



# NEWSLETTER

November 2011

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## Editorial

November was a particularly busy month on a European policy front, as you will see from this month's newsletter.



First, the Strategic Implementation Plan for the European Innovation Partnership on Active and Healthy Ageing was adopted. This highlights the need for greater collaboration on the development of integrated care models, the support of early diagnosis and assistive technologies and the prevention of falls and malnutrition.

Second, the Commission adopted its proposal for a new health programme and proposed a budget of EUR 446 million for its "Health for Growth" programme from 2014 to 2020.

Third, the Commission launched "Horizon 2020", the ambitious successor of its current research programmes with plans to allocate EUR 70 billion for research from 2014 to 2020.

All three programmes will be discussed by the European Parliament and the Council of Ministers over the coming months and Alzheimer Europe will closely follow the legislative programme and interact with the European institutions where necessary to make sure that Alzheimer's disease and dementia are recognised as priorities.

National dementia strategies stayed on the political agenda in November and the German Alzheimer's Association issued a call urging its government to follow the example of other European countries.

Northern Ireland has become the latest convert to our cause by issuing its own strategy entitled "Improving dementia services in Northern Ireland: a regional strategy".

In the Italian region of Lazio, a conference was organised with the aim of developing a regional Alzheimer's plan, as is already the case in the region of Emilia-Romagna.

Polish MEP Elżbieta Łukacijewska asked the European Commission which countries had dementia strategies and although the Commission did not have a detailed list, it highlighted the "Alzheimer Cooperative Valuation in Europe (ALCOVE)" project which aims at mapping existing and emerging good practices with regard to early detection and care of people with Alzheimer's disease.

It is very encouraging to see that our call for the development of national dementia strategies continues to gather support in a growing number of countries.

In our newsletter, we also report on an interesting study by our Danish member organisation on the cost of informal care and a conference of Alzheimer Portugal with a focus on guardianship systems and advance directives.

I hope you will enjoy this newsletter with such a clear focus on policy developments at a European and national level. We have not forgotten the importance of scientific developments, but have kept some of these for the December issue.

On behalf of the Alzheimer Europe Board and staff, I wish you a peaceful festive period and a happy New Year.

**Jean Georges**  
Executive Director

## Alzheimer Europe

### 29 November: Alzheimer Europe staff attends EMA training



On 29 November, Alzheimer Europe staffers Annette Dumas (EU Public Affairs Officer) and Alex Teligadas (Communications Officer) attended a training day at the European Medicines Agency (EMA) in London.

The training introduced delegates to EMA activities with a view to their becoming “experts”, i.e. active editors in the preparation of European Public Assessment Reports (EPAR) and Patient Information Leaflets (PIL). EPARs are the basis of the PIL leaflets found in drug packages and thus part of the process of approving medicines for human use in the European Union.

There were 24 participants at the training, mostly from patient care associations. In 2011, experts from 15 organisations reviewed 37 EPARs to ensure that texts were clear, complete and easy to understand.

## Alzheimer Europe Networking

From 1-3 November (Dublin, Ireland) Jean attended the CARDI International Conference “Global Ageing meets dementia”.

On 9 November (Luxembourg, Luxembourg), Jean met with representatives of the Executive Agency for Public Health for a negotiation meeting for the 2012 operating and conference grants of Alzheimer Europe.

On 9 November (Brussels, Belgium) Annette met Ole Christensen, MEP (Denmark) to discuss the European Alzheimer’s Alliance.

On 15 November (Luxembourg, Luxembourg) Alex attended a meeting of the Health-EU Portal Editorial Board.

On 17-18 November (Vienna, Austria) Gwladys met with BE Perfect Eagle Agency to plan the 2012 Alzheimer Europe Conference.

On 21 November (Luxembourg, Luxembourg), Jean met with representatives of Association Luxembourg Alzheimer.

