



# NEWSLETTER

October 2010

## Highlights in this issue

<b>1-2 October:</b> Alzheimer Europe organises 20 <sup>th</sup> Annual Conference	<b>2</b>
<b>6 October:</b> European Commission launches Innovation UNION	<b>6</b>
<b>7 October:</b> NICE rules dementia drugs to be cost effective	<b>8</b>
<b>8 October:</b> Irish Society calls for protection of basic levels of service for people with dementia	<b>9</b>



## Table of contents

Editorial.....	1
European Alzheimer's Alliance .....	2
Alzheimer Europe .....	2
Alzheimer Europe Networking .....	4
European developments.....	5
Policy Watch.....	7
Members' News.....	9
World Alzheimer's Day in Europe ....	12
Forthcoming members' events .....	13
Science Watch .....	14
Living with dementia .....	16
Dementia in society.....	16
New resources and publications .....	17
AE Calendar .....	18
Future Conferences.....	18

## Editorial



Despite the current economic challenges we all face, dementia remains on the political agenda and I am happy to report on several important developments.

No less than three European countries, the Czech Republic, Finland and Portugal, announced in October that work is to begin on developing a national dementia strategy.

Similarly, the European Parliament continues its analysis of the European Alzheimer's Initiative and dedicated a workshop on this issue to which Alzheimer Europe was invited to contribute and which we of course report on in this newsletter.

We also cover an interesting initiative in the UK, where 44 organisations have joined forces to create the "Dementia Action Alliance". One of the first areas which the Alliance seeks to address is the over use of anti-psychotic drugs for people with dementia. We wish them well in their endeavours.

It is no small victory for all those who have campaigned for people with dementia in the UK to have access to treatment, that it is likely more people will indeed be able to receive anti-dementia medicines as a review by the National Institute for Health and Clinical Excellence (NICE) concluded that these drugs are cost-effective.

After reporting on our Annual Meeting in last month's newsletter, we focus on our 20<sup>th</sup> conference in this edition. The two day conference held under the theme "Facing Dementia Together" was held in

Luxembourg and truly lived up to expectations as over 300 speakers and participants explored the importance of partnerships and collaborations to improve the lives of people with dementia and their carers.

The activities of our member organisations deserve of course a special mention and this month was no exception. You will see that Alzheimer Europe's member organisations have been busy in October and we also bring more news regarding the various celebrations which took place for World Alzheimer's Day in September and which we were unable to include in last month's newsletter.

I am proud to report that the EuroCoDe findings on the cost of illness of dementia have now been published in the International Journal of Geriatric Psychiatry.

We were also able to progress with our project on the ethical issues of assistive technologies and the meeting of the experts of our Dementia Ethics Network confirmed that we will be on target to publish our report before the end of this year. Similarly, Dianne was able to put the finishing touches to some of the reports on guardianship systems which will be the focus of our Dementia in Europe Yearbook which will also be published this year.

Finally, we updated our website and now provide information on the PharmaCog project that we are involved in and have included the various presentations of our Conference.

An impressive list of activities and achievements for this month!

**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:** Cabrnich Milan (ECR), Kohlíček Jaromír (GUE/NGL), Roithova Zuzana (EPP), **Denmark:** Schaldemose Christel (S&D), **Finland:** Jaakonsaari Liisa (S&D), Jääteemäki 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), Toja 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

### 30 September 2010: Alzheimer Uniti (Italy) joins Alzheimer Europe



Alzheimer Europe would like to welcome the Italian Alzheimer association "Alzheimer Uniti" to its membership. The decision to accept the application for membership was taken during Alzheimer Europe at

Alzheimer Europe's Annual General Meeting on 30 September 2010.

Created in 1999 in Rome, Alzheimer Uniti was set up to help people with Alzheimer disease and their families, provide information on the disease and to raise awareness among the general public. To this end, the association runs an Alzheimer café and provides call centres. Alzheimer Uniti also works hard to influence the political agenda to ensure that people with dementia and their carers receive the support they need. The chairperson is Luisa Bartonelli and she, along with other representatives of the association,

attended the 20th Alzheimer Europe conference, held in Luxembourg at the beginning of October (see picture on the right).



### 30 September-2 October 2010: Alzheimer Europe's 20th Conference takes place in Luxembourg



Over 300 delegates from 34 countries participated in Alzheimer Europe's 20<sup>th</sup> Annual Conference which was under the patronage of Her Royal Highness the Grand Duchess. Participants were from a variety of backgrounds and included people with dementia, their carers, representatives of national Alzheimer associations, healthcare professionals and national and European policy makers.

"Facing dementia together" was the conference motto and throughout the two days partnerships and collaborations were explored which could promote a better quality of life for people with dementia and their carers. The symposia were organised to consider relationships between people with dementia, their carers, professional carers, doctors and researchers, as well the relationship between the dementia community as a whole and policy makers.

At the opening ceremony, policy makers (Marie-Josée Jacobs, the Minister for Family and Integration in Luxembourg, Mars di Barolomeo, Minister for Health and Social Security in Luxembourg and Andrzej Rys, Director of Public Health, European Commission) spoke of the importance of working together to address dementia. This message was supported by the keynote speakers who represented all areas of the dementia community including:

- people with dementia (James McKillop),
- carers (Maureen McKillop),
- national representatives [Dieter Ferring and Jeannot Krecké (Luxembourg), Julian Hughes (UK), Christina Kuhn (Germany), Kaisu Pitkälä (Finland), Gerrit Rauws (Belgium) and Bengt Winblad (Sweden)],
- Alzheimer associations [Jean Georges and Dianne Gove (Alzheimer Europe), Iva Holmerová (Czech Republic) and Gráinne McGettrick (Ireland)] and
- representatives on the European level [Philippe Amouyel and Antoni Montserrat (European Commission) and Maria Isaac (European Medicines Agency (EMA))]. Participants reported that there were particularly happy that the conference received a high level of support from policy makers.

Whilst great interest was shown in all the symposia, participants were perhaps most moved when listening to James and Maureen McKillop share, with such touching honesty and humour, some of their experiences since James' diagnosis. Maureen and James concluded with the song from the film Gigi, "I

remember it well”, which illustrated rather beautifully the confusion dementia can bring,

Plenary sessions offered a wide range of topics from which to choose such as innovative care services, nursing home care, non-pharmacological approaches to the management of dementia, successful campaigning, organisation and financing of care, the international dimension of dementia and also national dementia strategies currently in Europe (which proved to be of particular interest to participants).

2010 also marks Alzheimer Europe's 20<sup>th</sup> anniversary and the Executive Director of Alzheimer Europe, Jean Georges, highlighted some of the key achievements of the organisation, citing the Lawnet projects and the Paris Declaration (which states Alzheimer Europe's political priorities). Mr Georges

remarked on how much Alzheimer Europe had grown from just seven national associations in 1990 to now being representative of 31 national organisations from 28 EU countries.

The conference received the support of the European Commission, which enabled Alzheimer Europe to offer (for the second year) some complimentary tickets for people with dementia to participate. The event was organised by Alzheimer Europe and Association Luxembourg Alzheimer (ALA) in collaboration with the Integrative Research Unit: Social and Individual Development, University of Luxembourg and the Association Luxembourgeoise de Gérontologie et Gériatrie.



Liane Kadusch-Roth welcoming the participants to the AE Conference



Mars di Bartolomeo, Liane Kadusch-Roth, Maurice O'Connell and Marie-Josée Jacobs during the opening ceremony



Luxembourg Health Minister, Mars di Bartolomeo



Andrzej Rys, European Commission



Jean Georges, AE Executive Director



Patrick Maugard, AE Board Member and Odile Desana, Chairperson of France Alzheimer



A view of the plenary room



Sabine Jansen, Deutsche Alzheimer Gesellschaft (Germany) and Jan Killeen, Alzheimer Scotland (United Kingdom)



AE Director with Antoni Montserrat, European Commission



Denis Mancini, Association Luxembourg Alzheimer (Luxembourg)



Jeannot Krecké, Luxembourg Minister of the Economy with AE Board member Alicja Sadowska



Heike von Lützu-Holbein, the new AE Chairperson closing the conference

### 28 October 2010: European cost of illness of dementia published

The findings from the socio-economic impact of dementia workgroup of Alzheimer Europe's European Collaboration on Dementia (EuroCoDe) project have been published in the peer-reviewed journal, the International Journal of Geriatric Psychiatry.

