



# NEWSLETTER

October 2011

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## Editorial

Our Annual Conference in Warsaw was the undoubted highlight of our activities in October. With close to 500 participants from 40 countries, the conference proved to be one of the most successful of the last years.



I am glad that we made the right choice with the conference motto "European Solidarity without borders" as well as the topics which we included in our call for abstracts.

The feedback we received was overwhelmingly positive: I was delighted to see that 98% of respondents said that they would recommend our conference to their colleagues. Quite an endorsement!

As every year, our Annual General Meeting was organised in the framework of the conference. It was a great opportunity to meet up with representatives of our member organisations, to report on recent activities and to present and discuss our plans for the future. The AE Board and staff were greatly encouraged to receive the unanimous support of all our members for the Annual Report, the new Strategic Plan and the 2012 Work Plan.

The Annual General Meeting also gave its near unanimous support to our new policy on involving people with dementia in our activities and to a change of our statutes which will result in the creation of a European Working Group of People with dementia and the appointment of the working group's chairperson to sit on the AE Board with full voting rights.

It was particularly touching to have this policy endorsed by the people with dementia attending our Annual General Meeting, with Helga Rohra from Germany calling our decision "a truly historical development."

In addition to this new policy, we were also able to provide bursaries for people with dementia to attend our conference. Their contributions in the different plenary and parallel sessions were unique, in particular in the session dedicated to the value of diagnosis where their insights provided a much needed endorsement of early diagnosis. This year, the bursaries were taken up by our member organisations in Belgium, the Czech Republic, England, Germany, Greece, Poland and Scotland.

The Conference was also an opportunity for DECIDE and PharmaCog, two important EU projects that Alzheimer Europe is involved in, to present some of their findings. We report on the key developments for both projects in our newsletter.

We also provide updates on a number of activities that were carried out by our member organisations to commemorate World Alzheimer's Day and which we were not able to cover in our last newsletter.

It also gives us great pleasure to welcome three new Members of the European Alzheimer's Alliance and to report on the activities of other Members of the European Parliament who show their clear commitment to our campaign to make dementia a public health priority.

**Jean Georges**  
Executive Director

## Alzheimer Europe

### 26 September: Dianne Gove attends Ambient Assisted Living Conference

On 26-28 September, Dianne Gove (Information Officer, Alzheimer Europe) attended the Ambient Assisted Living (AAL) Conference in Lecce, Italy. The conference brought together designers of assistive technology (AT), academics and policy makers.

Dianne chaired a session on the physical and mental wellbeing and care of older adults with cognitive impairments and their relatives and carers. The members of the panel presented their work on the development of various AT systems aimed at enabling people with dementia to remain in their homes for as long as possible without increasing the burden on carers.

At the end of the session, Dianne presented some of Alzheimer Europe's ethical recommendations on the use of AT for and by people with dementia.

### 6 October: Alzheimer Europe Board meets in Warsaw

The Alzheimer Europe Board met in Warsaw on 6 October. The Board meeting was primarily dedicated to the final preparations of the organisation's Annual General Meeting and Annual Conference.

In addition, the Board:

- Discussed the 2011 financial forecasts and welcomed that the accounts would result in a financial surplus.
- Was informed of the positive evaluation by the European Commission of the organisation's applications for an operating grant for 2012 and a grant for its 2012 conference.
- Adopted its 2012 budget taking into account EUR 250,000 in EU funding.
- Recommended to the AGM that the provisional membership of the associations in Bulgaria, Croatia, Estonia and Italy be continued for an additional year.
- Decided to create a working group to look into membership issues.
- Approved the report on the "Value of knowing" survey to be published and presented at a lunch debate in the European Parliament.

### 6 October: Alzheimer Europe holds Annual General Meeting

The Annual General Meeting (AGM) of Alzheimer Europe (AE) took place on 6 October in Warsaw. The meeting was quorate, as more than half of the member associations were present or represented. Highlights include:

- Adoption of the agenda and the minutes of the 2010 AGM.
- Discussion and adoption of the 2010 annual and financial reports.
- Retention of external auditor Mazars for the current financial year.

- Membership fees to remain unchanged in 2011-12. A working group will evaluate and propose changes at the next AGM.
- New full member: Jersey Alzheimer's Association.
- New provisional member: Compassion Alzheimer Bulgaria.
- Adoption of the Strategic Plan to 2015, which is based on making dementia a European priority.
- Approval for the creation of a new European Working Group: EWGPD will consist of people with dementia.
- Results of the 2011 Work Plan, which included research on the ethics of dementia and the Value of Knowing survey.
- AE's 2012 Work Plan, which continues ethical research, reaches out to new members and increases involvement in European and regional dementia programmes.
- Approval of the 2012 budget.

The next AGM will take place in October 2012 in Vienna.

### 6-8 October: Alzheimer Europe organises successful 21<sup>st</sup> Annual Conference in Warsaw

More than 470 delegates from nearly 40 countries gathered in Warsaw, Poland, to participate in Alzheimer Europe's 21<sup>st</sup> conference, which took place on 6-8 October under the Patronage of Mr Bronislaw Komorowski, President of Poland and of the European Parliament.

Participants represented a wide spectrum of backgrounds within the field of dementia, including people with dementia, their carers, representatives of national Alzheimer associations, healthcare professionals, academics and researchers, as well as policy makers. The motto of this year's conference was "European Solidarity without Borders".

