



# NEWSLETTER

March 2011

## Highlights in this issue

<b>9 March:</b> Report on care and treatment of people with dementia in hospitals published	8
<b>3-4 March:</b> PharmaCog project progress presented at Paris Meeting	6
<b>14 March:</b> Alzheimer Europe hosts public affairs meeting	2
<b>15 March:</b> Marina Yannakoudadis, MEP, hosts European Parliament lunch debate on long term care	3



## Table of contents

Editorial.....	1
European Alzheimer's Alliance.....	2
Alzheimer Europe.....	2
Alzheimer Europe Networking.....	4
Call for abstracts.....	5
PharmaCog.....	5
European developments.....	7
Other European organisations.....	8
Policy watch.....	8
Members' News.....	10
Science Watch.....	12
Dementia in society.....	14
New resources and publications.....	15
AE Calendar 2011.....	16
Future Conferences.....	16

## Editorial

In March, Alzheimer Europe hosted a meeting of public affairs representatives of its members during which the developments at European and national level were discussed. This proved to be a highly fruitful and interesting event and allowed members and Alzheimer Europe to get a better understanding of the commonalities and differences in national approaches to dementia.



The 9<sup>th</sup> Alzheimer Europe European Parliament lunch debate took place in March. It was hosted by the MEP Marina Yannakoudadis (UK) and dedicated to European activities on long-term care. Two European Commission representatives, Arnaud Senn and Wojciech Dziworski, gave informative presentations on the recently launched Innovation Partnership on Healthy and Active Ageing. I was delighted that participants actively engaged with the presenters enabling many issues on long-term care to be discussed.

As austerity measures are implemented in many countries, the concern that funding for research and services for people with dementia will be reduced, even withdrawn, is ever-present. In this issue we report on the call made in the US by some 400 Alzheimer's researchers and service providers who have combined forces and written to the US Senate to safeguard federal funding.

Two reports have been issued in the UK this month which highlight particular challenges which people with dementia face. The first report makes several important recom-

mendations on how to improve the care and treatment of people with dementia in hospitals.

The second report highlighted several shortcomings of dementia care in London including the lack of diagnosis of people with dementia. Alzheimer Europe has long been advocating the importance of a timely diagnosis and the need to inform people with dementia about their diagnosis. It was therefore truly exciting to get the first results from our survey of the general public in France, Germany, Poland, Spain and the US on views about the value of a diagnosis of Alzheimer's disease. These results will now be further discussed and presented during the ICAD Conference in Paris in July 2011.

In March, I also attended two meetings of the PharmaCog consortium. It was interesting to see both the progress achieved by the involved scientists, but also the willingness of different pharmaceutical companies to collaborate on how best to speed up the drug discovery process for treatments for Alzheimer's disease.

Members have been sending us their news throughout March and we report on awareness raising initiatives using Facebook (Portugal), a dementia friendly charter (Belgium) and new collaborations to raise money (UK).

Lastly, this month I ask for your help in ensuring the newsletter continues to be useful and informative for you. Please could you complete the form attached to your e mailed newsletter and return it to us. Many thanks.

**Jean Georges**  
Executive Director

## European Alzheimer's Alliance

Currently, the total number of MEPs in the Alliance stands at 50, representing 17 Member States of the European Union and all of the seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their continued support of the European Alzheimer's Alliance.

**Belgium:** Brepoels Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Sterckx Dirk (ALDE), **Bulgaria:** Parvanova Antonia (ALDE), Cyprus: Triantaphyllides Kyriacos (GUE-NGL), **Czech Republic:** Cabrnock Milan (ECR), Kohlíček Jaromír (GUE/NGL), Roithova Zuzana (EPP), **Denmark:** Schaldemose Christel (S&D), **Finland:** Jaakonsaari Liisa (S&D), Jääteenniemi Anneli (ALDE), Pietikäinen Sirpa (EPP), **France:** Audy Jean-Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Grossetête Françoise (EPP), Morin-Chartier Elisabeth (EPP), **Germany:** Niebler Angelika (EPP), Roth-Behrendt Dagmar (S&D), Ulmer Thomas (EPP), Weisgerber Anja (EPP), **Greece:** Chountis Nikolaos (GUE-NGL), Koppa Maria Eleni (S&D), Kratsa-Tsagaropoulou Rodi (EPP), **Ireland:** Aylward Liam (ALDE), Childers Nessa (S&D); Crowley Brian (ALDE), McGuinness Mairead (EPP), Mitchell Gay (EPP), **Italy:** Panzeri Pier Antonio (S&D), Toia Patrizia (S&D), **Luxembourg:** Lulling Astrid (EPP), **Netherlands:** De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP), **Portugal:** Coelho Carlos (EPP), Matias Marisa (GUE/NGL), **Romania:** Antonescu Elena Oana (EPP), **Slovakia:** Mikolasik Miroslav (EPP), Zaborska Anna (EPP), **United Kingdom:** Hall Fiona (ALDE), Lynne Liz (ALDE), McAvan Linda (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Taylor Keith (Greens/EFA), Watson Graham (ALDE), Willmott Glenis (S&D), Yannakoudakis Marina (ECR).

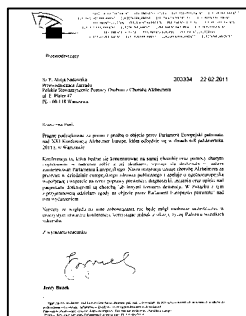
## Alzheimer Europe

In this section, we report on our current news, including our projects and events.

### 22 February 2011: AE Conference in Warsaw receives patronage of European Parliament

Alzheimer Europe was informed that its 21<sup>st</sup> Conference in Warsaw would receive the patronage of the European Parliament.

In a letter dated 22 February 2011, European Parliament President Jerzy Buzek wrote:



Dear Ms Sadowska,

I would like to thank you for your letter with request to provide patronage of the European Parliament over the 21<sup>st</sup> Alzheimer Europe Conference to be held in Warsaw from 6 to 8 October 2011.

The Conference which will focus on the

Alzheimer's disease and support for patients and their caregivers in coping with its consequences, fits very well into the scope of activities and interests of the European Parliament.

The Parliament recognizes Alzheimer's disease as a priority within the subject European public health and appeals for a paneuropean cooperation and support for the improvement of prevention, diagnosis, treatment and care for patients with Alzheimer's disease and other forms of dementia. Thus, it is with great pleasure that I agree to offer the European Parliament's patronage over this event.

Unfortunately, because of other obligations, I would not be able to participate personally in the opening ceremony of the Conference, however, I use this opportunity to wish you every success.

Faithfully yours,

Jerzy Buzek

### 13-14 March 2011: The Alzheimer Europe Board meets in Brussels

The Alzheimer Europe Board met in Brussels, Belgium on 13/14 March 2011. The Board Members:

- Discussed various meetings attended by representatives of Alzheimer Europe since December 2010
- Approved the 2010 Annual Report which will be presented at the AGM in October.
- Considered the 2010 financial accounts
- Discussed the progress of the 2011 Workplan. This included the preparations for the forthcoming 21<sup>st</sup> Alzheimer Europe Conference to be held in Warsaw, Poland; current projects (Value of Diagnosis and Lawnet); the Dementia in Europe magazine, which will be published three times during 2011 EU and public affairs work, in particular the summary paper on the Public Consultation for the pilot European Innovation Partnership on Active and Healthy ageing which was prepared by Annette Dumas
- Examined the status of the 2011 finances by being updated on the 2011 forecasts, project accounts, risk assessment and the cash flow situation
- Began planning the 2012 conference and discussed the conference guidelines and
- Considered how to amend the organisation's statutes to ensure people with dementia are represented on the Alzheimer Europe Board and also to form a working group of people with dementia.

The next Board meeting is scheduled for 26 June 2011.