The aim of the study was to describe the economic impact of dementia in Europe in 2008. The researchers found:

- The total cost of illness of dementia in the EU 27 in 2008 was estimated to be EUR 160 billion (EUR 22,000 per person with dementia per year)
- The corresponding cost of illness of dementia for the whole of the Europe to be EUR 177 billion.
- In northern Europe, the direct costs were estimated to be considerable, while the cost of informal care was found to be the major cost component in southern Europe.

The researchers concluded: "the cost of illness in this study to be higher than in previous studies. There are also large differences in different European regions. Notwithstanding the methodological challenges, the societal costs of dementia in Europe are very high which in turn have substantial resource impacts on the social and health."

EuroCoDe was carried out under the framework of the EU's 2005 workplan of the Community public health programme.

### 30 October 2010: Information on the European "PharmaCog" project now available on Alzheimer Europe's website

Details of the European project "Prediction of cognitive properties of new drug candidates for

neurodegenerative diseases in early clinical development" (PharmaCog) are now available on the Alzheimer Europe website. Information is divided under the following headings:

- Why PharmaCog?
- The PharmaCog approach
- How will PharmaCog benefit patients?
- Who are the PharmaCog partners?
- Who supports PharmaCog?
- Key contacts
- Publications and conferences and News



The PharmaCog project started in January 2010 and combines the efforts of academic institutions, global pharmaceutical companies, small and medium enterprises and patient representation from Alzheimer Europe.

### 30 October 2010: Presentation slides from Alzheimer Europe's 20<sup>th</sup> conference now available on-line

The available slides from the presentations made during Alzheimer Europe's 20<sup>th</sup> conference, Facing Dementia Together, (which took place in Luxembourg), are now available on the conference section of the Alzheimer Europe website ([www.alzheimereurope.org/EN/Conferences/Previous-conferences/2010-Luxembourg](http://www.alzheimereurope.org/EN/Conferences/Previous-conferences/2010-Luxembourg)).

The presentations can be located by selecting the relevant session from the detailed programme option and scrolling down to the downloads.

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## Alzheimer Europe Networking

On 1-2 October (Luxembourg, Luxembourg) the 20<sup>th</sup> Alzheimer Europe Conference took place.

On 1 October (Luxembourg, Luxembourg) representatives of Staff and Board attended the meeting with Nutricia.

5-9 October (Bad Hofgastein, Austria) Annette attended the European Health Forum: "Health in Europe, ready for the future?"

On 10 October (Brussels, Belgium) Annette went to the Ligue Alzheimer Café Day where they showed the film "La boîte de Pandore".

On 11 October (Brussels, Belgium) Annette attended the European Commission meeting "Healthy ageing workshop: adaptation of health systems".

On 13 October (Brussels, Belgium) Annette and Jean met with representatives of the Alzheimer's Society, Bristol Myers Squibb and Servier.

On 20 October (Brussels, Belgium) Annette had a meeting with the assistant of Marina Yannakoudakis, MEP (United Kingdom) to discuss the EP report on a European initiative on Alzheimer's disease.

On 25 October (Brussels, Belgium) Annette met with the assistant of Nessa Childers, MEP (Ireland) to discuss the EP report on a European initiative on Alzheimer's disease.

On 26 October (Brussels, Belgium) Annette attended a teleconference with Johnson & Johnson representatives.

On 26 October (Brussels, Belgium) Jean met with representatives of Lily to present the organisation's 2010 Work Plan and 2010 Sponsorship opportunities.

On 27 October (Brussels, Belgium) Annette and Dianne went to a seminar on the "human rights of persons in institutional care" (Forgotten Europeans- Forgotten rights) organised by the United Nations Human Rights Office of the High Commission, Europe Regional Office.

On 28 October (Brussels, Belgium) Jean gave a presentation on Alzheimer Europe's priorities at a hearing on Alzheimer's disease organised by the European Parliament Public Health Committee. Annette also attended the meeting.

On 28 October (Brussels, Belgium) Annette had a meeting with G. Willmott's assistant to discuss the EP report on AD.

## European developments

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

### 26 September 2010: Environment and Health Committee votes on report on Information to Patients

On 26 September, the European Parliament Environment and Health Committee voted on Christofer Fjellner's (Sweden, EPP) report on the Directive regarding the information provided to the general public on medicinal products for human use.

The aim of the Directive is to ensure the availability of good-quality, objective, reliable and non-promotional information on medicines. The Environment Committee vote emphasises the patients' rights to information rather than making the provision of information an option for the pharmaceutical companies as suggested by the European Commission.

The Envi specifies which data must be made available to the public by pharmaceutical firms, which information is optional and through which channels it is to be supplied. It also wants Member States to be required to give citizens objective and unbiased information on medicines.

#### Member States' obligation to provide information

A new article will oblige the Member States to ensure that "objective, unbiased information" is available to the general public on the medicinal products sold in that Member State. The following would have to be at least made available: a summary of product characteristics, a labelling and package leaflet, a publicly accessible version of the assessment report of the medicinal product; the diseases and health conditions which are to be treated with the medicinal product; information on how to prevent such diseases and conditions.

Such information would have to be made available both in electronic form (on dedicated websites set up by the Member State) and in printed form, and in a format accessible for people with disabilities.

#### Information by pharmaceutical companies

Pharmaceutical companies should be required to make available the approved and most recent contents of summaries of product characteristics, labeling and package leaflet and a publicly accessible version of the assessment report.

They may also provide the general public with other well-defined non-promotional information (environmental impact of the product, prices or pack changes, instructions for use of the product).

This information would have to be supplied both in electronic and printed form, and in formats appropriate for the blind and partially-sighted. Printed material may only be sent to members of the public at their specific request. The MEPs agreed with the Commission proposal that information on prescription drugs should not be broadcast on radio or TV. They

added that it should also not be published in newspapers or magazines.

### 27 September 2010: ENVI Committee votes on Françoise Grossetête report on the Directive on the application of patients rights in cross-border healthcare

On 27 October, the European Parliament Public Health Committee adopted Françoise Grossetête's report on the Directive on the application of patients rights in cross-border healthcare (COM(2008) 414 final) by an overwhelming majority (47 in favour, 2 against, 1 abstention). The Directive will lay down rights for patients to seek healthcare in another Member State and be properly reimbursed. As a rule, if a form of treatment is covered under their national health system, patients will be allowed to receive that treatment in another EU country.

The legislation clarifies a few points: the home state to pay bills directly if notified in advance, prior authorisation may be needed for hospital treatment, specific rules for patients with rare diseases will be added, national contact points should be established by the Member States to provide information to the patients. Long-term care and organ transplantation should be excluded from this directive.

The plenary vote is scheduled for 18 January 2011.

### 4 October 2010: Alzheimer drug fails to receive marketing authorisation by the European Medicines Agency



The European Medicines Agency (EMA) declined authorisation for the drug Galantamine Stada. A statement was released on the EMA website which reads "The European Medicines Agency has completed an arbitration procedure following a disagreement among Member States of the European Union (EU) regarding the authorisation of the medicine Galantamine Stada. The Agency's Committee for Medicinal Products for Human Use (CHMP) has concluded that the benefits of Galantamine Stada do not outweigh its risks, and the marketing authorisation cannot be granted in Austria or in other Member States of the EU: Czech Republic, Denmark, Finland, Ireland, Portugal, Slovakia and Spain."

Galantamine Stada should not be confused with galantamine which is the active ingredient of the drug Reminyl and which is unaffected by this decision.

### 6 October 2010: 13<sup>th</sup> European Health Forum Gastein focuses on the ageing population and health literacy

The 13<sup>th</sup> European Health Forum Gastein took place on 5-9 October in Bad Hofgastein, Austria and was entitled "Health in Europe, ready for the future?". Several discussions were dedicated to the ageing of the population and health literacy to empower citizens to engage in prevention measures to remain in good health and age better. It was emphasised that health is nevertheless intertwined with labour market, economic and social policies that need to be included in health policy discussions. Innovation in terms of disease management, care (be it long-term care, formal or informal care), new technologies,

employment strategies, living environment is key to unlock the challenges of an ageing population and reduce inequalities in Europe. This was in particular highlighted by Health Commissioner John Dalli at the closing session and Antonia Parvanova, MEP and European Alzheimer's Alliance member who closed the second Healthy Ageing forum.

Two fora were dedicated to the ageing of the European population and to how the health systems, the policy makers and stakeholders can provide responses to the challenges of the demographic change.