Welcoming delegates to the conference, the Chairperson of the Polish Alzheimer Association, Alicja Sadowska, reminded participants of the very special association which exists between the term solidarity and Central and Eastern Europe. Solidarity, she said, had changed the whole of Europe and she believes that European solidarity will change a lot for people with dementia. The Chairperson of Alzheimer Europe, Heike von Lützu-Hohlbein, also spoke of solidarity and illustrated significant achievements made in the last five years. She also emphasised her conviction that by standing together we can address the needs of people with dementia over the next five to ten years.

The conference programme focused on how societies can show greater solidarity with people with dementia and their carers. It also illustrated how Alzheimer organisations in all European countries have campaigned for greater inclusion and participation of people with dementia.

Throughout the two days, key note speeches highlighted issues such as what solidarity without borders means for people with dementia and their carers, the prevention, treatment and management of dementia, the value of diagnosis and dementia as a public health priority. These plenary presentations were made by:

- People with dementia: Archie Latta (Scotland), Marek Romecki (Poland) and Helga Rohra (Germany)
- Policy makers and civil servants: Geoff Higgins (Scotland), Florence Lustman (France) and Antoni Montserrat (European Commission)
- Health professionals and researchers: Sube Banerjee (United Kingdom), Maria Barcikowska (Poland), Alexander Kurz (Germany), Tadeusz Parnowski (Poland), Andrzej Szczudlik (Poland), Myrra Vernooij-Dassen (Netherlands)
- Representatives of Alzheimer Associations: Jean Georges (Alzheimer Europe), Maurice O'Connell (Ireland).

In addition, the parallel sessions offered over 90 different presentations on topics including psychosocial interventions, residential and community care, policy initiatives, family carers, behavioural and psychological

symptoms in dementia, the support of people with dementia and their carers, awareness campaigns and lobbying, the prevention of isolation and loneliness, effective communication, care evaluation, dementia strategies, end of life a, diagnosis and assessment, sexuality and relationships, legal systems and regulations.

A further four special symposia covered the following four areas: (1) primary care and the management of dementia, (2) biomarkers for the diagnosis of Alzheimer's disease, (3) a year-long campaign to raise awareness of Alzheimer's disease and (4) research advances from the IMI PharmaCog project.

Many participants commented on the high quality of presentations as well as the great variety of covered topics. The plenary session on the value of diagnosis was singled out as particularly moving, as people with dementia shared their own journey of being diagnosed and living with dementia.



The AE Executive reporting to the Annual General Meeting



Delegates endorsing the organisation's new strategic plan



An informal get-together at the welcome reception



An attentive audience at the opening ceremony



The AE Chair welcomes delegates to the conference



Myrra Vernooij-Dassen provides an update on psychosocial intervention



Polish parallel sessions were well attended



The PharmaCog team presents an update on its activities



People with dementia take centre stage at plenary on value of diagnosis



AE Executive Director presents findings of "Value of knowing" survey



The final plenary session was dedicated to comparing national dementia strategies



Delegates dancing at the gala dinner at the end of the conference

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## Alzheimer Europe Networking

From 6 to 8 October (Warsaw, Poland) AE Board, members and staff attended the Annual General Meeting and the 21<sup>st</sup> Alzheimer Europe Conference "European solidarity without borders".

On 11 October (Brussels, Belgium) Annette and Alex attended an Alzheimer's Society (UK) lunch debate in the European Parliament.

On 13 October (Esch/Alzette, Luxembourg) Jean gave a presentation on the activities of Alzheimer Europe at the 5<sup>th</sup> Networking Event of the Luxembourg BioHealth Community.

On 17-18 October (London, UK) Alex attended an IMI PharmaCog review.

On 20 October (Brussels, Belgium) Annette met Heinz K. Becker (MEP, Austria, EPP) to discuss the European Alzheimer's Alliance.

On 24-25 October (Brussels, Belgium) Annette attended the Horizontal Workshop organised by the European Commission on the European Innovation Partnership on Active and Healthy Ageing.

On 26-27 October (Rome, Italy) Alex attended a DECIDE project meeting.

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### DECIDE

#### 3 October: Fulvio Galeazzi is appointed new DECIDE Project Manager



Mr Fulvio Galeazzi, Technology Researcher at GARR, became the new DECIDE Project Manager on 3 October. He replaces Ms Laura Leone.

Mr Galeazzi has been with GARR since 2010. Previously, he was involved with projects EUMEDGRID-Support and EUChinaGRID (2005-2009) and with the BaBar, ATLAS and Argo experiments (2002-2010). He holds a PhD in Physics from the University of Padova.

#### 6 October: DECIDE project team completes first annual review



The DECIDE project team completed its first annual review by European Commission experts on 6 October in Warsaw. Presentations by DECIDE team members included:

1. Mr Fulvio Galeazzi (Project Manager) introduced the project and outlined the first year's achievements.
2. Dr Giovanni Frisoni (Scientific Manager) demonstrated the clinical benefits of the use of imaging markers.
3. Ms Valeria Ardizzone (Technical Manager) described the grid infrastructure, middleware standards and data management services.

