



NEWSLETTER

December 2011

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Editorial

Alzheimer Europe was busy in December as we produced two important publications and launched them at a meeting in the European Parliament.



First, we launched our 2011 Dementia in Europe Yearbook which is dedicated to national reports on the legal provisions relating to restrictions of freedom of people with dementia in the Member States of the European Union, as well as Croatia, Iceland, Norway, Switzerland and Turkey. For the different countries, we included as far as possible information on involuntary internment, coercive measures, mistreatment/abuse and driving.

Second, we presented the findings of our five country survey on public perceptions of Alzheimer's disease and views on the value of diagnosis in a report which is available in English, French, German, Polish and Spanish. This report highlights the key survey results, including an overwhelming willingness of the general public to confront the disease and get a diagnosis despite great fear of the condition. In addition, the survey revealed very high public support for increased spending on research and care in the field of Alzheimer's disease.

The Yearbook and survey were welcomed with great interest at a lunch debate in the European Parliament which was hosted by Frieda Brepoels, MEP and the Vice-Chairperson of the European Alzheimer's Alliance. The participants at the meeting highlighted in particular the public's support for greater investment in research and care.

They saw this as a clear indication of support of Alzheimer Europe's ongoing campaign to make dementia a European priority and the organisation's call for the development of national dementia strategies and greater European collaboration.

I am of course delighted that our campaign continues to gather support from Members of the European Parliament. In December, Alzheimer Europe was pleased to welcome Maria da Graça Carvalho (Portugal) and Elżbieta Łukacijewska (Poland) as new members of our European Alzheimer's Alliance, which now counts 58 members from 21 Member States and all political groups in the European Parliament.

In December, we also finalised our report on the ethical issues linked to dementia research and we will be launching this report in a forthcoming meeting in the European Parliament.

Alzheimer Europe successfully completed negotiations with the Executive Agency for Health and Consumers and in 2012 we will be able to count on the continued support of the European Public Health Programme through an operating grant of EUR 190,000.

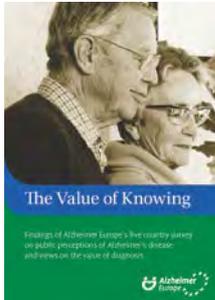
Finally, we have updated our website with all Powerpoint presentations which were made at our successful conference in Warsaw as well as videos of all plenary presentations. I hope these will be a useful resource for visitors of our website and will encourage you to submit abstracts and participate in this year's conference in Vienna.

I wish you all the best for 2012 and I look forward to our continued collaboration.

Jean Georges
Executive Director

Alzheimer Europe

2 December 2011: Alzheimer Europe publishes "Value of Knowing" survey



Alzheimer Europe has published a survey report showing overwhelming public support for greater investment in dementia care and research.

The "Value of Knowing" survey examined public perceptions and awareness of Alzheimer's disease and aimed to identify the views of the general public on the value of diagnosis. The

survey of 2,678 people in France, Germany, Poland, Spain and the US was designed and analysed by the Harvard School of Public Health and Alzheimer Europe.

The survey found that the majority of respondents in all five countries wish to see increased government spending on research into treatments for Alzheimer's disease and also on caring for people with this condition.

A large proportion of the public has had some experience with Alzheimer's disease. Majorities in all five countries say that they know or have known someone with Alzheimer's disease. This includes about seven in ten respondents in France (72%), Germany (73%), Spain (77%) and the US (73%) and 54% in Poland.

Alzheimer's disease is the second biggest health fear after cancer in four countries: respondents were asked to choose which disease they were most afraid of getting from a list of seven diseases including cancer, heart disease and stroke. Around a quarter of adults in four countries stated that they most feared getting Alzheimer's disease.

Fear of Alzheimer's disease increases with age, but even young adults are concerned, with approximately one in seven 18 to 34-year-olds reporting Alzheimer's as the disease they are most afraid of getting from the list provided.

The majority of respondents in all countries favour greater public investment in the care of people with Alzheimer's disease (60% in the US, 69% in Germany, 72% in Poland, 79% in Spain and 85% in France) with small minorities (between 1% in France and Spain and 5% in the US) wishing current spending to be decreased.

Similar majorities (67% in the US, 68% in Germany, 75% in Poland and 83% in France and Spain) support greater government spending on research for people with Alzheimer's disease.

Heike von Lützu-Hohlbein, Chairperson of Alzheimer Europe, said: "In times of economic difficulties, we should not forget the impact that dementia can have on people's lives and those of their families and carers. I am delighted that the general public supports Alzheimer Europe's call for greater investment in research and care.

"In some European countries (England, France, Norway and Scotland) we have already seen the development of comprehensive dementia strategies and it is now time for such programmes to be put in place in all European

countries to better support people with dementia and their carers."

A report with the detailed survey results is available in English, French, German, Polish and Spanish and can be ordered from Alzheimer Europe or downloaded on the Alzheimer Europe website: <http://www.alzheimer-europe.org/Research/Value-of-knowing>

Fieldwork for this survey was conducted via telephone (landline and cell phone) with nationally representative random samples of adults aged 18 and over in five countries by TNS, an independent research company based in London. The survey was supported by a grant to Alzheimer Europe from Bayer AG. Bayer was not involved in the design of the survey or the analysis of the findings.