Alzheimer Europe participated in the panel discussion of the second forum that focussed on the responses and actions to the demographic change and future of health along with representatives from the European Commission, the Health Ministry of Taiwan, Eurocarers, the Social Science Research Centre in Berlin and the vdek-Verband der Ersatzkassen in Germany.

#### 6 October 2010: European Commission presents the Innovation Union

On 6 October 2010, the European Commission presented the "Innovation Union", one flagship of the EU 2020 Strategy. 'Innovation Union' is a strategic approach to innovation, driven by the highest political level. It will rally Europe's efforts on challenges like health and ageing, alongside climate change, energy and food security.

The strategy will stimulate the private sector using public sector interventions and seek to remove the bottlenecks that stop ideas from reaching the market.

Elements of the 'Innovation Union' will include:

- European Innovation Partnerships which will mobilise a wide range of European, national, regional, public and private stakeholders behind well-defined goals in areas which combine tackling societal challenges with potential for Europe to become a world leader. The Partnerships will step up R&D, coordinate investment, speed up standards and mobilise demand. The Commission will provide "seed corn" funds to attract stakeholder funding. The aims of the innovation partnership are to enable the EU citizens to live longer independently in good health by increasing the average number of healthy life years by two.

In achieving this target, the sustainability and efficiency of the EU social and healthcare systems will be improved, and an EU and global market for innovative products and services with new opportunities for EU business will be created.

A pilot partnership on active and healthy ageing will be launched early 2011.

- A stepping up of existing research initiatives. The Commission will thus propose measures to complete the European Research Area by 2014 with more coherence between European and national research policies, cutting red tape, removing obstacles to researchers' mobility

and maximising open access to results of publicly-funded research. Framework Programme (FP) 8 will be designed to support Europe 2020. The European Research Council and the European Institute of Innovation and Technology will be further developed. The Commission will reinforce the scientific base for policy making through its Joint Research Centre.

- The launch by the Commission, in 2011, of a major research programme on public sector and social innovation as well as a European Social Innovation Pilot to provide expertise for social innovators. Social innovation will be proposed as a focus of European Social Fund programmes. Social partners will be consulted on how to spread the innovation economy to all occupational levels.
- An invitation to Governments to set aside dedicated budgets for public procurement of innovative products and services. This should create a procurement market worth at least EUR 10 billion a year for innovations that improve public services. The Commission will offer guidance on joint procurements between contracting entities from different Member States.
- A legislative proposal by the Commission, in early 2011, to speed up and modernise standard-setting to enable interoperability and foster innovation.
- Proposals by the Commission, in 2011, for a European knowledge market for patents and licensing.
- A review of structural funding and state aid frameworks in order to boost innovation. The Commission will assist Member States to use better the € 86 billion of structural funds programmed for research and innovation for 2007-13. It will propose a framework for post 2013 Structural Funds with more focus on innovation.

The Innovation Union will be discussed at the Competitiveness Council on 12 October 2010 and at the European Council in December 2010. Its progress will be monitored as part of the governance of the Europe 2020 Strategy and an annual Innovation Convention will discuss the state of the Innovation Union.

#### 11 October 2010: European Commission organises workshop to discuss healthy and active ageing in Europe

The European Commission (DG Health and Consumer Policy) organised the "Health Ageing workshop: adaption of health systems" which was one in a series of 3 workshops to discuss a shared vision on health and active ageing in Europe (1 - adapting the health systems to the future demographic, 2 - meeting the health needs of older people through innovation and technology and 3 - keeping older consumer active).

The areas identified for discussions and improvement in this workshop were in order of: social priorities and

equity, self management and formal and informal long-term care, fit for purpose (in the sense that the current situation may not fit the specific needs of the elderly population), funding of health systems for old people, training and education, greater priority to health promotion.

The new ideas to shape policy identified during the workshops will be further developed within the context of the EU 2020 strategy, in particular the pilot partnership on Healthy and Active Ageing, 2012 as the European Year of Active Ageing and Intergenerational Solidarity, and the EU Public Health policy strategy.

**11 October 2010: Results published on European survey on mental health**

The European Commission has published the results from its Eurobarometer survey on the self perceived Mental Health of European citizens. The survey was conducted in early 2010 in the 27 Member States of the European Union.

The survey revealed that during the 12 months preceding the survey:

- 15% of respondents across EU Member States sought professional help for psychological or emotional problems.
- 7% took antidepressants, mostly for depression or anxiety.
- there is still stigma attached to mental disorders, with 22% of those surveyed saying they would find it difficult to speak to a person with a "significant mental disorder".

The results will be discussed during the next thematic conference under the European Pact for Mental Health and Well-being.

**28 October 2010: UN seminar raises awareness of human rights of vulnerable groups in residential institutional care**

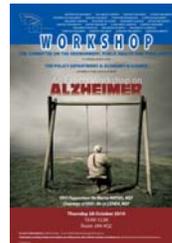
The United Nations Human Rights Office of the High Commissioner, Europe Regional Office organised the international seminar on human rights of persons in institutional care (Forgotten Europeans – Forgotten Rights) in Brussels, Belgium.

Discussions and presentations focused on issues relating to the human rights of children, elderly people and people with disabilities in need of care and support in settings other than their home environment, on the need to develop clear standards and on the need for governments to develop community-based alternatives to institutional care. Several NGOs were present (e.g. linked to family carers, independent living, mental health, disability and survivors of psychiatry). One of the overall aims of the seminar was to raise awareness of policy makers in the EU of the human rights of vulnerable and often invisible groups who are either in residential institutional care or risk going into it.

Alzheimer Europe (which was represented by Dianne Gove, Information Officer and Annette Dumas, Public Affairs Officer) hopes to remain involved in these discussions and to ensure that the specific situation

of people with dementia is recognised and understood.

**28 October 2010: Workshop on Alzheimer's disease and European Initiative organised**



The European Parliament Committee on the Environment and Public Health organised a workshop on Alzheimer's disease and an exchange of views on the report on a European initiative on Alzheimer's disease on 28 October in Brussels, Belgium.

Dagmar Roth-Behrendt, MEP (Germany) and Vice-Chair of the European Alzheimer's Alliance presided over this workshop that brought further food for thought to the Committee's discussions on the report on a European initiative on Alzheimer's disease and other dementias for which Marisa Matias, MEP (Portugal) and member of the European Alzheimer's Alliance has been appointed as Rapporteur.

Nick Fahy from the European Commission reminded participants that, while the EU has no competence in health decisions, the Commission will continue facilitating European initiatives that will support the Member States in tackling dementia. He particularly mentioned the European Commission Communication on Alzheimer's disease, the EU Action Plan on Dementia and the EU 2020 pilot partnership on Healthy and Active Ageing that must encompass dementia.

Jean Georges, Director of Alzheimer Europe presented the political priorities of the organisation and used the opportunity to thank Members of the European Parliament for their support for the organisation's campaign to make dementia a European priority.

The Committee is aiming to adopt its report in November with a vote in plenary in December or early January.

**Policy Watch**

In this section you can find articles on various national policies and initiatives which can have an impact on issues surrounding dementia.

**13 September 2010: Czech national Alzheimer Plan announced**

The government of the Czech Republic has invited, amongst others, the Ministry of Health, Ministry of Labour and Social Affairs, the Ministry of Finances and the Ministry of Justice to collaborate and prepare a "Plan Alzheimer" by June 2011.



The Czech Alzheimer Society has said it is delighted that its proposal for a national Alzheimer's Plan was taken up by the Committee for Seniors and Population Ageing, who in turn recommended it to the Czech government on 13 September. The Chair of the Czech Alzheimer Society,

Iva Holmerová (pictured left), will be able to

participate in the discussions regarding the national Plan as she is the coordinator on behalf of the Ministry of Social Affairs.

The announcement of a national plan has, say the Czech Alzheimer Association, created a huge amount of media coverage.

**7 October 2010: Alzheimer drugs ruled to be cost effective according to NICE**

 The National Institute for Health and Clinical Excellence (NICE) ruled that Alzheimer's disease medications are cost effective and should be available on prescription. If the draft decision is upheld, three drugs – Aricept, Exelon and Reminyl – would be available on the National Health System (NHS) for people in the early and moderate stages of Alzheimer's disease. These treatments have up to now been restricted to people in the moderate stages. A fourth drug, called Ebixa, would also be made available to people in the moderate to late stages.