### 14-15 March 2011: Alzheimer Europe hosts public affairs meeting for members

Members and staff of Alzheimer Europe participated in a Public Affairs meeting on 14 and 15 March 2011 in Brussels, Belgium. Representatives from ten national Alzheimer associations (Austria, Bulgaria, Denmark, France, Germany, Ireland, Italy, Malta, Poland and Portugal) attended. The first half of the meeting was dedicated to European policy developments including:

- The European policy context for dementia. This was presented by Alzheimer Europe's Public Affairs Officer, Annette Dumas who discussed the European Alzheimer's Initiative, the Joint Programming of Neurodegenerative Diseases, the European Joint Action, the Active and Healthy Ageing Innovation Partnership and the European year of Active Ageing. In addition, Annette also talked about cross border healthcare, the Pharmaceutical package, the Citizens' Initiative, the Alliance for MRI and the Clinical Trials directive.
- The development of a public affairs strategy within Alzheimer Europe. The team of Alzheimer Europe discussed various ways in which a strategy can be developed. Annette highlighted the work of the European Alzheimer's Alliance and the lunch debates held in the European Parliament. Julie Fraser (Communication Officer) illustrated various ways in which news can be reported in the newsletter and also in the Dementia in Europe magazine. Dianne Gove (Information Officer) presented the latest Dementia in Europe Yearbook (2010) and Jean Georges (Executive Director) discussed possible ways in which the 2006 Paris Declaration (which contains Alzheimer Europe's political priorities) can be updated.

In the second half of the meeting the floor was given to the national Alzheimer member organisations, representatives of which presented the current situation within their country regarding campaigns, national strategies and policy developments. Lively discussions ensued and the meeting ended by all participants discussing the development of a model dementia strategy (in line with Alzheimer Europe's 2011 workplan).

### 15 March 2011: Alzheimer Europe organises European Parliament lunch debate on long-term care

Marina Yannakoudadis, MEP (UK) and Member of the European Alzheimer Alliance hosted Alzheimer Europe's 9th lunch debate with the European Parliament which was dedicated to European activities on long-term care. Presentations were made by Arnaud Senn, Policy Officer, Social Protection, Social Services, European Commission, DG Employment, Social Affairs and Equal Opportunities and Wojciech Dziworski, Senior Economist and Political Analyst, Innovation and Health, Ageing, European Commission, DG Health and Consumers.

Mr Senn gave an overview of the common objectives between healthcare and long term care since 2006, the recognition of long term care on the EU health agenda and the main policy challenges to be addressed. He said that all issues surrounding long-term care are considered at EU level within the context of the Open Method of Co-ordination and that most recently, the European Commission had launched the Active and Healthy Ageing Innovation Partnership (AHAIP). The aim of the Partnership is to add two healthy life years to the average life expectancy by 2020. DG Social Affairs is currently working on a Staff Working Paper on long-term care which will map the needs across the EU and identify

the challenges faced in different Member States. The aim of the Partnership is to add two healthy life years to the average life expectancy by 2020. The Paper should be issued at the end of this year.

Mr Dziworski discussed how Alzheimer's disease fits into the AHAIP and explained that one of the challenges the Partnership attempts to address is that of the current unsustainable health systems within Europe. He cited the fact that aged-related spending is projected to increase by 4.75% points of GDP by the year 2060, whilst at the same time the workforce of the care sector is shrinking with a lack of health specialists being available. He said that if the aim of adding two healthy life years is achieved, that it will result in a triple win situation whereby there is not only an increase in healthy life years and quality of life, but also an increase in EU competitiveness and, at the same time, a decrease of health costs.

Issues surrounding Alzheimer's disease can be addressed within the Partnership and Mr Dziworski highlighted the actions areas are innovation in (a) support of people's health and well being (eg. prevention, early diagnosis, treatment etc), (b) support of collaborative and integrated health care systems and services for older people (eg. continuum of care, home and long-term care, training of workforce etc) and (c) products and services for active and healthy ageing (eg. reduction of unnecessary use of hospital services). If these can be addressed, he believes that the overall aim of adding two healthy life years can be achieved.

Mr Dziworski ended his presentation by explaining that at this stage a mapping exercise is required so that everyone can be made aware of the projects on healthy ageing which already exist. He cited some existing projects (eg. in Denmark, the Netherlands and UK) on healthy ageing which could be discussed, adapted and used by different Member States.

Lively discussions ensued about long-term care, including topics such as:

- the inclusion of end-users in the planning process (Sirpa Pietikäinen, MEP, Finland),
- how the Commission will work to ensure best practices are shared throughout Member States (Frieda Brepols, MEP, Belgium),
- the importance of including end-users throughout the whole process (Nis-Pieter Nissen, Alzheimer Denmark and Heike von Lützu-Hohlbein from the German Alzheimer Association and Chairperson of Alzheimer Europe),
- the sharing of ideas regarding long-term care from national Alzheimer associations (Annette Dumas, Public Affairs Officer, Alzheimer Europe)
- consideration of ways in which higher value can be found for people who work in the area of long-term care (Jean Georges, Executive Director, Alzheimer Europe)
- the inclusion of the European Parliament's own initiative report (Marina Yannakoudakis, MEP, United Kingdom) and

- de-stigmatisation (Heike von Lützu-Hohlbein).

Heike von Lützu-Hohlbein closed the debate by thanking all for participants for their interest and participation and affirming the important role which end-users have when acting as advocates on behalf of others.



Heike von Lützu-Hohlbein and Marina Yannakoudadis, MEP (UK)



Wojciech Dziworski



Arnaud Senn



Sirpa Pietikainen, MEP (Finland)

### 29 March 2011: Working group on "Value of Diagnosis" discusses survey results

Representatives of the working group for the AE project on the "Value of diagnosis" met in Toronto, Canada in the framework of the ADI Conference whilst other members joined the meeting via teleconference.

The meeting allowed the working group to discuss the top line results of the public opinion survey that

was carried out by TNS in France, Germany, Poland, Spain and the US. In each country, 500 telephone interviews (640 for the US) were conducted to ascertain the general public's:

- perceptions of Alzheimer's disease,
- knowledge and experience about Alzheimer's disease and
- views on the value of a diagnosis of Alzheimer's disease.

The highly interesting results were discussed by the participants and a report on the key results will now be developed by the Harvard School of Public Health and the members of the working group. The results and report will be launched at the ICAD Conference in Paris.

Alzheimer Europe gratefully acknowledges the support it has received from Bayer Healthcare for this project and survey.

### 30 March 2011: Registration facilities for the AE Conference in Warsaw now open

It is now possible to register for the 21<sup>st</sup> Alzheimer Europe Conference which will take place in Warsaw from 6-8 October 2011 and is held under the motto "European Solidarity without borders".

Reacting to concerns from representatives of Alzheimer associations and carers of people with dementia, Alzheimer Europe worked towards a significant reduction in the cost of registration and is able to offer registration fees of EUR 100 for delegates from Poland and from low and middle income countries and of EUR 200 for delegates from high income countries

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## Alzheimer Europe Networking

- On 1 March (Luxembourg, Luxembourg) Julie met with the publishers Binsfeld to finalise issue 7 of the Dementia in Europe magazine.
  - On 3-4 March (Paris, France), Jean attended the Steering Committee of the PharmaCog project.
  - On 9 March (Barcelona, Spain), Jean attended the Innovative Medicines Initiative Workshop at the AD/PD Conference.
  - On 10 March (Brussels, Belgium) Annette met with Laszlo Bencze, Health Attaché, Hungarian Permanent Representation.
  - On 13-15 March 2011 (Brussels, Belgium), the AE Board and staff attended the AE Board meeting and the lunch debate at the European Parliament.
  - On 14 March 2011 (Brussels, Belgium), AE Member representatives, AE Board and staff attended the AE Public Affairs Working Group.
  - On 15 March 2011 (Brussels, Belgium), the AE Board and staff attended the lunch debate, "European Activities on long-term care, what implications for people with dementia and their carers?" hosted by Yannakoudakis Marina (UK).
  - On 22 March (Brussels, Belgium) Annette attended a lunch debate on clinical trials organised in the European Parliament by Philippe Juvin, MEP, (France, EPP).
  - On 22 March (Brussels, Belgium) Annette attended a presentation of the Family Platform Research Agenda organised by Anna Zaborska, MEP, (Slovakia,EPP), Silvia Costa, MEP, (Italy, S&D), Nathalie Griesbeck, MEP, (France, ALDE) and Csaba Sogor, MEP, (Romania,EPP).
  - On 25 March (Toronto, Canada), Heike and Jean were invited to a meeting of the Elected Board of Alzheimer's Disease International to discuss a regional approach
  - From 26 to 29 March (Toronto, Canada), Heike and Jean attended the International Conference of Alzheimer's Disease International.
  - On 29 March (Toronto, Canada), Alzheimer Europe organised a meeting of the "Value of Diagnosis" working group to discuss the results of the survey on the general public's perceptions on the value of a diagnosis of Alzheimer's disease.
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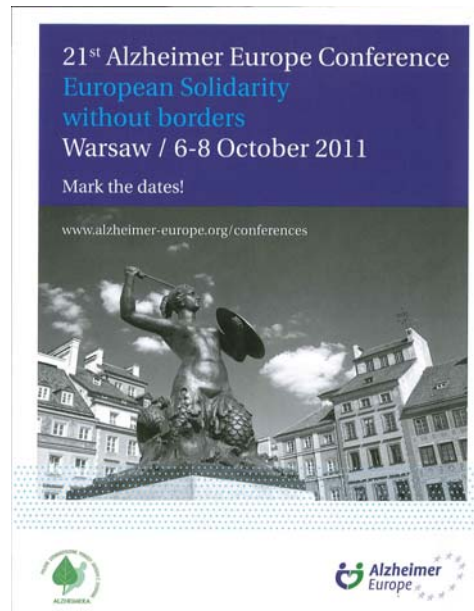


