brussels, Belgium) Annette attended the meeting organised by **Eurocarers** on the 'Social Package'.

On 7 November (Brussels, Belgium) Annette had lunch with **Agnieszka Szczesniak(J.T. Masiel's assistant)** to progress in the organisation on the EP lunch on the socio-economic costs of Alzheimer's disease.

On 11 November (Brussels, Belgium) Annette attended the EP lunch on '**Good nutrition in Europe**' organised by the European Nutrition Health Alliance.

On 12 November (Brussels, Belgium) Annette attended the Health for Europe congress on the '**Healthcare Challenges**'.

On 21 November (Brussels, Belgium) Annette attended the **EFPIA Think Tank**.

On 24 November (London, United Kingdom), Jean attended a project meeting of the **Pharmacog project** which is awaiting approval by the Innovative Medicines Initiative of the European Commission.

On 8 December (Brussels, Belgium), the **Alzheimer Europe Board** met.

On 9 December (Brussels, Belgium), Jan Tadeusz Masiel, MEP (Poland) hosted an Alzheimer Europe and European Alzheimer's Alliance lunch debate in the European Parliament **on the socio-economic cost of Alzheimer's disease**.

On 10 December (London, United Kingdom), Jean met with representatives from **Lundbeck** to present the 2009 Work Plan.

From 10 to 11 December (Brussels, Belgium) Annette attended the **EU Health Forum**.

On 11 December (London, United Kingdom), Jean attended a meeting with **Pfizer** to discuss barriers to early diagnosis.

On 15 December (Brussels, Belgium) Annette attended the **Commission's meeting with stakeholders** to discuss the Mental Health thematic conferences that will be organised.

On 16 December (Strasbourg, France) Annette was in Strasbourg to promote **the European Parliament Written Declaration** on Alzheimer's disease.

On 16 December (Luxembourg, Luxembourg), representatives of **Fondation Médéric Alzheimer** paid a visit to the Alzheimer Europe office for an exchange of views on the results of the French Presidency in the Alzheimer's field.

## European developments

### 2 October 2008: European Pharmaceutical Forum issues final report with recommendations

With the aim of addressing the declining competitiveness of the research-based pharmaceutical industry in Europe, the High Level Pharmaceutical Forum (HLPF) has completed its three year review. This work focused on three main topics:

1. information to patients (how to provide patients and citizens with high quality and accessible information on their diseases and treatments, whilst mobilizing knowledge and resources from all actors)
2. pricing and reimbursement (how to ensure patients' access to medicines and a fair reward for valuable innovation, while balancing limited national healthcare budgets) and
3. relative effectiveness (how to recognise and measure the value and benefits of new, innovative medicines.

The HLPF has made 10 recommendations, calling for action to:

1. Enhance the quality of information
2. Increase accessibility and dissemination of information
3. Provide a generation of information by making the best use of all actors
4. Continue the momentum on information to patients
5. Implement agreed good practice principles for relative effectiveness assessments
6. Promote the exchange of information on relative effectiveness assessments in order to improve the data of availability and transferability
7. Provide access to medicines for EU citizens
8. Expect, identify and reward valuable innovation
9. Achieve optimal use of resources
10. Continue the momentum of pricing and reimbursement.

### 30 and 31 October 2008: French President, Nicolas Sarkozy, and EU Health Ministers unite in their call for action against Alzheimer's disease

The French Health Minister, Roselyne Bachelot, organised the high-level conference "The fight against Alzheimer's disease and related disorders" welcoming delegates which included people with dementia, carers, Alzheimer associations, health care

professional, national and European policy makers and in particular, Nicolas Sarkozy, the President of France.

The first day of the conference was dedicated to explaining why the disease should be considered a European priority and the second day was dedicated to the various European policy makers sharing their experience and hopes for action at both a national and European level.

Closing the Conference with a passionate speech, Nicolas Sarkozy laid out concrete

ways in which he sees Europe addressing the "scourge" of Alzheimer's – by working together in research, care and support practices and by ethical reflection and exchange of best practices. He spoke of the need to continue in the fight against Alzheimer's in a time of economic downturn, explaining, "If we were dealing with people's health only when 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."



Didier Houssin of the French Health Ministry opens the conference



AE Chair Maurice O'Connell presents the priorities of Alzheimer Europe



Jan Henry Olsen, former Norwegian Fisheries Ministers talks of his personal experience of Alzheimer's disease



EU Commissioner Androulla Vassiliou highlights the success of the EuroCoDe project



A ministerial round-table with ministers from France, Sweden, Germany, Slovenia and Malta and the EU Commissioner for Health



President Sarkozy makes an impassioned case for European action on Alzheimer's disease

**6 November 2008: European Commission adopts a communication to support and improve access to telemedicine**

Following a call for action from Member States, the European Commission has adopted a Communication to support and improve access to telemedicine for EU citizens and healthcare professionals across Europe.

**11 November 2008: European Commission adopts a Communication and proposal for a Council recommendation on rare diseases**

The Communication and a proposal for a Council Recommendation on rare diseases sets out an overall Community strategy to support Member States in diagnosing, treating and caring for the 36 million EU citizens with rare diseases.

Three main areas are covered :

- improving recognition and visibility of rare diseases
- supporting national plans for rare diseases in the Member States
- strengthening cooperation and coordination for rare diseases at European level.

**9 December 2008: Common initiative launched on meeting the needs of ageing societies**

The European Older People's Platform (AGE), together with the Committee of Regions, announced their intention to launch a joint brochure in 2009 entitled "Ageing Well in Europe". This has been developed to offer a "toolkit for regional and local actors which provide information on relevant EU funding available ... with examples of good projects and practices to help them adopt policies and

initiatives to promote active ageing and greater solidarity between nations”.

