



# NEWSLETTER

September 2008

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## Editorial

What an exciting month September was!



It is in this month that Alzheimer associations across Europe commemorate World Alzheimer's Day to campaign to make dementia a priority and it seems this year as if this call did not fall on deaf ears.

In particular, Alzheimer Europe was greatly encouraged by the decision of the EU Council of Ministers on 26 September for concerted action in the field of dementia research. It was gratifying to see our long campaign paying off and our call heeded at the highest level. We will of course continue our campaign to make sure that concrete actions will swiftly follow this encouraging call.

On 1 September, the German Ministry for Health organised a workshop to launch the idea of a European network to exchange best practices on ethical issues.

A further 8 Members of the European Alzheimer's Alliance supported the campaign of Alzheimer Europe to make dementia a European priority and I am particularly grateful to the strong lobbying of our Danish and Portuguese associations towards their elected officials.

Our fourth lunch debate in the European Parliament seems to have been the most successful to date, with an impressive number of Members of the European Parliament and their assistants joining the event to listen to Prof. Alexander Kurz from Germany who gave an overview of current treatments and future perspectives. We have dedicated a full page to the photos of this event and hope they do justice to the energy and interest generated by our lunch-debate. Our thanks go to Katalin Levai, MEP (Hungary), who graciously agreed to host this event.

Another highlight of this newsletter is the long list of interesting initiatives from no less than 18 countries carried out by our member organisations on World Alzheimer's Day. The number and scope of those activities is truly inspiring.

For the first time, we also saw Members of the European Alzheimer's Alliance taking an active part in these activities and our thanks go to Jean-Pierre Audy (France), Maria Matsouka (Greece) and Pier Panzeri (Italy) for their support.

I hope that you will share our sense of achievement and progress when reading this month's newsletter.

**Jean Georges**  
**Executive Director**

## Making dementia a European priority

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



**Jean-Pierre Audy**  
France, EPP-ED



**Neils Busk**  
Denmark, ALDE



**Hanne Dahl**  
Denmark, IND/DEM



**Robert Goebbels**  
Luxembourg, PES



**Ana Maria Gomes**  
Portugal, PES



**Anne E Jensen**  
Denmark, ALDE



**Christel Schaldemose**  
Denmark, PES



**José Albino Silva Peneda**  
Portugal, 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 82. 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)

### Czech Republic

9. Cabrnoc Milan (EPP-ED)
10. Kohlicek Jaromir (GUE/NGL)
11. Roithova Zuzana (EPP-ED)
12. Vlasak Oldrich (EPP-ED)

### Denmark

13. Busk Neils (ALDE)
14. Dahl Hanne (IND/DEM)
15. Jensen Anne E. (ALDE)

16. Schaldemose Christel (PES)

### Finland

17. Myller Riitta (PES)
18. Pietikäinen Sirpa (EPP-ED)
19. Virrankoski Kyösti (ALDE)

### France

20. Audy Jean-Pierre (EPP-ED)
21. Bourzai Bernadette (France, PES)
22. Daul Joseph (EPP-ED)
23. De Veyrac Christine (EPP-ED)
24. Fouré Brigitte (EPP-ED)
25. Griesbeck Nathalie (ALDE)
26. Grossetête Françoise (EPP-ED)
27. Henin Jacky (GUE/NGL)
28. Lamassoure Alain (EPP-ED)
29. Morin Elisabeth (EPP-ED)
30. Onesta Gérard (Greens-EFA)
31. Toubon Jacques (EPP-ED)

### Germany

32. Niebler Angelika (EPP-ED)
33. Ulmer Thomas (EPP-ED)

34. Weisgerber Anja (EPP-ED)

### Greece

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

### Hungary

- 43. Levai Katalin (PES)
- 44. Surján László (EPP-ED)

### Ireland

- 45. Crowley Brian (UEN)
- 46. McDonald Mary Lou (GUE/NGL)
- 47. McGuinness Mairead (EPP-ED)
- 48. Mitchell Gay (EPP-ED)
- 49. Ryan Eoin (UEN)
- 50. Sinnott Kathy (IND/DEM)

### Italy

- 51. Battilocchio Alessandro (PES)
- 52. Panzeri Pier Antonio (PES)
- 53. Podestá Guido (EPP-ED)

### Lithuania

- 54. Dickute Jolanta (ALDE)

### Luxembourg

- 55. Goebbels Robert (PES)
- 56. Lulling Astrid (EPP-ED)
- 57. Spautz Jean (EPP-ED)

### Malta

- 58. Muscat Joseph (PES)

### Netherlands

- 59. Corbey Dorette (PES)
- 60. De Lange Esther (EPP-ED)
- 61. Wortmann Corien (EPP-ED)

### Poland

- 62. Masiel Jan Tadeusz (UEN)
- 63. Rogalski Boguslaw (UEN)

### Portugal

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

### Romania

- 73. Winkler Iuliu (EPP-ED)

### Slovakia

- 74. Mikolasik Miroslav (EPP-ED)

### Sweden

- 75. Cederschiold Charlotte (EPP-ED)

### United Kingdom

- 76. Bowis John (EPP-ED)
- 77. Hall Fiona (ALDE)
- 78. McAvan Linda (PES)
- 79. Moraes Claude (PES)
- 80. Stihler Catherine (PES)
- 81. Watson Graham (ALDE)
- 82. Willmott Glenis (PES)

## European Alzheimer's Alliance

**16 September 2008: Katalin Levai hosts the 4<sup>th</sup> Alzheimer Europe lunch debate in the European Parliament**



Katalin Levai, MEP (Hungary), and Vice Chair of the European Alzheimer's alliance hosted Alzheimer Europe's 4<sup>th</sup> lunch debate entitled "The treatment of Alzheimer's disease: current options and future perspectives". Please

see below for a summary of the meeting.

**21 September 2008: Bernadette Bourzai is elected to French Senate**

Bernadette Bourzai, MEP (France), an active Member of the European Alzheimer's Alliance from France, was elected as Senator of her department Corrèze.

Alzheimer Europe wishes her all success in her new position and thanks her wholeheartedly for the support she gave to the various initiatives of Alzheimer Europe in the European Parliament



### 26 September 2008: Maria Matsouka supports Greek World Alzheimer's Day event

Maria Matsouka, MEP (Greece), who is a member of the European Alzheimer's Alliance, supported the World Alzheimer's Day celebrations by attending the events in Athens organised by the Greek Alzheimer Association.



### 27 September 2008: Pier Antonio Panzeri joins Federazione Alzheimer Italia at gala concert

Pier Antonio Panzeri, MEP (Italy) and Member of the European Alzheimer's Alliance showed his support to Federazione Alzheimer Italia by attending the concert organised by the association in the Scala of Milan to commemorate World Alzheimer's Day.



### 30 September 2008: Jean-Pierre Audy addresses home care conference in Chamalières

Jean-Pierre Audy, MEP (France), and Member of the European Alzheimer's Alliance was invited to address a European conference on new approaches to home care for people with Alzheimer's disease in Chamalières. In his recorded message, the Alliance member highlighted the need for concerted action on this disease on a European level.