DECIDE has generated considerable interest in the European Commission. The technical and scientific aspects were examined in detail and proved their validity and scientific value. During the second project year, the DECIDE team will continue to work on these fronts and will also focus on:

- establishing user groups for service validation and testing
- developing user training programmes
- strategic planning to ensure that the service can reach the greatest number of users worldwide.

#### 7 October: DECIDE demonstrates algorithm to aid earlier diagnosis of Alzheimer's disease

The DECIDE project team demonstrated the potential of the GridSPM algorithm during a conference in Warsaw. This algorithm analyses brain perfusion and metabolism and provides a report containing a quantitative measure of the statistical deviation with respect to a set of normal cases. The report is delivered to researchers and doctors via the high-speed GÉANT network.

"DECIDE will ensure that the diagnostic process is much more straightforward and simple, using distributed computing resources and the power of the GÉANT network to create an advanced e-infrastructure that spans the entire European medical community" said Fulvio Galeazzi, DECIDE Project Manager.

### PharmaCog

#### 17 October: PharmaCog project team holds progress meeting

The PharmaCog project team held a pre-clinical and work package progress meeting on 17-18 October in Ascot, England.

More than 60 delegates attended the meeting, which was led by Mike O'Neill (Work Package 6 coordinator), Dr. Jill Richardson (EFPIA Coordinator) and Dr. Alexandra Auffret (Academic Coordinator).

The team concentrated on updates of Work Packages 1-8, in preparation for an annual review which will be published in February 2012. PharmaCog is approaching the end of the second year of a five year project life.



#### 24 October: Jean de Barry will lead Work Package 6 for PharmaCog

Jean de Barry will replace Phil Verwaerde as leader of Work Package 6, which deals with the characterisation of transgenics and marker development. Dr. de Barry (PhD, Chemical Engineering) is the scientific advisor of IHD and a senior researcher at Inserm.

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## European Alzheimer's Alliance

### 11 October: MEPs Taylor and Yannakoudakis host European Parliament debate



Keith Taylor, MEP (UK) co-hosted a lunch debate in the European Parliament on 11 October alongside Marina Yannakoudakis, MEP (UK). The debate was organised by the All-Party Parliamentary Group on Dementia in the UK (APPG) and the Alzheimer's Society (AS). APPG and AS presented the findings of their 2011 enquiry "The £20 billion question: an enquiry into improving lives through cost-effective dementia services."

The enquiry found that shifting resources away from hospitals into community-based services can improve the quality of life of the people with dementia and bring savings to the health and social care systems. These savings would in turn cover early intervention services, carer support services, mental health liaison teams for elderly people and prevention services.

Mr Taylor welcomed the event as a valuable opportunity to share best practice and knowledge at EU level on this crucial issue. As shadow rapporteur for the ECR group for the European Parliament Resolution on a European initiative on Alzheimer's disease, Ms Yannakoudakis reminded the audience about the necessity to increase awareness about dementia, the importance of early diagnosis and the need to increase research in dementia.

The lunch debate was well-attended with representatives from the European Commission, Members of the European Parliament and Permanent Representations to the EU, Belgian policy makers and social care professionals, health professionals, Alzheimer's disease associations, NGOs and industry.

### 13-19 October: AE welcomes three new members of the European Alzheimer's Alliance

In October, MEPs Heinz Becker (Austria), Ole Christensen and Jens Rohde (Denmark) joined the European Alzheimer's Alliance.

Mr Becker is a member of the European People's Party (Christian Democrats) and sits on the Employment and

Social Affairs Committee and on the Petition Committee. He is a substitute on the Culture and Education Committee.

Since 2001, MEP Becker has been Secretary-General of the Austrian Senior Citizens' Association (ÖSB) and a member of the Executive Committee of the European Senior Citizens' Union (ESCU) since 2005.

Mr Christensen, a member of Group of the Progressive Alliance of Socialists and Democrats in the European Parliament sits on the Employment and Social Affairs Committee and is a substitute on the Fisheries Committee.

Mr Rohde is a Member of the Bureau of the Group of the Alliance of Liberals and Democrats for Europe, sits on the Committee on Industry, Research and Energy and is a substitute on the Committee on Civil Liberties, Justice and Home Affairs.



Heinz Becker,  
Austria



Ole Christensen,  
Denmark



Jens Rohde,  
Denmark

### 21 October: MEP Yannakoudakis urges more funding and research for dementia



On 21 October, Marina Yannakoudakis organised a European information event in London to discuss Alzheimer's disease with guest speaker Dr. Simon Ridley, Head of Research at Alzheimer's Research UK. The event focussed on new treatments for Alzheimer's disease and other forms of dementia.

Ms Yannakoudakis said that increasing awareness about the disease can help early diagnosis, which in turn will lessen the effects of the disease while reducing healthcare costs. She added that best practices needed to be shared at EU level and research should be pooled for better use of resources. MEP Yannakoudakis called on the EU to dedicate more funding for dementia research.

## Members of the European Alzheimer's Alliance

Currently, the total number of MEPs in the Alliance stands at 54, representing 19 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.