The initiative was announced at a public hearing, which was organised by the Committee of Regions, the Intergroup on Ageing of the European Parliament and AGE.

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

**10 December 2008: European Commission’s publishes pharmaceutical package**

The EU has been losing ground in pharmaceutical innovation, European patients suffer from inequalities in availability and affordability of medicines and counterfeit medicines are on the rise. To address these challenges, and in order to ensure that “European citizens can increasingly benefit from a competitive industry that generates safe, innovative and accessible medicines”, the European Commission has adopted:

- (a) a Communication on the future of the pharmaceutical sector and
- (b) three legislative proposals:
  - (i) the first legislative proposal aims at ensuring that EU citizens have access to reliable information
  - (ii) the second legislative proposal aims at better protecting patients by strengthening the EU system for the safety monitoring of medicines (pharmacovigilance) and
  - (iii) the third legislative proposal aims at strengthening EU legislation to better protect EU citizens from the serious threats posed by fake medicines.

**10 December 2008: European Commission adopts Green Paper on the EU workforce for health**

The European Commission has adopted a Green Paper on the EU workforce for health in the EU and has launched a public consultation.

A high-quality workforce of sufficient capacity and with the right skills is an important development to face the challenges facing health systems in Europe.

The aim of the Green Paper is to increase the visibility of the common problems faced by the Member States and promote cooperation.

The public consultation seeks to gather different stakeholders views on a wide range of

issues connected with the health workforce and prepare the care of an ageing population. The consultation deadline is 31 March 2009.

**12 December 2008: Health Commissioner highlights Alzheimer’s disease at the opening of the EU Health Forum**

In her speech delivered at the opening of the EU Health Forum 2008, Health Commissioner, Androulla Vassiliou, announced that 2009 will be a pivotal year for the European Union, with – inter alia – an initiative on Alzheimer’s disease.

The Commissioner reminded the audience that the Commission is keen to pursue the partnership approach it has championed to working with key health stakeholders.

The Health Forum overall theme was ‘Developing and implementing Health in the European Union’.

**15 December 2008: European Commission adopts Communication and a proposal on patient safety**

Following the public consultation on patient safety earlier this year, the European Commission has adopted a Communication and a proposal for a Council Recommendation with specific actions that Member States can take to improve safety on patients.

Highlighting the most common types of adverse events in healthcare as (a) healthcare associated infections, (b) incorrect or delayed diagnoses, (c) surgical errors and (d) medication related errors, the Commissioner for Health, Androulla Vassiliou said “Patient safety is the cornerstone of good quality healthcare. I would like to see a Europe for patients where safety is paramount and citizens are confident and knowledgeable about the care they receive.”



By recommending a comprehensive approach to improve patient safety, the Commission’s Communication encourages Member States to put in place, and improve, strategies to prevent and control adverse events in all healthcare settings and the Commission will work with Member States to develop common definitions and indicators for patient safety. Recommendations for Member States include:

- Establishing or strengthening reporting and learning systems
- Embedding patient safety in the education and training of healthcare workers

- Involving patients in the development of safety measures
- Proving patients with relevant information on health risks and safety issues
- Sharing best practice and expertise in this field.

In the EU, the rate of hospital acquired infection is calculated to be one in twenty hospitalised patients (4.1 million patients), and recent studies suggest that such infections can be reduced by up to a third by certain preventative and control measures being in place. Therefore, the proposal includes a particular focus on healthcare associated infections.

#### **15 December 2008: European Commission stakeholders meeting to discuss the Mental Health Pact thematic conferences**

The European Commission meeting with NGOs aimed at giving them an update on the Commission progress regarding the implementation of the European Pact for Mental Health. The meeting discussed the thematic conferences that will be organised in the near future in order to move the Pact forward.

The High Level conference on mental health of June 2008 gave mental health a respected place in the EU health policy agenda. Since, the Commission has held several meetings with Member States representatives and Commission DGs. In November 2009, Hungary and Portugal will jointly organise a meeting on depression and suicide, the Swedish presidency will address mental health and youth and education, Spanish presidency will address mental health in older people. In 2010, the Commission will address combatting stigma and social exclusion. Mental health and well-being in the workplace will also be on the agenda in 2010.

#### **17 December 2008: EU Health Ministers call for European initiative on Alzheimer's disease**

The Council of European Health Ministers adopted far-reaching conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer's disease on 16 December 2008. Coming at the end of the French Presidency, the conclusions clearly recognise Alzheimer's disease as a priority for European action and call on Member States to develop national strategies or action plans in this field aimed at improving the quality of life of patients and their carers.

The Council of Ministers also called upon the European Commission to adopt an initiative in 2009 which would strengthen European collaboration in the field of research, exchange best practices on prevention, early diagnosis, health and social care treatments and rehabilitation, as well as on the ethical dimension of Alzheimer's disease and the protection of patients' rights. The conclusions also make a clear reference to the campaign of Alzheimer Europe and its member organisations to make Alzheimer's disease a public health priority and welcome the work carried out by these associations in defending and supporting patients and their carers.

## **Policy Watch**

#### **2 October 2008: Dementia research receives boost in United Kingdom**

The Medical Research Council and the Wellcome Trust announced the launch of a £30 million partnership on 2 October which will be targeted at neurodegenerative diseases, including Alzheimer's disease.

The funding initiative is aimed at leading UK research groups, potentially collaborating with international research groups, who can bring together disciplines that will help address the gaps in scientists' knowledge of the biological basis of neurodegenerative disease. These include neurophysiology, neuropsychology, clinical medicine, epidemiology, biochemistry and cell biology.