## Alzheimer Europe news

### 28 August 2008: Alzheimer Europe continues to fulfill European Medicines Agency eligibility criteria

The European Medicines Agency (EMA) confirmed that Alzheimer Europe fulfills the criteria required by Patients' and Consumers' organisations in order to be involved in the EMA's activities. The eligibility criteria are listed on the EMA website and cover an organisation's:

1. Legitimacy
2. Mission/objective
3. Activities
4. Representativity
5. Structure

6. Accountability and consultation modalities
7. Transparency

### September 2008: Alzheimer Europe listed as 7<sup>th</sup> biggest European health campaign organisation

The August-September 2008 edition of the publication "Health and Social Campaigners' (HSC) News International" carries a report on the size of European health campaign organisations according to their income.

According to HSC, Alzheimer Europe ranks in seventh place with an income of €871,000 behind such organisations as Eurordis (European organisation for rare diseases), Bureau européen des unions de consommateurs, Orphanet, European Disability Forum, Health Action International and AGE – the European Older People's Platform.

### 5 September 2008: EuroCoDe working group on the socio-economic cost of dementia meets in London

Working group 8 of the European Collaboration on dementia (Eurocode) met to review the progress of their findings regarding the socio-economic costs of dementia. Their results will be published in December as part of the 2008 Alzheimer Europe Yearbook. The meeting was chaired by Dr. Anders Wimo of the karolinska Institute in Stockholm.



### 15 September 2008: Alzheimer Europe Board reviews the progress of work in 2008 and plans for 2009

The Board of Alzheimer Europe met in Brussels, Belgium, to review the progress to date of the 2008 Workplan as well as discuss plans for 2009.

Jean Georges, Executive Director of Alzheimer Europe, presented 2008 activities of the organisation which included updates on the status of the:

- Oslo Conference – recognition was given by the Board of a successful annual conference as well as recognition for the strong collaboration between the organisers.
- Guidelines on End-of-Life Care – the final version will be presented to the Board in December for adoption.
- Dementia in Europe magazine – the first issue had been well-received and

the second issue will be published at the end of the year.

- Eurocode project – the working groups are in the process of finalising their reports which will be included in the 2008 Yearbook.
- Dementia Research Observatory – work has commenced on developing a research database.
- Involvement of People with dementia – the working group agreed to commence work as soon as possible.
- Dementia manifesto – Board members were invited to consider Alzheimer Europe’s draft manifesto which will be published.
- Paris Declaration Survey – Alzheimer Europe has begun to draft a survey for members so that each country’s adherence to the demands laid down in the Paris Declaration can be assessed.

The work plan for Alzheimer Europe in 2009 was then discussed which will include the:

- 2009 Conference,
- Possibility of a dementia ethics network,
- Development of the current websites,
- Development of an active role for the expert advisory panel,
- New technologies project,
- Project application for funding under the 7<sup>th</sup> framework project,
- New system of sponsorship opportunities for conferences,
- Adoption of new conference guidelines,
- Planning the 2010 (Luxembourg) and 2011 (Warsaw) conferences.

The Board will next meet in December.

**16 September 2008: Alzheimer Europe organises lunch debate on the treatment options of Alzheimer’s disease at the European Parliament**

Professor Alexander Kurz presented “The treatment of Alzheimer’s disease: current options and future perspectives” at Alzheimer Europe’s 4<sup>th</sup> lunch debate.

It was hosted by Katalin Levai (MEP, Hungary) who is the Vice Chairperson of the European Alzheimer’s Alliance. Approximately 50

attendees, including some 16 MEPs and/or their assistants, health attachés of permanent representations, representatives of pharmaceutical companies and Alzheimer organisations participated.



Professor Kurz explained that:

- Alzheimer’s disease lasts approximately 20 years, with physiological changes in the brain occurring well before the stage of dementia, which lasts approximately 9 years and becomes apparent by the loss of memory and cognitive function.
- Current treatments are targeted at the end of a complex cascade of events and aim at restoring neurotransmitter deficits rather than the underlying disease process. They have been successful in shifting the progression of the disease, but not delaying it.
- Studies have shown psychosocial treatment to be successful but this approach needs to be individualised and tailored.
- New approaches to medical treatment have targeted earlier stages in the cycle of Alzheimer’s disease and their results are mixed.
- Some studies, although initially exciting, have been disappointing in large scale trials (studies including non-steroidal anti-inflammatories, secretase inhibitors, lipid lowering agents, removal of metal ions and amyloid immunisation).
- Other studies appear to be encouraging (drugs targeting amyloid such as bapineuzumab or the aggregation of tau such as methylmethonium chloride, a nutritional compound using a combination of vitamins and fatty acids as well as an antihistamine known as dimebon) but further research is required.

The next Alzheimer Europe lunch debate in the European Parliament will take place in December 2008.

## Impressions from the European Alzheimer’s Alliance lunch-debate



Professor Alexander Kurz with AE Chair Maurice O’Connell



Katalin Levai, MEP (Hungary)



Sirpa Pietikäinen, MEP (Finland) asks for clarifications



Agnieszka Szczesniak, Assistant to Jan Tadeusz Masiel, MEP (Poland) with Polish AE Board member Alicja Sadowska



Elisabeth Morin, MEP (France)



Annette Dumas, EU Public Affairs Officer, in discussion with Marie Panayotopoulos, MEP (Greece)



Jean Spautz, MEP (Luxembourg)



Jean-Baptiste Brunet and Katalin Levai



Sabine Henry, AE Vice-Chairperson, in conversation with Sibylle Henter, assistant to Sommer Renate, MEP (Germany)



Prof. Alexander Kurz in full swing



Sirpa Pietikäinen together with Finnish AE Board member Pekka Laine



Katalin Levai in discussion with AE Executive Director Jean Georges

## Alzheimer Europe Networking

On 1 September (Brussels, Belgium) Annette Dumas met Marielle Helleputte of the **European Federation of Unpaid Paid Carers at Home (FEFAF)** to discuss the progress in the collection of information for the FEFAF campaign and how to proceed with the campaign.

On 1 September (Berlin, Germany) Dianne Gove and Jean Georges attended a workshop organised by the **German Health Ministry** on the development of a European Dementia Ethics Network.

On 3-4 September (Copenhagen, Denmark) Jean Georges attended the **European Geriatric Medicine Society (EUGMS) conference** and presented the results of the Alzheimer Europe Carers' survey.

On 11 September (Brussels, Belgium) Annette Dumas attended the **think tank of the European Federation of Pharmaceutical industries and associations (EFPIA)**.

On 15 September (Brussels, Belgium) the **Alzheimer Europe Board** met.

On 16 September (Brussels, Belgium) the Alzheimer Europe Board organised a **meeting with** the current and potential future **sponsors** of the organisation.

On 16 September (Brussels, Belgium), Alzheimer Europe organised a **lunch debate in the European Parliament on the treatment of Alzheimer's disease**.

On 16 September (Brussels, Belgium) Annette Dumas attended the **launch of the European Patients' Forum Manifesto**

On 19 September (Nyborg, Denmark) Jean Georges went to the **Danish Dementia Nurses Conference** to give a presentation on the impact of dementia in daily life.