NICE is inviting people to comment on the draft decision by 28 October, with a second meeting of the Appraisal Committee taking place on 25 November. The latest decision has been taken as part of a review cycle of Alzheimer's drug treatments by NICE.

**22 October 2010: Portuguese Parliament recognises dementia as a national priority**

At the Portuguese National Assembly, the Portuguese Parliament approved two resolutions (Projecto de Resolução n.º 265/XI/2 and Projecto de Resolução n.º 287/XI/2.<sup>a</sup>) proposing the recognition of dementia as a national priority and called for a Dementia National Plan to be drafted.

Alzheimer Portugal has played a pivotal role in this development. In October 2009, Alzheimer Portugal invited five members from Parliament to its annual conference which focused on current policies in several European countries (for example, the French National Plan and the Malta Strategy). At this conference each of the five MPs gave their personal commitment to ensure dementia become a priority in Portugal. Before October 2009 no political decision maker had talked about dementia, consequently, securing the MPs' personal commitment was a significant achievement.

The Parliament's approval of the two resolutions and call for a Dementia National Plan comes a year after the 2009 Alzheimer Portugal conference. Maria do



Rosário Zincke dos Reis, the Chairperson of Alzheimer Portugal commented, "this is a very meaningful step forward on the European dementia movement lead by Alzheimer Europe. The challenge of creating a National Dementia Plan is enormous and its implementation will depend on the serious involvement not only of the national and local policy makers, but also and largely, of the economic and social stakeholders and of the society as a whole.

"A special role will be played by Alzheimer Portugal as the only national Alzheimer's organisation in Portugal that, since 1988 promotes the quality of life of people with dementia and runs specific facilities and services for them and their carers."

**25 October 2010: Finnish Minister announces first steps towards the development of a Finnish dementia plan**

The Finnish Ministry of Health announced plans for the development of a Finnish Alzheimer's Plan and started the nomination process for members of the working group who will report by the end of next year

**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)

**27 October 2010: 44 organisations come together with the aim of improving the lives of people with dementia**

 The Dementia Action Alliance is launching a charter to improve the lives of people with dementia. The Alliance includes the Alzheimer's Research Trust, Alzheimer's Society, BUPA, Dementia UK, the Royal College of Psychiatrists, Royal College of General Practitioners and Stroke Association. Ruth Sutherland, interim chief executive of the Alzheimer's Society, said the alliance provided an "unprecedented opportunity to bring about real change for people with dementia".

One of their pledges is to reduce the use of anti-psychotic drugs for people with dementia. The drugs which are prescribed to treat aggression, agitation, shouting and sleep disturbance are believed to cause around 1,800 deaths a year in the UK and according to a Government-commissioned review there are about 145,000 people with dementia being wrongly prescribed these antipsychotic drugs.

Care Services Minister Paul Burstow said: "This dementia Declaration shows tremendous commitment from across health and care services and the voluntary sector, to transform services and tackle stigma to make a difference for people with dementia and their families. Willingness to join forces to act should spur more organisations to join this movement for change."

To help make decisions regarding the use of antipsychotic drugs the Alzheimer's Society released a list of questions which people with dementia and their carers should ask:

- What is the treatment being prescribed for and are the drugs appropriate for this?
- What are the benefits and risks of the treatment?
- How long has the person with dementia already been on the treatment? (It should be no longer than 12 weeks).
- What are the alternative non-drug and drug treatments? Why isn't the person with dementia receiving access to these alternatives?
- Does the person have capacity to give informed consent to continue treatment?

- If the treatment is continued and the person does not have capacity, will there be a best interest meeting to fully discuss all of the options?
- How long will the person with dementia remain on the treatment for and what are the arrangements for monitoring and reviewing the medication?

## Members' News

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

### 30 September 2010: Alzheimer Society benefits from corporate partnership with KPMG

The two-year partnership between the Alzheimer Society and the consultancy firm KPMG ended on 30 September. The partnership aimed to raise money and awareness of the disease and also offered an opportunity for employees of KPMG to do pro bono consultancy work for the charity. Awareness of dementia was raised among KPMG employees through drop-in lunchtime sessions at the firm's offices. The fundraising target of GBP 750,000 was more than achieved with a final figure being GBP 1.06 million.

The director of fundraising and marketing at the Alzheimer's Society, Jo Swinhoe, said that the partnership had made her realise how much charities can gain from corporate partnerships saying, "you need to think about what you can learn from them as a business. The money raised makes a difference now, but this other work can help make us more efficient in the long term."

### 1 October 2010: Czech Alzheimer Society participates in a project aimed to develop the quality of care for old people in residential care homes

Last year, the Czech Alzheimer Society, in collaboration with the regional government of South Moravia, developed a project known as Gerontologická a organizační supervise (GOS) - Gerontology, Management and Supervision. The aim of the project is to develop the quality of care (especially care for people with dementia), by focusing on gerontological practice, ethical issues, non-pharmacological methods, end-of-life care, management of care, supervision and staff development. Following an evaluation of the first year of the project, it has been recommended that the Czech Alzheimer Society continue to develop this project further. A collaboration between the Faculty of Humanities (Charles University), the Czech Alzheimer Society and the Centre of Gerontology, Prague is taking place to now implement this project.

The GOS project coordinators are Mgr. Dana Hradcová (Charles University in Prague), Mgr. Martina Mátllová (Czech Alzheimer Society), Prof. Iva Holmerová (Centre of Gerontology) and the project teams involve experts from different fields:

- Mgr. Dana Hradcová and Mgr. Petr Vrzáček – management, staff support and development,
- Prof. Holmerová - gerontology and geriatrics, dementia, Prof. Haškovcová - ethical issues,
- Mgr. Mátllová – care for persons with dementia, quality of care,
- Ms. Hýblová – practical aspects of care for persons with dementia,
- Mgr. Jitka Suchá – non-pharmacological methods for persons with dementia, occupational therapy for persons with dementia and others.

### 1 October 2010: Alzheimer Switzerland raises awareness with an information bus project

Alzheimer Switzerland has been raising awareness of dementia and the issues which surround this disease by using a mobile information bus, known as InfoMobil. For a period of 4 weeks the bus travels around a particular county, going from village to village and town to town. Each day the bus is manned by 2-3 volunteers who provide regional information for people with dementia and their carers. Six (out of 21) counties throughout Switzerland have used the InfoMobil in 2010 and already eight counties have made bookings for 2011.



The media coverage and feedback on this initiative has, say Alzheimer Swiss, been tremendous. The Association plans to continue the InfoMobil project to reach out to people in other counties

throughout Switzerland during 2011 and 2012.

### 8 October 2010: Alzheimer Society of Ireland calls on government to protect basic levels of service for people with dementia and their carers

The Alzheimer Society of Ireland has warned the Irish Government that further funding cuts to its services in the forthcoming Budget will result in some of the 44,000 people living with dementia and their 50,000 carers left without even basic support through community services. The Society has outlined the investment that it needs to maintain its services levels in 2011 in the document at its pre-budget submission 2011. The Society, which calculates the total package of funding required in 2011 to be EUR 19.81 million, calls on the government to protect basic levels of service by:

- Protecting current community services provided by the Alzheimer Society of Ireland nationally (funding requirement EUR 14.61 million)



- Extending current levels of services to the 1,000 people on waiting lists nationally (funding requirement EUR 4.6 million)
- Ensuring the 4,400 younger people with dementia have a regional Case Management Service (funding requirement EUR 350,000)
- Promoting risk reduction and prevention of dementia in the general public, through public health campaigning in order to delay the onset of dementia (funding requirement EUR 250,000).

These calls are supported by findings in the report entitled "An economic perspective of dementia care in Ireland" which the Alzheimer Society has produced with health economist, Dominic Trepel of the University of Limerick. The report outlines the economic case for urgent investment in dementia services in Ireland in order to have more community services. It also highlighted the fact that Ireland "spends only half of the OECD average on dementia services, despite the fact that it is predicted that Ireland faces the largest growth of dementia of all European countries in the coming decades."

The report was presented by Dominic Trepel at the pre-budget submission who said, "The economic cost of dementia ranks higher than stroke, heart disease and cancer combined. However, health care allocations for dementia continue to be substantially lower than each of these individual disease groups... My report shows the cost-effectiveness of supporting carers through home care relief and day care relief and other community services. Dementia caregivers who can access these services can care for longer, which is what they dearly want to do; this ultimately acts to lower health care costs and reduce the need for long term beds."