2 December 2011: Alzheimer Europe publishes 2011 Yearbook and Annual Report

On 2 December, Alzheimer Europe published its 2011 Yearbook and Annual Report. This year the highlight is on legal provisions relating to the restriction of the freedom of movement of people with dementia. All of the EU countries are covered, as well as Norway, Iceland, Switzerland and Turkey.



The main topics of discussion in the Yearbook are involuntary internment, the use of coercive measures and driving privileges. In general, there is a trend towards more and "smarter" laws concerning movements of people with dementia - which indicates higher awareness and understanding of the special needs of these people and their families.

The Annual Report describes Alzheimer Europe's 2010 activities and financial accounts and includes a record of all the meetings and events attended by staff during the year.

The 2011 Yearbook and Annual Report are available on the Alzheimer Europe website.

5 December: Alzheimer Europe holds Board Meeting in Brussels

The Alzheimer Europe Board met in Brussels on 5 December. The Board discussed the following items:

- 2011 financial forecast and 2012 budget
- feedback from AE's Annual Conference in Warsaw
- preparation for the 2012 Annual Conference in Vienna
- creation of an Alzheimer Europe Foundation
- approval of the new "Ethics of dementia" research report
- preparation for the European Parliament lunch debate on 6 December.

6 December: Alzheimer Europe holds 11th lunch debate at the European Parliament

On 6 December, Alzheimer Europe held its 11th lunch debate at the European Parliament in Brussels. "Public

perceptions of Alzheimer’s disease and the value of diagnosis” was hosted by Frieda Brepoels, MEP (Belgium) and Vice-chair of the European Alzheimer’s Alliance.

The debate focused on the results of the “Value of Knowing” survey, which was carried out by Alzheimer Europe in association with the Harvard School of Public Health in France, Germany, Poland, Spain and the US. A summary of the findings was presented by Jean Georges, Executive Director, Alzheimer Europe (see above for more details).

Ms Brepoels concluded that “this survey clearly shows significant public interest in dementia and reinforces the commitment to support early diagnosis in Europe. It also highlights the importance of managing false expectations and this is precisely why it is important that realistic awareness raising is supported by the EU.”

At the end of the debate, Heike von Lützu-Hohlbein, Chairperson of Alzheimer Europe, presented the 2011 Alzheimer Europe Yearbook. The new yearbook discusses the legal provisions relating to restriction of the freedom of movement of people with dementia.

MEPs Nessa Childers (Ireland), Vittorino Prodi (Italy) and Marina Yannakoudakis (UK) all attended the debate. Other participants included assistants to other MEPs, national policy makers, representatives from the European Commission, Alzheimer associations and pharmaceutical companies.

20 December: AE renews operating grant from European public health programme

Alzheimer Europe successfully completed its negotiations with the Executive Agency for Public Health and Consumers and signed an agreement for an operating grant for 2012. The public health programme will support the organisation’s activities with an amount of EUR 190,000

30 December: Videos from Warsaw are on the Alzheimer Europe website

Alzheimer Europe is pleased to announce that the videos of the Plenary Sessions from the conference in Warsaw are now available at <http://www.alzheimer-europe.org/EN/Conferences/Previous-conferences/2011-Warsaw/Conference-Photos-and-Videos>

Impressions from Alzheimer Europe’s lunch debate



Frieda Brepoels, MEP (Belgium) opens meeting



Jean Georges, AE Executive Director, presents survey results



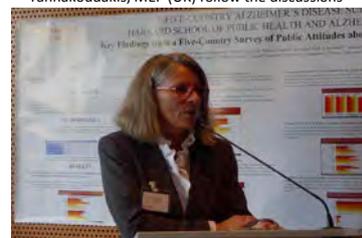
Nessa Childers, MEP (Ireland) and Marina Yannakoudakis, MEP (UK) follow the discussions



Vittorino Prodi, MEP (Italy)



Sigurd Sparr, AE Honorary Secretary, takes part in discussions



Heike von Lützu-Hohlbein, AE Chair presents 2011 Yearbook and closes meeting

Alzheimer Europe Networking

On 1 December (Brussels, Belgium) Annette attended the workshop "The benefits of a simplified and coherent clinical trials framework in Europe" organised by Europabio in the European Parliament.

On 5 December (Brussels, Belgium), Jean, Annette, Julie, Dianne, Gwladys and Alex attended the AE Board meeting.

On 6 December (Brussels, Belgium) the same people attended the AE / European Alzheimer’s Alliance lunch debate "Public perceptions of Alzheimer’s disease and the value of diagnosis" which highlighted the findings of AE’s "Value of Knowing" survey.

Also on 6 December (Brussels, Belgium) Annette met Agnieszka Schwarz, assistant to MEP Łukacijewska, to discuss the European Alzheimer’s Alliance.

On 12 December (Nijmegen, The Netherlands) Dianne gave a presentation on stigma and dementia at the "Quality Improvement in dementia care" seminar which took place at Radboud University Nijmegen Medical Centre.

Also on 12 December (Chilly Mazarin, France) Annette participated in the meeting "Alzheimer’s disease: the future alongside patients and their carers" organised by Sanofi.

On 21 December (Brussels, Belgium) Annette met Belgian MEP Marc Tarabella and his assistant to discuss the European Alzheimer’s Alliance.