## Call for abstracts

The call for abstracts for the Alzheimer Europe Conference is now online. Abstracts can be submitted via the Alzheimer Europe website on the following topics:

- Avoiding mistakes in care
- Carers' stories
- Day care centres – Innovative solutions
- Effective communication
- Family care versus institutional care
- Fundraising – Success stories
- How to recognise and cope with psychopathological symptoms in Alzheimer's disease
- Legal systems and regulations – a review
- Occupational therapy
- People with dementia speak up
- Policy initiatives and dementia strategies
- Preventing isolation and loneliness of people with dementia and their carers
- Problems and dilemmas in end-of-life dementia
- Raising awareness – successful campaigns
- Sexuality and relationships
- Support groups for carers

**Deadline: 30 April 2011**



PharmaCog short for "Prediction of cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development" is a project which is co-ordinated by GlaxoSmithKline R&D and the Université de la Méditerranée, Marseille, France and started its activities on 1 January 2010 thanks to significant funding (EUR 20.2 million) from the Innovative Medicines Initiative. Its launch marks the start of the most ambitious European project for tackling bottlenecks in Alzheimer's disease research and drug discovery.

The PharmaCog consortium consists of the following partners coming from 10 different EU Member States:

1. Alzheimer Europe (Luxembourg),
2. AstraZeneca (United Kingdom),
3. Boehringer Ingelheim (Germany),
4. Centre National de la Recherche Scientifique (France),
5. Eli Lilly and Company (United Kingdom),
6. Exonhit Therapeutics (France),
7. F. Hoffman-La Roche (Switzerland),
8. GlaxoSmithKline (United Kingdom),
9. H. Lundbeck (Denmark),

10. Innovatice Concepts in Drug Development (France),
11. Innovative Health Diagnostics (France),
12. Institut d'Investigacions Biomèdiques August Pi i Sunyer (Spain),
13. Institut de Recherche Servier (France),
14. Institut National de la Santé et de la Recherche Médicale (France),
15. Istituto di Ricerche Farmacologiche "Mario Negri" (Italy),
16. Janssen Pharmaceutica (Belgium),
17. Merck (Germany),
18. Novartis Pharma (Switzerland),
19. Ordine Ospedaliero di San Giovanni di Dio Fatebenefratelli (Italy),
20. Qualissima (France),
21. SAS Alzprotect (France),
22. UCB Pharma (Belgium),
23. Universidad de Murcia (Spain),
24. Università degli Studi di Foggia (Italy),
25. Università degli studi di Verona (Italy),
26. Universität Leipzig (Germany),
27. Universitätsklinikum Essen (Germany),
28. Université de la Méditerranée, Aix-Marseille II (France),
29. Université de Lille 2 (France),
30. Eisai Ltd (London).

Alzheimer Europe will represent the interests of people with dementia and their carers in this consortium and ensure the dissemination of research results to a lay audience. PharmaCog works closely

with the European Medicines Agency, as an associated partner of this project, to share project progress and discuss the implications for drug development in Europe.

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

**3-4 March 2011: PharmaCog Steering Committee discusses project's progress**

At its meeting in Paris on 3 and 4 March 2011, the PharmaCog Steering Committee was able to look back on a full year of PharmaCog activities and achievements.

During the first year of the project PharmaCog has largely focused on 7 key areas:

- 1) Maximising the opportunity of the diverse experience and background of the PharmaCog team to optimise clinical and pre-clinical study designs. Information gathered from literature reviews, protocols and data from studies conducted by participating EFPIA partners has been combined to optimise 3 clinical study designs and parallel pre-clinical research plans. Protocols have been finalised and enrolment is due to begin 2<sup>nd</sup> quarter of 2011 and literature reviews have been valorised by submission to scientific journals.
- 2) Harmonisation and standardisation of endpoints across all participating pre-clinical and clinical research sites. Endpoints were selected on the basis of sensitivity to disease progression, pharmacological intervention and translatability between species. Protocols for each endpoint have been agreed and procedures have been harmonised and standardised across all participating sites.
- 3) Investigating the feasibility of sleep deprivation as a model of cognitive impairment in pre-clinical models. Pilot studies have been completed demonstrating that robust cognitive impairment can be induced in a variety of models and can be reversed by Donepezil and Memantine.
- 4) Understanding the dynamic range for novel biomarkers in the models of Alzheimer's Disease. A range of pilot studies have been conducted to investigate the magnitude of change in the novel biomarkers, 2- deoxy glucose, MRI, DTI and MRI. The outcomes of this work will be presented in 5 posters at The Alzheimer's Association 2011 International Conference on Alzheimer's Disease (ICAD, to be held in Paris in July 2011).
- 5) Establishment of communication tools to support the effective dissemination of PharmaCog. A PharmaCog extranet facility has been developed to facilitate communication between partners including draft documents, meeting materials, timelines, financial and

project management documents. A section dedicated to PharmaCog has also been established on the Alzheimer Europe website. Regular updates on PharmaCog have been through the Alzheimer Europe newsletter and annual conference.

- 6) Establishment of Standard Operating procedures (SOPs) and guidance document for the governance of clinical trial preparation and management, data management, and publication policies in PharmaCog. Twenty-one SOPs were drafted and agreed by all partners to cover all key aspects of protocol development, human biological tissue sample management, data management and publication procedures.
- 7) Establishment of an ethics advisory board to oversee the ethical and scientific conduct of PharmaCog. An internal Ethics Advisory Board has been established to oversee and guide the project regarding ethical and safety aspects and scientific conduct of the study. Given the translational nature of PharmaCog this committee focuses on both human ethics and animal welfare.
- 8) PharmaCog partners have started to work closely with investigators in other major Alzheimer Initiatives across Europe and the USA. PharmaCog PK/PD groups have started effective collaboration with Coalition Against Major Disease (CAMD) initiative led by Marc Cantillon. First effective meeting will be held in Brussels in the coming months hosted by the IMI office (<http://www.c-path.org/CAMD.cfm/>). PharmaCog investigators worked closely with Alzheimer's Disease Neuroimaging Initiative (ADNi) with the help of Prof Giovanni Frisoni in particular to develop the WP5 clinical trial.

In addition, the Steering Committee was informed of some important administrative changes:

- Dr. Ceri Davies, Vice President, External Alliance & Development at GSK, has taken over as new EFPIA coordinator of the project from Dr. Elaine Irving who was thanked by the steering committee for her commitment and dedication to the project,
- Eisai Ltd joined the consortium and has started to work on the pre-clinical and clinical workpackages of PharmaCog. Eisai as a new partner brings the number of global pharmaceutical companies involved in the project to 12.