The Society also revealed at the launch of its pre-budget Submission that "for every EUR 18,500 cut from existing Health Service Executive (HSE) funding, four people with dementia and their carers will lose their service and one Alzheimer Society of Ireland job will be lost" and that "carers are at crisis point as figures show waiting lists for dementia services have shot up by 3% in the last year." In addition, an Alzheimer Society of Ireland survey showed that 68% of carers believe the Government's action on dementia is poor.



Alzheimer Society of Ireland CEO Maurice O'Connell said: "The Alzheimer Society of Ireland fully recognises the challenges of the current economic situation and its impact on the state and its citizens. However, we are acutely aware of the increasing numbers of people affected by dementia, their growing

health and social care needs and the cost to the state if waiting lists are not cleared."

He added: "Dementia is a disease that affects at least one family in every street around the country. We must act now to plan for the future. I firmly believe that the argument for our Pre-Budget demands for 2011 is not just a moral one but importantly an economic one too."

### 10 October 2010: German Alzheimer Society holds its 6th Conference

The 6th Conference of the German Alzheimer Society was entitled "Community life" was held in Berlin on 9 October 2010. 880 participants from all over Germany took part.

During the panel discussion, "Community life – perspectives for the future" the moderator, Burkhard Plemper asked Helga Rohra (who was diagnosed four years ago with Lewy body dementia) what had prompted her to be public about her disease. Helga replied: "I am going to argue for the rights of people with dementia. Immediately after the diagnosis I became a board member of the Alzheimer's Society in Munich, and am still on it now. There, I find human warmth and expertise that has given me strong support... It has given me lot of strength to speak at this conference. I would like to pass on to others."

Different ways of supporting people with dementia were discussed including Alzheimer cafes, counselling centres and specialised training courses for employees (in banks, supermarkets, taxi drivers, police officers and fire-fighters) which help people to recognise the signs of dementia and to help, in a sensitive manner, people who have dementia. The importance of awareness of dementia in society was also raised.



Heike von Lützu-Hohlbein, chairperson of the national Alzheimer's association said that the European Union can put pressure on member countries, but that everyone has part to play, including the

media who can raise awareness of the issues of ageing and dementia.

Awards were given to various projects including those by:

- Prof. Dr. Sabine Engel (Institute for Psycholinguistics Gerontology at the Friedrich-Alexander University Erlangen-Nuremberg) and Semra Altinisik (Neuperlach Hospital, Centre for Geriatrics and early rehabilitation) for their research project "EduKationTÜRKISCH. This project aims to help people with dementia by promoting communication among Turkish migrants with dementia and was awarded EUR 68,000.
- Gudrun Ulbrecht, Birgit Eichenseer (Area Medical Psychology and Medical Sociology of the Psychiatric University Clinic Erlangen, Germany) and Hans-Dieter Mückschel (family counselling, Nuremberg) for their project: "Improving the quality of life, motor function, cognition and quality of relationships at home living with dementia through targeted exercise training, dancing, or sensorimotor training in groups of relatives". This project was awarded EUR 73,000.
- Dr. Karl and Ruth-Schoenwald Foundation (received by Prof. Dr. Stefan Görres and Dr. Martina Stöver, Department of Public

Health and Nursing Research at the University of Bremen) for their project "Dementia Sensitive non-drug approaches in nursing schools : National Census of teaching nursing skills in training, which contribute to sustainable improvement in the care of people with dementia in acute hospitals ". This was awarded EUR 35,000 and

- Dr Harriet Heier, Hartmut Emme from Ahe, Harmut Schilling, who were awarded the EUR 10,000 "Hertie – Award for commitment and self-help" for the project "self-help groups for people with early dementia".

Concluding the conference, Heike von Lützuau Holhbein said "Listen to what people with dementia have to say and refer to them. People with dementia are part of our society. Only then will we live in community."

**11 October 2010: Alzheimer Uniti, Italy, opens new Alzheimer Café in Rome**



Alzheimer Uniti (AU) has opened its second Alzheimer Café in a highly-populated district of Rome. The café has two purposes: first, to allow families to get to know each other and share their experiences; second to offer a relaxed environment without embarrassment.

The Café was organised by AU with the help of a group of general practitioners in a locality that includes a coffee shop, book store and a shop that sells books, gift items and food from countries in the Southern Hemisphere and has the appropriate name of "360° Sud" (360° South).

At the opening ceremony, Luisa Bartorelli, president of AU, greeted the families and toasted the day with a glass of prosecco for everyone! She asked that the participants spread the word of this café to other families in the neighbourhood.

**21 October 2010: Alzheimer Society's communication team wins award**



The Communication team of the Alzheimer's Society won the 'PRWeek non-profit department of the year' Gold Award.

Commenting on the award, Senior Press Officer Hannah Clack said, "This is fantastic news for the Society and it recognises the hard work of many individuals and teams. As well as being very proud of my colleagues I am hugely grateful to all of the campaigners, fundraisers and spokespeople who have responded to our requests and helped us to build such a strong profile for people living with dementia."

In addition, Andrew Ketteringham, the Alzheimer Society's Director of External Affairs, said, "We are delighted. It represents a huge amount of work that was put in last year, when the Government's National Dementia Strategy was being implemented. The society has not only been instrumental in getting that under way, but has done a lot more besides".

**27 October 2010: Scotland celebrates 21 years of Dementia helpline**



Alzheimer Scotland 's free-phone 24 hour Dementia Helpline (the only one of its kind in the UK and one of only two in the whole of Europe) celebrated its 21st anniversary at a civic reception in Edinburgh Castle on 27 October.

The reception, hosted by Shona Robison MSP, Minister for Public Health, was attended by numerous Alzheimer Scotland staff and volunteers who have been involved in the Dementia Helpline since it began in 1989. Ms Robison said, "I'm delighted to be invited to mark Alzheimer Scotland's Dementia Helpline's 21st birthday, in recognition of the valuable service it offers to people with dementia, their carers and families. I know there are many people who devote their time to ensuring that the service is available around the clock. I wish them all every success for the future in continuing to provide this important source of information and support on dementia."

Helpline Manager, Elaine Harley, said, "The Dementia Helpline takes thousands of calls every year and is a lifeline to many people with dementia, carers and families across Scotland. We are incredibly proud of this vital service and of the important role it plays in seeking to ensure that no one goes through dementia on their own. We're very grateful to all those who have manned the Helpline over the past 21 years."

Alzheimer Scotland's Dementia Helpline relies almost entirely on donated income and is manned 24 hours a day, 365 days a year. Approximately 71,000 people in Scotland have dementia and 7,500 people are diagnosed with the illness every year.

**30 October 2010: German Alzheimer Society launches a DVD and its 2011 calendar**

During October the German Alzheimer Society has:

- published the DVD "Living with FTD" (fronto-temporal dementia). The DVD includes three documentaries illustrating the impact living with FTD can have. Produced in the Netherlands, the DVD has German subtitles and costs EUR 15.
- Helped to develop the website "leitlinie.de www.demenz", which provides information on dementia for family members, nurses and doctors. The section of the website aimed at relatives of people with dementia has now been fully translated into Russian and Turkish. The site was developed as part of a German Federal Ministry of Health funded project in cooperation with the German Alzheimer Society.
- Produced its 2011 calendar, which contains twelve pictures painted by people with dementia and costs EUR 10.

## World Alzheimer's Day in Europe

Last month we reported on several of our organisations' activities for World Alzheimer's Day, which was on 21 September. Below is more news about members' work to mark World Alzheimer's Day.

### 21 September 2010: The Romanian Alzheimer Society marks World Alzheimer Day



The Romanian Alzheimer Society organised a number of events to mark World Alzheimer's Day on Tuesday 21 September. Society volunteers participated in the free MMSE tests which were offered by 12 pharmacies in Bucharest. The Society also handed out information regarding Alzheimer's disease to whomever was interested. In the



afternoon there was a press conference with the president of SRA (Alzheimer Romanian Society), dr. Catalina Tudose. This was followed by the „Philharmonia” orchestra delighting a lot of carers and people with Alzheimer's disease with some well known pieces from Enescu, Corelli, Vivaldi, Silvestri and Mozart.

### 22 September 2010: The Cyprus Alzheimer Association celebrates World Alzheimer Day

For the World Alzheimer's Day 2010, the Cyprus Alzheimer Association organized a number of events. All the events aimed at raising awareness among the public.