Sir Leszek Borysiewicz, Chief Executive of the MRC, says: "The partnership between the Wellcome Trust and the Medical Research Council will pave the way for new innovative research to help prevent the onset of neurodegenerative diseases and develop more effective methods of treating them. Our research partnership, which will provide more opportunity for further collaboration across Europe, is a huge step towards achieving an earlier diagnosis of diseases such as Alzheimer's, multiple sclerosis and Parkinson's and improving the lives of the many people affected by them."

#### **23 October 2008 World Medical Association's Declaration of Helsinki is updated**

The Declaration of the World Medical Association on "ethical principles for medical research involving human subjects" has been updated and was officially adopted at the 59<sup>th</sup> WMA General Assembly in Seoul, South Korea. This version now replaces all previous versions and can be consulted at:

<http://www.wma.net/e/>. A French and Spanish version will soon be available.

Alzheimer Europe was involved in the consultation process but unfortunately its proposed amendments were not accepted. We nevertheless welcome this paper which provides concrete guidelines on how to protect the interests of people taking part in medical research.

We provide full references to articles on our website

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

### 29 October 2008: UK drug rationing body must disclose cost model for Alzheimer's drug

The House of Lords have refused leave to appeal to The National Institute for Health and Clinical Excellence (NICE), who have fought against earlier rulings that they (NICE) must disclose their cost model when working out cost effectiveness of the drugs donepezil, galantamine and rivastigmine. Neil Hunt, Chief Executive of the Alzheimer's Society, said "today is a small victor in the battle to see justice for thousands of people with Alzheimer's disease and their families... Having access to NICE's model will allow us to scrutinise NICE's calculation and to try and make sense of this unfathomable decision."

### 26 November 2008: UK report on end-of-life care highlights need for more support to care for people at home

A report by the UK National Audit Office on end-of-life care has stated that whilst most people want to die at home, the majority of terminally ill people spend their last days in hospital. Many are admitted to hospital on an emergency basis in the final days due to a lack of support at home or in care homes.

Another finding was that only 29% of doctors and 18% of nurses had received training in end-of-life care and that formal training in end-of-life care does not exist for care home staff.

The report concludes that families and care homes need more help to keep people at home or in care homes and that hospices need more funding and support from the National Health Service and local authorities.

Finally, Karen Taylor, head of health at the National Audit Office, drew attention to the need to develop basic measures to ensure that terminally ill people are treated with dignity and respect.

### 28 November 2008: Finnish prevention study kicks off with EUR 1.4 million funding

A unique dementia prevention study has been awarded EUR 1.4 million by the "Academy of Finland's Responding to Public Health Challenges Research Programme (SALVE)" to find out more about risk factors linked to dementia and possible ways to influence them.

The study will be carried out by FINGER (the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability) by seven Finnish research teams and one team from Canada, and will involve 1,200 participants living in five specific towns. Participants will be assigned either to a conventional counselling group or an intensive counselling group covering issues such as nutrition, exercise, social and mental activity and detailed monitoring and reduction of cardiovascular disease risks. In addition to monitoring for memory difficulties, the researchers will also observe depressive symptoms, cardiovascular diseases and risk, quality of life, use of health care services and, for some participants, changes in MCI scans.

The aim of the study is to reduce memory problems, delay the onset of dementia and have positive effects on other factors linked to memory. As such, it is a project of great importance to public health, the national economy and the planning of health education and healthcare services.

## Members' News

### 9 October 2008: Dr Sigurd Sparr, Honorary Treasurer of Alzheimer Europe, receives "The Kings Gold medal" for his work with dementia

Dr Sigurd Sparr, Honorary Secretary of Alzheimer Europe and Chair of the Norwegian Dementia Association (Nasjonalforeningen Demensforbundet), has been officially recognised for his work in the field of dementia. He was awarded the Norwegian Order of Merit (the King's Gold Medal) which was presented at the University Hospital of Northern Norway, Tromsø (photo by Stale P Fremnesvik, Bladet, Tromsø).



The Order of Merit was founded by King Haakon in 1908 and is granted for a nationwide lifelong contribution in the arts, science or business. Dr Sparr received the highest medal, namely the

Order of Merit in gold, for his extraordinary work on behalf of people with dementia and their carers. In addition to working as head of the Geriatrics department at the University Hospital in northern Norway, he has been travelling around the country on behalf of the Norwegian Alzheimer Association making dementia a political and public priority.

Alzheimer Europe and the Norwegian Dementia Association would like to congratulate Sigurd and are very proud that his important work for our cause has been acknowledged at the highest level.

### 9 October 2008: Polish Alzheimer Association interviews Jan Tadeusz Masiel, MEP about the Paris Declaration

Jan Tadeusz Masiel, MEP for Poland but also a psychologist and psychotherapist with a vast clinical and social experience acquired in Belgium and France, was recently interviewed by the Polish Alzheimer Association.



As the only Polish MEP to have signed the Paris Declaration, he declared that being aware of the significance of problems linked to dementia he had not needed any persuasion to sign the document. Furthermore, he was disappointed that his fellow Polish MEPs had not joined in the fight to make dementia a public priority, suggesting that their reticence may be linked to a reluctance to get involved in issues linked to disease and suffering.

He felt that the Paris Declaration was the most important initiative to publicise the problems faced by people with dementia and their carers and hoped that the French Presidency of the European Union would consolidate the common effort to make Alzheimer's disease (AD) a priority within European health policy. He congratulated Alzheimer Europe and its member associations on their work preparing the document and declared that he was pleased that the Polish Alzheimer Association had also been involved.

