



NEWSLETTER

February – March 2009

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Editorial



Our aim of producing a monthly newsletter was a very ambitious target.

With a growing list of activities and important deadlines, it was unfortunately not possible to send out our February newsletter as planned and this newsletter covers both February and March.

Since announcing in January's newsletter that we had secured enough support for the adoption of Written Declaration 80/2008 on the priorities in the fight against Alzheimer's disease, I am absolutely delighted to inform you that in the end this support came from nearly 60% of MEPs, a great achievement made possible thanks to the fantastic collaboration of all our national member organisations.

This is a strong signal and comes shortly after the adoption by the Council of European Minister in December of conclusions to combat neurodegenerative diseases.

These calls also seem to have been heard by the European Commission

and our chairperson and I attended a meeting of European experts on dementia at which the Commission gave an update on an initiative on Alzheimer's disease which will be launched later this year.

Our lunch debate in March was again well attended by Members of the European Parliament and was dedicated to discussing the aforementioned European initiatives.

These past two months have been particularly busy and we have made great progress on the development of our new website and the preparations of our third Dementia in Europe Magazine which will make for some interesting reading.

We have also worked hard to ensure that our forthcoming conference in Brussels will be highly relevant. The programme has now been finalised and I am confident that the many interesting presentations will make for a great experience for everyone who will attend.

Please remember to register!

Jean Georges
Executive Director

European Alzheimer's Alliance

5 February 2009: Nearly 60% of MEPs support the call for European Action Plan on Alzheimer's disease

As mentioned in our January newsletter, Written Declaration 80/2008 which calls for the development of a European Alzheimer's Plan was formally adopted by the European Parliament on 5 February.

Initiated by Françoise Grossetête (France), John Bowis (United Kingdom), Katalin Levai (Hungary), Jan Tadeusz Masiel (Poland) and Antonios Trakatellis (Greece), the Declaration was supported by close to 60% of all Members of the European Parliament.

Alzheimer Europe and its member organisations would of course like to thank all Members of the European Parliament who gave their support to this initiative and we enclose hereafter a list with all the signatories of the Written Declaration.

Austria

Berger Maria, Ettl Harald, Karas Othmar, Pirker Hubert, Prets Christa, Resetarits Karin, Rübiger Paul, Schierhuber Agnes, Swoboda Hannes

Belgium

Belet Ivo, Brepoels Frieda, Busquin Philippe, Claeys Philip, Corda Giovanna, Dehaene Jean-Luc, Deprez Gérard, De Vits Mia, El Khadraoui Saïd, Grosch Mathieu, Langendries Raymond, Neyts-Uytbroeck Annemie, Ries Frédérique, Staes Bart, Sterckx Dirk, Thyssen Marianne, Van Lancker Anne

Bulgaria

Baeva Mariela Velichkova, Binev Slavi, Hyusmenova Filiz Hakaeva, Jeleva Rumiana, Kazak Metin, Kirilov Evgeni, Lyubcheva Marusya Ivanova, Mladenov Nickolay, Panayotov Vladko Todorov, Papanizov 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, Flasarová Vera, Hybasjová Jana, Kohlíček Jaromír, Maštálka Jiří, Ransdorf Miloslav, Remek Vladimír, Roithova Zuzana, Rouček Libor, Škottová Nina, Stroz Daniel, Vlasák Oldřich, Zahradil Jan, Zatloukai Tomas, Zelezny Vladimír, Zvěřina Jaroslav

Denmark

Auken Margrete, Busk Niels, Camre Mogens, Christensen Ole, Jensen Anne E., Lebech Johannes, Rasmussen Poul Nyrup, Riis-Jørgensen Karin, Sondergaard Soren Bo, Thomsen Britta

Estonia

Mikka Marianne, Oviir Siiri

Finland

Itälä Ville, Lax Henrik, Myller Riitta, Paasilinna Reino, Pietikäinen Sirpa, Seppänen Esko, Takkula Hannu

France

Arif Kader, Audy Jean-Pierre, Beaupuy Jean Marie, Bennahmias Jean-Luc, Bono Guy, Cavada Jean-Marie, Cornillet Thierry, Daul Joseph, De Sarnez Marielle, Descamps Marie-Hélène, De Veyrac Christine, Douay Brigitte, Fontaine Nicole, Fouré Brigitte, Fourtou Janelly, Gaubert Patrick, Gauzès Jean-Paul, Gibault Claire, Gollnisch Bruno, Griesbeck Nathalie, Grossetête Françoise, Guellec Ambroise, Jouye de Grandmaison Madeleine, Lamassoure Alain, Lang Carl, Laperrouze Anne, Lefrançois Roselyne, Lehideux Bernard, Le Rachinel Fernand, Lienemann Marie Noëlle, Lipietz Alain, Louis Patrick, Martinez Jean-Claude, Mathieu Véronique, Morillon Philippe, Morin Elisabeth, Onesta Gérard, Saïfi Tokia, Savary Gilles, Schenardi Lydia, Sudre Margie, Teychenné Michel, Toubon Jacques, Trautmann Catherine, Vatanen Ari, Vergnaud Bernadette, Vlasto Dominique, Weber Henri, Wurtz Henri

Germany

Beer Angelika, Brie André, Bullmann Udo, Cramer Michael, Gröner Lissy, Hoppenstedt Karsten Friedrich, Horacek Milan, Kallenbach Gisela, Kaufmann Sylvia-Yvonne, Klass Christa, Lauk Kurt Joachim, Niebler Angelika, Özdemir Cem, Posdorf Horst, Posselt Bernd, Roth-Behrendt Dagmar, Rühle Heide, Schmidt Frithjof, Sommer Renate, Wagenknecht Sahra, Zimmer Gabriele

Greece

Angelakas Emmanouil, Arnaoutakis Stavros, Batzeli Katerina, Botopoulos Costas, Dimitrakopoulos Giorgos, Droutsas Konstantinos, Georgiou Georgios, Gklavakis Ioannis, Koppa Maria Eleni, Kratsa-Tsagaropoulou Rodi, Lambrinidis Stavros, Matsouka Maria, Mavrommatis Manolis, Pafilis Athanasios, Panayotopoulos-Cassiotou Marie, Papadimoulis Dimitrios, Papastamkos Georgios, Podimata Anni, Schinas Margaritis, Toussas Georgios, Trakatellis Antonios, Tzampazi Evangelia, Vakalis Nikolaos, Varvitsiotis Ioannis

Hungary

Becsey Zsolt Laszlo, Dobolyi Alexandra, Gal Kinga, Gurmai Zita, Hanargozó Gábor, Hegyi Gyula, Herczog Edit, Jaroka Livia, Kósáné Kovács Magda, Lévai Katalin, Mohacsi Viktoria, Olajos Peter, Óry Csaba, Schmitt Pal, Schöpflin György, Szájer József, Szent-Iványi Istvan, Tabajdi Csaba Sandor

Ireland

Aylward Liam, Burke Colm, Crowley Brian, de Rossa Proinsias, Doyle Avril, Harkin Marian, McGuinness Mairead, Mitchell Gay, Ó Neachtain Seán, Ryan Eoin, Sinnott Kathy

Italy

Agnoletto Vittorio, Albertini Gabriele, Antoniozzi Alfredo, Bartolozzi Paolo, Basile Domenico Antonio, Battilocchio Alessandro, Bonsignore Vito, Borghezio Mario, Boso Erminio Enzo, Braghetto Iles, Calia Maddalena, Cappato Marco, Carollo Giorgio, Chiesa Giulietto, Ciani Fabio, Cocilovo Luigi, Fatuzzo Carlo, Foglietta Alessandro, Frassoni Monica, Gardini Elisabetta, Gawronski Jas, Giuntini Monica, Kusstatscher Sepp, Losco Andrea, Lo Curto Eleonora, Marini Catuscia, Mauro Mario, Morgantini Luisa, Musacchio Roberto, Muscardini Cristiana, Napoletano Pasqualina, Patriciello Aldo, Pitella Gianni, Prodi Vittorio, Rivera Giovanni, Rizzo Marco, Robusti Giovanni, Romagnoli Luca, Susta Gianluca, Tatarella Salvatore, Toia Patrizia, Veneto Armando, Veraldi Donato Tommaso, Zani Mauro, Zappalà Stefano