**Next steps for PharmaCog**

The second year of PharmaCog will see the recruitment of patients into three clinical studies

- 1) to validate the utility of sleep deprivation induced cognitive impairment in assessing cognitive enhancing agents,
- 2) to identify central pharmacodynamic markers sensitive to donepezil and memantine,
- 3) to identify markers sensitive to disease progression and predictive of conversion from Mild-cognitive impairment to Alzheimer's disease.

Pre-clinical work will focus on the longitudinal assessment of single, double and triple APP transgenic mice and lemurs to identify translatable markers that correlate with amyloid pathology in each of these models. Touch-screen technology will be established and validated for the assessment of cognitive decline in APP transgenic animals.

Sleep deprivation and hypoxia will be validated as models for assessing cognitive enhancing agents and central pharmacodynamic markers will be identified.

In all clinical and preclinical studies PK samples have already been collected in preclinical assessments and will continue to be collected to allow the establishment of mathematical models to describe each model and the translational relationship with the clinic.

**9 March 2011: PharmaCog progress is presented at AD/PD Conference in Barcelona**

The progress of the PharmaCog project (see above) was presented at a symposium organised by the Innovative Medicines Initiative during the AD/PD Conference in Barcelona. The symposium entitled "Public private partnerships boost Alzheimer's disease drug discovery" was chaired by Elisabetta Vaudano, the IMI Programme Officer. From the PharmaCog team, Mike O'Neill (Lilly), Alexandra Auffret (University of Marseille) and Jean Georges (Alzheimer Europe) participated to present the rationale and progress of the project.



Jean Georges, Mike O'Neill, Elisabetta Vaudano and Alexandra Auffret

## European developments

Here we report on developments from the European institutions which may impact people with dementia and/or their carers.

**3 March 2011: EU launches 2011 Public Health Programme Call for Proposals**

Following the publication of the 2011 Work Plan of the EU Health Programme, the European Agency for Health and Consumers (EAHC) has launched calls for proposals for joint actions, operating grants, projects and conferences.

The amount of:

- EUR 17,040,000 will be dedicated to the funding of five joint actions.

- EUR 4,000,000 has been allocated towards operating grants for NGOs or organisations or specialised networks active in the field of Public Health.
- EUR 4,650,000 is reserved for the call for joint proposals. This call for proposals is seeking very specific projects in seven different areas, where only one project per call will be funded (exception in the case of rare disease networks).
- EUR 800,000 will be made available for grants for conferences.

Calls for tenders will be published during the course of the year. These will be for the provision of services, in particular preparation of surveys, analyses, training programmes and studies concerning public health. It is possible to be alerted of when these calls are launched by signing up to the mailing list.

**10 March 2011: Council announces the creation of a unitary patent protection**

On 10 March 2011, after months of negotiations, the Competitiveness Council of the EU gave its green light to the creation of a unitary patent system at European level. Through enhanced cooperation, this establishes a single patent that will be valid across the territory of the 25 participating Member States (apart from Italy and Spain who can nonetheless still join the cooperation whenever they feel it is appropriate).

The European Parliament gave its consent for using this procedure on 15 February 2011.

Having a unified patent system will make it easier, cheaper and more expedient for the businesses who wish to get EU-wide protection for their inventions. The single patent should support and stimulate innovation and help the EU to position itself as a competitive player in the global market.

The language regime for the future unitary patent system would be based on the language regime of the European Patent Office, where the official languages are English, French and German.

The next step for the Hungarian Presidency is to draw up detailed rules concerning unitary patents and expects the European Commission to submit relevant legislative proposals for the Council to be able to continue its work.

**10 March 2011: European Parliament adopts Written Declaration on European statutes for mutual societies, associations and foundations**

At its plenary sitting of 10 March 2011, the European Parliament adopted the European Written Declaration 84/2010 on establishing European statutes for mutual societies, associations and foundations.

The Declaration notes that 'there is a need to create a 'level playing field' that provides associations, mutual societies and foundations with instruments and opportunities equivalent to those available to other organisational legal structures, thereby giving a

European dimension to their organisation and activities'.

It calls on the European Commission to introduce proposals for European statutes for associations, mutual societies and foundations. It also calls on the Commission to propose a feasibility study as well as an impact assessment for the statutes for associations and mutual societies and to complete the impact assessment for the statute for foundations in due course.

The Declaration was initiated by Marc Tarabella (Belgium, S&D), Regina Bastos (Portugal, EPP), Pascal Canfin (France, Greens/EFA), Marie-Christine Vergiat (France, GUE/NLG) and Renate Weber (Romania, ALDE).



#### 11 March 2011: Council adopts Euro Pact

At an informal meeting on 11 March 2011, the Heads of State and Government of the Euro area countries reached an agreement on a Pact for the Euro. This Pact establishes a mechanism for the coordination of economic policies, whereby the member states will together choose policy areas and set common objectives that they want to achieve.

The Member States themselves will decide concrete actions to achieve those objectives. The implementation of their commitments will be "monitored politically" by Heads of State and Government on a yearly basis and against a set of indicators. The Commission will provide a report for this purpose.

The Pact proposes four policy areas for coordination and four goals that the euro area should achieve: increasing competitiveness, promoting employment, ensuring the sustainability of public finances and strengthening financial stability.

The Pact will be adopted at the Summit at the end of March to become part of the EU's comprehensive response to the sovereign debt crisis. Non-euro area EU member states can participate in this initiative on a voluntary basis.

#### 25 March 2011: EU register of clinical trials register launched on line

An official public register of authorised pharmaceutical clinical trials which are underway in the EU has been launched on line by the European Commission. The aim of the register is to "make clinical research on pharmaceuticals more transparent for patients and others and to avoid unnecessary duplication of clinical trials. Every year approximately 4,000 clinical trials are authorised in the EU. Since most of them last 2 to 3 years, this means that around 10,000 trials are ongoing at any given time." It is possible to search the register by disease type.

The clinical trials register is available on the European Commission website: [http://ec.europa.eu/health/human-use/clinical-trials/developments/index\\_en.htm](http://ec.europa.eu/health/human-use/clinical-trials/developments/index_en.htm)

## Other European organisations

#### 24 February 2011: European Medicines Agency publishes its vision for the development of medicines for older people

The European Medicines Agency's (EMA) geriatric medicines strategy document, which was adopted by the Committee for Medicinal Products for Human Use (CHMP) on 18 February 2011, is now available on the EMA website.

The strategy sets out the Agency's vision for the development of medicines for older people by building on its existing activities. The Agency aims to:

- ensure that the medicines used by older people are of high quality and are studied appropriately in the older population, both before and after authorisation;
- improve the availability of information for older people on the use of medicines.

## Policy watch

#### 28 February 2011: Nearly 400 Alzheimer disease researchers and service providers call on US Senate to safeguard federal funding

Nearly 400 Alzheimer's disease researchers and services provide across the US have sent a letter to the US Senate, calling for them to safeguard funding for the National Institutes of Health (NIH). They emphasised the advantages of NIH investment aimed at preventing or curing Alzheimer's disease, which they say, threatens to bankrupt the US healthcare system.

The President of the Alzheimer's Foundation of America, Eric J Hall, explained: "Failing to support promising research for a cure to this devastating disease is morally indefensible, especially as millions of American families are already struggling to care for loved ones with Alzheimer's disease. The time for investment in NIH research is now."

The letter was organised by USAgainst Alzheimer's and the Alzheimer's Foundation of America, two conveners of Leaders Engaged in Alzheimer's Disease (LEAD), a coalition of Alzheimer's-serving organisations committed to increasing America's commitment to stop Alzheimer's disease.

#### 9 March 2011: Report published on the care and treatment of people with dementia in hospitals

The report "Dementia: Decisions for Dignity" has been published by the Mental Welfare Commission for Scotland. The report contains the findings from the Commission's visits programme, the aim of which "is to assess and compare care and treatment for particular groups (in this case, people with dementia) in order that services can learn from good practice and respond to any issues that are identified." Representatives from the Mental Welfare



Commission made visits across Scotland over a three-month period in 2010 to people with dementia in acute wards in general hospitals.