### 18 November 2008: German Alzheimer Association publishes "Book of Memories"

In 2007, the German Alzheimer Society (Deutsche Alzheimer Gesellschaft) sent a book with empty pages throughout the whole of Germany to prominent people in the field of politics, science, the cinema, music and sport with the request that they write in it personal memories or thoughts that were meaningful to

them. The result of this novel idea is a book called the "Book of Memories" – a rich mosaic of memories, thoughts and lyrics which is an example of solidarity towards people with dementia and their carers. The book costs EUR 25 and can be obtained from the German Alzheimer Society.

### 24 November 2008: Neil Hunt is elected one of 50 most powerful people in NHS management policy and practice

Neil Hunt, Chief Executive of the Alzheimer's Society, is amongst the top 50 most powerful people in NHS management policy and practice in England according to the new HSJ50 2008 list. HSJ stands for Health Service Journal and this is the third year that this journal, in association with the recruitment and management consultancy firms Harvey Nash and Ernst & Young, have drawn up this list of managers, politicians and government advisors as well as people from other domains such as strategic health authority chief executives, policy experts and regulators.



Neil Hunt is commended for his role in developing England's first national dementia strategy. The HSJ also points out that as a result of the Alzheimer's Society challenging the court ruling on the NICE guidelines, they were found to be discriminatory and NICE was obliged to make its economic model publicly available.

Alzheimer Europe would like to congratulate Neil Hunt on this public recognition of his excellent work in the field of dementia.

### 27 November 2008: Winners announced for design projects which offer an improvement of home life for people with dementia

Cité du Design, Méotis (the Regional network for the memory of the Nord-Pas-de-Calais) together with France Alzheimer put out their last calls for Design projects to improve life at home for people with dementia last December. This call for projects was aimed at French and European schools of art, design and architecture and 30 entries were received from France, Switzerland, Italy and Bulgaria. The awards were presented on 27 November on the occasion of the Journée Santé of the Biennale Internationale Design 2008 Saint-Etienne.

The 1<sup>st</sup> prize was awarded to the designer of Deci Delà (a directional watch for safe wandering).

The 2<sup>nd</sup> prize was awarded to the designer of Repères (an orientation clock, bedside lamp and family tree magnets on a whiteboard).

The 3<sup>rd</sup> prize went to the designer of relational materials (bath towel, relational touch).

Other projects which were highlighted include: Poppy memory (a multi-functional robot), mémothèque (a memory library consisting of a camera and diary), a meal tray and a board game.

The top three entries were awarded a total of EUR 12,000 by the jury.



**9 December 2008: Questionnaires developed to enhance hospital care of people with dementia in Germany**

In order to enhance the quality and efficacy of hospital care that people with dementia receive, the German Alzheimer Association “Deutsche Alzheimer Gesellschaft” together with experts, has produced a questionnaire which is aimed to assist hospital staff. On admission to hospital, carers will complete the questionnaire on behalf people with dementia, from which their personal preferences, abilities regarding eating and drinking as well as cognitive limitations (eg.their ability to communicate) can be established. This information will then be forwarded to medical personnel. It is hoped that this measure will help to overcome the stress people with dementia can feel during hospital stays, due to their inability to understand and/or express themselves which can lead to, amongst other things, getting lost and not eating enough.

This was distributed to 2,000 hospitals throughout Germany at the beginning of December.

However, the Chair of the Deutsche Alzheimer Gesellschaft, Heike von Lützu-Holbein stresses that this in itself is not enough and that hospitals need more personnel as well as improved working conditions

**10 December 2008: Death certificates omit dementia as cause of death**

A study which examined the medical records of 165 people with advanced dementia, who died between 2003 and 2007 found that:

- (i) 37% of the death certificates didn't list dementia as the main cause of death or a contributing factor
- (ii) 16% listed dementia as the main cause of death.

The findings were published in a letter in the Journal of the American Medical Association by the report co-author, Dr Susan Mitchell, an associate professor of medicine at Harvard Medical School.

Dr Mitchell said this omission results in: (a) the severe underestimation of the number of deaths which result from Alzheimer's disease and dementia and (b) ill-informed decisions about patients at the end of life.

**Celebrations of World Alzheimer's Day**

Following our coverage of World Alzheimer's Day in September's newsletter, we are delighted to be able to include coverage of additional members' activities.

**15-21 September: Greek Association celebrates World Alzheimer's day**



In celebration of World Alzheimer's day, the Greek Association of Alzheimer's Disease and Related disorders had an information stand in Aristotelous

Square, Thessaloniki. Celebrations were also held in the Aristotle University of Thessaloniki (18<sup>th</sup> September), where Mrs Tsolaki, Chair of the Pan-Hellenic Federation of Alzheimer's disease, gave a presentation, as well as seminars on Alzheimer's disease being held in the Municipal Library.

Exhibitions on Alzheimer's disease were also organised in other Greek cities (eg. Athens, Volos, Crete, Xanthi, Xalkidiki).

**21 September 2008: Danish researchers receive grants on the occasion of World Alzheimer's Day to further their study into dementia**

On World Alzheimer's Day, the Danish Alzheimer Research Fund awarded grants to

scientists/researchers who, through their research, have contributed towards increasing our knowledge about Alzheimer's disease and dementia. The winners of the award were Prof. Dr Med. Bente Pakkenberg from the Bispebjerg University Hospital and Dr Nils Gulmann, former head of the geronto-psychiatric department of the University Hospital of Aarhus.

### **21 September 2008: Polish Alzheimer Association celebrates World Alzheimer's Day with a mass, picnic, stand and Alzheimer's café**

The Polish Alzheimer Association organised a series of events in the days leading up to World Alzheimer's Day. This started on 14 September with a mass dedicated to people with dementia and their carers in Warsaw's Cathedral in the Old Town.