On 21-22 November (Brussels, Belgium) Annette participated in the CARICT policy and expert workshop.

On 22 November (Brussels, Belgium) Annette had an EPDA lunch debate in the European Parliament on “Chronic Conditions in an Ageing Population - a Spotlight on Parkinson’s disease”.

On 24 November (Luxembourg, Luxembourg), Jean met with Nicole Huige from SCA Global Hygiene to present the organisation’s 2012 work plan.

On 28 November (Brussels, Belgium) Dianne attended the “Ageing in Dignity: Designing effective strategies for tackling elder abuse” conference organised by European Commission.

On 29 November (London, UK) Annette and Alex participated in the EMA training for patients representatives.

On 30 November (London, UK) Alex attended an EMA meeting of the Working Party with Patients’ and Consumers’ Organisations.



### 29 November: European Alzheimer’s Alliance members win MEP awards

Marisa Matias, MEP (Portugal) and member of the European Alzheimer’s Alliance, won the Health Award at the 7th MEP Awards ceremony. This Award recognises Ms Matias’ engagement in health issues in the European Parliament (EP).

Ms Matias was Rapporteur for the EP Report on European strategy on Alzheimer’s disease and other dementias (2010) and Co-Rapporteur for the EP Resolution on the

Joint Programming of research to combat neurodegenerative diseases, particularly Alzheimer’s disease (2009).

Other European Alzheimer’s Alliance members also received awards:

- Mairead McGuinness (Ireland): Agriculture and Rural Affairs
- Astrid Lulling (Luxembourg): Economic and Monetary Affairs
- Claude Moraes (UK): Justice and Civil Liberties
- Lambert van Nistelrooij (Netherlands): Regional Development

The annual MEP awards bring together members of the European parliament, EU stakeholders and industries and EU institutional staff to celebrate the work and highlight the outstanding achievements of MEPs over the last year.

## Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 56, representing 20 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), Rohde Jens (ALDE), Schaldemose Christel (S&D), **Finland:** Jaakonsaari Liisa (S&D), Jäättteenmäki 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 Blinkkeviciute (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), Zaborska Anna (EPP), **Slovenia:** Peterle Alojz (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), Vaughan Derek (S&D), Watson Graham (ALDE), Willmott Glenis (S&D), Yannakoudakis Marina (ECR).

## European developments

### 7 November: Commission responds to questions on national dementia plans

On 7 November, the European Commission (EC) responded to a Written Question dealing with national dementia plans from Ms Elżbieta Łukacijewska, MEP (Poland). Her questions were as follows:

- what does the EC think of existing measures taken by the Member States to implement national plans to combat brain diseases and neurodegenerative diseases?
- how many Member States have introduced or are drawing up such plans?
- will the EC publish a report detailing the most effective solutions, with a view to encouraging other countries to adopt such plans?

The reply came from Mr Dalli, European Commissioner for Health and Consumer Policy:

"The communication from the Commission to the Parliament and the Council on a European initiative on Alzheimer's disease and other dementias [in 2009] established the basis for the Commission to address Alzheimer and other dementias. The Commission intends to produce an implementation report on progress made under this communication in 2013.

"The main underlying activity in this context is the joint Action between the Commission and the Member States on 'Alzheimer Cooperative Valuation in Europe' (ALCOVE). This initiative maps existing and emerging good practices related to early detection and care for persons suffering from Alzheimer's disease and other forms of dementia and improves the dissemination and application of such practices.

"The Commission does not dispose of detailed information on the drawing up of national plans to combat brain diseases and neurological diseases."

### 7 November: Europe adopts a plan for active and healthy ageing

On 7 November, the Steering Group of the European Innovation Partnership on Active and Healthy Ageing (EIP AHA) adopted a Strategic Implementation Plan (SIP). The objective of the plan is to provide European citizens with an additional two years of active and healthy life expectancy by 2020.