European Alzheimer's Alliance

20 December: Two MEPs join the European Alzheimer's Alliance

In December, MEPs Maria da Graça Carvalho (Portugal) and Elżbieta Łukacijewska (Poland) joined the European Alzheimer's Alliance. Both are members of the European People's Party (Christian Democrats).

Ms Carvalho is a member of the Committee on Industry, Research and Energy (ITRE) and a substitute of the Budgets Committee and the Special Committee on Policy Challenges and Budgetary Resources for a Sustainable European Union after 2013 (SURE). She is also a former Minister of Science, Innovation and Higher Education in Portugal.

Ms Łukacijewska sits on the Committee on Legal Affairs and is a substitute for the Committee on the Environment, Public Health and Food Safety. She is the first Polish MEP to join the European Alzheimer's Alliance during the current mandate.



Maria da Graça Carvalho



Elżbieta Łukacijewska

Members of the European Alzheimer's Alliance

Currently, the total number of MEPs in the Alliance stands at 58, representing 21 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:** Cabrnoc Milan (ECR), Kohlíček Jaromír (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 Blinkevičiute (S&D). **Luxembourg:** Engel Frank (EPP), Lulling Astrid (EPP). **Netherlands:** De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP). **Poland:** Łukacijewska Elżbieta (EPP). **Portugal:** Carvalho Maria da Graça (EPP), Coelho Carlos (EPP), Matias Marisa (GUE/NGL). **Romania:** Antonescu Elena Oana (EPP). **Slovakia:** Mikolasik Miroslav (EPP), Záborská 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

18 November: 2012 European Union budget is approved

On 18 November, the European Parliament and the Member States agreed on the priorities and size of the EU Budget for 2012.

The priorities are growth, innovation, employment, border control, migration management and support of democratic development in the Arab world. The overall budget for next year will be EUR 129.1 billion in payments and EUR 147.2 billion in commitments.

Ms Francesca Balzani, MEP (Italy) and rapporteur for most of the budget, said "This is the first budget in real support of the EU 2020 strategy for growth and innovation. It means more money for research, better job qualifications and a competitive Europe."

1 December: 18 new Members have joined the European Parliament

The European Parliament has added 18 new Members to reach 751 total MEPs. The reason for the change is that the last Parliament elections in 2009 were held under the Nice Treaty, which set the number of MEPs to 736. The Lisbon Treaty increased that number to 751.

There are four new MEPs from Spain and two each from Austria, France and Sweden. Bulgaria, Italy, Latvia, Malta,

Poland, Slovenia, the Netherlands and the UK each have one new MEP. As of 1 December, the following had already taken office:

- Austria: Ewald Stadler, Josef Weidenholzer
- Bulgaria: Svetoslav Hristov Malinov
- France: Yves Cochet, Jean Roatta
- Italy: Gino Trematerra
- Latvia: Kārlis Sadurskis
- Malta: Joseph Cuschieri
- Poland: Arkadiusz Tomasz
- Slovenia: Zofija Mazej Kukovic
- Spain: Vicente Miguel Garcès Ramon, Dolores Garcia-Hierro Caraballo, Eva Ortiz Vilella, Salvador Sedo i Alabart
- Sweden: Amelia Andersdotter, Jens Nilsson
- UK: Anthea McIntyre.

1 December: EAHC adopts 2012 Work Plan for health activities

On 1 December, the European Agency for Health and Consumers (EAHC) published the 2012 Work Plan for Community action in the health field. The plan sets out activities to be co-financed and the full list of calls for tender to be published within the next months. The plan includes:

- Actions to promote health (EUR 4 million): increase healthy life years and promote healthy ageing. This activity will focus on activities in line with the European Innovation Partnership on Active and Healthy Ageing, including the deployment of new solutions for care provision and business models for collaborative and integrated care systems. The action will also focus on chronic disease management, particularly multiple chronic conditions
- Actions that will identify the causes of, address and reduce health inequalities in the Member States (EUR 3 million): forecast the healthcare workforce needs for effective planning in the EU. These actions will provide a common platform for Member States to forecast health workforce needs and workforce planning methodologies and to find possible solutions to the shortage of health workers in Europe.
- Actions that will address health determinants to promote and improve physical and mental health (EUR 1.5 million). This action will establish a process for structured work on mental health involving Member States, stakeholders in the health and other relevant sectors and international organisations. It will build on the 2009-2011 thematic conferences under the European Pact for Mental Health and Well-being.

1 December: New MEP Code of Conduct emphasises transparency

On 1 December, the European Parliament endorsed a new Code of Conduct for Members of the European Parliament (MEP). The Code sets out rules and principles which MEPs will need to follow in order to avoid conflicts of interest.

The code's guiding principle is transparency: MEPs must provide clear declarations of their paid activities outside the Parliament, as well as any other functions which might constitute a conflict of interest.

The code also includes an explicit ban on receiving payments or other rewards in exchange for influencing parliamentary decisions. There are clear rules on the acceptance of gifts and on the position of former MEPs working as lobbyists. Should a Member breach the Code, sanctions will be inflicted.

An advisory committee will provide guidance to MEPs and advise the President on what steps to take in the event of alleged breaches of the code.

The new rules became effective on 1 January 2012.

2 December: EPSO Council adopts conclusions on closing health gaps

On 2 December, the EPSO Council (Employment, Social Policy, Health and Consumer Affairs) adopted the following conclusions on "closing the health gaps within the EU through concerted action to promote healthy lifestyle behaviours":

1) to promote strategies to address health determinants using population-wide intervention, complemented by actions focusing on vulnerable groups - especially those arising from preventable unhealthy lifestyle behaviours.