On 18-19 September (Prague, Czech Republic) Dianne Gove attended the **"Consensus Conference on Ethics and Capacity in old age psychiatry" of the Section of Old Age Psychiatry of the World Psychiatric Association**.

On 20 September (Luxembourg, Luxembourg), Jean Georges met with Liane Kadusch-Roth, chairperson of the **Luxembourg Alzheimer Association** to discuss the possibility of organising the 2010 Alzheimer Europe Conference in Luxembourg.

On 25 September (Brussels, Belgium) Annette Dumas attended the **European Patients Forum policy meeting** on cross border healthcare.

On 30 September (Luxembourg, Luxembourg) Jean Georges and Julie Fraser met with **Binsfeld publishers** to organise the publication of the Dementia in Europe Magazine and the Alzheimer Europe 2008 Yearbook.

On 30 September (Chamalières, France) Annette Dumas attended a **European conference on new approaches to home care for people with dementia**.

## European developments

### 17 September 2008: European Parliament launches Europarl tv

Confirming its commitment to make its work more transparent and understandable to the public, the European Parliament has launched its own web TV channel on the Internet: Europarl tv. A regularly changing set of programmes around the EP activities will be broadcast to the public.

Europarl tv is split into four channels, each directed to a different audience:

- *Your Parliament* addresses those with a particular interest in politics at the EU level: informed citizens, industry groups, social partners, lobbyists, academics as well as those working in the EU institutions.

- *Your Voice* addresses the general public and provides the possibility of featuring user-generated content.
- *Young Europe* targets school-aged children.
- *Parliament Live* provides continuous coverage of live events in the Parliament, and a link to the audiovisual archives of previous sessions.

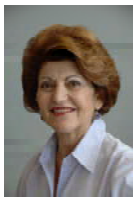
The "Discovering the European Parliament" section provides background material on the Parliament, programmes of the political groups and committees, as well as the history and operation of the Parliament.

### 25 September 2008: The European Parliament debates the application of patients' rights in cross-border healthcare

Members of the European Parliament (MEPs) held a plenary session to discuss the health aspects of the social package, in particular, to

discuss the directive on the application of patients' rights in cross-border healthcare.

Roselyne Bachelot, French Minister for Health, confirmed that the proposal which was adopted on 2 July for a directive on patients' rights in cross border healthcare will "remain a priority during the next 18 months, as this is included in the common agenda of the French, Czech and Swedish Presidencies."



Androulla Vassiliou, the European Commissioner for Health, opened her speech saying that the proposal "was without doubt the most important initiative on health of the present Commission." She explained that the proposal has

three objectives:

- a. To clarify the conditions under which patients are entitled to seek healthcare abroad
- b. To guarantee safe and high quality cross-border healthcare across the EU and
- c. To reinforce cooperation between the different healthcare systems.

Ms Vassiliou called for a new framework for Europe where "cooperation is key and where knowledge and skills are particularly important."

MEPs then discussed the Commission's proposal highlighting the following issues:

- a. To put patients at the centre of the issue,
- b. Legal certainty,
- c. Prior authorisation for care,
- d. Reimbursement and cost,
- e. Continuity of care,
- f. Quality and safety of care,
- g. Compatibility and interoperability of health information systems.

Political groups failed to find agreement on a joint motion for a resolution on the overall social package during the debate. John Bowis, MEP (United Kingdom) will now draft the report for the first reading report to be put before the European Parliament.

**26 September 2008: Alzheimer Europe welcomes call of EU Council of Ministers for action on Alzheimer's disease**

Alzheimer's disease has been acknowledged as a European priority by the Council of the European Union. At its meeting of 26 September, the Competitiveness Council adopted conclusions on a "common commitment by the Member States to combat

neurodegenerative diseases, particularly Alzheimer's".

In its conclusions, the Council recognises that:

1. Neurodegenerative diseases, and, in particular Alzheimer's disease, pose challenges and that the "stakes are significant both in terms of human suffering and the social and health burden, and on the grounds of the complexity of preventative or curative responses to such diseases"
2. There is a need to better understand, detect, prevent and combat the basic mechanisms which trigger neurodegenerative diseases, particularly Alzheimer's disease
3. Neurodegenerative diseases are now a major challenge for European societies and therefore a need to strengthen cooperation and coordination of research efforts, financial investment and mobility of researchers exists
4. Community initiatives exist. These should be continued with updates provided by the Commission
5. There is a need for the provision of a "real collaborative dynamic of all research stakeholders in Europe"
6. National research and development strategies for preventative action designed to delay the age of onset of neurodegenerative diseases are needed
7. A European initiative which brings together Member States, the Commission and other stakeholders in order to reduce neurodegenerative diseases is needed.

With regard to research and development, the Council invites Member States and the Commission to:

1. Create a forum with key players in European research
2. Consider existing national plans
3. Explore proposals for a commitment by Member States to establish closer and stronger collaboration.

Finally, the Council invites the Commission to explore forms of consultation and cooperation at international level.

Jean Georges, Executive Director of Alzheimer Europe, welcomed this clear call of EU Ministers: “For the first time, the Council of Ministers has clearly acknowledged the importance of increased research in the field of Alzheimer’s disease and the need for better collaboration between European countries in medical, biomedical and psychosocial research. We are delighted that our campaign to make dementia a European priority has been heard at the highest level and we offer our full collaboration in this important initiative.”

### 30 September 2008: Commissioner Vassiliou launches ‘Europe for Patients’ campaign

Androula Vassiliou, Health Commissioner, has launched the ‘Europe for Patients’ campaign.

The aim of this policy-driven campaign is to provide a coherent and tangible communication framework for the different healthcare policies that will be discussed at European level. The focus is to improve healthcare for all across Europe and ensure this is reflected in the different policy initiatives themselves.

10 initiatives, including the directive on cross border healthcare, cancer screening, patient safety, rare diseases, the health workforce, organ donation and transplantation will fall under this campaign.

A ‘Europe for Patients’ website was launched the same day. This website is to become a centre of information, with regular updates on the Europe for Patients healthcare initiatives.

To illustrate the Commission’s will to bring Europe closer to the citizens and sharing of information, interested national and regional health organisations will be invited to post their health stories and events in line with the Europe for Patients initiative.

## Policy Watch

### 29 August 2008: Scottish dementia research receives boost of £1 million investment

The Scottish Government has announced an additional £1 million funding for research into dementia which will be allocated to fund a new Dementia Clinical Research Network in Scotland. The network will consist of academics and clinicians.

### 1 September 2008: Workshop discusses the creation of a European Ethics Dementia Network

The German Ministry of Health organised a European workshop to discuss the possibility of

creating a cross-border ethics network/platform to facilitate discussions, the exchange ideas and the possibility to learn from each other. This meeting brought together policy makers, carers, ethicists, Alzheimer organisations and researchers to discuss ethical issues which surround dementia.



The German State Secretary, Klaus Theo Schröder, explained that ethical issues and the problems faced by people with

dementia and their carers, such as the feelings of loss, isolation and stigma, are not issues limited by national borders. Heike von Lützu-Holbein emphasised that economic considerations should come second.