The SIP is the first step towards that objective, with a focus on prevention, care & cure and independent living. Five priority actions are set to launch in 2012:

1. Finding new ways to ensure that patients comply with their drug prescriptions. Medication non-compliance is a particular issue for long-term care and increases with age: studies show that 79% of patients take their "once a day" dose, but this falls to 51% for those who should take four doses.

2. Helping people to prevent falls and supporting early diagnosis of functional decline
3. Co-operating to help prevent functional decline and frailty, with a particular focus on malnutrition
4. Developing integrated care models for older patients with chronic diseases
5. Improving the uptake of "smart home" technology to help older people stay independent, mobile and active for longer.

The SIP also calls for networking and knowledge sharing on innovation for age-friendly buildings, cities and environments.

The Steering Group of the pilot EIP AHA includes representatives from the health and social sectors, businesses, civil society and public authorities. The EIP AHA will be jointly overseen by the following:

- Neelie Kroes, Vice-President of the European Commission and Commissioner for the Digital Agenda
- John Dalli, Commissioner for Health and Consumer Policy
- Máire Geoghegan-Quinn, Commissioner for Research, Innovation and Science.

The Steering Group has invited the European Commission to address barriers to innovation in the field of active and healthy ageing and to foster a more effective use of EU funding.

The European Commission will work closely with national governments and other stakeholders to move the SIP forward. In 2012, the Commission will launch calls for involvement of stakeholders beyond those that participated in the Steering Group to implement the priorities and actions identified in the Strategic Implementation Plan.

### 9 November: European Commission adopts proposals for new Health Programme

On 9 November, the European Commission adopted proposals for the new Health Programme, which will run from 2014 to 2020 with a budget of Euro 446 million. "Health for Growth" will focus on fewer concrete actions than the previous plan, as the Commission believes this will offer clearer "EU added-value".

The budget of the new Health Programme will cover joint actions and grants to international organisations, grants to NGOs working in public health, and procurement contracts. The programme has four objectives:

#### 1. Create innovative and sustainable health systems

- address shortages of human and financial resources
- promote uptake of innovation through HTA and eHealth
- provide expertise on healthcare reforms and support to the European Innovation Partnership on Active and Healthy Ageing.

## 2. Provide access to better, safer healthcare for all EU citizens

- increase access to medical expertise and information for specific conditions
- develop solutions and guidelines to improve quality and patient safety, especially for cross-border healthcare, rare diseases, prudent use of antibiotics and high standards of quality and safety for organs and substances of human origin.

## 3. Promote good health and disease prevention

- address key risk factors (smoking, alcohol abuse and obesity) by identifying and disseminating best practices for cost-effective prevention and action on specific diseases such as cancer.

## 4. Protect people from cross-border health threats

- develop common approaches for better coordination during health emergencies.

## 15 November: European Parliament adopts a resolution to tackle demographic challenge

On 15 November, the European Parliament adopted the resolution "Demographic change and its consequences for the cohesion policy", which was introduced by MEP Morkūnaitė-Mikulėnienė from Lithuania.

The resolution states that Europe has the oldest population and the lowest population growth rate in the world, while life expectancy is increasing. This causes demographic changes which vary widely from region to region. Tackling this challenge should therefore be done at the regional level.

The resolution also stresses that European structural funds must be better adapted to combat the effects of demographic change. In the 2007-2013 financial framework, Member States have foreseen up to EUR 30 billion in their activity plans, i.e. 8.5% of overall structural funds.

The European Parliament urges a more holistic approach, which takes into account the link between cohesion policy and better economic, social and territorial integration. There are urgent needs for better coordination - to achieve more flexible structural assistance - and for better inclusion at local level, allowing local communities to influence decision-making. This approach must also take into account the needs of children, young people and families and disabled and elderly persons. Finally, the Parliament stressed the need to revise pension systems in the near future, as they will not be able to effectively handle the changing demographic situation.