2) To accelerate progress on combating unhealthy lifestyle behaviours, such as tobacco use, alcohol-related harm, unhealthy diet and lack of physical activity, which lead to increased incidence of non-communicable chronic diseases, such as cancer, respiratory diseases, cardiovascular diseases, diabetes and mental illnesses. All of these are recognised as important causes of premature mortality, morbidity and disability in the EU.

The Council conclusions also include a series of possible actions for the European Commission and the Member States to facilitate the implementation of the commitment expressed during the Council meeting.



8 December: IMI improves funding rules and simplifies procedures

On 8 December, the Innovative Medicines Initiative (IMI) announced details of significant changes to its rules. These will improve financial conditions and simplify management requirements for project participants. The new rules are set out in the newly-released model Grant Agreement and in the Financial Guidelines which will be available in early 2012.

From now on, participants in new and ongoing projects will be able to claim actual indirect (overhead) costs; previously only a flat rate of 20% of direct eligible costs was possible. Reporting and accounting procedures have also been simplified, allowing projects to cut administration costs and save more for scientific activities. For example, partners now have the option of declaring average personnel costs. In addition, IMI is currently working to simplify its application procedures and the scientific reporting procedures for ongoing projects.

8 December: EAHC launches calls for proposals

On 8 December, the Executive Agency for Health and Consumers (EAHC) launched calls for proposals for joint actions, operating grants, projects and conferences. This follows EAHC's adoption of the 2012 Health Programme Work Plan on 1 December.

Calls for tenders will be published throughout 2012. In order to be alerted when a new call for tender is launched, interested parties can sign up to the mailing list by writing to EAHC-HPTENDER@ec.europa.eu.

12 December: MEP Flašíková-Beňová asks Commission about tackling ageing through innovation

On 12 December, Ms Monika Flašíková-Beňová, MEP (Slovakia) submitted a question to the European Commission to ask how the Commission would support the Strategic Implementation Plan adopted in November 2011 by the High-Level Steering Group on the European Innovation Partnership on Active and Healthy Ageing and what steps the Commission would take to support it.

14 December: EP question to the Commission about 2014 as the European Year of Mental Health and the Brain

The co-Chairs of the Mental Health Interest Group in the European Parliament, Nessa Childers (Ireland), Marian Harkin (Ireland), Jean Lambert (UK) and Antonya Parvanova (Bulgaria) have asked the Commission to give its views on the designation of 2014 as European Year of Mental Health and the Brain, and to indicate whether a proposal is forthcoming on the matter.

The co-Chairs pointed out that such a year would increase awareness of all brain diseases and mental health problems across the EU and also mentioned the following facts:

- brain diseases and mental health problems affect more than a quarter of the European population
- the total annual cost of brain diseases and mental illness in Europe is an estimated EUR 798 billion
- mood disorders – including depression and bipolar disorder – represent the highest cost (EUR 113 billion), followed by dementia (EUR 105 billion).

We provide full references to articles on our website: www.alzheimer-europe.org

17 December: MEP Sârbu questions the Commission on demographic ageing and health services

MEP Daciana Sârbu (Romania) submitted a question to the European Commission (EC) about how the challenges posed by the ageing of the population in Europe will impact the Member States and their sectors of activity. Ms Sârbu is particularly interested in:

- whether it is advisable for the EC to create a European strategy to adapt national health systems to the challenges posed by demographic ageing
- what steps the EC will take to respond to the social challenges posed by demographic ageing.

Policy Watch

2 December: Survey highlights financial and health problems of UK carers

A survey conducted by charity Carers UK concluded that poverty and ill-health can push carers to the breaking point, leaving them unable to care. This brings great costs to family life and will also cost the state more in the long-term as the NHS and social care services are forced to step in. A proposed budgetary cut to disability payments will exacerbate this problem, both for carers and the people under their care.

Carers UK surveyed over 4,000 carers between September 2010 and July 2011. Nearly half of the respondents said that financial worries are causing them stress, anxiety and depression. 76% of respondents said they had suffered mental health problems and this rose to 85% when debt was involved. Carers currently receive an allowance of GBP 55.55 (EUR 67.2) per week, which is the lowest allowance in the UK benefit system.

Emily Holzhausen, Director of Policy for Carers UK, said “there are an estimated 6.4 million people in the UK providing unpaid care and they are saving UK economy £119bn [EUR 144 billion] every year – that is more than the social care services and private providers combined. It is a scandal that, despite this contribution, carers end up sick with worry about how to make ends meet.”

The government's proposed welfare reform could mean a reduction of GBP 2 billion (EUR 2.4 billion) to disability payments. A spokesman for Carers UK said: “We're concerned about the impact of the welfare reform package on carers. Cutting £2 billion from disability benefits could have serious knock-on effects for carers. If the person they care for loses their benefits, their carer's allowance will be lost too.”

Members' News

14 December: French report calls for better communication of Alzheimer's disease diagnosis

A series of 20 interviews carried out by France Alzheimer revealed that the announcement of a diagnosis of Alzheimer's disease is often a traumatic experience.