Encouragingly, the Mental Welfare Commission reports that:

- People with dementia are being admitted appropriately when referred to hospital
- People with dementia are, in general, not being moved unnecessarily between wards
- There were good examples of ways to obtain and record information about the person with dementia and use this to provide better care
- There was good attention to nutrition
- People with dementia were generally appreciative of the care they received
- Staff were dedicated, caring and had access to guidance and best practice and
- Specialist mental health services were generally available for advice and support.

However, the Mental Welfare Commission also had concerns which were listed as key messages in the report. These included:

- Few admissions could have been avoided at the point where people were referred to hospital. If more flexible and responsive care services for people with dementia and their carers had been available earlier, it may have been possible to prevent some admissions.
- General hospital staff did not always obtain and record information about their patients with dementia and involve relatives and friends in their care. Screening tests for dementia were performed routinely but in the absence of information from relatives made it difficult to differentiate delirium from dementia.
- Legal safeguards for people who lack capacity to consent medical treatment are not being applied. Clinicians do not always take specialist advice before prescribing psychoactive medication and do not always follow best practice guidance on administering medication covertly and on making decisions not to resuscitate.
- General hospital staff must ensure that measures to keep people with dementia safe are used lawfully and proportionately. They need to be more aware of human rights and incapacity legislation.
- It was disappointing that many wards did not have an environment which was dementia friendly. Much more could be done to make the environments enabling for people with dementia and afford them greater privacy and dignity.
- It was encouraging to see the benefit of training and support for general hospital staff. Specialist mental health expertise was usually regarded as valuable and should be properly resourced.
- People with dementia are very often discharged from general hospitals to care homes on a permanent basis instead of returning to their own homes. When someone with dementia who was living at home is discharged from hospital,

facilitating a return home should be the starting point whenever possible.

The Mental Welfare Commission lists ways in which the National Health System (NHS) Boards can improve these issues.

The Chief Executive of Alzheimer Scotland and Alzheimer Europe Board Member, Henry Simmons, said, "Whilst we acknowledge that progress is being made and that there are elements of the new National Dementia Strategy which will further improve practice, we are dismayed that some individuals are still being prescribed powerful psychoactive medication without the proper use of their only legal protection, the Adults with Incapacity Act (2000). This legislation is designed to protect people in this vulnerable position and there is no excuse for non-adherence. We are also deeply concerned that decisions not to resuscitate some patients have been taken without proper consultation with families. This is simply unacceptable and should never be allowed to happen.

"The report also reinforces our belief that too many people are admitted to residential care directly from hospital. Everyone should have the right to the opportunity to return home, or at the very least an intermediate support service. We urge all NHS Boards to follow in full the recommendations in the report."

### 16 March 2011: UK report highlights a lack of diagnosis for people with dementia

A report entitled "Dementia care in London" by Alice Sachrajda has been published by the institute for Public Policy Research. The executive summary highlights the following findings:

- General practitioners (GPs) in London that are able to diagnose dementia and provide sufficient advice and signposting are the exception, rather than the rule.
- Services for people with dementia often fall between the health system and care provided by local authorities, resulting in people with dementia losing out.
- Some community and voluntary organisations are struggling to receive commissioned funding and many organisations find partnership working and forming consortia extremely challenging.
- Service provision for people aged over 80 with dementia is weak compared to services for people with early onset dementia.
- Service provision for older black and minority ethnic Londoners with dementia is struggling to meet current needs.

The report includes recommendations on:

#### 1) Information:

- Training on dementia to be included early in medical training
- Voluntary and community groups should offer ongoing training packages to GPs to provide insight into local needs and services

- GPs should issue information prescriptions to ensure people are channelled towards the relevant advice.
- 2) The integration of health and social care services by:
- Embedding advice services in surgeries
  - Including dementia as a priority in health and wellbeing strategies
  - Co-location of health and social care in the same building.
- 3) Funding and service provision issues:
- Provision of an audit of services provided for people with dementia to identify good quality services within the community
  - Support by local authorities for community organisations that want to collaborate to bid for contracts
  - A recognition and response by voluntary and community organisations to fill the gaps in areas such as training for commissioners, information, advocacy, end of life planning, bespoke planning etc.
  - Awareness-raising campaigns
  - Inclusion of user groups in the design and delivery of services
  - Recognition by commissioners of the importance of outreach programmes
  - Ongoing training of health professionals.

**We provide full references to articles on our website. Please visit the Alzheimer Europe website on:**

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

**23 March 2011: UK Health guidance approval of Alzheimer's drug to include people with mild Alzheimer' disease**

The final guidance on four Alzheimer's drugs (Aricept, Exelon, Reminyl and Ebixa) was released today by the National Institute for Health and Clinical Excellence (NICE). By June 2011, they are to be available on prescription (Aricept, Exelon and Reminyl for people with early and moderate stages of Alzheimer's disease: Ebixa to be made available for people with the late stages of the disease).

This guidance replaces the earlier guidance from 2007 which limited access to drugs to those people with moderate stage Alzheimer's disease. The new guidance has been welcomed by many including Andrew Chidgey, Head of Policy and Public Affairs, Alzheimer's Society, who said, "It is excellent news that the right decision has finally been set in stone. These drugs can make a real difference to the quality of life of hundreds of thousands of people with Alzheimer's. While they don't work for everyone, this guidance means that for the first time, everyone diagnosed with this disease should be given the choice of finding out if the drugs are effective for them... This will hopefully encourage more people to go to their GP meaning diagnosis rates will improve

and more people will have access to the care and support they so desperately need."

## Members' News

In this section we report on our members' latest initiatives and work.

**1 March 2011: Alzheimer Portugal raises awareness of dementia via facebook and promotes music, art therapy and volunteering**



Throughout March, Alzheimer Portugal has been raising awareness and helping people

with dementia by promoting:

- The use of facebook: Alzheimer Portugal's facebook page now has 5,000 followers. The page was set up to provide a platform for sharing and reinforcing the link for all people dealing with Alzheimer's disease. Alzheimer Portugal set up a cause on the facebook page entitled "Alzheimer Portugal – No memory of a cause like that" to which 44,000 people have joined. Executive Director of Alzheimer Portugal, Antonio Oliveira Costa, said: "You must generate a greater empowerment of the population. Information is the basis for awareness and change attitudes and behaviours. This is one of the contributions of the Association to train and give some power to people who live every day with the disease."
- Music therapy: Alzheimer Portugal has promoted music therapy intervention sessions which aim to increase communication, socialisation, cognitive and physical functioning and reduce the anxiety and agitation, to improve the quality of life with people with dementia. Maria Gabriela Nicolau, music therapist in the association, said that "about 15 people with dementia who have participated in the sessions had visible cognitive and motor improvements, as well as the alleviation of symptoms related to loss of communication skills."
- Art Therapy: The Northern Delegation of the Alzheimer Portugal Association promoted the Art Therapy sessions under the theme of "Shape Memory". These sessions included the participation of the artist Paula Reis. The aim of the project is to stimulate the person with Alzheimer's disease and also to promote contact between carers and families.
- Volunteering: Within the context of the European Year of Volunteers, Alzheimer Portugal has been promoting the role of volunteers. Isabel Goncalves, President of the Centre Delegation of Alzheimer Portugal highlighted the importance that volunteering has within the association, saying: "With the growing number of people with dementia is imperative to support civil society, especially at the level of volunteering in the search for answers to the needs of people with dementia and their caregivers."

**1 March 2011: Organisations combine to raise awareness of dementia and low diagnosis rates**



The Alzheimer's Society, Alzheimer Scotland and supermarket Tesco have combined forces to raise GBP 5 million to help people with dementia and to help to raise diagnosis levels by 2014.

Following a study on the prevalence and diagnosis of dementia a dementia map has been launched which reveals diagnosis rates vary hugely around the UK and predicts that over a million people will have dementia by 2021.

The Tesco Charity of the Year partnership aims to help fund:

- New research
- Provision of professionals to help people with dementia
- A dementia community road show that will travel around the UK to raise awareness of the disease and also to encourage people who are worried about their memory to go to their GP.

Care Services Minister Paul Burstow said: "With our ageing population and the high number of people who never receive a diagnosis for their dementia, the need for raising awareness and encouraging people to seek help has never been greater. This initiative with Tesco, Alzheimer's Society and Alzheimer Scotland is exactly the kind of partnership working we need to get out into communities and encourage people to talk about dementia."