**Austria:** Becker K. Heinz (EPP), **Belgium:** Brepoels Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA) **Bulgaria:** Parvanova Antonia (ALDE), **Cyprus:** Triantaphyllides Kyriacos (GUE-NGL), **Czech Republic:** Cabrnock Milan (ECR), Kohlicek Jaromir (GUE/NGL), Roithova Zuzana (EPP), **Denmark:** Christensen Ole (S&D), Schaldemose Christel (S&D), **Finland:** Jaakonsaari Liisa (S&D), Jäätteenmäki 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), **Lithuania:** Vilija Blinkėvičiūtė (S&D), **Luxembourg:** Engel Frank (EPP), 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), Zaboriska Anna (EPP), **United Kingdom:** Derek Vaughan (S&D), 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).

## European Developments

### 21 September: European Medicines Agency announces support for World Alzheimer's Day

The European Medicines Agency issuing the following press statement on 21 September to announce its support of World Alzheimer's Day:

The European Medicines Agency supports World Alzheimer's Day which is taking place on Wednesday 21 September 2011.

World Alzheimer's Day is held each year on 21 September and is dedicated to raising awareness of dementia and to educate and challenge people's misconceptions about dementia. In 2011, the theme of the day is 'faces of dementia'.

The Agency plays a key role in the authorisation of medicines to treat dementia. In the European Union (EU), all medicines for the treatment of diseases causing degeneration of the brain and nervous system, including dementia, must be authorised centrally at a European level, rather than in each Member State separately.

To date, a total 11 medicines for use in patients with Alzheimer's disease have been authorised in the EU on the recommendation of the Agency, including medicines for the treatment and for the diagnosis of the disease. The Agency has also recommended the authorisation of medicines used to treat other types of dementia.

Earlier this year, the Agency also carried out a public consultation on a qualification opinion for a clinical biomarker intended to identify patients who can be recruited for clinical trials of treatments for pre-dementia Alzheimer's disease. Information on this biomarker was recently published in the journal *European Neuropsychopharmacology*.

The Agency works closely with organisations representing patients with dementia through Alzheimer Europe, an umbrella organisation of 31 national Alzheimer associations from 27 European countries. It also interacts with organisations representing healthcare professionals in the field of dementia, and works with European and international scientific organisations such as the Critical Path Institute.

The Agency organises regular events and meetings, many of which cover issues related to dementia, as well as providing guidance for companies developing medicines for the treatment and diagnosis of Alzheimer's disease and related illnesses.

### 12 October: European Medicines Agency released qualification opinion on diagnosis of pre-dementia Alzheimer's for public consultation

The European Medicines Agency (EMA) sought opinions from the public on a qualification opinion describing a biomarker to help identify patients who can be recruited for clinical trials of treatments for early Alzheimer's disease.

The draft opinion states that patients with a low hippocampus volume detected with a magnetic resonance imaging (MRI) scan, together with cognitive deficit

(problems with thought processes), may be in the pre-dementia stage of Alzheimer's disease. Such patients may therefore be suitable for inclusion of clinical trials of medicines that might slow the development of dementia. The hippocampus is a region of the brain that is involved in memory.

This draft qualification opinion is the second that the Agency has issued for use in humans. The first such opinion, issued in February 2011, was also for the detection pre-dementia Alzheimer's disease and was based on the levels of two proteins in the blood.

The opinion was developed in co-operation with the Critical Path Institute and was open for comments until 1 November 2011.

### 12 October: European Commission adopts revised proposals on information about prescription medicines to the public

On 12 October 2011, the European Commission adopted revised proposals clarifying the information that industry can supply to the public on prescription-only medicines. The revised proposals amend the original 2008 proposals and constitute a response to requests from the European Parliament.

The proposals maintain the current advertising ban on prescription-only medicines and also decree that:

1. Only limited information on prescription-only medicines would be allowed. This includes information on the label, on the packaging leaflets and instructions for use. Other examples are information about prices and clinical trials.
2. Publication of information on prescription-only medicines will only be allowed through limited communication channels. These include officially registered websites and printed material made available when specifically requested by members of the public. Publication in general print media will not be permitted.
3. Information must fulfil recognised quality criteria. For example, it must be unbiased and must meet the needs and expectations of patients. It must also be evidence-based, factually correct and must not be misleading. Finally, information must be understandable to the general public.
4. As a general principle, information which has not previously been approved must be verified by competent authorities prior to dissemination. The revised proposals will now be debated by both the European Parliament and the Council of Ministers.

### 18 October: Court of Justice rules on patentability of human embryos in scientific research

On 18 October, the European Court of Justice (ECJ) ruled that the use of human embryos for therapeutic or diagnostic purposes which are applied to the human embryo and are useful to it is patentable. However, their use for purposes of scientific research is not patentable.

The ECJ had been called upon to rule whether a process which involves removal of a stem cell from a human

embryo at the blastocyst stage, entailing the destruction of the embryo, could be patented.

After examining the concept of "human embryo", the ECJ pointed out that it was not called upon to broach questions of a medical or ethical nature, but restricted itself to a legal interpretation of the relevant provisions of Directive 98/44/EC on the legal protection of biotechnological inventions.

**18 October: MEP Rossi questions Commission on link between disturbed sleep and Alzheimer's disease**

On 18 October, Oreste Rossi, MEP (Italy) asked the European Commission if it will carry out research to establish a link between regular sleep and a reduction in the risk to develop Alzheimer's disease.