Ms Judith Mollard, psychologist and project manager at France Alzheimer, interviewed people who had recently been diagnosed with early-onset Alzheimer's disease. The results indicate that, in general, diagnoses are delivered rather abruptly; there is little or no effort by the physician to soften the psychological blow which interviewees and their families feel upon learning they have an incurable disease.

As a result, mental anguish - including depression - often follows diagnosis, as families try to find ways to accept and cope with what some interviewees described as a virtual death sentence. People have to struggle through the process to restore their levels of self-worth and confidence, in order to regain a functional and productive life.

The report concludes that improvements are needed in the doctor-patient relationship, particularly in the way diagnoses are presented and discussed. Ms Mollard pointed out that people with recent diagnoses of Alzheimer's disease are likely to still have many of their faculties intact.

14 December: Alzheimer's Society aims to help victims of financial abuse

The UK Alzheimer's Society reports that 15% of people with dementia have been victims of financial abuse, including cold calling, scam mail or mis-selling. This represents more than 112,000 people in the UK.

The figures come from a study conducted by the Society, which spoke to 47 people with dementia, 104 carers and focus groups with nursing staff, social workers, and other professionals. 62% of carers said the person they cared for had been approached by cold callers or salespeople on the doorstep, and 70% had been targeted by telephone cold callers.

The Society is putting together a training programme for financial service providers such as banks. It is also urging families to discuss money management, consider the

power of attorney, speak to their local bank manager about difficulties, and stop junk mail. In addition, the UK police is looking at updating the way they treat victims of financial crime.

"We are merely scratching the surface of the frightening hidden depths of financial abuse," said Jeremy Hughes, chief executive at the Alzheimer's Society.

23 December: Italy hosts art exhibition with works produced by people with dementia



On 23 December, Italian association Alzheimer Uniti Onlus launched an art exhibition with 48 pieces created by people attending the Alzheimer Day Centre in Rome. The exhibition is the final result of an art therapy programme carried out over the past three months, with artists working under the guidance of a psychologist and an art-therapist.

"Art - here and now: an art-therapy project" can be seen at the Alzheimer Centre Fondazione Roma.

Science Watch

8 November: New mouse model carries Hirano bodies

Scientists at the University of Georgia (UGA) have developed a new transgenic mouse model that carries Hirano bodies. These intracellular bodies are made of actin proteins and exist in the brain cells of people with Alzheimer's and other neurodegenerative diseases.

The existence of Hirano bodies has been known since 1965, but researchers were not sure if they helped cause the conditions, or if they appeared after the onset of the disease. The UGA researchers now believe that they may play a protective role in the progression of neurodegenerative diseases.

"This work gives us a first view of the possible effects of Hirano bodies," said Marcus Fechheimer, Professor of cellular biology at UGA. "Now we know that Hirano bodies do not kill cells and are not toxic to mice. This new model will allow us to ask whether Hirano bodies have any effect on progression of disease in the brain."

27 November: Cambridge University will host a new public-private research centre

Cambridge University and Elan, a private biotech company, will create a new research centre focused on therapies for neurodegenerative disorders. The Cambridge-Elan Centre will concentrate on the molecular basis of protein misfolding and aggregation, and their links to both Parkinson's and Alzheimer's diseases. This public-private partnership will last for ten years and will be based on the university's grounds in England.

2 December: VPS35 protein may be a new biomarker for Alzheimer's disease

Researchers at the Georgia Health Sciences University (GHSU) in Atlanta have discovered that a reduction of the VPS35 protein leads to increased activity of fellow protein

BACE1, which is responsible for the production of beta amyloid plaque.

Dr. Wen-Cheng Xiong, developmental neurobiologist and Weiss Research Professor at GHSU, led the research team which modified an Alzheimer's mouse model so that VPS35 production was halved. As a result, BACE1 activity increased, causing accelerated ageing, memory deficits, poor communication between brain cells and accumulation of beta amyloid.

"It was known that expression of VPS35 was down and BACE1 was up in Alzheimer's but the direct relationship was unknown", said Dr. Xiong.

The discovery of this relationship makes VPS35 a potential biomarker for both Alzheimer's and Parkinson's diseases as well as a target for new therapies to keep VPS35 elevated.

2 December: MAKs system extends quality of life for people with dementia

A new German study shows that a regime of behavioural and mental exercises may slow the progression of dementia.

The study was carried out by a team from Friedrich-Alexander-University in Erlangen and led by Prof Graessel. The subjects were people with dementia living in nursing homes. This group followed a year-long programme of two hours of group therapy per day, six days per week. Therapy followed the MAKs system, which combines motor and cognitive stimulation, daily living activities and a spiritual element such as singing.

After 12 months of therapy, the group maintained their level on the Alzheimer's Disease Assessment Scale (ADAS) and also maintained their ability to carry out activities of daily living. The control group all showed a decrease in cognitive and functional ability.

Prof Graessel concluded that "...MAKS therapy is able to extend the quality of, and participation in, life for people with dementia within a nursing home environment. We are currently in the process of extending these preliminary results to see if this prevention of dementia decline can be maintained over a longer time period."

5 December: O4 molecule prevents the formation of toxic amyloid plaque

Scientists in Germany have reported that a red dye called orcein and a similar molecule called O4 appear to reduce the amount of small amyloid assemblies which are the precursors to toxic brain plaque. Orcein and O4 both bind to the protein assemblies and cause them to convert to large, mature plaques. These large plaques are believed to be mainly non-toxic to brain cells.