The main event took place in Nicosia on Wednesday 22<sup>nd</sup> September 2010. It was a pleasant music event under the auspices of the Minister of Health Dr. Christos Patsalides. The Minister attended the event, gave an inspirational speech and pledged his support towards the Alzheimer cause.

During her welcome speech the President of the Cyprus Alzheimer Association, Mrs.



Antigoni Diakou referred to the role of the association, the work done by the volunteers and the close cooperation with the Ministry of Health. She also emphasised on the important role of Alzheimer's Disease International (ADI) and Alzheimer Europe.

In September 2010, a new team of volunteers came together in the Famagusta area, thus covering now the whole of Cyprus. These volunteers set up a kiosk between 24-26 September 2010, handing out free leaflets and giving information about Alzheimer's disease. The Famagusta volunteers held a successful 'Cheese and Wine' garden party in October 2010. Mr. Antonis Tsokkos, the Mayor of

Ayia Napa (which is a major municipality in Famagusta), congratulated the volunteers and also promised his full support.

### 19 September 2010: Greece (Athens) supports World Alzheimer's Day



The Greek Athens Alzheimer association generated a lot of media coverage during their celebrations of World Alzheimer's Day, which included:

- An information kiosk at the central metro station for four days. Staff and volunteers handed out over 10,000 information packs about dementia.
- A Memory Walk on 19 September. Some 3,000 people (including people with dementia, their carers) took part. This was also supported by the Minister of Health, the Mayor of Athens and other Greek politicians.
- A petition supporting the Greek Alzheimer's initiative was signed by 18,000 people and presented to the Minister by people with dementia.

### 21 September 2010: Alzheimer's Day celebrated in Denmark



The Danish Alzheimer's Association carried out an awareness campaign entitled "Remind and Remember" by sending out 80,000 yellow 'post it' notes (one for each person in Denmark who suffers from dementia) on World Alzheimer's Day. On



the notes were printed words like 'bicycle', 'door' and 'shopping trolley'. The notes were placed on the relevant items by local volunteers to remind people all over Denmark of those who cannot remember. On the back of the notes were references to the Alzheimer's Association.

In addition, two well-known Danish TV chefs created a fancy cake to be sold on the World Alzheimer's Day. The cake was named 'Huskekage', Remembrance Cake. 38,731 cakes were sold, and the chairman of the Danish Alzheimer's Association, Anne Arndal, went to the Danish parliament to give a Remembrance Cake to each of the 179 members.

A representative of the Danish Alzheimer's Association said that "these activities on the World Alzheimer's Day made a strong impression on the public and the press in Denmark. Dementia and the Alzheimer's Association became the talk of the day."

### 21-25 September 2010: Portugal celebrates World Alzheimer's Day



World Alzheimer's Day was celebrated throughout Portugal with awareness raising events about Alzheimer's disease and ways in which to involve people with dementia and their carers in activities which promote

well-being. The events were organised and promoted by the various branches of Alzheimer Portugal. National and local media supported these events and also reported on Alzheimer Portugal's press release to recognize dementia as a national priority. The celebration included events held in:

**Lisbon:** People with dementia, their carers and the staff of the Alzheimer's Day Care Centre came together and enjoyed listening to two guitarists (João Moreira Rato and Rúben Morais), who played several "fados".

**Central Portugal:** A seminar entitled "Remember Alzheimer" was given which included a large panel of experts on Alzheimer's disease. This was supported by local policy makers.

**Northern Portugal:** Alzheimer Portugal attended and participated in several activities including:

- A presentation "III Show of Health of Vila Nova de Gaia".
- Lectures including the theme "Caring for the person with Alzheimer's disease" and "Caring for Seniors with Alzheimer's disease".
- The congress, "Third National Congress of Brain Ageing and Alzheimer's Disease".
- A lunch in the City Park of Oporto, in which people with dementia and their carers participated.
- A visit to the Tram Museum and a ride on the tram for people with Alzheimer's disease and their carers.
- A Salon on Dementia at the Hospital Magalhães Lemos Amphitheatre. Sara Sousa, Occupational Therapist in the Association, attended this along with several health professionals.
- A fundraising dinner in Madeira which enjoyed the support of around 140 people.

Also a solidarity meeting was held at, what will be, Alzheimer Portugal's first nursing home "Casa do Alecrim" (The Rosemary House) for people with dementia. More than 130 volunteers (many of whom work for one of Alzheimer Portugal's sponsors, Generali) helped to prepare garden areas, paint walls and decorate the rooms.

**25 September 2010: Alzheimer association in Iceland hosts a conference to mark World Alzheimer's Day and celebrates its 25th anniversary**



The Alzheimer association in Iceland, Félag aðstandenda alheimersjúklinga (FAAS), hosted a conference on Saturday, 25 September, to mark World Alzheimer's day. Fanney Proppé Eiríksdóttir, Chairman of FAAS Iceland, said: "It was a whole day of working together, exchanging ideas in a workshop as to how we and our clients want to see the organisation work in the next 10 years. There was also time for lunch, some amusements and interesting lectures.

Ms.Vilborg Ingólfssdóttir from the Department of Administration and Human Resources, addressed the assembly. Dr. Jon Snædal held a lecture "Known facts about the Alzheimer disease." Results from a survey regarding how people are diagnosed with Alzheimer's disease and the effects of the disease were presented in the lecture "Life after Alzheimer's disease diagnosis" which was given by Erla Gretarsdóttir, Psychologist. Last, but not least, Ms. Halldora Arnarsdóttir, an art historian and an Icelander now residing and working with people with Alzheimer's disease in Murcia, Spain, had a lecture in regards to memory workshops in which she shared some very interesting and new approaches. All in all it was a good day with over 100 people attending both the workshop and the lecture programs.

"We also celebrated our 25<sup>th</sup> anniversary. FAAS was founded in March 1985 and we were lucky enough to be able to host a party in March where all five previous and current Chairpersons attended. The first Chairperson, and one of the founding members of FAAS is Ms. Gerdur Palmadóttir, who now resides in The Netherlands. It was our pleasure and honour to greet her and especially to make her the first honorary member of FAAS. We created a special anniversary edition of our magazine "FAAS frettir", with a new look."

**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)

## Forthcoming members' events

**19 February 2011: Romanian National Conference**



The first announcement of the forthcoming 2011 National Alzheimer Conference in Romania has been made by the Romanian Alzheimer Society. Dr Cătălina Tudose, Chairperson of the Romanian Alzheimer Society, explained "All stages of dementia management will be debated – early symptom recognition, diagnostic criteria, early detection possibility as well as possibilities of differentiating the type of dementia in normal clinical conditions, etiopathogenic mechanisms, pharmacological and non-pharmacological therapeutic interventions, available care services, ethical and legal aspects."

There are also two pre-conference courses available:

Neuropsychological evaluation of the elderly and Brain neuro-imaging.

The conference will be held in the National Institute of Statistics, Bucharest, Romania and there is the possibility of a reduced registration fee if registration is made before 1 December 2010.

## 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.

### 5 October 2010: Study examines the use of MRI scans and the risk of cognitive decline

Radiologists who aimed to test whether magnetic resonance imaging (MRI) may help predict cognitive decline have found that "analysis of iron deposition at baseline performed with an SVM might help identify individual patients with mild cognitive impairment at risk for cognitive decline." By identifying people at risk at an early stage of cognitive decline, the researchers hope that the study could result in earlier and specific treatment.

The study, led by Sven Haller from the Department of Diagnostic and Interventional Neuro-radiology, DISIM, University Hospitals of Geneva, rue Gabrielle Perret-Gentil 4, 1211 Geneva 14, Switzerland was published on-line in the journal Radiology.

### 6 October 2010: Study suggests potential biomarker for Alzheimer's disease

A study which aimed to "develop an algorithm that separates patients with Alzheimer's disease by controls" has found that "serum protein-based biomarkers can be combined with clinical information to accurately classify Alzheimer's disease.

The study was conducted by researchers from the Southwestern Medical Center, USA and colleagues and published in the journal Archives of Neurology.

### 9 October 2010: New Research criteria for the diagnosis of dementia proposed by International working group

The International Working Group for New Research Criteria for the Diagnosis of Alzheimer's disease has published a paper in the Lancet Medical journal which, they hope, will "advance the scientific discussion by providing broader diagnostic coverage of the Alzheimer's disease clinical spectrum and by proposing a common lexicon as a point of reference for the clinical and research communities." This would mean that diagnosis could be made at an early stage of the disease on the basis of biomarkers (such as those identified using a brain scan or a test known as cerebrospinal fluid (CSF) analysis) in people living with the disease together with episodic memory impairment.