Latvia

Andrejevs Georgs, Krasts Guntars, Kristovskis Ģirts Valdis, Pīks Rihards, Zdanoka Tatiana

Lithuania

Andrikiene Laima Liucija, Budreikaitė Danutė, Dičkutė Jolanta, Maldeikis Eugenijus, Paleckis Justas Vincas, Sakalas Aloyzas

Luxembourg

Goebbels Robert, Hennicot-Schoepges Erna, Lulling Astrid, Spautz Jean, Turmes Claude

Malta

Attard-Montalto John, Bedingfield Glen, Busutil Simon, Casa David

Netherlands

Belder Bastiaan, Blokland Johannes, Bozkurt Emine, Buitenweg Kathalijne Maria, Corbey Dorette, Cremers Jan, Doorn Bert, Hennis-Plasschaert Jeanine, Jacobs Lily, de Lange Esther, Liotard Kartika Tamara, Manders Toine, Martens Maria, van Nistelrooij Lambert, Oomen-Ruijten Ria, Wortmann-Kool Corien

Poland

Chmielewski Zdzislaw Kazimierz, Chruszcz Sylwester, Czarnecki Marek Aleksander, Czarnecki Ryszard, Foltyn-Kubicka Hanna, Geringer de Oedenberg Lidia Hoanna, Grabowski Dariusz Maciej, Golik Bogdan, Handzlik Małgorzata, Janowski Mieczysław Edmund, Kaczmarek Filip, Krupa Urszula, Kuc Wiesław Stefan, Kuzmiuk Zbigniew Krzysztof, Liberadki Boguslaw, Libicki Marcin, Masiel Jan Tadeusz, Olbrycht Jan

Pek Bogdan, Piniór Józef, Podkański Zdzisław Zbigniew, Protasiewicz Jacek, Rogalski Boguslaw, Rutowicz Leopold Józef, Saryusz-Wolski Jacek, Siekierski Czesław Adam, Staniszevska Grażyna, Szejna Andrzej Jan, Tomaszewska Ewa, Tomczak Witold, Wielowieyski Andrzej, Wojciechowski Bernard, Wojciechowski Janusz, Zapalowski Andrzej Tomasz, Zaleski Zbigniew, Zwiefka Tadeusz

Portugal

Capoulas Santos Luis Manuel, Casaca Paulo, Coelho Carlos, Esteves Maria da Assunção, Estrela Edite, Fernandes Emanuel Jardim, Ferreira Elisa, Figueiredo Ilda, França Armando, Freitas Duarte, Gomes Ana Maria, Guerreiro Pedro, Madeira JAMILA, Marques Sérgio, Pinheiro João de Deus, Portas Miguel, Queiró Luis, Ribeiro e Castro José, Santos Manuel António dos, Silva Peneda José Albino

Romania

Bodu Sebastian Valentin, Bulzesc Nicodim, Buşoi Cristian Silviu, Cretu Gabriela, Csibi Magor Imre, David Dragoş Florin, Dumitriu Constantin, Filip Petru, Manescu Ramona Nicole, Marinescu Marian-Jean, Matula Iosif, Oprea Dumitriu, Petre Maria, Sógör Csaba, Ticau Silvia-Adriana

Slovakia

Baco Peter, Bauer Edit, Belohorská Irena, Duka-Zólyomi Árpád, Gála Milan, Kozlik Segej, Šťastný Peter, Záborská Anna

Slovenia

Brejc Mihael, Drčar Murko Mojca, Jordan Cizelj Romana, Juri Aurelio, Kacin Jelko, Novak Ljudmila, Peterle Alojz

Spain

Ayuso Pilar, Barón Crespo Enrique, Cercas Alejandro, Díaz de Mera García Consuegra Agustín, Fraile Cantón Juan, Galeote Gerardo, Garcés Ramón Vicente Miguel, García-Margallo y Marfil José Manuel, Garriga Polledo Salvador, Grandes Pascual Luis de, Grau i Segú Martí, Guardans Cambó Ignasi, Gutiérrez-Cortines Cristina, Herranz García Esther, Herrero-Tejedor Luis, Iturza-Gangula Carlos José, López-Istúriz White Antonio, Luque Aguilar Florencio, Martínez Martínez Miguel Angel, Mendez de Vigo Iñigo, Menéndez del Valle Emilio, Miguélez Ramos Rosa, Moreno Sánchez Javier, Naranjo Escobar Juan Andrés, Ortuondo Larrea Josu, Pleguezuelos Aguilar Francisca, Pomés Ruiz José Javier, 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, Holm Jens, Schlyter Carl, Schmidt Olle, Segelström Inger, Svensson Eva-Britt, Wijkman Anders

United Kingdom

Ashworth Richard James, Atkins Robert, Attwooll Elspeth, Beazley Christopher, Bowis John, Bowles Sharon, Bushill-Matthews Philip, Callanan Martin, Chichester Giles, Corbett Richard, de Brún Bairbre, Deva Nirj, Dover Den, Duff Andrew, Elles James, Evans Jill, Evans Jonathan, Evans Robert, Ford Glyn, Hall Fiona, Harbour Malcolm, Honeyball Mary, Hudghton Ian, Hughes Stephen, Jackson Caroline, Kinnock Glenys, Kirkhope Timothy, Lambert Jean, Lucas Caroline, Ludford Sarah, Lynne Elizabeth, Martin David, McAvan Linda, McCarthy Arlene, Moraes Claude, Morgan Eluned, Newton Dunn Bill, Nicholson James, Purvis John, Simpson Brian, Stevenson Struan, Stihler Catherine, Sumberg David, Tannock Charles, Tittley Gary, Van Orden Geoffrey, Wallis Diana, Watson Graham, Wilmott Glenis

OVERVIEW

Country	Signatures	MEPs	Percentage
Austria	9	18	50.00%
Belgium	17	24	70.83%
Bulgaria	16	18	88.89%
Cyprus	6	6	100.00%
Czech Republic	16	24	66.67%
Denmark	10	14	71.43%
Estonia	2	6	33.33%
Finland	7	14	50.00%
France	49	78	62.82%
Germany	21	99	21.21%
Greece	24	24	100.00%
Hungary	18	24	75.00%
Ireland	11	13	84.62%
Italy	45	78	57.69%
Latvia	5	9	55.56%
Lithuania	6	13	46.15%
Luxembourg	5	6	83.33%
Malta	4	5	80.00%
Netherlands	16	27	59.26%
Poland	36	54	66.67%
Portugal	20	24	83.33%
Romania	15	35	42.86%
Slovakia	8	14	57.14%
Slovenia	7	7	100.00%
Spain	36	54	66.67%
Sweden	7	19	36.84%
United Kingdom	49	78	62.82%
Total	465	785	59.24%

Alzheimer Europe

2-3 March 2009: Alzheimer Europe Board reviews the progress of work for 2009 and plans for 2010

The Board of Alzheimer Europe met in Brussels, Belgium, to review the progress to date of the 2009 work plan as well as discuss future plans. After presenting the 2008 Draft annual report and finances, Jean Georges, Executive Director of Alzheimer Europe, presented the activities currently being worked on including:

- 2009 Alzheimer Europe Conference which will be held in Brussels in May
- Dissemination of the successful adoption of the Written Declaration 80/2008
- Plans to set up an informal Dementia Interest Group during the next European Parliament
- Preparation of issue 3 of the Dementia in Europe magazine
- Review of the status of the Dementia Ethics Network
- Collection and drafting of information for the Dementia research observatory
- Redesign of Alzheimer Europe's websites (Alzheimer Europe, Dementia in Europe and the Conference website)
- Active involvement of people with dementia, which includes the allocation of five free places for people with dementia to attend this year's Alzheimer Europe conference in Brussels
- Planning future conferences (2010 in Luxembourg and 2011 in Warsaw).