## 16 November: Council of Europe urges greater participation of disabled people in political and public life

On 16 November, the Council of Europe Committee of Ministers adopted a Recommendation on the participation of persons with disabilities in political and public life.

The objective of the recommendation is to propose principles and measures that increase the participation of

people with disabilities in politics and public life in the Member States.

More specifically, the recommendation aims to remove discrimination and barriers which may hinder disabled people from enjoying active citizenship. It also aims to facilitate the expression of their opinions and their right to vote and stand for election.

Recommendations from the Council of Europe are not legally binding, but they carry significant political weight as they are adopted by consensus by all 47 Member States.

## 17 November: Commission replies to question on link between 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 was prompted by results of a study which revealed a connection to disturbed sleep.

On 17 November, the following reply was sent by Ms Máire Geoghegan-Quinn, European Commissioner for Research, Innovation and Science:

"The Commission is aware of the studies published on the potential relationship between perturbation of the circadian rhythm and mild cognitive impairment and dementia (including Alzheimer's disease).

"A particular effort to support research on neurodegenerative diseases and more specifically on Alzheimer's disease has been achieved in the Seventh Framework Programme for Research and Technological Development (FP7, 2007-2013). Indeed from 2007 until now, more than EUR 300 million has been dedicated to support research on neurodegenerative diseases, including EUR 100 million specifically on Alzheimer's disease. In this regard, the project PHARMA-COG, supported by the Innovative Medicines Initiative Joint Undertaking, aims at discovering new tools to improve the efficacy of drugs against Alzheimer's disease and will investigate the feasibility of sleep deprivation as a model of cognitive impairment in pre-clinical models. The Innovative Medicines Initiative Joint Undertaking has recently published a new call for proposals, which includes a topic on "protective and precipitating markers for the development of Alzheimer's disease (AD) and other dementias", which may be relevant for research on the relationship between sleep disturbance and Alzheimer's disease.

"In addition, a major initiative undertaken by the Member States to coordinate research on Alzheimer's disease is currently implemented through the Joint Programming Initiative on Neurodegenerative Diseases, in particular Alzheimer's. This Joint Programming Initiative includes 23 countries and is currently drafting its Strategic Research Agenda, expected to be finalized and approved by the end of 2011."

## 18 November: Poland hosts European Day of the Brain conference

The "European Day of the Brain. Ageing, Stroke and Alzheimer's Disease - Finding Innovative Solutions"

conference was organised in Warsaw on 18 November by the Polish Ministry of Health in cooperation with the European Brain Council.

The conference was dedicated to the implementation of the second health priority of the Polish Presidency of the Council of the European Union, namely the prevention of brain and neurodegenerative diseases – including Alzheimer's disease.

Delegates formulated the following recommendations for Member States:

- determine a strategy for increasing the population's awareness of the issues connected with the ageing of the European society
- define the organisational scheme for the development of care structures for elderly persons and undertake initiatives which will enable the identification of threats to elderly patients
- exchange best practices between Member States in the area of patient rights protection, and good practices with regard to ethical aspects related to old age, in order to ensure healthy ageing with dignity
- define common methods of introducing recommendations in the area of diagnosing old age diseases, particularly clinical diagnostics, laboratory diagnostics and neuroimaging
- prepare a common concept of European cooperation and coordination in the field of scientific research to allow better understanding, diagnosis and treatment of old-age diseases, in particular brain diseases.

### **29 November: Council of Ministers adopts conclusions on partnering in research**

On 29 November, the Council of Ministers adopted conclusions on "Partnering in Research and Innovation". These conclusions reflect the recommendations of the European Commission Communication on Partnering in Research and Innovation of 21 September.

The Council recognises the need to evaluate existing partnerships and also to further develop the partnering approach. This includes public-public and public-private partnering approaches and should reduce duplication of initiatives and fragmentation of research and innovation (R&I) investment.