Mr Rossi's question (E-009315/2011) was prompted by a study conducted by researchers at Washington University School of Medicine in St. Louis (USA), which revealed a connection to disturbed sleep.

The scientists ascertained that in subjects aged about 60 with brain plaques, amyloid beta levels remained close to constant, whereas the opposite was the case in the group of the same age without brain plaques and in the group of healthy subjects aged between 18 and 60, in whom the levels rose and fell, the highs and lows being particularly pronounced in young subjects.

**Policy Watch**

**27 October: UK sees sharp cut in social care funding for elderly people**

Local councils in the UK have cut back on social care for people over 65 by some GBP 1.3 billion (Euro 1.5 billion) in 2011. This includes government funding for home care and specialist dementia and nursing homes.

Councils are generally increasing the fees they charge families for home help and meals on wheels. They are also reluctant to pay more for places in private care homes, which has put several care home operators in a perilous position.

"Older people, their carers and families are seeing services reduced, charges increased and support restricted to those only with the most critical needs," said Liz Kendall, the shadow minister for care and older people.

"These cuts will cost everyone more in the long run, as older people who could remain healthy and independent in their own homes end up in hospital when they don't need to."

Emily Holzhausen, director of policy at Carers UK, said "[i]t is extremely worrying as we look at what the impact is on families' lives. We know that families are already under an enormous amount of stress and that will only get worse with these cuts."

The Government is considering plans to overhaul funding for care home places and home help services, with a decision due to be published in the spring of 2012.

Research into the social funding cuts was carried out by the House of Commons, Ms Liz Kendall, Age UK and the Daily Telegraph.



**Members' News**

**21 September: Lithuania organises conference for World Alzheimer's Day**



The Alzheimer Care Houses Association (ACHA) in Lithuania organised a conference called "Care of people with dementia and Alzheimer's disease" to commemorate World Alzheimer's Day.

The conference attracted 170 delegates and was hosted by Mr. Edmundas Jonynas-Kožechnikovas, President of ACHA. The main topics were an update of the care systems in Lithuania and the process of monitoring, selecting and disseminating research results about Alzheimer's disease and other forms of dementia within the country.

*Note: ACHA is not a member of Alzheimer Europe. However, we are pleased to report on all activities surrounding World Alzheimer's Day.*

**21 September: Alzheimer Uniti celebrates World Alzheimer's Day in Italian piazzas**

Alzheimer Uniti celebrated World Alzheimer's Day by handing out information leaflets in historic piazzas in many Italian cities. In Rome, the gendarmerie band accompanied volunteers' efforts. Other activities included film projections and meetings to discuss financing of a regional Alzheimer's disease project in southern Italy.



**21 September: Turkey asserts the importance of remembering on World Alzheimer's Day**

Alzheimer Turkey trained policemen, produced a play and conducted a survey to commemorate World Alzheimer's Day.



During September, 250 police officers were trained to recognise the differences between Alzheimer's disease and other forms of dementia and also how to deal with disappearances of elderly people. The officers received diplomas on 21 September, which also saw the last performance of the play "Alzheimer is on the stage".

Prof. Dr Murat Emre (Chairperson of Alzheimer Turkey) and Vice Chair Prof. Dr Işın Baral Kulaksızoğlu held a press conference to present the following:

- There are some 400,000 people with Alzheimer's disease in Turkey.
- 75% of these people lack sufficient information about the disease.
- Over 50% of all people who died with Alzheimer's disease had not received any related treatment.

**21 September: Belgium holds national Café Day on World Alzheimer's Day**



The Belgian Alzheimer's Association (LINAL) held its annual Alzheimer Café Day on 21 September to commemorate World Alzheimer's Day. This year's theme was "Alzheimer & Cie: the volunteers". The event included speeches and volunteer testimonies.

LINAL was also involved in the organisation of the "Dementia-Friendly Cities" charter, which was signed by 15 Belgian cities on 20 September. This network of cities actively develops activities related to Alzheimer's disease, such as Café Days, training sessions and home assistance to carers.

**21 September: German experts hold press conference on World Alzheimer's Day**

Alzheimer Germany held a press conference in Berlin to focus attention on Alzheimer's disease and other forms of dementia. The main speakers were:

- Heike von Lützu-Hohlbein, chair of both the German Alzheimer Society and Alzheimer Europe
- Prof Dr. Hans Gutzmann, president of the German Association for Geriatric Psychiatry and Psychotherapy
- Prof Dr. Ralf Ihl, board member of Hirnliga, an association of Alzheimer's disease researchers in Germany.

The main topic was the growth trend of Alzheimer's disease, which accounts for two thirds of all dementia cases today. Currently, around 1 in 4 people aged 80+ in Germany are affected, for a total of some 1.2 million people. This is forecast to double to 2.4 million by 2050.

The speakers also pointed out that Alzheimer's disease is now one of the most expensive diseases to treat, due to its long duration and large number of cases.

**21 September: Alzheimer Slovakia conducts training sessions and releases a book on World Alzheimer's Day**



Alzheimer Slovakia organised its third annual conference to commemorate World Alzheimer's Day on 20-21 September. The conference included

a training session on non-pharmacological treatments and workshops for professionals, caregivers and volunteers. In addition, a new book in Slovak was introduced: this is a translation of "Talking to Alzheimer's" by American author Claudia J. Strauss. The conference was covered nationally, both in print and on television.