Jean Georges, Executive Director of Alzheimer Europe, presented the concept of how an ethics network could work and asked the participants for their support in putting such a network into action. Jean Georges also spoke of the need to focus on the positive side of dementia whilst maintaining a balance with the realities of the disease.

### 16 September 2008: NIHR announces £18 million investment in health research collaborations in the UK

In May, the United Kingdom launched the National Institute for Health Research (NIHR) Collaborations for Health Research and Care. Seven partnerships between the National Health Service and leading universities were identified to be a part of the NIHR. On 16 September, two further partnerships have been identified (in Nottinghamshire and in Cambridgeshire & Peterborough) who will receive £18 million to “conduct research and improve care in conditions including dementia.”

The aim of the collaborations is to “bring together universities and their surrounding NHS organisations to test new treatments and new ways of working in specific clinical areas, to see if they are effective and appropriate for everyday use in the health service. Where potential improvements are identified, the collaborations will help NHS staff to incorporate them into their everyday working practices, so that patients across the local community receive a better standard of healthcare”.

### 18 September 2008: UK Poll finds political parties not to have clear plans for older people

A poll, carried out by the Alzheimer’s Society, found that 72% of those people asked were

unable to name a political party that has clear policies for older people. Further, the over 55s identified dementia as the disease/illness that they fear the most in later life.

Neil Hunt, Chief Executive of the Alzheimer's Society said "The results will torment political parties who will rely on the votes from an ageing British population to win the next election. Pensioners now outnumber children in the UK. The first ever National Dementia Strategy for England will be published in November (...) We will be asking the parties about their commitment to the strategy."

## Members' News

### 3 September 2008: Alzheimer Scotland highlights challenges ahead

Speaking at the Dementia Services Development Centre Conference in Stirling, Henry Simmons, Chief Executive of Alzheimer Scotland, highlighted the challenges which lie ahead:

- For all stakeholders, but in particular for social care resources and local authorities to meet the expected increase of the number of people with dementia as well as "meet the aspirations of the personalisation agenda that is currently evolving".
- To develop dementia-friendly communities and to ensure that people are supported to remain active and involved for as long as possible.
- To ensure that people with dementia and their carers are at the centre of planning and more advanced person-centred planning.
- To address the current low accessibility of specialist palliative care.

### 2008-9-10: The winners of the German Youth Competition to raise awareness of Dementia are announced

In order to explore ways in which young people can support people with dementia, and to raise their awareness of the disease, the German Alzheimer's Association, (Deutsche Alzheimer Gesellschaft) launched their youth competition on World Alzheimer's Day 2007.

Subsequently, some 600 young people took part in the competition submitting 110 creative contributions which took the form of photographic works, texts or project reports. The winners were announced on 10 September under three categories:

- **Individuals:** Painting by Lisa Maassen (aged 17) from Hamburg. During her internship in a nursing home, Lisa was moved by watching an old lady, who absent mindedly filled her shoes with water whilst her husband anxiously looked on. It was this scene she portrayed in her painting.
- **Schools:** Project by St Xavier High School from Bad Driburg. The religious class submitted interviews, recordings of music lessons in a nursing home and their thoughts about dementia. The judges had been particularly impressed with a ballad which the school had composed.
- **Training college:** Concept for pet therapy by nursing school, Goslar. The judges selected this concept due to its relevance to practice.



The prizes were presented by the Parliamentary State Secretary, Dr. Hermann Keus and Heike von Lützau-Hohlbein, Chair of the German Alzheimer's Society.

Heike said, "The competition entries demonstrate that the young generation shows a willingness to help and to respect people with dementia."

### 17 September 2008: The Danish Alzheimer Association calls on Danish Members of the European Parliament to join the European Alzheimer's Alliance

Alzheimerforeningen, the Danish Alzheimer Association, has sent a letter to all Danish Members of the European Parliament (MEPs) which highlights the fact that out of the 76 MEPs who are members of the European Alliance and/or have signed the Paris Declaration, none of them are Danish.

Calling on the 14 Danish MEPs to take action, Anne Arndal, Chairperson of the Danish Alzheimer's Association said "It is high time that Danish MEPs take the problem of Alzheimer's disease and other forms of dementia seriously."

N.B. Since this news release four Danish MEPs have now signed the Paris Declaration.

## Celebrations of World Alzheimer's Day

On 21 September each year, people with dementia, their carers and Alzheimer associations from nearly 80 countries come together to raise awareness amongst all about the realities and effects of dementia on individuals, families and societies

### 12-20 September 2008: Cypriot Alzheimer's Organisation celebrates World Alzheimer's Day with a series of events throughout the country

This year's World Alzheimer's Day saw a series of events throughout Cyprus organised with the Cypriot Alzheimer Association. Events included:

On 12 September, in Nicosia, a press Conference was given by the Minister of Health, Mr Christos Patsalides.

On 16 September, all the national newspapers and television talk shows discussed doctors' articles about Alzheimer's disease.

On 17 September, the Larnaca District committee organised a public cocktail event and invited a doctor to speak, after which there was a question and answer session.

On 20 September, throughout towns in Cyprus, leaflets about Alzheimer's disease were distributed and doctors were present at specified centres to answer questions.

Also on 20 September, in Nicosia, Alzheimer's Day will be celebrated by an open day with doctors and carers.

### 14 September 2008: Icelandic Alzheimer's Association holds special World Alzheimer's Day meeting



The Icelandic Alzheimer Association, Félag aðstandenda Alheimerssjúkra (F.A.A.S), held a special World Alzheimer's Day meeting at the Grand Hotel in Reykjavik on September 14. The event was attended by the Minister for Social Affairs, Jóhanna

Sigurðardóttir (pictured left) and included a lecture by Dr. Jón Snædal as well as an introduction to the new Icelandic Day Care Centre Maríuhús which opened on 1 September.

### 15-21 September 2008: Spanish Alzheimer Association (CEAFA) conducts Memory Bus Project

The Memory Bus is a project which offers "memory workshops", information about dementia and Alzheimer's disease, as well as information about the local Alzheimer associations. It consists of two adapted buses visiting 14 different cities and is a collaborative project between the Spanish Alzheimer Association, Confederación Española de Familiares de Enfermos de Alzheimer y otras demencias (CEAFA) and Pfizer-Eisai.

### 17 September 2008: Spanish Alzheimer Association (CEAFA) gives recognition to people and institutions involved with Alzheimer disease

In Madrid, the Spanish Alzheimer Association, Confederación Española de Familiares de Enfermos de Alzheimer y otras demencias (CEAFA) presented awards which honour the outstanding work of people and institutions who work in the area of Alzheimer disease.

### 18 - 21 September 2008: Alzheimer Bulgaria celebrates World Alzheimer's Day

On 18 September, the Bulgarian Alzheimer's association raised the awareness of Alzheimer's disease and the problems that people with dementia, and their carers, face by holding a press conference where media representatives from television stations, information agencies, the Bulgarian National radio station, newspapers and magazines were present.



The Association also used this opportunity to present the Paris Declaration and thank Dushanka Zdravkova, Member of the European Parliament for Bulgaria for her support in signing the Declaration.