The Member States and the European Union must both make the most efficient use of their public and private resources to achieve sustainable growth. Many of these resources already exist within Europe's large pool of intellectual capital and excellent science base.

There is a need to improve the conditions which enable partnerships. These include the differing national approaches to research funding and the administrative burden of rules and procedures. Even so, all public and private players should be encouraged to participate, especially small and medium-sized enterprises.

### **30 November: Commission proposes EUR 80 billion investment in research and innovation**

On 30 November, Máire Geoghegan-Quinn, Commissioner for Research, Innovation and Science, presented Horizon

2020, a package of measures to boost research, innovation and competitiveness in Europe.

The package will bring together all EU research and innovation funding under a single programme. In addition, the current bureaucratic rules and procedures will be reduced, in order to attract more researchers and a broader range of businesses. Horizon 2020 will focus on three objectives:

- support the EU's position as a world leader in science, with a budget of EUR 24.6 billion. This includes a major increase in funding for the European Research Council.
- secure industrial leadership in innovation (EUR 13.7 billion) in key technologies and support for SMEs.
- address key concerns in areas including health, demographic change, food security, sustainable agriculture, marine research and clean energy (EUR 31.7 billion).

The funding programmes will run from 2014 to 2020.

## **Policy Watch**

### **21 October: Alzheimer Germany urges government to enact national dementia plan**

In a letter dated 21 October, Alzheimer Germany asked Chancellor Merkel to enact a national dementia plan. The association proposed a national strategy that provides a coordinated approach to improve the lives of people with dementia and their families.

Heike von Lützu-Hohlbein, chair of the German Alzheimer Society, wrote that an ever-growing older population is likely to increase dementia cases from the present 1.2 million to 2.6 million cases in 2050. She also pointed to the current shortcomings in care provision for people with dementia in Germany.

Ms von Lützu-Hohlbein, who also chairs Alzheimer Europe, proposes that Germany follow the example of countries like France, Norway and Scotland, where national dementia plans are already in existence.

### **8 November: Northern Ireland publishes a new regional dementia strategy**

On 8 November, the Northern Ireland Ministry for Health, Social Services and Public Safety has published a new document entitled "Improving dementia services in Northern Ireland: a regional strategy".

The strategy makes recommendations aimed at improving the services and support arrangements currently available for people with dementia, their families and their carers. There are currently some 19,000 people living with dementia in Northern Ireland. This is expected to rise to some 23,000 by 2017 and 60,000 by 2051.

The dementia strategy also aims to reduce the risk or delay the onset of dementia in the population; it is estimated that delaying the onset of dementia by five years could halve its prevalence.

Finally, new legislation is being developed to deal with mental capacity and mental health. This will include powers and protections relating to substitute decision

making for those who are unable to make their own decisions, including people with dementia.



## Members' News

### 21-22 October: Portugal organises annual Alzheimer's disease conference

On 21-22 October, Alzheimer Portugal organised its annual pan-Iberian conference on Alzheimer's disease together with AFALcontigo, an association from Spain.



Nearly 300 delegates from both countries attended the conference, including students, family carers and health and social care professionals. The main topics were clinical issues and research, psychological interventions, quality of life and legal rights of guardianship and advance directives.

The presentations on legal rights were of particular interest to the Portuguese delegates. In Spain it is legally possible for an organisation to become a guardian of a person with dementia, whereas in Portugal only a physical person can be a guardian. If a person with dementia has no family, it is common for the chairperson or owner of a nursing home to be appointed as guardian. This continues to raise various legal and ethical issues such as privacy and conflict of interest.

On a brighter front, delegates learned about the new provisions of living wills which were recently approved by the Portuguese parliament. The most significant (and long-awaited) provision specifies the conditions under which a living will may coexist with a guardian named by the Court or with a health care proxy.

The organisers received very good feedback from the conference, with delegates citing both the eloquence of the speakers and the relevance of the topics.