The authors of the paper highlight the need for the debate saying: "The potential for drugs to intercede in the pathogenic cascade of the disease adds some urgency to this debate."

The working group was led by Prof Bruno Dubois, Pierre & Marie Curie University, Paris, Research Centre of the Institute of the Brain and Spinal Cord, Institute for Memory and Alzheimer's Disease, UMR-S975, AP-HP, Pitié-Salpêtrière Hospital Group, Paris, France and consisted of representatives from Canada, France, Germany, Italy, Japan, Netherlands, UK and USA.

### 10 October 2010: Study examines gene activity in the brain and Alzheimer's disease

A study from the Netherlands which examined brain tissue of deceased people who had Alzheimer's disease found that some 500 genes in the front part of the brain (para-hippocampal cortex) become extra active when there are still no visible symptoms of the disease and it was when these genes became less active that memory impairment became apparent. The researchers hope this will be useful for future drug treatment targets.

Led by Dick F Swaab of the 2 Neuropsychiatric Disorders Group, Netherlands Institute for Neuroscience, an Institute of the Royal Netherlands Academy of Arts and Sciences, The Netherlands, the research was published in the journal Brain.

### 11 October 2010: Animal study examines the development of potential beta-amyloid vaccine

Researchers claim to have developed an "experimental vaccine against beta-amyloid" (the protein associated with Alzheimer's disease). The researchers will now focus on the vaccine's ability to protect mental function in animals, as well as its safety.

The study's senior author was Dr Roger Rosenberg, director of the Alzheimer's disease Center at UT Southwestern Medical Center, USA and it was published in the journal Vaccine.

### 12 October 2010: Mouse study examines the relationship between type 2 diabetes and Alzheimer's disease

A study on mice (which had been genetically engineered to have Alzheimer's disease) found the gene known as proliferator-activated receptor coactivator 1 (PGC-1) decreased in Alzheimer's disease. PGC-1 is a key regulator of glucose and currently being investigated as a target for Type 2 diabetes. The researchers claimed that their study is the first to find that PGC-1 "is a common denominator between Type 2 diabetes and Alzheimer's disease" reporting that the decrease of PGC-1 "might be causally linked to the promotion of Alzheimer's disease."

The research was led by Giulio Maria Pasinetti, the Saunder Family Professor in Neurology, and professor of Psychiatry and Geriatrics and Adult Development at Mount Sinai School of Medicine and was published in the journal Aging Cell.

### 13 October 2010: Mouse study examines the role which the apoE4 gene plays in Alzheimer's disease

Researchers have found that mice which had been genetically engineered to produce human apoE4 lose a specific type of neuron (GABAergic interneurons) which is in the part of the brain associated with learning and memory. To enhance the GABA action, the apoE4 mice were administered injections of pentobarbital and this resulted in the learning and memory deficits being 'rescued'.

Further, the researchers examined the effects of apoE4 on a protein associated in Alzheimer's disease known as tau and found that when the tau was removed from the apoE4 mouse that the loss of the GABAergic interneuron stopped, preventing the loss of learning and memory functions.

The researchers concluded that, "reducing Tau and enhancing GABA signalling are potential strategies to treat or prevent apoE4-related Alzheimer's disease".

The study was led by Yadong Huang, University of California, San Francisco, USA and it was published in the Journal of Neuroscience.

**13 October 2010: Mouse study examines the relationship between plant compound and memory**

A mouse study suggests that a diet rich in a plant compound known as luteolin may "reduce age-related inflammation in the brain and related memory deficits by directly inhibiting the release of inflammatory molecules in the brain." Luteolin is found in plants including carrots, peppers, celery, olive oil, peppermint, rosemary and chamomile.



The research was led by Rodney W Johnson, University of Illinois, Urbana, USA and published in the Journal of Nutrition.

**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)

**13 October 2010: Mouse study investigates drug treatments and the blood brain barrier**

A mouse study suggests that, unlike many drugs, the microtubule-stabilising agent known as epothilone D is capable of crossing the blood-brain barrier and that a 3 month treatment, amongst other things, reduced cognitive deficits. This led researchers to call for further testing in the hope that the drug could be eventually used to treat people with Alzheimer's disease.

Senior authors were virginal MY Lee, Director of the Center for Neurodegenerative Disease Research (CNDR), University of Pennsylvania and John Trojanowski. The research was funded by the National Institute on Aging and the Marian S. Ware Alzheimer Program and published in the Journal of Neuroscience.

**13 October 2010: Study examines the relationship between walking and brain grey matter volume**



A study on nearly 300 people from the Cardiovascular Health Study monitored the association between grey matter volume, physical activity and cognitive impairment. Nine years after the physical assessment brain scans were taken and 13 years after baseline clinical adjudication for cognitive impairment took place. The researchers found that "Greater amounts of walking are associated with

greater gray matter volume, which is in turn associated with a reduced risk of cognitive impairment".

The study was published in the journal Neurology and the author was KI Erickson PhD, the University of Pittsburgh, Pennsylvania.

**14 October 2010: Results of US survey on carers of people with dementia published**

A US survey on over 500 carers of people with dementia found that:

Difficulties faced by caregivers

- Over half of the carers surveyed said that caring for their loved one has taken a toll on their own health
- Women surveyed were more likely to worry "all the time" compared to men. Also, women were less likely than men to feel that they have enough support to take care of themselves and their own needs
- Over half of the carers of people with dementia who were surveyed said they feel overwhelmed
- Women surveyed were more likely to consider "maintaining relationships with family or friends" as a challenge compared to men
- A high proportion surveyed said caring frequently stops them from participating in activities that they enjoy, which was more than reported by the carers of people with mild or moderate Alzheimer's disease.

Concerns about disease progression

- The carers' three greatest concerns for those they cared for as the disease progressed were memory loss, personal safety and confusion (27%)
- Over half of the carers of people with dementia who were surveyed named at least one change in cognitive symptoms as a main concern about the progression of their loved one's Alzheimer' disease
- Men surveyed were more likely to be concerned about memory loss compared to women.

Discussions with Health care professionals

- Men surveyed were more likely to be satisfied with communication with their health care professional compared to women
- Also, men were more likely to regularly discuss options for information or support
- Just over half of carers of people with Alzheimer's disease surveyed who said they were not very involved (somewhat or not at all involved) the interactions with their health care professional, were dissatisfied with their loved one's treatment.

The survey was carried out by on behalf of Eisai Inc., Pfizer Inc., and the Alzheimer's Foundation of America.

**18 October 2010: Study examines the relationship of vitamin B12 components and the risk of incident Alzheimer's disease**

A Finnish study on over 250 people suggests that the protein homocysteine (tHcy) and the protein of vitamin B12, holotranscobalamin, (holoTC) may play a role in the development of Alzheimer's disease. The researchers found that for "each small increase of tHcy the risk of Alzheimer's disease also rose but that with each small increase in vitamin B12 the risk of Alzheimer's disease dropped."

Led by B. Hooshmand, Karolinska Institutet, Sweden the article was published in the Journal of Neurology.

**25 October 2010: Study investigates the long-term association of amount of smoking in middle age on the risk of dementia**

A study involving analysis of data from a cohort of 21,123 members of a health care system suggests that "heavy smoking in midlife was associated with a greater than 100% increase in risk of dementia, Alzheimer's disease, and vascular dementia more than 2 decades later. These results suggest that the brain is not immune to long-term consequences of heavy smoking."

Researchers from Finland, Sweden and the USA conducted the study which was published in the Archives of Internal Medicine.

**26 October 2010: Study examines the relationship between severe sepsis and cognitive impairment and physical functioning**

A study has found that older adults who "survive hospitalisation involving severe sepsis are at higher risk for cognitive impairment and physical limitations than older adults hospitalised for other reasons." The researchers said that the study highlighted the need to continue to address problems after the sepsis has been controlled.

Carried out by the University of Michigan and supported by the National Institute on Aging (NIA), the research was published in the Journal of the American Medical Association.

## Living with dementia

**13 October 2010: Book about a personal experience of dementia published**

Mike Livni, who served on the boards of Alzheimer's and Related Disorders Association (ARDA) in South Africa and of Alzheimer's Disease International (ADI), has worked in dementia care for over 20 years. He has written the book "The Japanese Therapists" in which he shares his own, first-hand experience of his being diagnosed with dementia. The book has not been edited as Mr Livni wishes the reader to



understand what it is like for him to have Alzheimer's disease.