The events to highlight World Alzheimer's Day continued on 21 September in Sofia where medical examinations were offered and some 150 people were screened. In addition, information leaflets and balloons were handed out.

**18 September 2008: Alzheimer’s Disease International launches Global Charter**

Alzheimer’s Disease International (ADI) launched their global Alzheimer’s Disease Charter for which they hope to secure over 10,000 signatures and use them as a lobbying tool in targeting the World Health Organisation (WHO) and national governments. The charter is available on line ([www.globalcharter.org](http://www.globalcharter.org)) with translations available. There is also a short film to support the launch of the Charter.

**20 September 2008: Luxembourg Association organises Memory Walk**

As in previous years, the Luxembourg Alzheimer’s Association organised a Memory Walk to commemorate World Alzheimer’s Day. During the whole day, the organisation was present with stands in one of the main squares of Luxembourg City and provided information on Alzheimer’s disease and the many services of the organisation.



At the same time, guided tours were organised which showed participants some of the highlights of the town. This year, the focus of the guided tours was a history of the German occupation of Luxembourg during the Second World War.

**20 September 2008: Portugal marks World Alzheimer’s day by carrying messages of hope**



People with dementia’s messages of hope were released by using homing pigeons in the City Park in Almeirim, Portugal, to mark World Alzheimer’s Day. Messages had been gathered from people with Alzheimer’s disease during weekly Gestalt Psychotherapy group sessions, which were then attached to the homing pigeons. Examples of the messages included:

- “I wish that all the people with this problem have courage and strength. I feel a lot of peace, love and affection in the group.”
- “I feel good in the group. I can talk about everything (...) I feel better and more relieved when I leave the sessions (...) People are trustworthy.”
- “I wish health and peace to everyone who is in the same condition as I am.”

After this symbolic display of peace and hope, traditional folk dancing was followed by lunch and live music. People with dementia, their carers, the Gestalt Psychotherapy Group participants, representatives of the City council, members of the Alzheimer Board and staff were all present at the event.



This was just one of the events by which Alzheimer Portugal marked World Alzheimer’s Day celebrations, promoting the integration of people with Alzheimer’s disease and helping to minimise social stigma. Some of the celebrations will be continuing throughout October in the branches and headquarters of Alzheimer Portugal.

**21 September 2008: Queen of Sweden helps to mark World Alzheimer’s Day**

Queen Silvia of Sweden, (pictured left) sent a written personal greeting to Alzheimerföreningen i Sverige, the Swedish Alzheimer Association, in support of the World Alzheimer’s Day event which was held in Stockholm.



Over 1550 people attended a special performance of acting and singing. On stage was also Bengt Winblad, Professor of Geriatrics, Karolinska Institutet, Sweden and three of his colleagues, who informed the large audience about Alzheimer’s disease. The performance is due to be released onto the Swedish Association’s website ([www.alzheimerforeningen.se](http://www.alzheimerforeningen.se)).

**21 September 2008: Swiss Alzheimer Association organises “Unforgettable Memories” concerts**

To celebrate both World Alzheimer’s Day and its 20<sup>th</sup> anniversary, the Swiss Alzheimer Association organised three concerts. In the capital, Berne, and in Yverdon-les-Bains, people with dementia, members, donors and friends of the Association enjoyed the performance by the orchestra “I Salonisti”, (pictured), which is well-known from soundtracks such as “unforgettable memories” in the film Titanic as well as from melodies of the fifties and sixties. The third concert was held in



Locarno, with the Quattrocento Quaranta Core Orchestra.

In addition, the 21 regional Swiss Alzheimer member associations organised award ceremonies to recognise a special person, or group of people, who improved the quality of life of a person with dementia. Awards were given to neighbours, caregivers, family members, a home care organisation (pictured) as well as a



journalist. These awards were given media coverage in the newspapers, radio and television.



Finally, in order to further raise awareness of the disease and make it a Swiss public health priority, the Association promoted its Alzheimer's Charter, "Priority Dementia", securing over 8000 signatures during September.

### 21 September 2008: French Alzheimer Association's organises Nordic walking event



World Alzheimer's Day was highlighted by the French Alzheimer Association (FA) with a Nordic walk, starting at the Château in the Parc des Sceaux, near Paris.

French Health Minister Roselyne Bachelot honoured the French organisation by actively showing her support to the cause and participating in the Nordic walk.

### 21 September 2008: Alzheimer's Society celebrates World Alzheimer's Day with nationwide Memory Walks

The 2008 Alzheimer's Society Memory Walk had some 200 walks taking place nationwide, organised to coincide with World Alzheimer's Day. The Memory Walk is the Alzheimer's Society biggest annual fundraiser and all money raised is used to support people with dementia and their carers.



The Memory Walk website has information on the walks, ideas for fundraising as well as a page dedicated to allow carers and people with dementia to share their experiences ([www.memorywalk.co.uk](http://www.memorywalk.co.uk)).



### 21 September 2008: Greek Alzheimer's association organises Memory walk and screening of 1,500 people

The "Greek Association of Alzheimer's disease and related disorders" used World Alzheimer's Day to successfully raise awareness of the disease by organising:



- A week of free memory testing in Athens, which resulted in 1,500 people being screened for Alzheimer's disease,
- the distribution of 10,000 pamphlets on the disease
- performances of monologues by professional actors
- a Memory Walk (this was the first time this has happened in Greece) with some 500 people participating, wearing t-shirts and hats with the association's logo on. Participants were accompanied by the band of the Athens Municipality.
- full media coverage of all events



Maria Matsouka, MEP (Greece), attended the World Alzheimer Day celebrations.

For further information please see the Greek Association's website:

<http://www.alzheimer-hellas.gr>

### 21 September 2008: Ireland launches report on social model of dementia on World Alzheimer's Day

The Alzheimer Society of Ireland held a series of events, meetings and celebrations throughout Ireland to commemorate this year's World Alzheimer's Day. These included a concert for carers and also the launch of their report "Social Space: Equal Place, The social model of dementia care" which offers ways to address the social barriers of isolation and stigmatisation for couples living with dementia.

Katherine Keogh, co-author of the Social Space report, explained that "Traditionally Alzheimer's services were designed to support the person and their carer separately. This new model provides an environment to support and stimulate both, equally, together. As part of a jigsaw of care services, the social club is really helping couples to get connected again and make new friends."

Currently there are three pilot social clubs in Ireland (Dublin, Wicklow and Kildare) and the benefits to members are proving to be very positive.

For further information please see:

Web: <http://www.alzheimer.ie>

### 21 September 2008: Flemish organisation organises successful Memory Walk

The World Alzheimer's Day 2008 was held in Ghent on 21 September for the whole Flemish population of Belgium. Bie Van Waeyenberghe, the Chairperson of the Flemish Alzheimer Ligue, was very pleased to welcome the



President of the Ligue nationale Alzheimer Belgium, Sabine Henry, and the Vice President, Jan Hertecant, both of whom were present for this event. In addition,

delegations from all Flemish regional Alzheimer associations were there.

The day started with a warm welcome from the Mayor of Ghent, Daniël Termont. Afterwards Prof. Christine Van Broeckhoven, University of Antwerp, presented results of recent research and highlighted the importance of having an annual World Alzheimer's Day.