### 2 November: Alzheimer's Society volunteer receives award at Buckingham Palace



Angela Clayton-Turner, a very active Alzheimer's Society volunteer, was awarded a William Brooks award on 2 November during ceremonies at the Royal Society and Buckingham Palace.

The William Brooks award is bestowed upon ten people each year for their "outstanding contribution to Alzheimer's Society and dedicated volunteering for people with dementia and their carers."

Amongst her many volunteer activities, Ms Clayton-Turner sits on the Society's nominations committee and is also part of the Alzheimer Europe working group on the ethics of dementia research.

### 4 November: John Laurie is the new Chair of Alzheimer Scotland



On 4 November, Alzheimer Scotland named John Laurie as the new Convener (Chairperson) of the association.

Mr Laurie spent his working life as an engineer and manager in the construction industry in Scotland. He retired in order to become a full-time carer for his wife Avril, who suffers from vascular dementia.

John Laurie initially became aware of Alzheimer Scotland in 2000 and joined the Council in 2004. Since then he has also served on the Executive and Staffing Committees. He replaces Ms Noni Cobban.

### 10 November: Alzheimer Uniti (Italy) attends conference for regional Alzheimer Plan



On 10 November, Alzheimer Uniti took part in a conference aiming to create a regional Alzheimer's disease plan for the Lazio region of Rome. The conference was headed by the President of the Lazio region. If the regional plan becomes reality, Lazio will be only the second Italian region (of 20) after Emilia –Romagna to implement a regional dementia plan.

### 10 November: Alzheimer's Society announces new Director of External Affairs

The Alzheimer's Society named Andrew Chidgey as the new Director of External Affairs. Mr Chidgey, previously Head of Policy and Public Affairs, will take over the new post on 8 January 2012. He replaces Andrew Ketteringham.

### 10 November: "Tommy on Tour" dementia campaigner reaches the Scottish Parliament

In January 2011, Thomas Whitelaw decided to walk through Scotland's towns and cities, collecting letters from fellow carers of people with dementia. Since then he has spoken to thousands of carers and collected letters and emails from all over Scotland. He also maintained a blog and made a film about his campaign. On 10 November, "Tommy on Tour" reached a successful conclusion when Thomas delivered all correspondence to Nicola Sturgeon, Deputy First Minister, at the Scottish Parliament.



### 18 November: Denmark publishes report on the costs of informal care for people with dementia

Alzheimer Denmark, in cooperation with Pfizer Denmark, has co-authored a study on the costs of informal care for people with dementia. The aim of the study was to estimate the time spent by family and friends on informal care of persons suffering from dementia in Denmark and calculate the economic implications.

Results for a typical day show that informal care time was 4.97–6.91 hours for primary caregivers and 0.70–1.06 hours for other caregivers. This translates to daily costs of EUR 160-223 for primary caregivers and between EUR 23-34 for others.

The report concludes that informal care delivered by family and friends is significant. The value of informal care constitutes an important part of the societal cost of dementia in Denmark, where some 70-80,000 people (1.3% of the population) live with dementia.

The survey was conducted by consulting company COWI with funding from Pfizer Denmark. Results are based on the responses of 469 primary caregivers.

## Science Watch

### 2 November: Alzheimer's disease tangles contain more than one protein

Scientists from the US National Institutes of Health have discovered that the protein tangles which are a hallmark of Alzheimer's disease involve at least three different proteins rather than just the tau protein. These additional proteins are called neurofilaments and vimentin.

"This is a breakthrough of great importance: tau is not the only target," said Dr. Gerald Weissmann. "Before this discovery, we approached these tangles as if they were woven of one piece of string. Now we know that there are at least three proteins involved, we're much closer to untangling the Alzheimer's web. Without question, discoveries like this bring us closer than ever to advanced Alzheimer's treatments..."