Dr. Erich Wanker, researcher at the Max Delbrück Center for Molecular Medicine (MDC) in Berlin, said "This is a new mechanism. Up to now it has been considered to be very difficult to stop the formation of small toxic protein assemblies. If our hypothesis is correct that the small aggregates, which are precursors of plaques, indeed cause neuronal death, with O4 we would have a new mechanism to attack the disease."

On a parallel track, a synthetic dye called methylene blue is currently undergoing clinical trials. This dye also seems to stimulate the formation of large plaques.

Further studies will be necessary to determine whether the accelerated formation of large plaques can be a therapeutic approach. "We hope that our findings will stimulate research activities in this direction, especially in drug discovery" concluded Dr. Wanker.

7 December: Hippocampal hyperactivity may be a precursor to neurodegeneration

Researchers at Brigham and Women's Hospital, an affiliate of Harvard Medical School, have linked hyperactivity of the hippocampus and atrophy in various areas of the brain typically affected by Alzheimer's disease.

Hippocampal hyperactivity is considered unusual because dying neurons typically display little activity. However, it may be a signal of imminent clinical decline, particularly in older people with normal or slightly impaired cognition. According to Dr. Reisa Sperling, Associate Professor of Neurology at Harvard Medical School, "one of the early things that may happen in AD before cells die is that they have this aberrant increase in activity. When they're firing in an abnormal way, that may be a sign that they are dying."

The researchers used MRI (Magnetic Resonance Imaging) to analyse 18 cognitively intact seniors and 16 with early mild cognitive impairment. The affected brain areas included the medial temporal lobe, the angular gyrus and the inferior temporal gyrus.



www.alzheimer-europe.org/Donation

8 December: Biomarkers in blood serum could lead to diagnosis of Alzheimer's disease

Researchers from the Texas Alzheimer's Research and Care Consortium (TARCC) have found that biomarkers in blood serum could be combined with existing clinical information to accurately identify people with Alzheimer's disease.

Sid O'Bryant, Ph.D., of the Texas Tech University Health Sciences Center, led the research team. "Basically we created a simpler version of a recent blood test," O'Bryant said. "We created a briefer screen test in the TARCC cohort and then applied it to the Alzheimer's Disease Neuroimaging Initiative (ADNI) national cohort and found we still accurately identify 88% of those with and without the disease."

The team's analysis of serum biomarker proteins were conducted on 197 participants with Alzheimer's disease and 199 control participants of the TARCC cohort, with further analysis conducted on plasma proteins from 112 people with Alzheimer's disease and 52 control participants from the ADNI cohort.

TARCC is a consortium of five medical research institutions which specialises in Alzheimer's disease and is funded by the state of Texas. ADNI is a research project to

study the rate of change of cognition, function, brain structure and biomarkers of Alzheimer's disease.

8 December: A new tool allows earlier diagnosis of Alzheimer's disease

A European project team has developed a tool to allow earlier diagnosis of Alzheimer's disease. The PredictAD tool compares various measurements of a person with Alzheimer's disease and provides a simple index about the severity of the disease. Results show that the tool improves both the accuracy of diagnosis and clinicians' confidence about their decision.

PredictAD gathers measurements from such biomarkers as magnetic resonance imaging (MRI), positron emission tomography (PET), cerebrospinal fluid (CSF) and genetic biomarkers, as well as less tangible indicators like memory loss. This data is compared with measurements of other people in various databases and PredictAD provides an index and graphical representation reflecting the state of the patient.

"The PredictAD tool provides a new option to support decision making by providing objective information about the patient", said Prof Hilikka Soininen from the University of Eastern Finland, who led the clinical validation of the project.

This study was supported by the project "From patient data to personalised healthcare in Alzheimer's disease" (PredictAD) which was supported by the European Commission under the 7th Framework Programme.

8 December: Tau immunisation slows progress of Alzheimer's disease in mice

Researchers at Sydney University have developed a vaccine which targets the tau protein and appears to slow the progress of Alzheimer's disease in mouse brains.

Tau proteins work inside the neuron to help maintain the neuron's structure intact. When tau proteins are defective, this structure is weakened and the neuron no longer functions normally. This causes neurodegeneration and can lead to Alzheimer's disease or other forms of dementia.

The research team, led by Dr. Lars Ittner from the Alzheimer's and Parkinson's disease laboratory at Sydney University, worked over ten months to immunise mice in groups of increasing ages. The older the group, the more advanced was the stage of Alzheimer's disease.

The immunised mice showed significantly lower levels of neurodegeneration and Dr. Ittner pointed out that "the older group with the very advanced Alzheimer's actually benefited the most" from the vaccination. He added that it is the first time researchers had proved a vaccine targeting the tau protein in mice could be effective after the disease had set in.

12 December: PKR molecule inhibitor may help boost learning and memory

Researchers at Baylor College of Medicine (Houston, Texas) recently reported that inhibiting the activity of the PKR molecule in the brain resulted in better learning and memory in mice.

PKR is the double-stranded, RNA-activated protein kinase and is normally elevated during viral infections. Dr. Mauro Costa-Mattioli, Assistant Professor of Neuroscience said "...PKR was originally described as a sensor of viral infections, but its function in the brain was totally unknown. We found that when we genetically inhibit PKR, we increased the excitability of brain cells and enhanced learning and memory, in a variety of behavioral tests."