This was followed on 18 September with a picnic in the garden of a residential home, which was organised for the 12<sup>th</sup> time. Apart from people with dementia and their carers, there were representatives of local government, the town council and staff of other residential homes. The Mayor of Warsaw sent an official letter in which she expressed her willingness to provide support and respite for people with dementia and their carers.

On the evening of 19 September, the Association met for the first time in an Alzheimer Café in the centre of Warsaw. The idea was to attract people who had never been in touch with the association before. Visitors had a chance to talk to specialists (a neurologist, psychiatrist, nurse and psychologists) as well as with experienced carers. It is planned to continue the idea of Alzheimer Café meetings, at first once a month, and if successful, more frequently.

Finally, on 20 September, the organisation had a stand in the city centre together with a huge number of NGOs as a part of the Civic Society Picnic. The stand was visited by hundreds of people. Leaflets and bulletins were distributed along with small gingerbread cakes prepared by volunteers.

## **Science Watch**

### **19 October 2008: Mouse study leads to further clarification of the link between fatty acids and AD**

There is already evidence to suggest that the relationship between the fatty acids Omega 3 and 6 (i.e. too much of the latter at the expense of the former) might be linked to the development of Alzheimer's disease (AD). The results of a recent study led by Lennart Mucke

from the Gladstone Institute of Neurological Disease at the University of California now suggest that turning off the mechanism which interacts with the fatty acids in the brain might help prevent neurological impairments in AD. So far this has only been tested on mice and further research is necessary before human trials can be conducted. Nevertheless, it is a promising area of research particularly as fatty acids can be partly controlled by diet and drugs.

### **20 October 2008: Fears over possible consequences of future blood test for variant CJD**



Four people in the UK are suspected of having contracted vCJD (variant Creutzfeldt-Jakob disease) through blood donations but a 2004 study of 13,000 appendix and tonsil samples revealed that thousands of people may be unaware that they have the disease. Some blood donors may therefore be unwittingly transmitting it through blood donations.

A blood test to screen for vCJD in blood donors may be available in about 18 months' time. However, the UK Safety of Blood Tissues and Organs advisory committee advises against its use until it can be considered 100% accurate.

The experts are concerned that the test could identify false positives thereby raising false alarms amongst donors. They also point out that correct positives do not necessarily imply that the people identified would ever develop the symptoms of vCJD. For those who do, it is not known how long this would take.

### **21 October 2008: Higher education and mentally demanding job may delay the onset of Alzheimer's disease**

Researchers led by Dr Valentina Garibotto from San Raffaele University in Milan, Italy, have found that having a stimulating occupation and high level of education might serve as a buffer against the effects of dementia on the brain or as a kind of cognitive reserve.

The study involved 242 people with probable Alzheimer's disease (AD), 72 with mild cognitive impairment (MCI) and 144 healthy volunteers. At follow-up 21 subjects with MCI had progressed to AD. Damage to the brain was assessed by measuring brain glucose metabolism using scanning techniques.

According to Dr Garibotto, there are at least two explanations for the results: 1. the brain could be made stronger through education and occupational challenges or 2. genetic factors, which contribute towards people attaining a

higher level of education and occupational achievement, might determine the amount of brain reserve.

However, whilst these results are encouraging for people with higher levels of education and stimulating jobs, the benefits of a healthy diet and keeping the mind and body active should also be emphasised.

We provide full references to articles on our website

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

### **23 October 2008: Group of pharmaceutical companies develop imaging agent to show up amyloid on PET scans**

Having developed imaging agents designed to allow amyloid to be detected on positron-emission tomography (PET) scans, Bayer Healthcare Pharmaceuticals, GE Healthcare and Avid Radiopharmaceuticals have asked the Food and Drug Administration (FDA) for advice on how to design the clinical studies necessary to get the agents approved.

The companies point out that the imaging agent could be used as a tool in detecting Alzheimer's disease or at least in ruling it out if no amyloid is detected. Prof. Larry Goldstein, acting chair of the outside panel of experts convened by the FDA, commented that a lot more research was needed but noted that the agents could eventually also be used by drug companies developing drugs to attack amyloid.

### **24 October 2008: A new embryology test has been developed which can detect almost any genetic disease**

Whilst preimplantation genetic diagnosis (PGD) has been available since 1989, its use has been somewhat limited as it is time consuming and expensive. A new technique, called karyomapping, has been developed by Professor Alan Handside of the Bridge Centre in London in collaboration with Gary Harton from the Genetics and IVF Institute in Fairfax, Virginia. It builds on the standard PGD procedure but can produce results much faster even for very rare inherited illnesses and it is expected that costs will soon be comparatively lower. It cannot, however, detect genetic conditions which arise spontaneously as a result of a genetic mutation. On the other hand, if reused once a screened embryo has developed into a child, it could reveal genes likely to increase the risk of Alzheimer's disease or heart disease.

### **28 October 2008: Epilepsy drug leads to lower levels of amyloid plaques in mouse model**

A study, led by researchers at the University of British Columbia (CAN), has looked at the effects of the epilepsy drug, valproic acid (VPA), on mice which were genetically modified to develop a condition similar to Alzheimer's disease. They found that VPA resulted in lower levels of amyloid plaques in the brains of these mice. The effects on memory were only detected in the mice which received VPA at an early age.

Further research is necessary to determine whether the drug has similar effects on humans. However, it should be noted that this drug has already been tested on people with Alzheimer's disease with agitation. It was not found to have a significant effect and there was some evidence of side effects such as sedation at high doses. Nevertheless, a pilot test involving people with Alzheimer's disease is now underway.