The Board also discussed the finances for 2009 together with the draft plan and budget for 2010.

3 March 2009: Françoise Grossetête hosts lunch debate on Alzheimer's disease

"Towards a European Action Plan on Alzheimer's Disease" was the focus of Alzheimer Europe's 6th lunch debate which was hosted by Françoise Grossetête (MEP, France) and presented by Florence Lustman, the Co-ordinator of the French Alzheimer Plan, together with Antoni Montserrat, the Policy Officer for rare diseases, neurological and neurodevelopmental disorders, Directorate of Public Health, European Commission.

Jean Georges, Executive Director of Alzheimer Europe, explained that both the host of lunch debate, Ms Grossetête, and presenters, Ms

Lustman and Mr Montserrat, had been hugely instrumental in helping to make dementia a European priority.

Ms Lustman took to the floor first and gave an overview of the comprehensive 3rd French Alzheimer's Plan highlighting that this 3rd Plan took a global perspective and also included research issues. In addition, Ms Lustman explained that there is a direct report line to the President of France, Nicolas Sarkozy, and that this personal commitment ensures that the Plan is taken seriously at the highest level of State.

Reflecting on the achievements in the field of Alzheimer's disease which had been made during the recent six-month French Presidency, Ms Lustman highlighted the conclusions regarding neurological degenerative disease which were made by the Competitiveness Council as well as the conclusions by the Health Council which decided to combat age-related diseases and called on Member States for national initiatives and the Commission for an initiative. However, she reminded the audience that we still do not know for certain the number of people with disease at a European level as many countries have poor systems of diagnosis and this, she stressed, has to be addressed.

Françoise Grossetête then spoke of her delight that the European Parliament's Written Declaration had been adopted and acknowledged the role that Alzheimer Europe and the national associations had made by asking MEPs directly to give their support and spoke of her pride in her Parliamentary colleagues', of which some 60% had signed the Written Declaration. The first step, said Ms Grossetête, has been made and it was now time to "roll up our sleeves" to continue the work carried out by the Council and Commission.

Speaking on behalf of the European Commission, Antoni Montserrat, explained that the Commission does not have a tradition for "disease specific" actions plans with the exception of cancer, communicable diseases and, just recently, rare diseases. He also said that the Commission does not have the means to adopt action plans for all different kinds of diseases. Nevertheless, the Commission is in a position to engage Member States in addressing a particular issue and monitor implementation of the recommendations. This is why the two recent Council's recommendations, which call for action in the field of Alzheimer's disease, together with the momentum built in the French Presidency, have stimulated the Commission to act and work on an Alzheimer's initiative and Mr

Montserrat proceeded to lay down the Commission's plans to do so.

A joint programming initiative on research is being developed, with the aim of avoiding the current waste and duplication of research by inviting national member states, on a voluntary basis, to pool ideas together. The Commission also hopes to build on information gained from EuroCoDe, which, he said, was an excellent project achieved by good collaboration with Alzheimer Europe. To contribute to track early diagnosis of dementia across Europe, the Commission plans to carry out "The European Health Exam Survey", which includes a cognitive decline module for which people are invited to go to a clinician and be examined. The Commission can also employ initiatives used by the Social Protection Committee in order to establish agreement and definition for standards of care. Therefore, various initiatives are open for consideration by the Commission

when addressing Alzheimer's disease. Whilst their approach is not extensive nor ambitious, it is possible to reuse existing initiatives in an imaginative way.

However, in order for the Commission to be effective for people with dementia and their carers, it is essential, said Mr Montserrat, that it works with a solid partner, such as Alzheimer Europe, as they need organised dialogue with access to EU patient organisations.

The interest from the audience was obvious with MEPs, journalists and Alzheimer associations asking for more information about how to move forward. Jean Georges thanked the host and presenters for their commitment and having so strongly supported making dementia a European priority. In particular he thanked again the Written Declaration's initiators and ended by wishing all MEPs the best of luck with their forthcoming elections.



Françoise Grossetête, MEP (France) welcomes the participants



Florence Lustman (right) with representatives of the French Health Ministry



Antoni Montserrat explains the plans for a European Alzheimer's initiative



Sirpa Pietikäinen, MEP (Finland) prepares for the meeting



Iva Holmerová in conversation with Milan Cabrnock, MEP (Czech Republic)



Alicja Sadowska and Jan Tadeusz Masiel, MEP (Poland) during the presentations



Participants are keen to engage the three key speakers



Elisabeth Morin, MEP (France) pays close attention



Jean Georges, AE Executive Director thanks Françoise Grossetête for her support to the organisation

Alzheimer Europe Networking

On 9 February (Brussels, Belgium), Annette attended the **EFPIA think tank** and had a **meeting with the assistant of Jan Tadeusz Masiel, MEP (Poland)**.

On 9 and 10 February (Warsaw, Poland), Jean met with the **Polish Alzheimer's Association** to discuss the organisation of the 21st Alzheimer Europe Conference in Warsaw in 2011.

On 12 February (Brussels, Belgium), Jean attended the meeting of the **Organising Committee of the 19th Alzheimer Europe Conference** in Brussels.

On 16 February (Brussels, Belgium), Annette attended an **EPPOSI dinner debate on animal research**.

On 17 February (Brussels, Belgium), Annette attended a **press conference of the ALDE group in the European Parliament on counterfeit medicines** and attended the exchange of the **EP Committee on Public Health with Commissioner Verheugen on the pharmaceutical package**.

On 18 February (Belfast, United Kingdom), Maurice attended the **Conference on Consent in Dementia** of the Dementia Services development Centre and gave a presentation on the use of advance directives by people with dementia.

From 19 to 21 February (Thessaloniki, Greece), Annette attended the **6th Panhellenic Conference on Alzheimer's disease** and participated in the opening ceremony of the conference as a representative of Alzheimer Europe.

On 20 February (Luxembourg, Luxembourg), Julie and Jean met with **Visual Online** to discuss the redevelopment of the Alzheimer Europe websites.

On 2 and 3 March (Brussels, Belgium), the **Alzheimer Europe Board met**.

On 3 March (Brussels, Belgium), Alzheimer Europe AE lunch **"Towards a European action plan on Alzheimer's disease"**.

On 4 March (Brussels, Belgium), Jean attended the meeting of the **Organising Committee of the 19th Alzheimer Europe Conference** in Brussels.

On 5 March (Luxembourg, Luxembourg), Julie and Jean met with **Binsfeld** to discuss the new concept for Alzheimer Europe Conference publications.

On 7 March (Brussels, Belgium), Annette Dumas had a meeting at the King Baudouin Foundation on **"Dealing with Alzheimer's disease and related diseases"**.

On 9 March (Luxembourg, Luxembourg), Julie and Jean met with **Visual Online** for the redevelopment of the Alzheimer Europe website and **Meetincs SA** for discussions on the organisation of the 20th Alzheimer Europe Conference in Luxembourg in 2010.

On 12 March (Brussels, Belgium), Annette attended the **EuropaBio Patient Advocacy Group meeting**.

On 13 March (Brussels, Belgium) Annette had **lunch with the assistant of Jan Tadeusz Masiel , MEP (Poland)**.

On 17 March (Luxembourg, Luxembourg), Maurice and Jean attended a **European Expert Panel on dementia** at which the European Commission unveiled its plans for a European Alzheimer's initiative.

On 18 March (Brussels, Belgium), Jean participated in a **workshop organised by Novartis** giving a presentation on the organisation's guidelines for working with pharmaceutical companies.