In a warm and sunny Ghent, all invited people with dementia and carers, members of the regional Alzheimer associations, walked through the town amongst thousands of visitors, who were there for the historical parade of the city Ghent. The Memory Walk participants were made extremely visible by wearing fluo-jackets with the message of the day: "Samen Dementie Draagbaar Maken" ("Let's make Alzheimer's disease more bearable together").

### 21 September 2008: German Alzheimer Association launches blog page for carers and people with dementia

To highlight World Alzheimer's Day, Deutsche Alzheimer Gesellschaft, the German Alzheimer Association, launched their new blog page at [www.alzheimerblog.de](http://www.alzheimerblog.de) where exchanges of carer's experiences and of people with dementia can be found.

Additional information about Alzheimer's disease is also available, such as reports from experts, the work of the Alzheimer association, books and film tips

### 21 September 2008: Dutch organisation raises the profile of Alzheimer's disease

World Alzheimer's Day generated a lot of publicity in the Netherlands. All associations of the Alzheimer Nederland organised a wide variety of activities to commemorate World Alzheimer's Day.

Nationally, Alzheimer Nederland launched a special music album, featuring famous songs relating to dementia. All artists provided their songs for free. From every copy sold, some 10 euros will be spent on scientific research into the causes of dementia.

Throughout the country, regional associations organised lectures and musical events to support people living with dementia as well as their caregivers. The Zeeland association offered people a trip on a boat, with lots of music and food. As one of the participants stated: "Participating in this event leads to in-depth conversations on dementia. From now on, we will surely visit an Alzheimer Café since we have found that discussing this awful disease offers us relief. Thank you so much!"



In Amstelveen, Alzheimer Nederland director, Gea Broekema, participated in one of the many memory walks. "It was – as always – a wonderful event. Hurray for all the volunteers who invested so much time to enable this to take place".

For more information visit [www.alzheimer-nederland.nl](http://www.alzheimer-nederland.nl)

### 22 September 2008: Alzheimer Scotland organises World Alzheimer's Day Lecture

Alzheimer Scotland held its 8<sup>th</sup> annual World Alzheimer's Day lecture in Glasgow with tickets for the lecture being snapped up well in advance. This year, people with dementia,



family and professional carers, and Alzheimer Scotland members, volunteers and staff gathered to hear Clive Ballard, Professor of Age

Related Diseases, King's College London and Director of Research, Alzheimer's Society speak on the subject of "Treating Psychiatric and Behavioural Symptoms in People with Alzheimer's Disease".

Professor Ballard looked at the findings, some from his own research, on the short-term (up to 3 months) and longer-term (6-12 months or more) use of anti-psychotics, particularly in relation to symptoms in Alzheimer's disease where there is most research evidence.

He pointed out that antipsychotics have been shown to double the risk of death and triple the risk of stroke in people with dementia and asked the audience to consider under what circumstances they would agree to take a drug that could have that outcome.

He concluded that:

- Atypical antipsychotics have short term efficacy for the treatment of aggression, but have considerable adverse effects
- There are several candidate alternative pharmacological therapies, but better evidence is urgently needed
- Aromatherapy with melissa (lemon balm) or lavender are evidence based alternatives
- Psychological therapies are a safe alternative with emerging evidence of efficacy.

**27 September 2008: Alzheimer Italia celebrates World Alzheimer's Day with an "extraordinary concert" in La Scala.**

On 27 September 2008, Federazione Alzheimer Italia organised the Third Extraordinary Concert to celebrate the 15th World Alzheimer's Day. The concert took place in the famous Theatre La Scala of Milan with the Staatskapelle Dresden, directed by the famous conductor Fabio Luisi.

The event had the Patronage of the Republic's President, the Prime Minister, the Health and Social Minister, the Lombardia Region, the Province and the Municipality of Milan.

**27 September 2008: Malta Dementia Society calls to place dementia "on top of the national health agenda"**

The Malta Dementia Society organised their celebration of World Alzheimer's Day on 27 September. The event was well-attended and a lot of people stopped by to get more information about dementia, its causes and the services that are available in Malta.

Mr. Mario Galea, Parliamentary Secretary for the Elderly also attended the event and



participated in the Memory Walk which was held in Valletta, the capital City of Malta. In a short speech, Mr. Galea stressed the need to take dementia seriously by placing it on top of the national health agenda. He also highlighted the fact that the number of people with dementia worldwide is expected to triple in the next 35 years. "It is our duty to take care of this rising phenomenon by investing more in the services, both for the patients and their respective caregivers", he concluded.



## Members' Forthcoming Events

**5-14 May 2009: The Irish Alzheimer's Society's Cuban cycle challenge**

An opportunity to get fit and raise funds is offered by the Alzheimer Society of Ireland in the form of an "8 day, fully supported point-to-point road tour" in Cuba. 325km will be covered over five days of cycling and the Society says that it can be completed by anyone of average fitness after training.



Guided cultural and historical visits are included such as trips to:

- An underground cave system
- An invigorating sulphur bath
- Che Guevara's secret HQ and
- a UNESCO World Heritage site

## Science Watch

**September 2008: Study investigates the effect of fatty acids on cognitive decline**

A study, published in Neurology, investigated the effect of a high intake of fatty acids [eicosapentanoic acid (EPA) and docosahexaenoic acid (DHA)] on cognitive function.

The study consisted of a group of 302 cognitively healthy individuals aged 65 and older who were randomly assigned to

- 1800mg/d EPA-DHA or
- 400mg/d EPA-DHA or
- placebo capsules for 26 weeks.

At the end of the 26 week trial researchers concluded that “overall, there were no significant differential changes in any of the cognitive domains for either low-dose or high-dose fish oil supplementation compared with placebo.

### **2 September 2008: Study examines the effect of physical activity on cognitive function in adults at risk of Alzheimer’s disease**

Researchers monitoring 138 people aged 50 and over, who had reported memory problems but did not have dementia, found that participants who exercised had a modest improvement in cognition over an 18 month follow-up period. The study was led by Nicola T Lautenschlager MD of the University of Melbourne, Australia.

We provide full references to all science articles on our website

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

### **3 September 2008: Pfizer and Medivation agree on joint strategy for Alzheimer’s drug candidate**

Pfizer and Medivation Inc. have agreed a strategy to market the drug, Dimebon, which is undergoing Phase III trials for treatment of people with mild-to-moderate Alzheimer’s disease.

### **8 September 2008: Study examines the effect of vitamin B12 on brain shrinkage**

A study carried out by Professor David Smith of the University of Oxford and published in the journal Neurology, monitored 107 people aged between 61 and 87 over a five year period and found that those people with a vitamin B12 deficiency were also likely to show signs of brain shrinkage.

Whilst acknowledging that “shrinkage is usually associated with the development of dementia”, Dr Susan Sorensen from the Alzheimer’s Society said “This is another example of why it is crucial for people to lead a healthy lifestyle with a balanced diet rich in B vitamins and antioxidants”.

Professor David Smith plans to carry out a trial of B vitamins to see if taking them could slow down brain shrinkage.