**5 March 2011: German Alzheimer Association publishes manual and DVD to help teach children about dementia**

The German Association has released "Dementia – a practical manual for teaching". It is aimed to help school teachers (of children and adolescents) introduce and discuss dementia during school activities. Many examples and suggestions are given for various topics surrounding dementia. It is accompanied with a DVD and costs EUR 10.

**17 March 2011: Alzheimer Society of Finland launches a book about memory and early-onset dementia**

The main focus of Muistiliitto, the Alzheimer Society of Finland, in 2011 is people of working age. To celebrate this, the Society has brought out a 400-page book about the memory of the working population and early-onset dementia. Entitled "Työkäisen muisti ja muistisairaudet" ("The memory and memory related diseases of working-aged people"), it is the first comprehensive book in Finnish for this age group about memory, brain health and dementia. Contents include up-to-date knowledge about:



- memory and forgetting
- brain health

- early-onset dementias
- good care and rehabilitation
- social security.

Life with dementia is also discussed extensively with quotes from people with early-onset dementia and their caregivers.

The book was published during International Brain Awareness week. Also the occupational health care departments were approached with the book and other campaign material, in order to reach the middle-aged people and to awaken them to take care of their brain health.

The authors are Finnish experts including Kati Juva (University Lecturer, M.D., Ph.D., Specialist in Neurology), Jaana Suhonen (University Lecturer, MBA, M.D., Ph.D., Specialist in Neurology), Anna Mäki-Petäjä-Leinonen (Doctor of Law) and Sanna Aavaluoma (psychotherapist). All authors are specialised and accomplished in the field of dementia. (Härmä & Granö (edit.) 2011, WSOYpro).

**27 March 2011: UK Alzheimer Society calls for screening of dementia for people aged 75 and over**

Many people with dementia do not receive the care and support they need because they do not receive a diagnosis. To combat this, the Alzheimer's Society has called for screening of people aged 75 and over for dementia. Professor Clive Ballard, Director of Research for the Alzheimer's Society, has proposed that GPs could offer a cognitive test (with questions on time, date, place, memory and understanding) and an interview with a relative or carer. This could be followed by a full clinical assessment and, in the case of a diagnosis being made, treatment and care to delay deterioration as well as future planning could be addressed.

However, the UK National Screening Committee, which advises the NHS, has said tests and treatments need to improve first and the British Medical Association says carrying out the checks (which would take around an hour) would mean there was less time for other services.

**30 March 2011: Belgian Alzheimer association helps to draft the "Dementia Friendly Cities' Charter"**

The Belgian French-speaking Alzheimer association, La Ligue Alzheimer and its partners, has written the final version of the 'Dementia Friendly Cities Charter'.

The Dementia Friendly Cities are a network of cities which hold and develop activities related to Alzheimer's disease (such as training sessions 'Circle of Care'; Alzheimer Cafés; home assistance to carer givers) in consultation with La Ligue Alzheimer. These activities must be free of charge.

The initiative's objective is to encourage the integration of people with dementia within the city. Each activity must contribute to the improvement of the quality of life of people with dementia and their carers and this objective is stated on the March 2011 Charter. The Charter specifies the sharing out of the tasks between each signatory. The objective has

been set up on the basis of the World Health Organisation's (WHO's) Age-friendly Cities. La Ligue Alzheimer has been invited to present the initiative at the WHO European Healthy Cities Networks Phase V (2009-2013) Third Annual Business and Technical Conference, to be held in Liège, Belgium, on 15-18 June 2011.

## Science Watch

This section has highlights of the most recent published research on dementia, including research on the prevention, diagnosis, and treatment of the disease.

**We provide full references to articles on our website. Please visit the Alzheimer Europe website on:**

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

### **1 March 2011: Study examines family history of Alzheimer's disease and inherited risk of the disease**



A study suggests that the risk of inheriting Alzheimer's disease from parents is higher from the side of the mother than the father. The findings suggest that people whose mothers had Alzheimer's disease "had twice as much gray matter atrophy as the other groups. Whole brain shrinkage was around 1.5 times more per year in the maternally linked group." The participants were dementia-free people aged 60 and over (11 had a mother with Alzheimer's disease, 10 had a father with Alzheimer's disease and 32 had no history of the disease in their family). The participants were monitored for a two-year period.

The study author was Robyn Honea, University of Kansas School of Medicine, USA and the research was published in the journal *Neurology*.

### **4 March 2011: Mouse study suggests accumulation of beta amyloid may be linked to the liver**



A mouse study suggests that three genes protect brain amyloid accumulation and that "for each gene, lower expression in the liver protected the mouse brain. One of the genes encodes presenilin – a cell membrane protein believed to contribute to the development of human Alzheimer's. The researchers found that higher expression of presenilin 2 in the liver correlated with greater accumulation of beta amyloid in the brain and development of Alzheimer's-like pathology".

Greg Sutcliffe, Scripps Research Institute, California, USA, was the lead researcher and hopes to further test these findings by carrying out clinical trials. The study was published in the journal of *Neuroscience Research*.

### **7 March 2011: UK health service employs new method to help early diagnosis of Alzheimer's disease**

UK National Health Service memory clinics are testing a computer programme which compares a

person's brain scan with a database of some 1,200 existing images of brains already affected by Alzheimer's disease to diagnose early signs of Alzheimer's disease. It is hoped that this system could offer a much faster and reliable diagnosis than currently available.

Researchers from the Biomedical Research Centre for mental health, Maudsley Hospital and Kings College London together with Karolinska Hospital in Stockholm developed the system.

### **7 March 2011: Study examines the effect of the process of autophagy on protein associated with Alzheimer's disease**

A study has found that the levels of amyloid- $\beta$  peptide (often associated with Alzheimer's disease) were decreased following starvation or by the induction of autophagy (the process of degradation of intracellular components) by molecule enhancers rapamycin (SMER)28. On the other hand, accumulation of amyloid- $\beta$  peptide and a diminished effect of SMER 28 occurred by the pharmacological inhibition of autophagy. The authors concluded, amongst other things, that the results support the involvement of autophagy in the clearance of amyloid- $\beta$  and, as such, may have therapeutic potential for the treatment of Alzheimer's disease.

The study was led by P Greengard, Laboratory of Molecular and Cellular Neuroscience, Rockefeller University, New York, New York, USA and published in the journal of the Federation of American Societies for Experimental Biology (FASEB).

### **7 March 2011: Study examines relationship between alcohol consumption and dementia in the elderly**



A study in which 3,200 people, aged 75 and over, without dementia were monitored over a three-year period found that of the initial participants, 217 met criteria for dementia during the follow up period and that "subjects consuming alcohol had approximately 30% less overall dementia and 40% less Alzheimer dementia than did non-drinking subjects. No significant differences were seen according to the type of alcoholic beverage consumed. The authors' conclusions suggest that light-to-moderate alcohol consumption is inversely related to incident dementia, also among individuals aged 75 years and older."

The study was led Siegfried Weyerer of the Central Institute of Mental Health in Mannheim in Germany and published in the journal *Age and Aging*.

### **7 March 2011: Study investigates the effects of gene therapy on the brain of mice predisposed to Alzheimer's disease**

A mouse study suggests that gene therapy (with parkin genes) may promote removal of toxic proteins inside brain cells which prevents the plaque formation associated with Alzheimer's disease. The researchers found that by providing the brain with parkin protein to processes were activated: Firstly, "ubiquitination in which toxic proteins were targeted for destruction and recycling within the cell" and secondly, "autophagy, in which membranes form around damaged mitochondria (which have been



found to clog the insides of neurons affected by Alzheimer's disease) and then destroy them, allowing cells to produce new and healthy mitochondria."

The study, led by Charbel E-H Moussa, was conducted by researchers from Georgetown University Medical Center, USA and published in the journal Human Molecular Genetics.

**7 March 2011: Study develops neurons associated with Alzheimer's disease from stem cells**

Researchers have "transformed a human embryonic stem cell into a critical type of neuron (basal forebrain cholinergic neurons) that dies early in Alzheimer's disease and is a major cause of memory loss." The researchers hope to be able to study the neurons to find out how to prevent them from dying.