On 19 March (Brussels, Belgium), Jean attended the meeting of the **Organising Committee of the 19th Alzheimer Europe Conference** in Brussels.

On 20 March (Luxembourg, Luxembourg), Julie and Jean met with **Binsfeld** for the redesign of Alzheimer Europe conference publications and the third edition of the Dementia in Europe magazine.

On 23 March (Brussels, Belgium), Annette and Jean **met representatives from Baxter** (Anne-Toni Rodgers and Jan Maarten Ten Brundel).

On 25 March (Brussels, Belgium) Annette attended **the European Commission conference** on the outcomes of the Pharmaceutical Forum.

On 26 March (Brussels, Belgium), Annette attended the **European Patient's Forum general assembly meeting**.

On 30 March (London, United Kingdom), Jean attended a **Health Advisory Board of GlaxoSmithKline**.

European developments

21 January 2009: Commission provides update on proposal for initiative on Alzheimer's disease

During the EU Health Policy Forum meeting on 21 January, an update was given on the Commission's key policies, including a proposal for a Commission initiative on Alzheimer's disease. The proposal's main policy objectives are listed as:

1. to provide political leadership on the importance of Alzheimer's and related conditions as a vital issue for Europe as a whole, in the context of demographic ageing, and to propose clear shared values and principles for action;
2. to improve and share knowledge on Alzheimer's, through generating timely and accurate European data to enable benchmarking and through cooperation on generating new knowledge through scientific research;
3. to identify and share good practices in how to respond to the challenge of Alzheimer's and related conditions on which Member States can draw.

3 February 2009: EPP presents group's draft 10 priorities for 2009-2014

The EPP Political Bureau has approved the group's draft election manifesto that will be approved at the end of April during a Congress in Warsaw.

The election manifesto will place the European citizen at the heart of Europe. The economic crisis and Europe safety will be on the top of the agenda.

The manifesto 10 priorities evolve around 4 headings: Europe of values (strong values, transatlantic solidarity, sharing of European values with Europe's neighbours); Growth and Jobs (pragmatic response to the economic crisis, better coordination of financial policies and completion of the Single Market, reform and financing of the European budget); Safe Europe (terrorism, climate change, food safety, immigration policy); Solidarity between the Member States (cohesion policy, European social model).

In the meantime, the party members will be able to amend this manifesto until end of February. Civil society, citizens will be closely associated to the consultation.

17 February 2009: EP Environment Committee supports a derogation for MRI from the EMF Directive

The European Parliament Committee voted on a report drawn by Belgian MEP Frédérique Ries (ALDE) on health concerns associated with electromagnetic fields.

The amendment calling for the European Commission to introduce a derogation for MRI from the scope of the Electromagnetic Field Directive (Amendment 35) received cross-party support.

The plenary vote will take place on 26 March.

25 February 2009: European Commission launches consultation on health inequalities in Europe

The European Commission is consulting key stakeholders involved in European work in the area of social policy and employment policy before developing a Commission Communication aiming to support the reduction of health inequalities in the EU.

The deadline for submission is 1 April 2009.

26 February 2009: European Commission publishes its 2009 work plan in the field of health

The European Commission has adopted its annual work plan for 2009 for the implementation of the second programme of health (2008-2013).

The European Commission will organise an information day on the work plan on 18 March 2009.

26 February 2009: European Commission launches calls for new funding opportunities in health

In the wake of the publication of its Work Plan for 2009 for the implementation of second programme of Community action in the field of health, the European Commission has opened the calls for proposals.

The total budget available for the execution of the 2009 Work Plan is 48.2 million EUR.

All proposals should address important problems in the European public health and be in line with the Commission's priorities expressed in the Work Plan.

The successful proposals should concentrate on aspects of public health that cannot be achieved on a national level. They should ensure a significant impact across the EU.

The deadline for submission of proposals is 20 May 2009.

Note: the European Commission amended the text of the calls on 3 March 2009.

March 2009: Czech Presidency announces conference on Care and Protection of Senior Citizens, 25-26 May 2009, Prague



The Czech Presidency will organise a conference on Care and Protection of Senior Citizens, the Dignity and Hazard of Elderly, in Prague on 25-26 May 2009.

The conference has the patronage of Commissioner Spidla, Mirek Topolánek, CZ Premier Minister, Džamila Stehliková and Petr Necas, Ministers of Czech Government. The programme will include health aspects of long term care, elderly abuse and neglect.

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

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

The MEPs agree the proposal is about patients and their mobility within the EU, not about the free movement of service providers and that it fully respects the national competences in organising and delivering healthcare. It does not oblige health care providers in a Member State to provide health care to a person from another Member State. The new directive will not affect current patient rights, which are already codified under another EU regulation, or the regulations on the co-ordination of social security systems.

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

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

The MEPs also added a provision that Member States may offer their patients a system of voluntary prior notification. In return,

reimbursement would be made directly by the Member State to the hospital of treatment. The Commission is to examine whether a clearing house should be established to facilitate the reimbursement of costs.

The committee added special rules for patients with rare diseases and disabilities that might need special treatment. Patients affected by rare diseases should have the right to reimbursement even if the treatment in question is not provided for by the legislation of their Member State. Special costs for persons with disabilities must also be reimbursed under certain conditions.

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

Long term care and organ transplantation are excluded from the directive.

The vote in plenary will take place in May.

31 March 2009: Employment and Social Affairs Committee votes on the UN Convention on the Rights of People with Disabilities and the Optional Protocol

The European Parliament Committee on Employment and Social Affairs overwhelmingly adopted a Report by Rumiana Jeleva (EPP-ED, Bulgaria) on the United Nations Convention on the Rights of People with Disabilities and the Optional Protocol.

The European Commission now has to sign the protocol to the Convention on behalf of the EU before December 2009. This will be followed by ratifications and implementation by the Member States aimed at reinforcing the rights and basic freedoms and preserving the human dignity of people with disabilities. This is the first United Nations Convention that the EU has joined.

The Employment Committee agreed to ask the European Commission and the Member States to inform the European Parliament every three years about the application of the protocol and the cases that have been resolved.

The European Parliament will adopt a Motion for Resolution during the May plenary session

Policy Watch

3 February 2009: English Health Secretary launches National Dementia Strategy

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

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

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

4 February 2009: Experts call for more funding into dementia research in England

After the launch of the first-ever national English Dementia Strategy, calls have been made for more funding to be made available for research into dementia. Rebecca Wood, Chief Executive of the Alzheimer's Research Trust said "The government expects its strategy's dementia care services to save £1 billion over the next ten years. If the government was really committed to social justice and financial prudence, it would reinvest this money into dementia research. We have world-leading dementia experts in the UK, making exciting progress in their fight against this disease, but they are struggling for want of funds. If research results in a five year delay in the development of dementia, we could halve the number of people who die with the disease." This sentiment is shared by Greg Mulholland MP, Liberal Democrat shadow health minister who said "The long overdue strategy is a fundamentally missed opportunity. No increase in research funding means we will remain no closer to understanding dementia or addressing the devastating impact that it has."

19 February 2009: New UK Guideline on advance care planning includes the right to decide one's own treatment or care

A guideline containing recommendations on advance care planning (ACP) and aimed at assisting professionals involved in ACP (especially geriatricians, psychiatrists, general practitioners, general physicians and acute medicine specialists) has been issued in the UK. It contains recommendations including:

- The training for and implementation of ACP,
- When and with whom to consider having ACP discussions, the context and content of discussions,
- The preparation of ACP documents,
- Dealing with individuals with progressive and cognitive impairment.

This guideline was prepared by the British Geriatrics Society, Royal College of Physicians, Royal College of Nursing, Royal College of Psychiatrists, Royal College of General Practitioners, British Society of Rehabilitation Medicine, Alzheimer's Society, Help the Aged and the National Council for Palliative Care.