### **1 November 2008: Researchers warn of possible silent-epidemic of alcohol-related dementia**

Whilst certain health benefits have been associated with moderate drinking, a study carried out by London-based psychiatrists Dr Susham Gupta and Dr James Warner suggests that we may be heading for a silent epidemic of alcohol-related dementia. They point out that heavy alcohol consumption and binge drinking could lead to high blood pressure, raised levels of harmful blood fats and brain damage. According to the researchers, the price of alcohol in the UK has halved since the 1960s but consumption has risen from under 6 litres of pure alcohol to more than 11.5 litres per person per year. Susanne Sorensen, from the Alzheimer's Society (UK), welcomes the research and highlights the need for further research into the long-term effects of all types of alcohol consumption.

### **5 November 2008: Study examines the proximity of pylons and the risk of dementia**

A five-year study led by Professor Matthias Egger of the Bern University Institute of Social and Preventative Medicine, Switzerland suggests that there is a link between the risk of dementia and living close to high-voltage power lines for a length of time. The research has been published in the American Journal of Epidemiology.

**6 November 2008: Stem cells used to form tissue**

Researchers from Japan managed to create tissue by leaving some 3,000 embryonic stem cells in a culture solution, which after 46 days formed a 2mm sphere of tissue, which was split into four areas. It is hoped that in the future such tissue may be used to help in the study of diseases including Alzheimer's.

Conducted by researchers from by the RIKEN Center for Developmental Biology, Japan, the corresponding author is Yoshiki Sasai.

**11 November 2008: Mice study examines the relationship between isoflurane anesthesia and development of amyloid-beta protein**

Research carried out on mice by Zhongcong Xie, MD and associates from the Massachusetts General Hospital and Harvard Medical School, MA, USA examined the effects of isoflurane on, amongst other things, levels of Alzheimer's disease-associated amyloid  $\beta$ -protein ( $A\beta$ ). They found that after administering the anesthetic isoflurane that the levels of the protein were enhanced and called for further research to be done in order that the implications for use of isoflurane in humans be studied. The research was published in the Annals of Neurology.

**16 November 2008: Study examines brains of elderly with high memory performance**

A study examined the brains of five deceased people who were considered "super aged" (because of their high performance on memory tests when they were over 80 years old), against the brains of elderly, non-demented individuals. Whilst the number



of plaques in the brains of both groups were found to be similar, the researchers found that the "super aged" brains had fewer tau tangles than the other group and this led them to conclude that the critical difference in maintaining memory skills were the lower number of tangles. Led by Changiz Geula, research professor of neurology at the Cognitive Neurology and Alzheimer's disease Center at Northwestern's Feinberg School, the researchers are due to commence further study to ascertain what makes the "super aged" brains more resistant to tangle formation.

**24 November 2008: Study examines the reliability of the administration and scoring on the Alzheimer's Disease Assessment Scale – Cognitive**

The Alzheimer's Disease Assessment Scale – Cognitive (ADAS-Cog) is commonly used in clinical trials to measure changes in some symptoms of Alzheimer's disease. A study of 26 volunteers to assess whether there exist variations of how the ADAS-Cog is administered has been published in the Journal of Alzheimer's disease. Researchers, Donald J Connor and Marwan N Sabbagh found "notable protocol variations in the forms used, administration procedures and scoring rules".

**30 November 2008: Study on mice examines the relationship between a diet high in fat, sugar and cholesterol and the physiological changes associated with Alzheimer's disease**

Genetically modified mice were fed a diet rich in fat, sugar and cholesterol for nine months. Amongst other things, the research found that the genetic mutation, together with the modified diet resulted in a change in the tau protein, similar to the changes associated with Alzheimer's disease.

The study, published in a doctoral thesis from the Karolinska Institute, was carried out by Susanne Akterin and colleagues.

**1 December 2008: The safety and efficacy of the drug galantamine assessed in severe Alzheimer's disease**

The drug Galantamine (Reminyl) is prescribed in the UK to patients with mild-moderate Alzheimer's disease, but not for severe Alzheimer's disease. A study to be published in the Lancet Neurology in January 2009 by Alistair Burns and colleagues from the University of Manchester, found that people with severe Alzheimer's disease also benefitted from receiving Galantamine.

The European, randomized, placebo-controlled, double-blind trial was carried out between 2003 and 2007 on 407 people, with 207 receiving Galantamine and 200 receiving a placebo.

Campaigners hope the study helps to achieve a revision of the National Institute for Health and Clinical Excellence (NICE) guidelines which have caused much controversy in the last few years.

**4 December 2008: Report suggests that military personnel who suffer from traumatic brain injury may be at a greater risk of developing symptoms akin to dementia**



A report compiled by the Institute of Medicine and funded by the US Department of Veteran Affairs suggests that traumatic brain injury (TBI) may lead to the development of symptoms similar to those found in, amongst other diseases, Alzheimer's disease.

The report, led by George Rutherford of the University of California, is entitled "Gulf War and Health: Volume 7: Long-Term Consequences of Traumatic Brain Injury" and is published by the national Academies Press.

We provide full references to articles on our website

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

**6 December 2008: Study suggests that the brain's circuitry survives longer than previously thought in diseases of ageing, such as Alzheimer's disease**

Research suggests that the ability for nerve cells to communicate with each other is present for longer than previously thought in the cases of diseases such as Alzheimer's disease. The communication is passed down through "axons" and "dendrites". In Alzheimer's disease, the axons swell dramatically to 10 or 20 times their original diameter and whilst this swelling disrupts the communication between the nerve cells, it is however continued for up to a year or more.

The study was led by Dr Michael Coleman and colleagues from the Babraham Institute, Cambridge which was supported by the Alzheimer's Research Trust and the Biotechnology and Biological Sciences Research Council.