The book was reviewed by Robyn Yale who said of the book: "What may at first seem scattered and disorganised quickly becomes quite engaging. One must admire the skill and courage it took to persevere in recording his story whilst simultaneously facing and integrating his decline. We are with him as he painstakingly write the book while poignantly searching for answers that were unknowable for quite some time". Of Mr Livni, Robyn Yale said: "After championing early stage work in his own country and internationally, Mike Livni now contributes to our understanding of the early dementia experience and reminds us of the power one can find to cope with it."

The Japanese Therapists costs USD 25 and can be ordered from [livni@corpdiol.co.za](mailto:livni@corpdiol.co.za)

## Dementia in society

**4 October 2010: Sir Norman Wisdom's children talk about their experience of his having dementia**



The well-known British actor and comedian Sir Norman Wisdom died aged 95 on 4 October 2010. He had dementia.

His son, Nick Wisdom spoke of the impact dementia had had on his father, saying, "His dementia and a series of ever-worsening mini-strokes were stripping him away, layer by layer. There were times he didn't know who we were or even know who he was. He would watch his films and not even recognise himself."

Jacqui Wisdom, his daughter also spoke of her father, saying, "He would glance up from reading his newspaper and blow me a big kiss. Five seconds later all the love would have drained from his eyes and he'd ask me politely who I was. It was hard having to say: 'I'm your daughter, dad.' That really upset him. Sometimes he would respond in a quiet, lost voice: 'I'm only joking.' But he wasn't. He still had good days when he was on top form. He was in his own little world but he was beautifully looked after and still a very, very cheeky little man." Jacqui added, "People with dementia need specialist care. We got a lot of flak for putting him in a home but it is not an easy decision for any child to make."

A memorial service is planned to take place in London on 4 February 2011, to mark the comedian's birthday.

**6 October 2010: US poll suggests that voters want Congress to make Alzheimer's disease a priority**

The independent advocacy network known as USAgainstAlzheimer's has published the results of a national survey carried out on 867 voters. The aim of the survey was to ascertain public attitudes to the disease and the findings suggest that

- 88% of registered voters believe it is important for Congress to make Alzheimer's disease a priority
- 2/3 of votes prefer to vote for a candidate who supports Alzheimer's funding
- 77% had been touched by the disease.

**19 October 2010: US football union to expand their assistance to players with dementia to include Lou Gehrig's disease**



Since 2007, the National Football League (NFL) has, under the 88 Plan, assisted former players with medical expenses related to dementia. The qualifications have now been expanded to include former players with amyotrophic lateral sclerosis, or Lou Gehrig's disease.

**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.

**1 October 2010: European Commission issues a newsletter dedicated to the International Day for the Elderly 2010**



On the occasion of The International Day of Older People on October 1st, The EU-Health

Portal of The European Commission has Issued a newsletter and dedicated to the Day. The newsletter includes a selection of EU and national initiatives, events and publications to Promote Healthy Ageing and well-being in old age and this edition is available in 22 languages on their website.

**15 October 2010: US journalist Maria Shriver raises awareness of dementia**



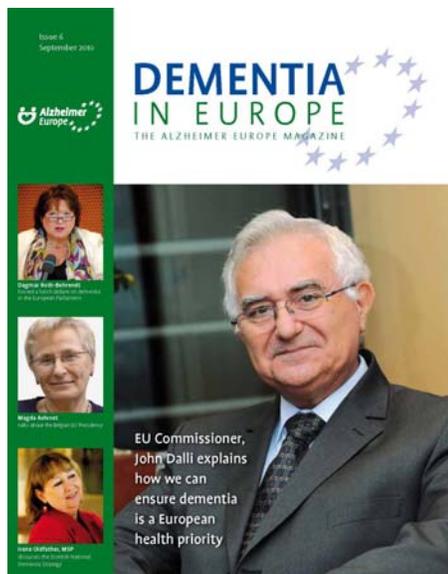
US journalist, Maria Shriver, has raised awareness of dementia by publishing a report and participating in a March on Alzheimer's disease.

Together with the Alzheimer's Association Ms Shriver has published "The Shriver Report: A Woman's Nation Takes on Alzheimer's". The report, which was backed by a poll of over 3,000 adults of which there were more than 500 carers of people with Alzheimer's disease, is an examination of the impact which Alzheimer's disease has on American women by analysing current approaches toward Alzheimer's disease and medical research. Personal experiences of living with dementia or caring for someone with dementia are also given in the report. The poll found that women constitute two-thirds of those who live with Alzheimer's disease and that 60% of carers for people with dementia are women.

In addition, funds were raised during the Maria Shriver March on Alzheimer's and candlelight vigil took place on October 24 in Long Beach, CA.

Maria Shriver's father was diagnosed with Alzheimer's disease in 2003.

**Order the latest Dementia in Europe Magazine from Alzheimer Europe**



**The Dementia in Europe magazine (issue 5)**

Issue 5 reports on the Alzheimer Europe lunch debate in the European Parliament on national dementia strategies in France and Germany, the national dementia strategy in Scotland, on legal developments in Switzerland and the services provided by national Alzheimer associations.

The magazine includes interviews with EU Commissioner John Dalli on his views on European action on dementia, Astrid Lulling, MEP (Luxembourg) on the situation of people with dementia and their carers in Luxembourg and Irene Oldfather, Member of the Scottish Parliament on the national dementia strategy in Scotland.

EUR 2.50 plus EUR 2.70 handling and postage costs

## AE Calendar

The following meetings will be attended by representatives of Alzheimer Europe

Date	Meeting	AE Representative
3-4 November	Steering Committee of the Alzheimer Europe "Value of Diagnosis" Project (London, UK)	Jean
8 November	Expert meeting in familial neuro-degenerative disorders at the European Medicines Agency (London, UK)	Jean
15 November	Meeting with Pfizer (Brussels, Belgium)	Jean
16 November	ILC Expert Working Group meeting on dementia in the European Parliament (Brussels, Belgium)	Jean and Annette
17 November	AGE conference on Elderly abuse in the European Parliament (Brussels, Belgium)	Annette
18 November	EFPIA Think Tank (Brussels, Belgium)	Annette
24 November	Meeting with AGE and presentation of AE's work (Brussels, Belgium)	Annette
25-26 November	Belgian EU presidency conference "Improving the quality of life of people with dementia: A challenge for European society" (Brussels, Belgium)	AE Board, Member organisations and staff
29-30 November	Training session on the review of product information as well as the plenary meeting at the European Medicines Agency (London, UK)	Julie and Dianne
30 November	ENVI vote on M. Matias report on a European initiative on dementia (Brussels, Belgium)	Annette
30 November-1 December	Council of Europe Seminar on decision making process regarding medical treatment in end-of-life situations (Strasbourg, France)	Jean

## Future Conferences

Date	Meeting	Place
3-5 November 2010	Third Conference: Clinical Trials on Alzheimer's Disease (CTAD), <a href="http://www.ctad.fr">http://www.ctad.fr</a>	Toulouse, France
16-20 February 2011	The 7th Pan – Hellenic Conference of Alzheimer Disease and Related Disorders, <a href="http://www.alzheimer-hellas.gr">http://www.alzheimer-hellas.gr</a>	Thessaloniki, Greece
19-20 February 2011	2011 National Alzheimer Conference: New insights into dementia, <a href="http://www.alzcongres.ro">www.alzcongres.ro</a>	Bucharest, Romania
9-13 March 2011	The 10th International Conference on Alzheimer's & Parkinson's Diseases (AD/PD 2011), <a href="http://www.kenes.com/adpd">www.kenes.com/adpd</a>	Barcelona, Spain
26-29 March 2011	26th International Conference of Alzheimer's Disease International, <a href="http://www.adi2011.org/default.aspx?PageID=Home">http://www.adi2011.org/default.aspx?PageID=Home</a>	Toronto Canada
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
28-30 January 2011	4 <sup>th</sup> Edition of the European Neurological Conference on Clinical Practices (ENCCP), <a href="http://www.paragon-conventions.net/enccp2011">www.paragon-conventions.net/enccp2011</a>	Lisbon, Portugal



The Alzheimer Europe newsletter arises from the 2010 Work Plan of Alzheimer Europe, which has received funding from the European Union, in the framework of the Health Programme.