7 March 2009: Laurette Onkelinx presents Belgian initiatives in the field of dementia

On 7 March, the King Baudouin Foundation organised a conference when the conclusions drawn by a multidisciplinary group of 13 experts on how to improve the quality of life of persons with dementia, give them greater autonomy, reduce their dependence and strengthen social ties were presented.

State Minister Madga Alvoet, who presided the group's work, told the audience that the work had focused on the person (help the person to retain as many faculties as possible); painful episodes (announcement of the diagnosis, entry in a nursery home); quality of the end of life (palliative care); home care; ethics (better implementation of the existing rules).

M. Alvoet presented the recommendations and way forward drawn up by the group: a more nuanced image of the disease; a step-by-step and patient-tailored announcement of the diagnosis; the reinforcement of home-care; the official recognition of the family carer; a culture of palliative care and planned care; demand-tailored care; a greater respect for the autonomy of the person; increased local initiatives. The group recommends that the persons with dementia be involved in social life longer. A number of suggested actions can be

realised within the existing structures and involve civil society.



Health Minister Laurette Onkelinx presented Belgium's initiatives in the field of dementia. The recent chronic disease programme includes dementia. The underlying thread is to better accompany the person with dementia over the years as the disease progresses.

A budget dedicated to the training of healthcare professionals is being set aside. General practitioners will be trained to better and earlier detect the disease. Home care nurses will be included. The reimbursement of treatment and day care will be revised. Around 10 memory clinics will be open. The carers will be able to benefit from psychological help. Long term care will also be considered with training of the staff, reinforcement of the function of the 'dementia referent', opening of the long term structures to people below 65 years of age. Respite care, career break, carer's statute are other areas that will be considered to help the carer. Finally, research will have an important role. Belgium is one of the countries who have agreed to participate in the European Research Network initiated by the EU French Presidency. This network will reflect on how to optimise research into dementia and avoid duplication and waste of resources.

The leading thread of the meeting being the quality of life of people with dementia and their carers, along with the integration of the former in society, the different speakers who presented at the meeting illustrated the report recommendations by sharing their experiences and views on the different themes of the report. The first workshop discussed the legal status of the patient, the second presented areas for more humanised care while the third workshop presented different advance care planning projects. In this workshop, Ms Sabine Henry, Ligue Alzheimer, stressed the importance of advanced directives and referred to Alzheimer Europe's work in this field. A final session was devoted to the announcement of the diagnosis to the people with Alzheimer's disease: a Belgian study shows that only 40% of the specialists (neurologists and geriatricians) impart the diagnosis to their patients.

9 March 2009: President Obama lifts stem cell research funding restrictions



US President Barack Obama has lifted the ban imposed by Ex-President George W. Bush on the federal funding of stem cell research using new stem cell lines.

New research will have to meet strict ethical guidelines and human cloning will not be permitted, he has stated.

17 March 2009: Report highlights lack of dementia specialist care in care homes

"Dementia care services – UK Market Briefing 2009" publishes the findings from a survey of 6,000 care homes in the UK which provide care for people with dementia. The survey was carried out by Laing & Buisson, healthcare market analysts and it examined services provided for 142,000 residents of care homes for whom dementia was a known cause of admission yet found that just over half of the residents were receiving dementia specific care. Further, the survey reveals that a third of care homes claiming to offer "dedicated dementia provision had no specific dementia training for staff."

Neil Hunt, Chief Executive of the Alzheimer's Society said of the findings "it is a sad indictment of the current state of dementia care that a third of care homes specifically registered for dementia fail to provide their staff with any dementia care training. This is probably the tip of the iceberg, with many thousands more people with dementia in non-specialist homes."

20 March 2009: Pfizer CEO talks of his commitment to work on Alzheimer's disease

In an interview with Dow Jones Newswires in New York, Jeffrey Kindler, Pfizer Chief Executive, said he that the area of research he would be most proud of, if an important treatment advance were achieved, would be Alzheimer's disease. Mr Kindler said "It's an area where the science is, frankly, in a relatively early stage, which is both daunting and exciting. But it's one in which we've committed a significant amount of resources to try to find, if not a cure, at least a (better) treatment".

24 March 2009: New report reveals significant health costs for people with Alzheimer's disease and other dementias

Released by the US Alzheimer's Association, the "2009 Alzheimer's Disease Facts and Figures" report details the costs associated with Alzheimer's disease and prevalence, revealing that "total healthcare costs are more than three times higher for people with Alzheimer's and other dementias than for people aged 65 and over".

Members' News

3 February 2009: France Alzheimer participate in the first evaluation of the French Alzheimer Plan

Arlette Meyrieux, President of France Alzheimer, participated in the first evaluation of the French Alzheimer Plan which was launched in 2008.

When objective 1 (provide increased support to caregivers), measure 2 (strengthening of caregivers rights and education) was reviewed, Ms Meyrieux said that as the France Alzheimer association has been an officially recognised training organisation for over 20 years, it is ready to assume the responsibility for the training of family carers. Nicolas Sarkzoy, President of the Republic of France, responded by asking ministers to proceed with the implementation of measure 2 as quickly as possible.

Ms Meyrieux also voiced her concerns that care homes may reduce accessibility by limiting care to only those people with behavioural problems. Finally, she gave her support to the initiative aimed at creating regional bodies for the Plan, which she believes will facilitate the provision of information to all local actors.

10 February 2009: Polish organisation holds a press conference about the state of dementia care in Poland



The Polish Alzheimer association hosted a press conference to highlight the state of dementia care in Poland in comparison to other EU countries. Jean Georges, Executive Director of Alzheimer Europe, participated as well as key medical personnel. Welcoming the adoption of the European Parliament's Written Declaration 80/2008 on the priorities in the fight against Alzheimer's disease, Alicja Sadowska, the Chair of the Polish Alzheimer association, hoped it would result in dementia being given a higher priority throughout Poland.

13 February 2009: German Association welcomes the adoption of the European Parliament's Written Declaration on the priorities in the fight against Alzheimer's disease

Welcoming the European Parliament's decision to adopt the Written Declaration 80/2008 on the priorities against Alzheimer's disease, Heike Hohlbein Lützu, Chairperson of the German

Alzheimer Society, said "(this) is an important confirmation of our work." However, she went on to say that "we are somewhat disappointed that only 21 of the 99 deputies of the German Members of the European Parliament supported the European Alzheimer's initiative."

In addition, Ms Lützu said that despite there being many positive initiatives in Germany, she would like to see a coherent national dementia plan.

19-22 February 2009: Greek organisation hosts 6th Panhellenic Conference on Alzheimer's Disease

The 6th Panhellenic Conference on Alzheimer's Disease and Related Disorders took place from 19-22 February 2009 in Thessaloniki, Greece. About 1,000 health care professionals attended and the Conference hosted a number of sessions with each one covering a distinct thematic area which allowed both experts and interested attendees to focus on particular aspects related to the disease.

Annette Dumas attended on behalf of Alzheimer Europe.

24 February 2009: EasyJet selects the Alzheimer's Society as its charity partner

Following a vote of EasyJet's 7,000 staff across Europe, the company has announced that its charity partner for 2009 is the Alzheimer's Society. The Society will benefit from donations from in-flight collections over the summer and be granted a percentage of the proceeds from the scratch cards sold on flights.

27 February 2009: France Alzheimer launches call for proposals

France Alzheimer has launched a call for proposals on developing innovative technologies and design methods and tools for existing technologies. They plan to award more than EUR 1 million during 2009. The successful team will be funded for two years.

The call for proposals has two stages:

- a) submitting a form of intent by the teams
- b) invitation to selected teams to send a complete dossier

The selected team must include at least one young researcher in doctoral or post-doctoral research.