**7 December 2008: Study examines effect of the sodium valproate on Alzheimer's disease**

A study led by Professor Tony Turner and colleagues of Leeds University's Institute of Molecular and Cellular Biology, UK, found that the drug, sodium valproate, enabled the reactivation of the body's defences against the protein amyloid beta peptide, which is the main component of the brain plaques characteristic

in Alzheimer's disease. Sodium valproate is currently used to treat epilepsy.

**8 December 2008: Study examines relationship between cold sore virus and Alzheimer's disease**

A small study examined whether there is a relationship between the cold sore virus (herpes simplex 1 virus or HSV 1) and the existence of Alzheimer's disease. The brains of 11 (6 with Alzheimer's disease and 5 without) deceased people were examined, and it was found that the HSV 1 virus was present in 90% of the brain plaques in the samples from people with Alzheimer's disease and in 80% of those samples taken from people without Alzheimer's disease.

The study was conducted by Professor Itzhaki and colleagues from the University of Manchester and published in the Journal of Pathology. Further research is required to establish whether there is a link between the HSV 1 virus and Alzheimer's disease.

**11 December 2008: Study examines role of collagen in Alzheimer's disease**

Researchers who had found that levels of collagen VI were significantly higher in the brains of modified mice and subsequently also higher in the brain tissue from people with Alzheimer's disease, discovered that the cellular source of the collagen VI in the brain was neurons, which are the cells which the disease attacks. They sought to establish whether this collagen contributed to neuronal damage in Alzheimer's disease or was produced as a defense mechanism against it and so carried out a series of informative cell culture experiments which revealed when amyloid-beta protein was added to neurons grown in culture the expression of collagen VI was increased. In addition, the researchers found that by increasing the amount of collagen VI in the cultures the neurons were protected against the amyloid-beta protein toxicity.

The team was led by Lennart Mucke, MD and colleagues from the Gladstone Institute of Neurological disease, UCSF and Stanford. The research is reported in the journal Nature Neuroscience.

**16 December 2008: Study examines the relationship between the ability to detect sarcasm and frontotemporal dementia**

A study published in the journal Brain, suggests that the ability to detect sarcasm may be a helpful tool when diagnosing frontotemporal dementia (FTD).

Led by John Hodges, with researchers from the University of New South Wales, he explained "It shows people with FTD are very literal because the differences were all about tone of voice, mannerisms and subtle social clues... When we tried this on 19 people with Alzheimer's disease, they had no trouble with it, so this could be very helpful in diagnosing the condition."

## Dementia in Society

### 30 October 2008: Short film about Alzheimer's disease played at Chicago International Children's film festival

A short film about a girl's experience of her mother having Alzheimer's disease was shown at the Chicago International Film Festival in October 2008. The film also won the best short film of the year on YouTube and has been played online by 2.4 million viewers. It has been shown at a few other film festivals and the director, Ben Shelton, hopes to eventually make it into a feature film.

### 26 November 2008: Terry Pratchett hands in petition to 10 Downing Street

Terry Pratchett, a famous UK writer who was recently diagnosed with a rare form of Alzheimer's disease, has handed in a petition to 10 Downing Street calling for increased funding for research into dementia. 20,000 people, including over 100 top scientists, have signed the petition which describes the current level of funding as appalling with dementia only receiving 3% of government medical research funding.



Mr Pratchett stated "There's only two ways it can go: researchers, with as much help you can give them, may come up with something that reduces the effects of this dreadful, inhuman disease, or we will have to face the consequences of our failure to prevent the final years of many of us being a

long bad dream."

He urges the Prime Minister to take radical action fast.

### 16 December 2008: Daughter seeks legal guardianship of father, Columbo star, Peter Falk, who has Alzheimer's disease

Catherine Falk, daughter of the actor, Peter Falk, who starred in the detective series, Columbo, has asked the Los Angeles Superior

Court for legal guardianship of her father due to his having Alzheimer's disease. Ms Falk explained that her father can no longer recognise "familiar people, places or things" and "forgets events that occurred and remembers events that did not occur."



Mr Falk was nominated twice for an Oscar: in his first movie in 1960 "Murder Incorporated", and his second in 1961 "A pocketful of miracles". He has acted on stage (in shows such as The Price of Tomatoes, The Prisoner of Second Avenue, Mr Peter's Connections), on TV (most notably as Lieutenant Columbo) as well as in feature films. He is also an artist and exhibits his paintings.

## New resources and publications

### October 2008: Report calls for better understanding, information, diagnosis and support for dementia

The research "Dementia: Out of shadows" (2008) was undertaken by the Mental Health Foundation and commissioned by the Alzheimer's Society. A total of 61 people participated in the research, 32 of whom had dementia. The report covered four main areas:

1. An investigation of the most common forms of dementia. Most of the participants had been diagnosed for 2-3 years at a relatively early stage.
2. People's experience of finding out that something was wrong and the experience of getting a diagnosis. For some, the process was quite quick but for many patients it was a long and distressing experience for a number of reasons but particularly because of unhelpful and uninformed responses from GPs.
3. People's lives after receiving a dementia diagnosis. People described a range of practical and psychological coping mechanisms that they had developed to cope with having dementia. These coping 'tips' and strategies offer professionals precious "tools" that can be used to support people with dementia and their carers.
4. People's views on what they considered a "good" diagnostic process to be. A number of generic features were identified such as good communication and being listened to. Others were more specific to the experience of people with dementia. People's reactions on how dementia was reported by the media

were mixed, but the general feeling was that the wider public was still getting a skewed picture.