**23 September: Alzheimer Germany answers questions about dementia at a youth fair**

The German Alzheimer Society presented its project "Alzheimer's and You" at the youth fair "You" in Berlin on 23-25 September. This project included a dedicated website and a stand that featured a quiz about Alzheimer's disease. Numerous counsellors and youth workers were on hand to answer questions.

During a radio interview, Sabine Jansen (Executive Director, Alzheimer Germany) stressed the importance of educating young people about dementia and encouraged listeners to participate in volunteer projects.

**24 September: Local artists donate works to Alzheimer Portugal**



Some 30 Portuguese artists donated drawings and paintings to Alzheimer Portugal. These works of art were displayed and offered for sale during most of October in Cascais, a seaside town near Lisbon.

All proceeds will be used by Alzheimer Portugal to fund "Rosemary's House", the association's first nursing home. Rosemary's House will be home to 30 people with dementia and will host a further 15 people on a daily basis. In addition, staff will provide external support services to 50 homes in the area.

**24 September: Jersey hosts multiple activities for World Alzheimer's Day**

The Jersey Alzheimer's Association celebrated World Alzheimer's Day with a new website, a demonstration of music therapy and an award ceremony. The day-long event attracted 100+ people and was prominently featured in the local media.

Jim Hollywood, Chairman of the Jersey Alzheimer's Association, spoke about recent activities including a media campaign which raised GBP 3 million for a local hospital. Mr Hollywood also stressed the importance of raising awareness of dementia, as the number of people with dementia will increase dramatically over the next decade.

There are currently more than 1,000 people with Alzheimer's disease or other forms of dementia in Jersey.





**24 September: Danish teenagers sing for World Alzheimer's Day**

Alzheimer Denmark mobilised a "flash mob" of teen choir singers to spontaneously burst into song in Copenhagen's central train station. The teens also distributed silk flowers to travellers, all part of the commemoration of World Alzheimer's Day.

**24 September: Alzheimer Hellas raises funds with Zumba**



The Greek Alzheimer Association organised a fundraising event featuring Zumba on 24 September in Thessaloniki. Zumba combines dance moves with a fun and effective workout system. This event was open to the public and encouraged people to have fun while donating money for a good cause. The Zumba fundraiser was the last of many events organised in Greece during World Alzheimer Month.

**24 September: Slovenia organises concert on World Alzheimer's Day**



Alzheimer Slovenia organised a concert and distributed newsletters and brochures in the eastern town of Šentjur during World Alzheimer's Day. In addition, volunteers met

and spoke to people whose lives are being touched by Alzheimer's disease.

The organisers were also able to raise awareness of the "Touch of Memory" project. This publicly funded project aims to provide local children with better education about dementia. Touch of Memory will run until the end of 2012.

**24 September: Malta Dementia Society organises Memory Walk**



The Malta Dementia Society organised a Memory Walk during a sunny World Alzheimer's Day in Valletta. This event was very well attended, with organisers distributing information packs to participants and spectators.

There are some 4,500 individuals with dementia in Malta. This number is expected to double in the next 30 years to reach 2% of the general population.

The Malta Dementia Society has been instrumental in the drafting of the Malta Dementia Strategy, which should be launched in 2012. Our Maltese colleagues continue to work hard to increase dementia awareness and to make dementia the top health care priority in the country.

**1 October: Patrick Maugard becomes Vice President of France Alzheimer**



Patrick Maugard has been appointed Vice President of France Alzheimer. Mr Maugard has been an active member of the French association for many years, but had voluntarily taken a back seat due to health reasons. He has now recovered and is very pleased to take on new responsibilities within France Alzheimer.

**10 October: Malta raises dementia awareness during Mental World Health Day**

The Malta Dementia Society and the Malta Pharmaceutical Student Association organised a dementia awareness campaign at the University of Malta Campus during Mental World Health Day on 10 October.



The aim of this campaign was to raise dementia awareness among lecturers, staff and university students. In addition, members of the public became acquainted with the Malta Dementia Society as volunteers distributed information leaflets, journals and books. Application forms were also distributed so as to encourage carers to join the society.

This event was very successful in raising awareness about dementia, especially among students studying various sectors of the health profession.

**14 October: Alzheimer Uniti Italy promotes museum visits for people with Alzheimer's disease**

On 14 October, Alzheimer Uniti participated in a conference organised by Professor Roberto Bernabei, geriatrician at Catholic University in Rome, to discuss and promote museum visits for people with Alzheimer's disease. The conference was moderated by Luisa Bartorelli, Chairperson of Alzheimer Uniti Italy. The conference was entitled "La memoria del bello" (Memory of Beauty) and included presentations by geriatricians, psychologists and staff from the museum.

**Science Watch**

**24 September: Researchers watch amyloid plaques as they form**

A new technique called optical trapping allows researchers to observe amyloid-beta peptides as they aggregate to form plaque. This technique was developed

by scientists at the University of Toronto Scarborough (UTSC) and Osaka University in Japan.

Optical trapping involves a laser focused into a very thin beam and aimed at a solution containing amyloid-beta particles. The beam creates a magnetic field which attracts and holds the particles in place. Amyloid aggregates stained by a dye will glow under the laser light and this image can be captured by a fluorescence microscope.