### **9 September 2008: Study examines the role of protein in memory creation and retention.**

A study published in the journal Nature Neuroscience, examined the role the protein PSD-95 has during memory creation and memory retention in mice.

Two groups of mice were tested for their memory of new tastes. One group of mice were genetically engineered to have their production of PSD-95 halted, the other group’s production was left unaltered. No memory of new tastes was exhibited in the group whose PSD-95 was stopped, whereas the mice with continued PSD-95 production remembered the tastes. The researchers concluded that a new memory was created when PSD-95 was induced.

The effect of PSD-95 production on existing memories was also examined with mice, that had already remembered certain tastes, being found to still remember the tastes even after being genetically engineered to stop producing PSD-95. This suggests that PSD-95 is not necessary for memory retention.

The research was led by Prof. Kobi Roseblum, from the University of Haifa.

### **12 September 2008: Research studies effects of a Mediterranean diet on Alzheimer’s disease**



In order to systematically review all prospective cohort studies that have analysed the relation between adherence to a

Mediterranean diet, mortality and incidence of chronic diseases, Dr Francesco Sofi and colleagues affiliated with the University of Florence in Italy, examined results from 12 studies. These studies followed some 1,500,000 subjects over a period of time ranging from three to 18 years.

A Mediterranean diet was considered to be high in legumes, cereals, fruits, vegetables, fish, monounsaturated fat, moderate in alcohol intake and low in meat and meat products as well as low in milk and dairy products.

The study found that greater adherence to a Mediterranean diet was associated with a significant improvement in health status as well as a reduction in the risk of various conditions, including a 13% reduction in the risk of developing Alzheimer’s disease.

**16 September 2008: AstraZeneca announces results of clinical trial of Alzheimer's drug AZD3480**

Drugs firm AstraZeneca and partner Targacept Inc released the results from their Phase IIb clinical trial of AZD3480 in which the drug, was found to be statistically insignificant.

In the study, the drug AZD3480 was compared to the drug donepezil. Both drugs were impacted by the improvement of the placebo group and AstraZeneca says further investigations are required.

**17 September 2008: Study examines the effect of inflammation on dementia**

A study published in the journal "Biological Psychiatry" found that the "inflammatory response to infection in mice with prior neurodegenerative disease leads to exaggerated symptoms of the infection, causes changes in memory and learning and leads to accelerated progression of dementia."

The study was a collaboration between Dr Colm and colleagues from Cunningham at Trinity College, Dublin, Ireland and Professor Hugh Perry at the University of Southampton and was funded by the Wellcome Trust.

**Correction**

Alzheimer Europe would like to sincerely apologise for inadvertently reporting that studies led by Lon Schneider had identified a slower decline rate in placebo-treated patients (newsletter July/August 2008, p14). The report should have read as follows:

**2008-07-28 Analysis of clinical trials does not support the theory that participants have a slower rate of cognitive decline than in the past**

A study, led by Professor Lon Schneider of the University of Southern California (USA), analysed published and unpublished randomised, double-blind, placebo-controlled Alzheimer's clinical trials of six months or more between 1991 and 2005.

The aim of the study was to assess the truth of the popular opinion that AD patients entered into clinical trials now were somehow different from early patients, that perhaps they were healthier or that their use of Aricept was lessening the decline seen in the past. It was found that mild to moderate AD patients enrolled in clinical trials and randomized to placebo did not show slower rates of cognitive decline than in previous trials, or any change in the rate of decline over the years from 1991 to 2005. They decline as slowly now as they did then.

Another key finding was that recently many highly publicised trials, both negative and positive, used small sample sizes of less than 150 patients in the placebo group. This size trial has a high likelihood of the placebo group not worsening significantly from baseline, thus the trial will be negative.

Professor Schneider concluded from the analysis that a reliable approach to maximise the likelihood of demonstrating efficacy in a 6-month study would be to have a placebo group size greater than 200 and to use the ADAS-cog subscale at least four times and in English; and larger placebo groups when the ADAS-COG is done less frequently and across languages.

**Dementia in Society****1-3 September 2008: Scotland hosts conference on dementia**

"Celebrating Innovation and Excellence: Making Change Happen" was the title of this year's Dementia Services Development Centre's international conference in Scotland, which brought together delegates to hear from dementia care experts, healthcare professionals and campaigners. Keynote speakers included:

- Sube Banerjee of King's College London - who spoke about the quality of life and the quality of care, and the relationship between the two. He also

spoke of "dangerous inactivity" which can arise from stigmatisation issues, false perceptions whereby people believe nothing can be done after diagnosis and from the belief that dementia is a normal part of ageing.

- Neil Hunt, Chief Executive of the Alzheimer's Society - who spoke about the English Dementia Plan (which is due to be launched in October) and the "once-in-a-generation opportunity to make substantial changes"
- Henry Simmons, Chief Executive of Alzheimer Scotland, - who spoke of a "light touch" approach which advocates the effective use of "small

amount of money to make a tremendous difference” and

- Shona Robinson, the Scottish Government’s Minister for Public Health – who spoke of the support from the Government for dementia services.

**20 December 2008: Controversial remarks by UK moral philosopher cause outcry**

In an interview with the Church of Scotland’s magazine, Life and Work, former Government advisor, Lady Warnock, said “If you’re demented, you’re wasting people’s lives – your family’s lives – and you’re wasting the resources of the National Health Service”.

Lady Warnock, 84 who has had a long career in academia, specialising in ethics also recently wrote an article for a Norwegian periodical entitled “A Duty to Die?” in which she suggests “that there’s nothing wrong with feeling you ought to do so for the sake of others as well as yourself.”

Neil Hunt, Chief Executive of the Alzheimer’s Society, said “I am shocked and amazed that Baroness Warnock could disregard the value of the lives of people an dementia so callously. With the right care, a person can have a good quality of life very late into dementia. To suggest that people with dementia shouldn’t be entitled to that quality of life or that they should feel that they have some sort of duty to kill themselves is nothing short of barbaric.”

**21 September 2008: French TV shows documentary of French actress, Annie Girardot who lives with Alzheimer’s disease**

The French channel TF1 broadcast a documentary about Annie Girardot, the famous French actress, who lives with Alzheimer’s disease on World Alzheimer’s Day.



Annie Girardot was diagnosed with Alzheimer’s disease in 1998. With her consent, her daily life was filmed by her close friend, Nicolas Beaulieu, during 2006 and 2007. She continued to act, but when she began to feel lost and alone, Ms Girardot moved into a specialised home.

The documentary ends stating “Annie, despite her family’s efforts, forgot everything about Girardot.”

**29 September 2008: Terry Pratchett calls on politicians to prevent the “tsunami” of dementia**



Speaking at the Conservative Party conference, Terry Pratchett, the best-selling author and Patron of the Alzheimer’s Research Trust, likened the impending dementia epidemic to that of a “Tsunami of dementia suffering” and asked the delegates “Is there going to be a government willing to put its money where its mouth is or will dementia remain the most feared disease for the over 55s? (...) What is unthinkable is to do nothing at all.”