The report gives 5 recommendations:

- Improve public understanding of dementia.
- Improve GPs' understanding of dementia.
- Develop better specialist diagnostic assessment services for dementia.
- Provide information which is timely and accessible.
- Develop stronger peer support networks to help people cope.

### **26 November 2008: Important recommendations for all those working with patients with memory disorders**

On invitation of the Finnish Alzheimer's Disease Research Society a panel of Finnish experts drew up recommendations for best practices in the treatment of progressive memory disease. The Finnish Medical Journal published the most important ones:

1. Prevention is up to all of us. It is possible to influence the development of memory disease by recognising and treating the risk factors.
2. Symptoms of memory disease should be recognised as early as possible.
3. The reason for any memory symptom expressed by a patient must be examined.
4. The diagnosis and organisation of treatment of memory patients should be concentrated in memory clinics.
5. The diagnosis of memory disease should be explained to patients and relatives.
6. After diagnosis, a care and rehabilitation plan should be written.
7. The memory coordinator ensures outpatient care of patients with memory disease.
8. Symptomatic pharmacotherapy of progressive memory disease needs to be monitored.
9. Special know-how is needed to predict and treat behavioral symptoms.
10. Holistic treatment of somatic diseases in patients with memory disease is worthwhile.
11. Supervision of interests, a living will and an assessment of the patient's right to drive are part of the treatment.

12. The special needs of people of working age with memory problems should be taken into consideration.

13. 24-hour care of dementia patients requires special know-how.

14. Private and third sectors also provide services required by patients with memory disease.

For more information: Finnish Medical Journal (2008; 63, Supplement 10).

### **December 2008: World Health Organization publish "Home care in Europe"**

WHO (World Health Organization) published the magazine "Home care in Europe" in conjunction with "Università commerciale Luigi Bocconi". This publication explains why health and social services should provide high-quality and targeted home care for disabled and older people. It provides evidence for the effectiveness of home care, shows how it can be improved and explains the need to ensure equitable access.

### **December 2008: Alzheimer's Society launches "Growing"**

The Alzheimer's Society, UK, launched this week "Growing", David Sheard's new book at the third national Dementia Congress in Bournemouth. The author sets clear guidelines for organisations to develop a person-centred learning and development training strategy.

### **December 2008: New website on Patients Rights Legislation launched**

The Centre for Biomedical Ethics and Law of the Catholics University of Leuven (Belgium) has got a new website on Patient Rights Legislation in all 25 EU Member States. This website contains 3 groups of information:

- Biomedicine Convention: information on the Convention on Human Rights and Biomedicine
- EU Member States: information on existing national patient rights legislation in the EU
- Types of Patient Rights Legislation: on this section all the national patient rights legislation is categorised according to the types of legislation.

### **December 2008: The Athens Alzheimer Association publication helps children to understand Alzheimer's disease**

"Learning about Alzheimer's disease: Why does grandma forget my name?" is a book written for children and published by the Athens

Alzheimer Association. Presented through narration, examples and various educational games (puzzles, quizzes, labyrinths and colouring pages), the colourful publication illustrates how someone with dementia may be affected in everyday life, covering:

- Feelings and reactions to diagnosis
- Biological basis of Alzheimer's disease
- Cognitive symptoms of the disease
- Non-cognitive symptoms of the disease
- Feelings of the person with Alzheimer's disease
- Frequently asked questions
- Ways to enhance communication
- Enjoyable activities suitable for the person and dementia and his/her family
- Prevention – healthy lifestyle

Author, Olga Lymperopoulou, Cognitive neuropsychologist and General Secretary of the Athens Association of Alzheimer's disease and related disorders, said "many caregivers who read this book before giving it their grandchildren told us that the book is appropriate even for adults because it says the truth about Alzheimer's disease, even on matters considered to be sensitive in a most honest and simple way".

Available in Greek from the Athens Association of Alzheimer's disease and Related Disorders, 89, M. Mousourou str. & 33, Stilponos str. 116 36 Athens, Greece.

12 December 2008: Resource guides on dementia published, written by people with dementia

"By Us For Us ©" are a series of guides on dementia which are written by people with dementia and are "designed to equip people with dementia with the necessary tools to enhance their well-being and manage daily challenges". Some 40 people with the disease contributed to the two new guides:

- The "enhancing wellness" guide covers the importance of support, whether that be physical, psychological, emotional, social and/or spiritual

- The "Tips and Strategies" guide which gives suggestions for daily living with memory 'workout' tips

And these compliment their three guides published previously:

- The "memory workout" guide which gives examples of cognitive exercises
- The "managing triggers" guide offers solutions on how to alleviate the main triggers experienced by people with dementia
- The "enhancing communication" guide outlines the main challenges which are associated with communication as experienced by people with dementia.

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#### Alzheimer Europe Board

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## AE Calendar





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

Date	Meeting	AE Representative
6 January	Meeting with Visual Online on Alzheimer Europe website plans (Luxembourg, Luxembourg)	Jean Georges, Julie Fraser
13-14 January	Written Declaration Campaign during plenary session of the European Parliament (Strasbourg, France)	Annette Dumas
30 January	Meeting with Pfizer (London, United Kingdom)	Jean Georges,

## 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 Neuroepidemiology <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



				
Françoise Grossetête (France)	John Bowis (UK)	Katalin Lévai (Hungary)	Jan Tadeusz Masiel (Poland)	Antonios Trakatellis (Greece)

Call on all MEPs to sign the European Parliament’s Written Declaration n° 80/2008 on priorities in the fight against Alzheimer’s disease

“As members of the European Parliament, we cannot remain indifferent to the 6.1 million European citizens who live with Alzheimer’s disease or a different form of dementia” (Françoise Grossetête).

Help 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

Please sign the Written Declaration before 22 January 2009

Thank you.