The forms of intent must be received by:

6 April 2009 for projects in medical science and

10 April 2009 for projects in human sciences and new technologies.

27 February 2009: German Alzheimer Society offers new internet service

A new link on the German Alzheimer Society website <http://www.deutsche-alzheimer.de/index.php?id=48&news=124> facilitates the search for support and respite services for the relatives of dementia sufferers. Users of the website can now search by type of service including:

- Advice centres
- Support groups
- Helper circles
- Clinics
- Short-term care
- Care services
- Residential care
- Day care
- Doctors

It is then possible to narrow the search by the region and users will be shown both a rating of services offered as well as details of the services themselves.

Heike Hohlbein-von-Lützu, Chairperson of the German Alzheimer Society, explained why they had developed this service “More and more people want to inform themselves, but also obtain personal advice. With the new internet service account this is what we hope to provide.”

March 2009: Alzheimer Scotland is given “Committed to Excellence” award

Alzheimer Scotland has been awarded a “Committed to Excellence” award from Quality Scotland for their work including their Staff and Volunteer Recognition Scheme, improvements made on their intranet with space allocated for the sharing of ideas and for “creating a culture of continuous improvement”. The award, which is valid for two years, is part of the European Foundation of Quality Management (EFQM) Levels of Excellence Scheme.

**Members
Forthcoming Events**

14 April 2009: Play about dementia to debut in London’s West End will donate profits to Alzheimer’s Society

The new play, “For Once I Was”, which opens in London’s West End in April, is about the

impact of early onset Alzheimer’s disease on a father and daughter’s relationship. Billed as an “uplifting play, both comic and moving at every turn, (which) charts the heart breakingly surreal reality of living with Alzheimer’s”, “For Once I Was” was initiated by Becca Stevenson whose father, John, was diagnosed with early onset Alzheimer’s disease nine years ago.

With all profits being donated to the Alzheimer’s Society, the play opens on 14 April 2009 at the Tristain Bates Theatre, Tower Street, London.

Science Watch

9 February 2009: Study examines driving safety in Alzheimer’s disease

A study published in Neurology which assessed 45 drivers with probable Alzheimer’s disease and 115 elderly drivers without neurologic disease found that drivers with Alzheimer’s disease “exhibit a range of performance on tests of cognition, vision, and motor skills”.



Participants were tested on their cognitive ability, visual perception, motor function and their driving skills. The researchers believe that these tests offer additional predictive value of driving performance and maybe therefore be of use to predict whether a person with Alzheimer’s disease can safely operate a vehicle.

11 February 2009: Study compares the characteristics of people with different types of dementia

A French study, led by F. Pasquier (University Hospital of Lille, France) found that the both initial and the follow-up characteristics presented by people with dementia varied depending on the type of dementia they had. This comparison of demographic features, cognitive decline and survival was made between vascular dementia, Alzheimer’s disease with cerebrovascular disease and Alzheimer’s disease.

11 February 2009: Phase II clinical trial announced of Alzheimer drug

The biopharmaceutical company, Octapharma AG, has announced the start of a phase II clinical trial of its drug octagam 10% in mild to moderate Alzheimer’s disease.

The prospective, double-blind, randomised, multicenter, placebo-controlled phase II trial will be with male and female subjects, aged 50-85 years old with mild to moderate Alzheimer’s disease to assess the safety, tolerability and efficacy of different doses of octagam 10%.

The study will be carried out in eight centres in Germany and the USA and led by Professor Richard Dodel, MD, Department of Neurology, Philipps University, Marburg, Germany. It will be sponsored by Octapharma AG.

12 February 2009: Study examines the relationship between secondhand smoke and cognitive impairment in non-smokers



Researchers, led by Iain A Lang, (Research Fellow, Public Health and Epidemiology Group, Peninsula Medical School, Exeter, UK), collected data on more than 4,800 nonsmokers. The participants' levels of cotinine (a product of nicotine which can be found in saliva for around 25 hours after exposure to smoke) were recorded and participants took neuropsychological tests. Researchers found that people who had the highest cotinine levels had an increased risk of cognitive impairment and they concluded that "Exposure to secondhand smoke may be associated with increased odds of cognitive impairment. Prospective nationally representative studies relating biomarkers of exposure to cognitive decline and risk of dementia are needed".

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12 February 2009: Study reviews research for brain training programmes in healthy older people

Researchers who carried out a review of brain training programmes found no evidence that they had any impact on brain ageing or the onset of conditions like dementia.

Dr Peter J. Snyder, (Professor of Clinical Neurosciences, Warren Alpert Medical School of Brown University, USA) who led the review, said, "The marketing for several of these commercial 'games' and devices make some unwarranted claims that prey on people's fears about getting older. Just as an example, one major manufacturer makes marketing claims that a 70-year-old person can use their device to take 15 or 20 years off their 'brain age'! This is frankly a bizarre claim to make."

Whilst acknowledging that there may be some benefit in remaining cognitively active, Dr Snyder explained that "the point of my paper is to show that there is no credible data to support the use of brain training over keeping socially active and remaining engaged with family and friends, learning new hobbies, doing Sudoku or

crossword puzzles, or reading good books on a regular basis."

18 February 2009: Study examines the effects of antihypertensive drug use and the risk of dementia

Published research carried out by the Departments of Epidemiology, Neurology and Internal Medicine, Erasmus Medical Center Rotterdam and the Inspectorate for Health Care, The Hague, The Netherlands, found a reduction in the risk of dementia for participants who had used antihypertensive drugs compared to those who had never used them.

24 February 2009: Study suggests that drug led to the improvement of memory in mice

Researchers from the Center for Applied Medical Research (CIMA) of the University of Navarra, believe they have found a way to increase learning capacity in mice. This was achieved by administering sodium phenylbutyrate, a drug which has been used previously to treat people with alterations in the urea cycle. The researchers found that the drug "eased the fusion of proteins responsible for neuron connections" in the mice and hope that further research will be conducted to investigate new perspectives for the treatment of Alzheimer's disease.

24 February 2009: Study examines the application of the current criteria for the diagnosis of behavioural variant frontotemporal dementia

Research led by Prof. John Hodges of the Prince of Wales Medical Research Institute, NSW, Australia, found that "the strict application of the criteria (for the diagnosis of behavioural variant frontotemporal dementia) misses a significant proportion of patients." Highlighting the need to also include varying levels of certainty (definite, probable, possible), the researchers encouraged a revision of the current criteria.

25 February 2009: Study examines link between working hours and cognitive function

A study led by Dr Marianna Virtanen of the Finnish Institute of Occupational Health examined the relationship between long working hours and cognitive function in middle age. The sample included over 2800 British civil servants, in full-time employment, whose data was collected and analysed (from 1997-1999 and from 2002-2004). The findings suggest that those who worked long hours had lower scores in the



vocabulary and reasoning tests which led the researchers to conclude that “long working hours may be one of the risk factors that have a negative effect on cognitive performance in middle age”.

28 February 2009: Study examines the link between the levels of vitamin B12 and cognitive performance

Research carried out by Professor David Smith (of the Oxford Project to Investigate Memory and Ageing), and colleagues from Oslo and Bergen Universities, suggests that low levels of vitamin B12 may result in poorer cognitive performance. Researchers found that the absorption by the body of vitamin B12 was found to be highest when the source of the vitamin came from milk. Calling for further research to be carried out in this area, the research concludes saying “pending the outcome of better trials, it is suggested that the elderly in particular should be encouraged to maintain a good, rather than just an adequate, vitamin B12 status by dietary means”.

9 March 2009: Claims about the benefits of oily fish questioned



A new study from the London School of Hygiene and Tropical Medicine (UK) casts doubt on the benefits of eating oily fish. Previous studies have suggested that people who regularly eat oily fish such as mackerel or salmon have higher scores on tests of cognitive function. However, Dr Alan Dangour, lead researcher of this latest study, explains that this association disappears when adjustments are made for education and mood. Further study is needed to clarify this issue.