"Since neurofilaments are the predominant protein in nerve cells, our study suggests that we should refocus our research on the biology of these filamentous proteins in an effort to understand how they are normally regulated and deregulated in response to human aging," said Harish Pant, Ph.D.

### 2 November: Gene causes life-long changes in brain cells

Researchers at Edinburgh University found that genes known as retrotransposons cause thousands of changes in brain cell DNA. These genes are particularly active in areas of the brain linked to the renewal of cells. The scientists are now researching whether brain tumours and diseases like Alzheimer's disease are linked to changes in retrotransposon activity.

Researcher Dr Geoff Faulkner said: "This research completely overturns the belief the genetic make-up of brain cells remains static throughout life and provides us with new information about how the brain works.

"If we can understand better how these subtle genetic changes occur we could shed light on how brain cells regenerate, how processes like memory formation may have a genetic basis and possibly link the activity of these genes to brain diseases."

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

### 8 November: A large US neuropathological database is open to all researchers

The US National Alzheimer's Coordinating Center is offering free access to its large relational database of standardised clinical and neuropathological research data. The database holds records from the 29 Alzheimer's Disease Centers in the US and has been developed in partnership with the Alzheimer's Disease Genetics Consortium and the National Cell Repository for Alzheimer's Disease.

Longitudinal, cross-sectional and neuropathology data are available for cognitively normal and mildly impaired subjects and for a number of specific dementia subtypes.

### 16 November: Tau protein in nose may allow early dementia diagnosis

Scientists at Darmstadt's University of Technology and City Hospital have found that deposits of the tau protein are detectable on mucous nasal membranes, sometimes years before dementia commences.

They also found a close correlation between the nasal deposits and the level of plaque on the brains of people with Alzheimer's disease. It is hoped that this will contribute to early diagnosis of dementia.

Prof Boris Schmidt of the Clemens Schöpf Institute for Organic Chemistry and Biochemistry at the Darmstadt University of Technology said "The more nasal tau-protein deposits we found in patients, the worse were their brain structures infested..."

The Darmstadt team investigated the mucous nasal membranes of 100 people who had died of Alzheimer's disease, to determine the earliest stage at which the disease could be diagnosed. In parallel, a clinical trial was conducted among people with Alzheimer's disease at the Ludwig-Maximilians-Universität in Munich.

## Dementia in society

### 1 November: Alzheimer's disease is among the most feared in Germany

A recent survey on health and the fear of diseases revealed that the most feared diseases in Germany are:

- 73% Cancer
- 53% Accident with serious injuries
- 52% Alzheimer's disease or other form of dementia (AD/dementia)
- 52% Stroke
- 45% Heart attack.

Younger respondents are more likely to fear cancer and serious accidents, while older people have a greater fear of strokes, AD/dementia and heart attacks.

Women are much more likely to fear AD/dementia than men (59 vs. 49%) but all people fear it more as they grow older (41% for ages 14-29 vs. 62% for ages 60+).

The survey was commissioned by DAK, a large public health insurer, and was conducted in October 2011 among 3018 respondents all over Germany.

**7 November: UK runs advertising campaign for early diagnosis of dementia**

The UK Department of Health (DOH) ran a EUR 2.3 million advertising campaign aimed at improving early diagnosis of Alzheimer's disease during the whole month of November.

This campaign is the result of DOH pilot studies, which suggested that it helps people to realise that early diagnosis of dementia can lead to better treatment and the slowing down of symptoms.

Paul Burstow, UK care services minister, said: "People are afraid of dementia and rather than face the possibility someone we love has the condition, we can wrongly put memory problems down to 'senior moments'.

"But if we are worried, the sooner we discuss it and help the person seek support the better. Don't wait until a crisis. Being diagnosed with dementia won't make the condition worse but leaving it untreated will. We can't cure dementia, but we can help keep the person we love for longer."

The advertisements appeared on TV, radio and in print, telling the story of a forgetful man who is helped by his daughter and a doctor to find out that he has a degenerative brain condition.