The research team found that when PKR is inhibited, the increased synaptic activity (i.e. the enhanced communication between neurons) is caused by gamma interferon, another molecule involved in immunity.

"These data are totally unexpected, and show that two molecules classically known to play a role in viral infection and the immune response regulate the kind of brain activity that leads to the formation of long-term memory in the adult brain", said Dr. Costa-Mattioli.

Another key finding was the fact that this process could be mimicked by a PKR inhibitor - a small molecule that blocks PKR activity and thus acts as a "memory-enhancing drug".

"It is indeed quite amazing that we can also enhance both memory and brain activity with a drug that specifically targets PKR. Definitely then, the next step is to use what we have learned in mice and to try to improve brain function in people suffering from memory loss", concluded Dr. Costa-Mattioli.

13 December: Neoprobe licenses imaging agent for amyloid detection

Neoprobe Corporation has obtained worldwide exclusive rights from AstraZeneca to the late-stage radiopharmaceutical imaging candidate, AZD4694, for aiding the diagnosis of Alzheimer's disease.

AZD4694 is a Fluorine-18 labeled precision radiopharmaceutical candidate for use in the imaging and evaluation of patients with symptoms of cognitive impairment such as Alzheimer's disease. It binds to Beta-amyloid deposits in the brain and can then be viewed in positron emission tomography (PET) scans. Clinical studies in more than 70 patients suggest that AZD4694 works quickly and safely. A phase 3 clinical programme is planned for early 2013.

14 December: Blood test may provide biomarker for early diagnosis of Alzheimer's disease

A new study from Finnish research centre VTT suggests that a simple blood test may provide a biomarker for early diagnosis of Alzheimer's disease.

Mild Cognitive Impairment (MCI) is considered as a transition phase between normal ageing and Alzheimer's disease, but not all people with MCI make the transition. This study allowed researchers to identify those diagnosed with MCI who later progressed to Alzheimer's disease, but also to derive the blood biomarker which can identify these people at an early stage.

236 people took part in the study: 143 people with MCI, 47 with Alzheimer's disease and 46 healthy controls. 52 of the people with MCI progressed to Alzheimer's disease and researchers were able to identify components in their blood which led to the progression. The research team

also found that hypoxia and oxidative stress play a role in the early progression stage.

The research teams were led by Dr. Matej Orešič, Research Professor, Systems Biology and Bioinformatics, VTT and Prof Hilka Soininen, School of Medicine, University of Eastern Finland.

This study was supported by the project "From patient data to personalised healthcare in Alzheimer's disease" (PredictAD) which was supported by the European Commission under the 7th Framework Programme.

We provide full references to articles on our website: www.alzheimer-europe.org

16 December: Prana to begin trial of PBT2 for Alzheimer's disease

Prana Biotechnology has started recruiting and screening patients for a 12-month phase 2 trial of PBT2, a drug designed to treat Alzheimer's disease.

Professor Colin Masters, Prana consultant and Director of the Mental Health Research Institute (Melbourne, Australia), explained that "we are using PiB-PET imaging to measure the drug's effects on the insoluble form of Abeta [amyloid beta], and we are using a recently developed blood test to measure levels of the soluble oligomers of Abeta.

19 December: New drug candidate prevents brain damage in Alzheimer mice

A recent study from the Salk Institute for Biological Studies reports that drug candidate J147 improved memory and prevented brain damage when given to mice with Alzheimer's disease.

Researchers showed that J147 prevented cognitive decline in animals with Alzheimer's disease. Mice and rats treated with the drug also produced more of a protein called brain-derived neurotrophic factor (BDNF). This is a molecule that protects neurons from toxic insults, helps new neurons grow and connect with other brain cells and is involved in memory formation.

27 December: Proteins in cerebrospinal fluid can be biomarkers for Alzheimer's disease

Researchers at the University of Gothenburg's Sahlgrenska Academy in Sweden have developed a method of measuring proteins and protein fragments in cerebrospinal fluid (CSF) so that they can be used as biomarkers for Alzheimer's disease.

Beta amyloid causes clumps to accumulate between brain nerve cells and also triggers the formation of tangles, which in turn releases proteins into the CSF. "We found that levels of these proteins change in the CSF even with early symptoms, and we will probably be able to detect changes in the brain at a very early stage of the disease," explained doctoral student Niklas Mattsson. This research project was led by Prof Kaj Blennow.

Dementia in society

12 December: UK telephone hotline helps to reduce abuse in care homes

A UK telephone whistleblowing hotline for abuse in care homes has registered over 2,200 calls in six months of operation.

The hotline is operated by the Care Quality Commission (CQC), a government watchdog agency for hospitals, care homes and care services. The CQC encourages calls from health and care workers who see cases of abuse or neglect. A spokesperson said "The volume of calls is higher than we anticipated and it is on a rising trend."

The agency takes action by contacting local authorities who send in inspectors. During a recent visit to a care home, inspectors confirmed that one resident was attacking several others, but also that the home was in poor hygienic condition.

In other efforts to improve care conditions, the government announced plans to include relatives of residents on committees scrutinising standards in care homes and to publish an online ratings guide for care homes.

16 December: UK hospitals are often unable to manage people with dementia

A new report outlines the conclusions of the first national audit of dementia, which covered 210 hospitals in England and Wales. It reveals that only 6% of hospitals have an actual written plan on how to admit, treat and manage people with dementia when they are admitted.