9 March 2009: Blood biomarker found for frontotemporal dementia

Belgian researchers have discovered that the growth factor progranulin may be a biomarker for frontotemporal dementia (FTD). Many people with frontotemporal dementia (FTD) have a defect on chromosome 17 which results in the production of less progranulin. Reduced levels of progranulin in the blood lead to the destruction of brain cells in the frontal lobe. The researchers believe that this simple blood test can be used in the diagnosis and early detection of FTD.

9 March 2009: Diabetes and high cholesterol may be linked to faster cognitive decline

The results of a longitudinal study involving 156 people with diagnosed Alzheimer’s disease

suggest that a history of diabetes and high cholesterol levels may lead to a faster rate of cognitive decline. Another finding was that heart disease and stroke also affected cognitive decline but only in people who had the APOE ϵ 4 gene. Commenting on the results, Dr Stern from the Columbia University Medical Center (USA) stated, “Preventing heart disease, stroke and diabetes – or making sure these conditions are well managed in patients diagnosed with them – can potentially slow the disease progression of Alzheimer’s.” He and his colleagues are now continuing their work using epidemiologic and imaging approaches. Results of this study are published in a special edition of the March edition of the Archives of Neurology.

11 March 2009: Direct relationship found between antibodies and severity of Alzheimer’s disease

Researchers in the USA have discovered that the concentration of two antibodies, which react in response to amyloid-beta protein and another protein called RAGE, increases in line with increases in the severity of Alzheimer’s disease. It is hoped that this may eventually lead to a blood test but this could take several years to develop.

16 March 2009: Study examines links between loss of brain cells in hippocampus and dementia

Brain shrinkage in a certain part of the brain may increase the likelihood of developing dementia. Using MRI scans, researchers from the VU University Medical Centre of Amsterdam (NL) found that people who did not have dementia at the start of the study but who had smaller hippocampal volumes and higher rates of shrinkage were two to four times more likely to develop dementia. The loss of cells was more widespread in the brains of people who already had Alzheimer’s disease.

16 March 2009: Study examines use of cerebrospinal as biomarker for future Alzheimer’s disease

Building on previous work which suggested that pathological cerebrospinal fluid (CSF) might serve as a biomarker for Alzheimer’s disease, researchers at the University of Pennsylvania School of Medicine (USA) have found that it may also predict whether someone with mild cognitive impairment will develop Alzheimer’s disease. They also found that people with 2 copies of the APOE ϵ 4 had the lowest concentrations of amyloid beta42 which is a sign of increased plaque deposition. Work is currently underway to validate these findings

17 March 2009: Researchers suggest possible need to develop combination therapy

Numerous researchers have pointed to the probable role of amyloid plaques and tau tangles in the development of Alzheimer's disease. Researchers from the University of Illinois (USA) have suggested that tau tangles and amyloid beta work together to cause the damage to neural function and memory. On the basis of an investigation into the role of CK2, a transport-regulatory enzyme, they conclude that it may be necessary to think in terms of combination therapy that would allow many targets to be tackled at one.

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19 March 2009: Possible link between epilepsy and Alzheimer's disease identified

About a third of people with Alzheimer's disease suffer from some degree of epilepsy. Researchers at the University of Aberdeen (UK) have identified the actual process that links the two conditions. Professor Tibor Harkany explains that beta-amyloid protein leads to oversensitive nerve cells which fire too many electrical signals and lose the ability to communicate effectively with each other. This may open up new lines of research into drugs which treat both conditions at the same time.

23 March 2009: Lower risk of MCI progressing to dementia than previously thought

Results of a 5-year study published in the Acta Psychiatrica Scandinavica based on an analysis of data from 41 studies has revealed that the risk of mild cognitive impairment (MCI) progressing to dementia is lower than previously thought. Previous estimates were for a risk of up to 15% per year whereas the new study estimates risk at 10% for high risk groups and 5% for low risk groups.

Dr Alex Mitchell and Dr Shiri-Feshki, lead researchers of the study, point out that only 20-40% of people with MCI went on to develop dementia even after extended follow-up, with many people remaining stable over a lengthy period and some improving.

Dementia in Society**5 February 2009: Terry Pratchett makes documentary about a year in his life with Alzheimer's disease**

"Living with Alzheimer's" is a two-part BBC programme which documents the life of the famous author, Terry Pratchett, through his first year with a posterior cortical atrophy, an early onset type of Alzheimer's disease. The first part includes Terry's reaction to knowing he has posterior cortical atrophy and his willingness to try different treatments. The second part sees Terry travelling to the USA and finding out about a controversial new treatment.

18 February 2009: New dementia support group is set up in Gibraltar

The Gibraltar Alzheimer and Dementia Support Group were officially recognised as a charity on 18 February. Set up in November 2008, the group launched an awareness campaign which raised enormous public interest and the Group discovered that around 10% of the population in Gibraltar is affected in some way by the disease. To help families, the Group are organising their first family meeting on 17th March. They are keen to develop information packs for carers, as at present there is very little information available, and also hope to one day open a day-care centre. On 13 February members of the committee will receive training from the Day Centre in Algeciras. Anyone wishing to contact them should write to the chairperson, Maricela Jaen-Hook.


18 February 2009: UK broadcaster talks of the need to support the carers of people with Alzheimer's disease

In a bid to raise awareness of the help available for people with Alzheimer's disease and their carers, John Suchet, a British broadcaster who presented the ITN news for nearly 30 years, spoke openly about his wife, Bonnie, who was diagnosed three years ago. He explained that whilst he had been determined to be supportive and understanding after his wife's diagnosis that "every now and then you just explode... I remember the first time I did it. I just went ballistic. It was a culmination of little things – dinner plates going straight back onto the shelf instead of going into the dishwasher or being wiped dry whilst

they were still dirty. It just built up and up and I exploded. I felt so guilty afterwards.”

Mr Suchet has help from another carer whose wife has Alzheimer’s disease and an Admiral Nurse who is a specialist nurse working with people with dementia and their carers, but there are only 60 such nurses in the country. He said “It is so important for people to get help, as the very nature of dementia means that the full burden falls on the shoulders of the carers. I am so fortunate, I have derived so much benefit from these people, I want others to be aware what help there is.”

18 March 2009: Jim Broadbent, Oscar-winning actor, calls for government to “seize the moment” to address dementia


Speaking at the Alzheimer’s Research Trust annual conference, actor,  Jim Broadbent, spoke about his own experience with dementia, having lost his mother to the disease. He went on to say that ministers “have an opportunity to think about how they fund research into dementia, which has long been marginalised... The leaps forward taken with cancer should be the inspiration. Once we conquered the stigma attached to cancer, we took arms: the Government and public put force and funds behind our scientists, and now we have a much fairer fight on our hands.”

“This must happen now for dementia. The stigma is lifting, but we need more people out there discovering, understanding and, ultimately, creating the treatments that people need. The government must seize the moment and help to give hope that one day we will live in a world free of the curse of dementia.”

In 2002, Mr Broadbent played the husband of Iris Murdoch (who suffered from dementia) in the film *Iris*, for which he won an Oscar.

19 March 2009: Recognition from the Prince of Wales of the “burden we will all face if (dementia) is left unchecked will be catastrophic”

At the Alzheimer’s Research Trust’s 10th annual conference, a statement from His Royal Highness the Prince of Wales was read out in which he congratulated the Trust for their work “to lift the shroud of mystery that has long surrounded dementia” and recognised the “emotional, social and economic burden we will all face if (dementia) is left unchecked will be catastrophic”. His statement read:




“I am delighted to be able to welcome you to the Alzheimer’s Research Trust’s Annual Conference as I am more than conscious of the enormous effect that dementia has on people’s lives and the lives of those who care for them.

Sadly, dementia will have an even greater impact as, in the future, the risk of dementia increases as people live longer, and the emotional, social and economic burden we all will face if this threat is left unchecked will be catastrophic.