Researchers hope to explore how the aggregates are formed and to eventually discover the role of amyloid aggregates in Alzheimer's and other neurodegenerative diseases.

"This technique could accelerate the drug discovery process. It gives us a new way to examine the early phase of plaque formation, when the most toxic species of oligomers are formed," said Kagan Kerman, Assistant Professor at UTSC.

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

### **30 September: Kibra protein is a big influence on learning and memory**

Researchers from the Johns Hopkins University School of Medicine have found that both learning and memory are significantly affected by changes in the level of kibra protein in mouse brains.

Kibra is already linked to memory and protection against late-onset Alzheimer's disease in humans. The new work shows that kibra is essential in controlling the sculpting of brain circuitry, which is the process that encodes memory.

"There are populations of humans who are slightly smarter and have better memory recall than others, and these traits have been mapped to the gene that codes for the kibra protein," said Prof Richard Hagan, director of the Department of Neuroscience at Johns Hopkins.

"In addition, as kibra has been associated with protection against early onset Alzheimer's disease, these studies may help define novel therapeutic targets for the treatment of age-related memory disorders."

### **1 October: APP protein destroys nerve cells in the nose**

A new animal study has determined that the amyloid precursor protein (APP) destroys nerve cells which detect odours. The study was led by Dr. Leonardo Belluscio at the National Institute of Neurological Disorders and Stroke.

He said that "deficits in odor detection and discrimination are among the earliest symptoms of Alzheimer's disease, suggesting that the sense of smell can potentially serve as a 'canary in the coal mine' for early diagnosis of the disease." Dr. Belluscio added that "the changes taking place in the olfactory system as a result of Alzheimer's disease may be similar to those in other regions of the brain but appear more rapidly."

The study also showed that APP alone may be the cause of death of the nerve cells. It was previously thought that amyloid plaque - directly derived from APP - was

responsible for the deaths. The new findings indicate that cell death also occurred in the absence of amyloid plaques.

### **3 October: Clinical trial planned for Colombian family with history of Alzheimer's disease**

The Betancur family and their extended relatives constitute a group of some 5,000 people that is known for the disposition to contract the presenilin 1 (PS1) mutation of Alzheimer's disease. In 2012, researchers from the Banner Alzheimer's Institute in Phoenix, Arizona will begin a new clinical trial among this group, which hails from the area around Medellín, Colombia. The aim is to help determine whether Alzheimer's disease can be prevented before it begins.

The 2-year trial will test a drug - as yet undisclosed - which modifies or attacks amyloid  $\beta$ , the basis of amyloid plaques. "We need to find out when these amyloid plaques accumulate, how advanced they are by the time they enter the prevention trial," said Dr. Eric Reiman, Executive Director of the Banner Alzheimer's Institute. "This information will provide a foundation for knowing how much these brain changes have occurred roughly at the time people at their age will enroll in the trial."

The Colombian family group is considered ideal for preventive testing, as scientists know which members will develop Alzheimer's disease and also when they will develop it. More than 2,000 relatives have already undergone genetic testing in connection with dementia research.

### **10 October: Targacept launches a new clinical trial of Alzheimer's disease drug**

Targacept has announced that it will conduct a new Phase 2b trial of the AZD3480 drug. The initial trial ran for 3 months but the outcome was inconclusive, suggesting that a longer duration may yield better results.

300 people will now take part in a 12 month trial, which will rate the performance of AZD3480 compared to donepezil, a commonly prescribed drug for Alzheimer's disease.

### **11 October: Roche announces early results of Gantenerumab trial**

Roche announced that its experimental drug Gantenerumab has successfully removed amyloid plaques from the brains of people with early-stage Alzheimer's disease. This was the result of a small study on 16 people over six months.

Gantenerumab is designed to bind to amyloid plaques in the brain and remove them. It targets the early stages of Alzheimer's disease and aims to slow progression of the disease.

### **18 October: Antiviral drugs may slow progression of Alzheimer's disease**

Scientists at the University of Manchester have shown that antiviral drugs used to treat herpes simplex virus type 1 (HSV1) may also slow the progression of Alzheimer's disease.

The researchers found that HSV1 causes accumulation of amyloid beta (Aβ) and abnormally phosphorylated tau (P-tau) proteins. These are, respectively, the main components of the plaques and tangles associated with Alzheimer's disease.

"We have found that the viral DNA in AD brains is very specifically located within amyloid plaques," said Prof Ruth Itzhaki, who led the team in the University's Faculty of Life Sciences. "This, together with the production of amyloid that the virus induces, suggests that HSV1 is a cause of toxic amyloid products and of plaques. Our results suggest that HSV1, together with the host genetic factor, is a major risk for AD, and that antiviral agents might be used for treating patients to slow disease progression."

## Living with Dementia

### 10 October: L'Oréal heiress Bettencourt is placed under guardianship

A French judge has ruled that L'Oréal heiress Liliane Bettencourt, who just turned 89, will become a legal dependent of her daughter and grandsons.

The ruling came after medical experts concluded that the cosmetics billionaire suffers from "mixed dementia" and "moderately severe" Alzheimer's disease, and was in the midst of a "slow and progressive process of cerebral degeneration".

The experts had asked Ms Bettencourt to repeat three words as part of a test on her mental health. She was able to do so straight away, but then forgot them almost immediately. She was also unable to tell them her age, her location and the day of the week.