UK Care services minister Paul Burstow said: "We set this audit up to put dementia care in hospital under the spotlight. It has found some excellent practice, but it has revealed far too many hospitals failing to put in place dementia-friendly care."

Professor Peter Crome, Chairman of the national audit of dementia steering group, said "around a whole range of issues to do with people's functions, their mental state, the policies were in place but the practice was not undertaken."

The report criticised the "impersonal" way in which dementia patients are treated – despite them occupying a quarter of all the beds. Staff do not always greet or talk to patients during care. They do not always explain what they are doing or offer a choice, and sometimes they do not respond to requests for help, the report added.

Hospital staff pointed out a lack of education: just one in three staff said they had sufficient training in caring for people with dementia and half are not properly trained to communicate with those suffering from Alzheimer's or deal with aggressive behaviour.

Jeremy Hughes, Chief Executive of the Alzheimer's Society, said "this shocking report proves once again that we urgently need a radical shake-up of hospital care. Given that people with dementia occupy a quarter of hospital beds and that many leave in worse health than when they were admitted, it is unacceptable that training in dementia care is not the norm."

Prof Come admitted that "hospitals need to gear up their services on the assumption that the next patient who comes through the front door may have dementia - they often may not be diagnosed but they may have that condition - and they have to adapt the services, procedures, policies to manage such patients appropriately with compassion for their dignity."

Job opportunities

14 December: ADI is hiring a Director of Development

Alzheimer's Disease International (ADI) is recruiting a Director of Development for a full-time, fixed-term contract based in London. More details can be found at www.alz.co.uk/jobs

Contact Alzheimer Europe at:

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AE Calendar 2012

Date	Meeting	AE Representative
5 January 2012	Meeting with Erick Tyssier of Sanofi (Brussels, Belgium)	Annette
11 January	DG Sanco & EAHC Information Day for 2012 EIP AHA projects (Brussels, Belgium)	Annette
11 January	Meeting with MEP Ashworth to discuss European Alzheimer's Alliance (Brussels, Belgium)	Annette
12 January	Meeting with Maria Gomez Iglesias about EIP AHA Strategic Implementation Plan (Brussels, Belgium)	Annette
12-14 January	"Lexicon of Alzheimer's" conference (Miami, USA)	Jean
16 January	EFID Awards ceremony (Brussels, Belgium)	Annette
16 January	PharmaCog Annual General Meeting (Marseille, France)	Alex
19 January	Meeting with Fondation Roger de Spoelberch	Jean

24-25 January
7 February
7 February
15-16 February

European Forum for Good Clinical Practice annual conference (Brussels, Belgium)
Visit Merck clinical trial centre (Aalst, Belgium)
Launch of JPND Research Agenda (Brussels, Belgium)
NILVAD first project meeting (Dublin, Ireland)

Dianne
Dianne & Annette
Jean
Alex

Future Conferences

Date	Meeting	Place
14 February 2012	International Symposium on Promoting the Well-being of People with Dementia through Creative Arts "Kunststücke Demenz", www.ibk-kultur.de	Bonn, Germany
22-23 February 2012	8 th Annual Update Symposium on Clinical Neurology and Neurophysiology, www.neurophysiology-symposium.com	Tel Aviv, Israel
7-10 March 2012	27 th ADI Conference "Science Fact Fiction", www.adi2012.org/	London, UK
8-11 March 2012	6 th World Congress on Controversies in Neurology (CONy), www.comtecmed.com	Vienna, Austria
9-12 May 2012	12 th International Stockholm/Springfield Symposium on Advances in Alzheimer Therapy, www.ad-springfield.com	Stockholm, Sweden
16-19 May 2012	7 th World Congress for Neurorehabilitation 2012 (WCNR 2012), www.dconferences.net.au/wcnr2012/	Melbourne, Australia
12-13 July 2012	International Academy on Nutrition and Aging (IANA), www.iagg.info	Albuquerque, New Mexico,
14-15 June 2012	4 th Biannual NUBIN Symposium on Biomarkers in Neurodegenerative Disease, http://www.vumc.nl/afdelingen/NUBIN	Amsterdam, The Netherlands
4-6 October 2012	22 nd Alzheimer Europe Conference "Changing perceptions, practice and policy", www.alzheimer-europe.org/EN/Conferences	Vienna, Austria
25-27 January 2013	5 th European Neurological Conference on Clinical Practices: Neurovascular and Neurodegenerative Diseases, www.enccp.net	Krakow, Poland
6-10 March 2013	11 th International Conference on Alzheimer's and Parkinson's Diseases, www.kenes.com/adpd	Florence, Italy
21-23 March 2013	57. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), www.dgkn-kongress.de	Leipzig, Germany
23-27 June 2013	The 20 th IAGG Congress of gerontology and geriatrics, www.iagg2013.org	Seoul, Korea
20-23 March 2014	58. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), www.dgkn-kongress.de	Berlin, Germany
21-24 March 2014	30. International Congress of Clinical Neurophysiology (ICCN), www.iccn2014.de	Berlin, Germany



22nd Alzheimer Europe Conference
Changing perceptions, practice and policy
Vienna / 4-6 October 2012
Mark the dates!
www.alzheimer-europe.org/conferences

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