The study was led by Christopher Bissonnette and researchers from the Northwestern University, Feinberg School of Medicine, Chicago, USA and published in the journal Stem Cells.

**8 March 2011: Study examines link between strokes, heart condition and dementia**



A study suggests that stroke survivors with the heart condition atrial fibrillation (AF) were 2.4 times more likely to develop dementia than stroke survivors without AF. The researchers carried out an analysis of 15 separate studies (amounting to nearly 50,000 patients' records) and examined records of people with and without atrial fibrillation (AF) to see how many went on to develop dementia. They found that around a quarter of people with stroke and AF developed dementia.

The study was led by Phyoo Kyaw and conducted by researchers from the University of East Anglia, UK. It has been published in the journal Neurology.

**16 March 2011: Study suggests pathological changes may occur 20 years before symptoms of certain types of dementia appear**

The first findings of the Dominantly Inherited Alzheimer Network (DIAN) study have found that the pathologic changes of Alzheimer's disease may begin as early as 20 years before the expected onset of the disease, at least in people whose families carry a high-risk gene. DIAN is an 'an international research partnership of leading scientists determined to understand a rare form of Alzheimer's disease that is caused by a gene mutation.' It is hoped that by understanding this form of Alzheimer's disease future development of treatments may be helped. It is funded by a research grant from the National Institute on Aging and involves ten research institutions from the US, UK and Australia. Speaking at the International Conference on Alzheimer's and Parkinson's diseases, the principal investigator of the DIAN study, J. C. Morris (from the Washington University School of Medicine, St Louis, USA), explained that 'the use of PET and cerebrospinal fluid biomarkers of beta-amyloid and tau protein may allow researchers to select enriched pools of subjects for the testing of potential drug treatments, and,

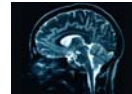
someday, allow clinicians to target patients with incipient disease for preventive treatment.'

**18 March 2011: Study identifies potential biomarker for Alzheimer's disease**

A pilot study on 40 people (20 with Alzheimer's disease and 20 without) has shown that an immune gene which clears amyloid beta (which is associated with Alzheimer's disease), is expressed differently in different people with Alzheimer's disease. The gene identified is known as mannosyl (beta 1,4) glycoprotein beta 1,4,N acetylglucosaminyltransferase (MGAT3) and researchers hope this could provide more highly individualised disease prognoses in the future.

The study was reported in the Journal of Alzheimer's disease and carried out by researchers from the University of California, Los Angeles (UCLA), USA.

**21 March 2011: Mouse study examines delivery of drugs directly to the brain**



One of the obstacles in the treatment of Alzheimer's disease is the ability to get effective drugs from blood to the brain. A study has found that tiny particles known as exosomes are able to carry a drug across the normally impermeable blood-brain barrier to the brain where it is needed. Exosomes are produced naturally by the body and the researchers adapted them to deliver a gene therapy which, once in the brain, switched off a gene associated with the build up of protein in Alzheimer's disease. Researchers hope to continue to test this process on mice to find out if it can impact on disease progression.

The research was carried out by Dr Matthew Wood and colleagues from Oxford University, UK and published in the journal Nature Biotechnology.

**27 March 2011: Mouse study examines effect of asthma drug on amyloid plaques**

Led by Domenico Praticò, associate professor of pharmacology, Temple University School of medicine, the study was published in the American Journal of Pathology.

In a study of a mouse model of Alzheimer's disease it was found that treatment with the drug Zileuton (an inhibitor of 5-lipoxygenase) resulted in reduced production of amyloid beta and subsequent build up of amyloid plaques in the brain by more than 50 percent.

Zileuton is currently used to treat asthma. The researchers hope to develop these findings to help treat people with Alzheimer's disease and have begun further investigations in an attempt to create more potent inhibitors that can target 5-lipoxygenase in the brain with the consequence of reducing amyloid plaque formation.

**28 March 2011: Trial to examine the effect of sleep hormone on the symptoms of people with dementia**



A six-month trial is to commence to examine the role of the sleep hormone melatonin on the symptoms associated with dementia. Researchers hope that

the findings may help people with dementia and their carers enjoy a better quality of life and the ability to manage the disease more effectively.

Researchers (from CPS Researchers, Scotland, UK) are hoping to recruit fifty people with Alzheimer's disease to participate in the trial, called the Melatonin in Alzheimer's Disease Project.

### **29 March 2011: Survey suggests slightly overweight elderly men less likely to develop dementia.**

A survey carried out over a ten-year period on men aged between 65 and 84 found that those men who were slightly overweight were less likely to develop dementia. The study was carried out by researchers at the University of Western Australia.

### **31 March 2011: Worm study examines role of dye in ageing process**

A study suggests that a dye [basic yellow 1 or Thioflavin T (ThT)] used to detect damaged protein in Alzheimer's disease may, in small doses, extend the lifespan of healthy nematode worms and slow the progression of Alzheimer's disease in genetically modified worms.

The study was led by Gordon Lithgow with researchers from the Buck Institute for Research on Aging, Novato, California, USA and published in the journal Nature.

## **Dementia in society**

In this section we report on how dementia is portrayed by the general media (for example, on television and in films).

### **25 February 2011: British broadcaster speaks about dementia and calls for greater priority for research funding of dementia**

The British broadcaster, Sir Michael Parkinson, spoke of his mother's, Freda Rose Parkinson's, dementia when he was talking at a meeting in Sydney, Australia. He said, "It was because she was so independent and mettlesome that her swift decline into senility became so wretched to witness. There were humorous episodes. She started imagining that my (late) father had returned but was spending all of his time getting drunk at the pub. She would wait up for him and, on one or two occasions, rang the pub asking the baffled landlord to return her husband forthwith before she came across and sorted them both out. Anybody who has gone through this knows there is a mix of laughter and tears in confronting this situation."

Mr Parkinson called for greater priority to be given to dementia research, highlighting the disparity between funding allocation he said: "The figures in England are something like GBP 50 million pounds spent on dementia research, GBP 580 million pounds on cancer research. Now, I'm not denying cancer research, we need more and more, but this is disproportionate given what we have been talking about ... a growing concern and a growing problem."

### **28 February 2011: French actress Annie Girardot dies with Alzheimer's disease**

French actress Annie Girardot died on 28 February 2011, at the age of 79. She had been suffering from Alzheimer's disease for 10 years. Her daughter, Giulia Salvatori, had made the disease public in 2006 to stop degrading rumours about her mother.

Two books have been published about Annie Girardot and her disease: in 2007, Giulia Salvatori published "La mémoire de ma mère" (My mother's memory) and in 2009, Léo Brandon, Ms Girardot's personal secretary published "Annie, te souviens-tu..." (Annie, do you remember...).

In September 2008, French TV TF1 broadcast a documentary on Annie Girardot - Annie Girardot, ainsi va la vie (Annie Girardot, as life goes by...). In this documentary that followed the actress during 8 months, Annie Girardot spoke about her past and the impact the disease had on her life.

### **4 March 2011: Three Hungarians win Grethe Lundbeck Brain Price**

On 4 March 2011, in Copenhagen, Denmark, three Hungarian scientists – Péter Somogyi, Tamás Freund and György Buzsáki - were awarded The Brain Price 2011 by the Grete Lundbeck European Brain Research Foundation.

The three scientists are all native Hungarians, who from their current locations in Europe and the USA share an interest in the way in which circuits of nerve cells process information in the brain.

### **15 March 2011: Pilot project provides alternative to nursing home care for people with dementia**

A pilot project has been announced in Chicago, USA by Illinois Medicaid officials to provide an alternative to nursing home care for low-income elderly people with Alzheimer's disease and other types of dementia. Private apartments (with bathrooms and kitchens) and services (e.g. personal care, exercise programmes, assistance to take medicines) will be provided for the residents.