He explained “the toll of this nasty disease is greater than you think. An appreciable number of people in this room will be affected by it. Dementia isn’t a disease of the bumbling elderly. People get it in their 50s and 60s.” He believes that people with dementia are stigmatised as “superfluous old farts”.

Mr Pratchett again highlighted the lack of funding for research for Alzheimer’s disease and related diseases. The delegates gave him a standing ovation

**New resources and publications**

**8 September 2008: Guidelines for companies developing medicines for the treatment of Alzheimer’s disease published**

Following recent scientific progress in the understanding of Alzheimer’s disease, the European Medicines Agency (EMA) has released a “guideline on medicinal products for the treatment of Alzheimer’s disease and other dementias.”

**9 September 2008: Dementia in Europe magazine is available online**



Following the publication of Alzheimer Europe’s Dementia in Europe magazine in June, issue 1 of the magazine is now available as a download from the publications section of the website.

The first edition covers such different subjects, as the French Alzheimer’s Plan, the UK Dementia Strategy, the Hague Convention on the International Protection of Adults, as well as interviews with

Françoise Grossetête, chairperson of the European Alzheimer's Alliance, Florence Lustman, coordinator of the French Alzheimer's Plan and Brian Peddie, Head of EU and International Law Branch of the Scottish Executive.

The magazine also gives details on some Alzheimer Europe's activities to make dementia a European priority, such as the lunch debate on prevention in the European Parliament or the Alzheimer Europe Conference "Breaking barriers" in Oslo.

### 10 September 2008: DG SANCO launches website for health promotion videos

A new website for health promotion videos produced in Europe has been launched by DG Health and Consumers of the European Commission at the International Union for Health Promotion and Education (IUHPE) Conference. The aim of [www.Healthclips.eu](http://www.Healthclips.eu) is to "share ideas and best practice and to show what has been done in public health campaigns".

### 11 September 2008: EU Health Conference summary is published on-line

A summary of the speeches given at the EU high Level Conference held in June which led to the European pact "Together for Mental Health and Well-being", is now available on line.

The summary includes the comments from Mr Didier Houssin, Director General, Ministry of Health, France, who highlighted the priority that dementia has under the French presidency and highlighted the usefulness of the European Pact in that it can "bring together researchers, social care and health professionals and stimulate the exchange of good practice, and failures, between member States."

Jointly closing the conference, the Slovenian Minister of Health, Ms Sofia Mazej-Kukovič reminded delegates that "this pact is not an obligation, but a commitment" and Ms Androulla Vassiliou, the European Commissioner for Health called the Pact "the beginning of a new chapter in health policy".

### September 2008: Alzheimer's Society publishes information on dementia with Lewy bodies

The Alzheimer Society has published "An introduction to dementia with Lewy bodies" which encompasses

- How this form of dementia affects people physically and emotionally
- How and why it is different from other forms of dementia
- How to provide care and support for people who are experiencing dementia with Lewy bodies

Neil Hunt, chief executive of the Alzheimer's Society, commented that the guide "demonstrates the desperate need for specialist, person-centred dementia care by highlighting the fact that no two people with dementia are the same."

#### Contact Alzheimer Europe at:

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#### Alzheimer Europe Board

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

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

**Honorary Secretary:** Sigurd Sparr (Norway)

**Honorary Treasurer:** Heike von Lützu-Hohlbein (Germany)

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Neil Hunt (United Kingdom)

Pekka Laine (Finland)

Patrick Maugard (France)

Alicja Sadowska (Poland)

Charles Scerri (Malta)

Marc Schaefer (Luxembourg)

Maria do Rósario Zincke dos Reis (Portugal)

## AE Calendar

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

Date	Meeting	AE Representative
2-4 October	3rd National Alzheimer's Conference (Vigo, Spain)	Maurice O'Connell
8 October	Dr Paul Coleman from Biogen Idec (Brussels, Belgium)	Jean Georges
8 October	Shelagh Kerr and Chris Ward from PhRMA (Brussels, Belgium)	Jean Georges
10 October	Europa Bio Patients Advisory Group Meeting (Brussels, Belgium)	Annette Dumas
10 October	Meeting with Alzheimer Scotland (Edinburgh, Scotland)	Jean Georges
11 October	Emma Reynish – Eurocode Prevalence Group (Edinburgh, Scotland)	Jean Georges
13-14 October	General Meeting of Innomed (Basel, Switzerland)	Jean Georges
13-14 October	French Presidency Conference "A Europe for patients" (Paris, France)	Annette Dumas
14 October	Intergroup on Ageing, AGE and EPHA debate "Mainstreaming Healthy Ageing in the renewed Social Agenda (Brussels, Belgium)	Dianne Gove
14 October	Eucomed dinner debate "The Future of Homecare Policy in Europe" (Brussels, Belgium)	Dianne Gove
16 October	FEFAF Conference on "Women, Families and Society" (Brussels, Belgium)	Annette Dumas
17 October	Epilepsy and Society Conference (Marseilles, France)	Jean Georges
18 October	Seminar on Grandchildren and Grandparents (Bradford, England)	Dianne Gove
27 October	2009 Conference Organising Committee (Brussels, Belgium)	Jean Georges
30-31 October	French Presidency Conference "The fight against Alzheimer's disease" (Paris, France)	Alzheimer Europe Board and staff
12 November	Health First Europe New Horizons Congress: "Tackling the healthcare challenges of today for a healthier tomorrow" (Brussels, Belgium)	Annette Dumas
17-18 November	Meeting with Polish organisation (Warsaw, Poland)	Jean Georges
21 November	EFPIA Think Tank (Brussels, Belgium)	Annette Dumas

## Future Conferences

Dates	Meeting	Place
9-11 October	5 <sup>th</sup> Congress for the German Alzheimer Association (Alzheimer Gesellschaft) <a href="http://www.ctw-congress.de/alzheimer">www.ctw-congress.de/alzheimer</a>	Erfurt, Germany
11 October	9 <sup>th</sup> International Conference and Alzheimer's and Parkinson's Disease <a href="http://www.kenes.com/adpd/">http://www.kenes.com/adpd/</a>	Prague, Czech Republic
16 October	6 <sup>th</sup> International Congress on Mental Dysfonctions and Other Non-Motor features in Parkinson's Disease <a href="http://www.kenes.com/pdment2008/">http://www.kenes.com/pdment2008/</a>	Dresden, Germany
23 October	The 2 <sup>nd</sup> World Congress on Controversies in Neurology (CONy) <a href="http://comtecmed.com/cony/2008/Default.aspx">http://comtecmed.com/cony/2008/Default.aspx</a>	Athens, Greece
30-31 October	French EU Presidency conference on Alzheimer's disease: Europe against Alzheimer's disease <a href="http://www.eu2008.fr/PFUE/lang/en/accueil/PFUE-10_2008/PFUE-30.10.2008/L_Europe_contre_la_maladie_d_Alzheimer">http://www.eu2008.fr/PFUE/lang/en/accueil/PFUE-10_2008/PFUE-30.10.2008/L_Europe_contre_la_maladie_d_Alzheimer</a>	Paris, France
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	Bordeaux, France

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28-30 May 2009	<a href="http://www.neurosciences.asso.fr">www.neurosciences.asso.fr</a> 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

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