This ruling is likely to settle all doubts about whether Ms Bettencourt is mentally fit to manage her huge fortune. A lawyer associated with the case said the ruling came as an "immense relief" to the family.

## New publications & resources

### 28 October: New Oxford University report estimates cost of dementia to Euro 190+ billion per year in Europe

A new report from Oxford University shows that the cost of Alzheimer's disease and other forms of dementia has risen to Euro 193 billion per year in 15 European countries. There are an estimated 6.4 million people with diagnosed and undiagnosed dementia in these countries.

More than two thirds of this cost (Euro 131 bill.) is due to informal care by families and carers. Over a quarter of the

costs are for social care, mainly in residential and nursing homes. Costs to national healthcare systems make up just 5% of the total burden.

"Dementia has a very significant impact across European countries, and the burden falls mainly on unpaid carers," says Dr Ramon Luengo-Fernandez of the Health Economics Research Centre at the University of Oxford, who led the work. The costs of informal care arise from the estimated 4.4 million people with dementia living in the community across Europe, who receive 11.9 billion hours of unpaid care from friends and relatives.

The other main cost was in funding long-term care in nursing or residential care homes. Dr Luengo-Fernandez said "[s]ocial care has always been the forgotten bit of the healthcare system. As its funding in the UK is not centralised – bits of funding come from Whitehall, others from local authorities, some of it is private – it has probably not received the required attention. This is true for the majority of European countries."

The Oxford University researchers collected data and valued resources related to dementia in each of the 15 countries that made up the EU before 2004. The report concludes that dementia poses a significant economic burden to European health and social care systems. It also highlights the need for more accurate and comparable dementia-related data across the European countries.

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## AE Calendar

Date	Meeting	AE Representative
1-3 November	CARDI International Conference "Global Ageing meets dementia" (Dublin, Ireland)	Jean
9 November	Meeting with Helena Real (FIPRA) to discuss the MRI Alliance and the Directive on electromagnetic fields new developments (Brussels, Belgium)	Annette
9 November	Meeting with Ole Christensen (MEP, Denmark, S&D) to discuss the European Alzheimer's Alliance	Annette
22 November	EPDA lunch debate in the European Parliament on 'Chronic Conditions in an Ageing Population - a Spotlight on Parkinson's disease' (Brussels, Belgium)	Annette
30 November	GSK Health Advisory Board (London, United Kingdom)	Jean

## Future Conferences

Date	Meeting	Place
2-3 November 2011	Ageing Globally – Ageing Locally: Planning for all our futures	Dublin, Ireland
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
3-5 November 2011	4th edition of our Clinical Trials for Alzheimer's Disease CtaD 2011, <a href="http://www.ctad.fr">www.ctad.fr</a>	San Diego, USA
8-11 November 2011	Thailand dementia 2011 and 14 <sup>th</sup> Asia-Pacific Regional Conference of ADI, <a href="http://www.azthaimeting.com">www.azthaimeting.com</a>	Bangkok, Thailand
27-29 January 2012	5th European Neurological Conference on Clinical Practices: Neurovascular and Neurodegenerative Diseases, <a href="http://www.enccp.net">www.enccp.net</a>	Krakow, Poland
22-23 February 2012	8 <sup>th</sup> Annual Update Symposium on Clinical Neurology and Neurophysiology, <a href="http://www.neurophysiology-symposium.com%20">www.neurophysiology-symposium.com%20</a>	Tel Aviv, Israel
7-10 March 2012	27th ADI Conference "Science Fact Fiction", <a href="http://www.adi2012.org/">www.adi2012.org/</a>	London, UK
8-11 March 2012	6th World Congress on Controversies in Neurology (CONy), <a href="http://www.comtecmed.com">www.comtecmed.com</a>	Vienna, Austria
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
16-19 May 2012	7th World Congress for Neurorehabilitation 2012 (WCNR 2012), <a href="http://www.dccconferences.net.au/wcnr2012/">www.dccconferences.net.au/wcnr2012/</a>	Melbourne, Australia
4-6 October 2012	22 <sup>nd</sup> Alzheimer Europe Conference "Changing perceptions, practice and policy", <a href="http://www.alzheimer-europe.org/EN/Conferences">www.alzheimer-europe.org/EN/Conferences</a>	Vienna, Austria
21-23 March 2013	57. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), <a href="http://www.dgkn-kongress.de">www.dgkn-kongress.de</a>	Leipzig, Germany
23-27 June 2013	The 20 <sup>th</sup> IAGG Congress of gerontology and geriatrics, <a href="http://www.iagg2013.org">www.iagg2013.org</a>	Seoul, Korea
20-23 March 2014	58. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), <a href="http://www.dgkn-kongress.de">www.dgkn-kongress.de</a>	Berlin, Germany
21-24 March 2014	30. International Congress of Clinical Neurophysiology (ICCN), <a href="http://www.iccn2014.de">www.iccn2014.de</a>	Berlin, Germany



22<sup>nd</sup> Alzheimer Europe Conference  
 Changing perceptions, practice and policy  
 Vienna / 4-6 October 2012  
 Mark the dates!  
[www.alzheimer-europe.org/conferences](http://www.alzheimer-europe.org/conferences)

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