I know that 700,000 people in the United Kingdom live in hope for an effective treatment for their dementia – and surrounding them are those who face the devastation of watching their family and friends slip away before their eyes. This is why the continued work of the Alzheimer’s Research Trust and the scientists the charity funds are so very important – and why it gives me such pleasure to send you all of my very best wishes for your endeavours at your conference.”

23 March 2009: Kevin Whately, British actor, raises awareness of the state of dementia care in the UK

Known to many for his role as television detective Robbie Lewis over the last 20 years, actor Kevin Whately instead investigated dementia in a documentary for ITV1 *Tonight*. Sharing the story of his mother’s struggle with Alzheimer’s disease for the last eight years, Mr Whately, an Ambassador for the Alzheimer’s Society, also looked at the diagnosis, nursing home care and treatment of dementia, finding that vast differences exist.



Explaining why he decided to participate in the programme Mr Whately said “I agreed ... after witnessing my mother’s heartbreaking decline from Alzheimer’s disease – a devastating condition. As a family we have had to fight to get the best possible care for our mother to ensure she has support from properly trained care staff...I felt that the programme will go some way to bring dementia out of the shadows.”

New resources and publications

5 January 2009: Genetics website updated

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

February 2009: French guidelines published on good practice for people with Alzheimer's disease

The French national agency of evaluation and quality of social and socio-medical establishments and services ("anesm") has published guidelines of good practice for people with Alzheimer's disease or related disorders, for all ages and all degrees of severity of the disease. It gives recommendations on residential, day and night care.

February 2009: Researchers database available on line

Researchers may be interested to know that the US-based National Alzheimer's coordinating Center's website, www.alz.washington.edu, contains data containing standardized Uniform Data collected longitudinally from the 30 Alzheimer's disease centers in the US. This part of the database consists of around 15,000 subjects and in addition there is an autopsy series which include approximately 9000 subjects. The data is available to all without charge.

12 February 2009: The Alzheimer's association issues the "Principles for a Dignified Diagnosis"

"Principles for a Dignified Diagnosis", which has been produced by the Alzheimer's association after consultation with people with Alzheimer's disease, contains guidelines aimed at assisting clinicians on how to give a diagnosis of Alzheimer's disease.

25 March 2009: US Alzheimer's Study Group publishes National Alzheimer's Strategic Plan

"A National Alzheimer's Strategic Plan" was presented by the Alzheimer's Study Group, which was established in 2007 and charged with creating a National Alzheimer's Strategic Plan in order to address the growing challenges created by Alzheimer's disease. The Group was co chaired by Newt Gingrich, Founder, Center for Health Transformation and Bob Kerrey, President, The New School.

In the conclusions, it is recommended that a "Alzheimer's Solutions Project" is established. This will be achieved through three core initiatives, which the Plan lists as:

"(1) The Alzheimer's Prevention Initiative. As a national priority, urgently focus on developing the capability to delay and, ultimately, prevent, Alzheimer's disease. This capability will depend on the advancement of development science as well as basic research.

(2) The Alzheimer's Care Improvement Initiative. By 2012, the value-based payments to reimburse providers for at least 20 percent of health and social services for people with dementia, and for half of these services by 2016. Value-based payments will reward health care and social services professionals for providing the coordinated care dementia patients most need for better health and a higher quality of life.

(3) The Alzheimer's Public-Private Partnership. By 2010, establish an outcomes-orientated, project focused Alzheimer's Solutions Project Office within the Federal Government. Backed by an appropriate scale of funding and through active collaboration with other stakeholders outside the Federal Government, this office will lead the successful implementation of the Alzheimer's Prevention and the Alzheimer's care Improvement initiatives, together with supporting efforts."

The report concludes that "through the implementation and successful execution of these initiatives, American will travel a path to a much better world – a world without Alzheimer's".

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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
1 April	Binsfeld (Luxembourg, Luxembourg)	Julie Fraser and Jean Georges
3 April	Dementia Ethics Network (Luxembourg, Luxembourg)	Jean Georges
16 April	Meeting with Petra Wilcon from Cisco (Luxembourg, Luxembourg)	Jean Georges
20-21 April	Recognition programme (Barcelona, Spain)	Jean Georges
24 April	Meeting with Lukas Pfister of MSD (Brussels, Belgium)	Jean Georges
28 April	Preparatory Meeting of Swedish Presidency Conference on Healthy and Dignified Ageing (Stockholm, Sweden)	Jean Georges
30 April	Organising Committee of 19 th Alzheimer Europe Conference (Brussels, Belgium)	Jean Georges

Future Conferences 2009

Date	Meeting	Place
17-19 May 2009	5 th International Conference on Alzheimer's Disease and related Disorders in the Middle East www.medneuro.com	Limassol, Cyprus
26 May 2009	9e Colloque de la Société des Neurosciences www.neurosciences.asso.fr	Bordeaux, France
28-29 May 2009	Managing, Challenging Behaviours in older people with cognitive impairment	Melbourne, Australia
28-30 May 2009	The 19 th Alzheimer Europe Conference www.alzheimer2009.eu	Brussels, Belgium
8-10 June 2009	World Summit & Symposium on Elder Mediation www.alzheimer.ie	Dublin, United Kingdom
11 June 2009	The 5 th Kuopio Alzheimer Symposium www.uku.fi/alz2009	Kuopio, Finland
5 July 2009	19 th World Congress of Gerontology www.gerontologyparis2009.com/site/view8.php	Paris, France
27 August 2009	1 st international Congress on Clinical Neuro-Epidemiology www.neuro2009.com	Munich, Germany
15-16 September 2009	Dementia Services Development Centre's 3 rd International Conference: Facing the future www.dementia.stir.ac.uk	York, United Kingdom
24 October 2009	19 th World Congress of Neurology www.wcn2009bangkok.com/index.cfm	Bangkok, Thailand
19-22 November 2009	The 6 th International Congress on vascular dementia www.kenes.com/vascular	Barcelona, Spain
2-5 September 2010	Dignity for the Frail Old: From dilemmas to solutions www.dignity.no	Bergen, Norway

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Do not miss:



The Alzheimer Europe Conference will take place in Brussels from 28 to 30 May 2009.

The conference has been set under a clear European theme and the motto "Stars for Help", a reminder of the European flag, should highlight the significant advances that the European Union has made in recognising Alzheimer's disease and other forms of dementia as a public health priority. We are therefore delighted to have representatives of the European Commission taking part in the conference to present in more detail how they intend to address dementia in a new Alzheimer's initiative to be launched this year.

The conference will also be the opportunity for Alzheimer Europe to launch the results of its three-year project "European Collaboration on Dementia" which was financially supported by the European Commission and which provided us with new insights into the prevalence, the diagnosis and treatment, the psycho-social interventions, the cost and the prevention of dementia, as well as the varying degrees of social support provided by governments to people with dementia and their carers. Without the support of the stars of Europe, these new insights would not have been possible and what better place to present these results than in a true European capital in the heart of Europe.

But the stars of our conference motto are not just a reminder of the European flag.

Celebrities giving their support to our cause are of course also "stars" and we are delighted to have the presence of Giulia Salvatori, the daughter of well-known actress Annie Girardot and Philippe Vanclès a popular Belgian singer who show that stars can indeed be asked to help our cause.

But we would equally like to acknowledge the contributions of everyone and we dedicate this conference to the many people with dementia, their carers, professional carers, health care professionals and politicians and all who contributed in these past years to a profound shift of our view of dementia. It is thanks to their individual and collective involvement that governments on a national level and the European Union have started to develop concrete action plans to improve the current situation of people with dementia and their carers.

The conference sessions will focus more specifically on the quality of life of people with dementia and their carers, on ethical and legal issues, as well as on new and innovative policy initiatives in our field. With close to 100 speakers from 21 different European countries participating as speakers, the conference promises to be a truly European event. We hope that the conference will provide a number of opportunities for all of us to learn from one another and to share experiences, new ideas and solutions on how best to approach dementia in the future.