### **21 March 2011: Call for proposals launched to promote local initiatives to promote a better quality of life for people with dementia and carers launched**

A group of foundations, composed of the Atlantic Philanthropies, the Fondation Médéric Alzheimer, the King Baudouin Foundation and the Robert Bosch Stiftung, have launched the 'Living well with Dementia in the Community - European Foundations' Initiative on Dementia (EFID)-Awards' in order to improve perceptions of dementia and to stimulate solidarity at the local level. The aim of the Initiative is to contribute to a better quality of life for people with dementia and their carers.

By rewarding the best local initiatives that promote social inclusion, through a Europe-wide awards scheme, EFID wishes to encourage context relevant projects in the field of awareness-raising on dementia. Up to 10 projects will be funded with up to EUR 10,000.

The deadline for applications is 31 August 2011. Details of the call for proposals, application form and the selection criteria relevant to the awards are available on The Network of European Foundations (NEF) website. Winners will be announced in January 2012.

### 31 March 2011: Training initiative developed to help carers of people with dementia be more empathetic

A mental health nurse and drama therapist (Maizie Mears-Owen) has developed a training workshop designed to help carers of people with dementia empathise with those they care for. The workshops aim to give insight into how people with dementia can feel by exposing carers to a sense of frustration, confusion and loss of control. Participants have their vision distorted (by goggles), their sense of touch reduced (by wearing gloves) and hear loud white noise whilst being constantly interrupted. The workshops have been piloted in the UK in nine care homes.

Ms Mears-Owen, said, "I find I learn much better if I can experience something rather than sitting and taking notes. I absorb it and it stays with me longer. From the beginning of the workshop I create confusion and frustration and get the staff to really understand and walk in the shoes of those who have dementia."

One participant, carer Jeni Beck, said of the training that: "It gives you much greater awareness of what someone with dementia has to battle with on a daily basis and a better understanding of how to approach somebody. It reinforces that you need to communicate all the time and slowly, always telling the resident what you are doing - making sure your sentences are clear and that you are talking to the individual and not over them."

## New resources and publications

By reporting on recently published books, reports and information videos on dementia we hope to offer updates on the current resources available to anyone who is affected by dementia.

### 8 March 2011: New market research available on Alzheimer's disease

A market research report has been published, entitled "Alzheimer's disease – New drugs, markets and companies". The report considers the current diagnostic methods, approved treatments, management of the disease and the development of new compounds (currently over 300 are at different stages of development) and therapies. The report includes an analysis of the Alzheimer's disease market during 2010 and the profiles of 141 companies involved in developing diagnostics and therapeutics for the disease are presented along with 107 collaborations. The report is divided into:

- Clinical features, epidemiology and pathology of Alzheimer disease
- Diagnostic procedures for Alzheimer's disease
- Management of Alzheimer's disease

- Research in Alzheimer's disease
- Drug discovery and development for Alzheimer's disease
- Marketing and financial aspects of Alzheimer's disease
- Companies.

The electronic version of the report, "Alzheimer's disease – New drugs, markets and companies" (524 pages) costs EUR 2,800 and is published by Jain PharmaBiotech.

### 9 March 2011: EADC launches revised and updated website

The European Alzheimer's Disease Consortium (EADC) has revised and updated its website, which can now be found at [www.eadc.info](http://www.eadc.info). The site contains information about the EADC regarding:

- The activities of the organisation
- Special interest groups
- Research projects
- Publications
- Structure of the organisation
- Contact.

The EADC is a network of over 50 European centres of clinical and biomedical research excellence working in the field of Alzheimer's disease and related dementias. It aims to provide a setting in which the basic scientific understanding of Alzheimer's disease can be increased and ways in which to prevent and or slow symptoms of the disease can be developed.

### 16 March 2011: Report published on the care of the elderly in England

The Health Service Ombudsman for England, Ann Abraham, has published a report entitled "Care and compassion?" which catalogues ten investigations into complaints made to her about the standard of care provided to elderly people by the NHS. Ms Abraham said that she collated the report because of the 'common experiences of the patients concerned and the stark contrast between the reality of the care they received and the principles and values of the NHS.'

One of the complaints concerned Mrs H, who had dementia and the Ombudsman concluded that as a result of service failure Mrs H's dignity and individuality were compromised, and that her niece also suffered unnecessary distress as a result of this failure.

Ms Abraham called for all members of Parliament to reflect on her findings: 'that the reasonable expectation that an older person or their family may have of dignified, pain-free end-of-life care, in clean surroundings in hospital, is not being fulfilled. Instead, these accounts present a picture of NHS provision that is failing to respond to the needs of older people with care and compassion and to provide even the most basic standards of care.'

**16 March 2011: US report “Facts and Figures” on Alzheimer’s disease published**

The 2011 Alzheimer’s Disease Facts and Figures report has been published by the Alzheimer’s Association. It includes a special report on early detection and diagnosis. The report includes findings that, in the US:

- There are nearly 15 million carers of people with dementia providing 17 billion hours of unpaid care valued at US \$ 202 billion.
- Carers not only suffer emotionally but also physically. Because of the toll of care-giving on their own health, carers of people with Alzheimer’s disease and dementia had US \$ 7.9 billion in additional health care costs in 2010.
- More than 60 percent of family carers report high levels of stress because of the prolonged duration of care-giving and 33 percent report symptoms of depression.

- Alzheimer’s disease is the sixth-leading cause of death in the country and the only cause of death among the top 10 in the United States that cannot be prevented, cured or even slowed. Based on mortality data from 2000-2008, death rates have declined for most major diseases while deaths from Alzheimer’s disease have risen 66 percent during the same time.

Facts and figures are given on the following areas:

- Prevalence
- Mortality
- Care-giving
- Use and costs of health care, long-term care or hospices
- Early detection and diagnosis.

The report, “2011 Alzheimer’s Disease Facts and Figures” is available on the Alzheimer’s Association website.

## AE Calendar 2011

The following meetings will be attended by representatives of Alzheimer Europe

Date	Meeting	AE Representative
1 April	GSK Health Advisory Board (London, UK)	Jean
7 April	EFPIA Think Tank (Brussels, Belgium)	Annette
12-13 April	EPF General Assembly Meeting and spring seminar on Capacity Building (Brussels, Belgium)	Annette
14-15 April	4th annual meeting of the fundamental rights platform (European Agency for Fundamental Rights) (Vienna, Austria)	Dianne

## Future Conferences

Date	Meeting	Place
13-14 April 2011	The 7th Annual World Health Care Congress—Europe, <a href="http://www.worldcongress.com/events/HR11015/">http://www.worldcongress.com/events/HR11015/</a>	Brussels, Belgium
14-17 April 2011	The VII International Association of Gerontology and Geriatrics (IAGG) – European Region Congress “Healthy and Active Ageing for all Europeans II”, <a href="http://www.iaggbologna2011.com">www.iaggbologna2011.com</a>	Bologna, Italy
13-15 June 2011	14th Kuopio Bio-NMR Workshop: MRI of stroke, epilepsy and neurodegenerative diseases and the PredictAD Workshop, <a href="http://www.uef.fi/predictad-ws">http://www.uef.fi/predictad-ws</a>	Kuopio, Finland
6-8 October 2011	Alzheimer Europe’s 21 <sup>st</sup> Annual Conference “European Solidarity without borders”, <a href="http://www.alzheimer-europe.org/EN/Conferences/Warsaw-2011">http://www.alzheimer-europe.org/EN/Conferences/Warsaw-2011</a>	Warsaw, Poland
20-23 October 2011	7 <sup>th</sup> International Congress on vascular dementia: Facing the challenges of dementia, <a href="http://www.cts.vresp.com/c/?KenesInternationalVA/e06f64a56d/5ba2f9d3c6/0d0ca1445f/ref5=db1">http://www.cts.vresp.com/c/?KenesInternationalVA/e06f64a56d/5ba2f9d3c6/0d0ca1445f/ref5=db1</a>	Riga, Latvia
2-4 November 2011	38 <sup>th</sup> Congress of European Association of Geriatric Psychiatry (EAGP), <a href="http://www.apgerontopsiquiatria.com">www.apgerontopsiquiatria.com</a>	Porto, Portugal
9-12 May 2012	12th International Stockholm/Springfield Symposium on Advances in Alzheimer Therapy, <a href="http://www.ad-springfield.com">www.ad-springfield.com</a>	Stockholm, Sweden



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