**8 November: Singer David Cassidy talks about family's struggle with dementia**

American singer, songwriter and actor David Cassidy has recorded a YouTube video in which he speaks about his family's struggle with dementia. The video was produced by the Alzheimer's Research and Prevention Foundation and can be seen at <http://www.youtube.com/user/preventalzheimers>

**28 November: Alzheimer Australia launches free iPhone application**



Alzheimer Australia and the Bupa Health Foundation have launched a free iPhone application called BrainyApp, in order to raise awareness of the risk factors for Alzheimer's disease and other types of dementia.

**New publications & resources**

**8 November: "Home For The Holidays" offers Christmas guide for families of people with dementia**

A local Alzheimer Association in California has published "Home For The Holidays", a short publication which offers tips and advice for families caring for a loved one with Alzheimer's disease. Its purpose is to help alleviate some

of the stress associated with the additional activities and changes in routine at this time of year.



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

**14 November: Launch of the European Portal for Action on Health Inequalities**

On 14 November, the European Portal for Action on Health Inequalities was launched. This new portal provides information on health inequalities and the social determinants of health. Its aim is to share practical and useful information and offer opportunities for contributors to promote their work. The portal - still under development - provides the following tools:

- databases of good health practices and health policy
- country profiles, including main actors, policies and tools
- EU health policies, programmes and initiatives
- glossary of health and sociological terms.

The European Portal for Action on Health Inequalities was developed by EuroHealthNet on behalf of the Equity Action Programme. This programme is part of the EU funded Joint Action on Health Inequalities, which aims to develop knowledge for action on health inequalities and to share learning and action at a European policy level.

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**AE Calendar**

Date	Meeting	AE Representative
5 December 2011	Alzheimer Europe Board Meeting (Brussels, Belgium)	AE Board and staff
6 December 2011	Meeting with AE sponsors (Brussels, Belgium)	AE Board and staff
6 December 2011	European Parliament lunch debate "Value of Knowing" and launch of Alzheimer Europe 2011 Yearbook (Brussels, Belgium)	AE Board, members and staff
9 December 2011	Meeting with auditors Mazars (Luxembourg, Luxembourg)	Jean

Date	Meeting	AE Representative
12 December 2011	Presentation on stigma and dementia at the seminar "Quality improvement in dementia care" organised by the Scientific Institute for Quality of Healthcare, (Radboud University Nijmegen Medical Centre, Netherlands)	Dianne
21 December 2011	Meeting with Salvatore Tarabella, MEP (Brussels, Belgium)	Annette
12-14 January 2012	"Alzheimer's Lexicon" meeting (Miami, USA)	Jean
16 January 2012	PharmaCog Annual General Meeting (Marseille, France)	Alex

## Future Conferences

Date	Meeting	Place
22-23 February 2012	8 <sup>th</sup> Annual Update Symposium on Clinical Neurology and Neurophysiology, <a href="http://www.neurophysiology-symposium.com">www.neurophysiology-symposium.com</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.dccferences.net.au/wcnr2012/">www.dccferences.net.au/wcnr2012/</a>	Melbourne, Australia
14-15 June 2012	4 <sup>th</sup> Biannual NUBIN Symposium on Biomarkers in Neurodegenerative Disease, <a href="http://www.vumc.nl/afdelingen/NUBIN">http://www.vumc.nl/afdelingen/NUBIN</a>	Amsterdam, The Netherlands
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
25-27 January 2013	5th European Neurological Conference on Clinical Practices: Neurovascular and Neurodegenerative Diseases, <a href="http://www.enccp.net">www.enccp.net</a>	Krakow, Poland
6-10 March 2013	11th International Conference on Alzheimer's and Parkinson's Diseases, <a href="http://www.kenes.com/adpd">www.kenes.com/adpd</a>	Florence, Italy
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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