



NEWSLETTER

November 2012

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Editorial

I am happy to report a number of important developments in our activities. We held the first official meeting of the new Alzheimer Europe Foundation, which will operate alongside AE in all its activities. We also signed a new cooperation agreement with Newsweaver, an email software provider. The company's expertise will help to enhance our external communications.



The European Working Group of People With Dementia (EWGPWD) now has a web presence on the AE website, so you can follow the group's activities online. We suggest frequent visits; their agenda is quite full and they are very active. The presentations from the Vienna conference are also online and will soon be followed by videos. If you can't wait, there's a sneak video preview on YouTube.

In EU news, Tonio Borg has taken office as the new Health Commissioner in Brussels. In addition, the Commission and the OECD published a new health report which points out that life expectancy is up while spending on disease prevention is down.

Amongst our members, the best news comes from Bulgaria: the government has promised to partially reimburse dementia drugs, beginning next month. In a separate action, Bulgarian GPs are lobbying the government to create a national dementia plan.

There were two birthdays in November: the Luxembourg association celebrated 25 years of operation while the Czech society marked 15 years of activity. We wish them many more productive

years of helping people with dementia and their families.

Meanwhile, a Spanish journalist continued his walk from Spain to Jerusalem, on behalf of CEAFA; he recently passed through Greece and visited Alzheimer Hellas.

We've also covered various World Alzheimer's Day activities. While this may seem like old news, each year we see ever more creative campaigns that deserve to be shared.

On the science front, an international research team has linked a rare mutation of the TREM2 gene to a very high risk of Alzheimer's disease. This finding gives us important new clues about the origin and development of the disease.

Our Resources section covers two new interesting resources. The first is a site that provides information about intellectual disability (ID) and dementia. There is a growing number of people living with a combination of these conditions. The site offers resources, training and discussion forums.

The other website is dedicated to people with dementia. It provides a free and open space where people can express themselves, make new contacts and tell their own stories as they see fit.

This is the last of the newsletters to be sent in 2012. We hope you've enjoyed them all and will continue to send us your comments and contributions in 2013.

The entire Board and staff of Alzheimer Europe wish you a very pleasant break over the festive period.

Jean Georges
Executive Director

Alzheimer Europe

5 October: Alzheimer Europe sets up Foundation

On 5 October 2012, the Alzheimer Europe Board and Annual General Meeting approved the plans to set up an independent Alzheimer Europe Foundation. The Foundation will be set up with an initial grant of EUR 120,000 from Alzheimer Europe. The aims of the Foundation are the following:

- To support networking activities of national Alzheimer's associations in the framework of Alzheimer Europe
- To encourage the involvement of people with dementia in European conferences, meetings and projects
- To promote European dialogue on legal and ethical issues in dementia
- To support the exchange of information and good practices on national dementia strategies and Alzheimer's plans.

The first meeting of the Board of the Alzheimer Europe Foundation, also on 5 October, saw Maria do Rosário Zincke dos Reis (Portugal) elected as Chairperson, Heike von Lützu-Hohlbein (Germany) as Vice-Chairperson and Iva Holmerová (Czech Republic) as Treasurer.

The Statutes of the Foundation will be registered in Luxembourg and are awaiting final approval by the Luxembourg Ministry of Justice.



1 November: AE posts conference presentations on its website

At the Alzheimer Europe Conference in Vienna in October 2012, over 100 speakers gave presentations in four plenary and 24 parallel sessions. These presentations are now available on the AE website.

Please note that only those presentations have been included for which the author(s) had given express consent.

www.alzheimer-europe.org/Conferences/Vienna-2012/Detailed-Programme-abstracts-and-presentations

1 November: The next AE conference is on 10-12 October 2013

Following a date change, we received several queries about the dates of our next conference. We hereby confirm that the 23rd Alzheimer Europe Conference will take place on 10-12 October 2013 in St. Julian's, Malta.

1 November: AE delegation visits Lilly research plant

On 1 November, an Alzheimer Europe delegation visited the Lilly research plant in Erl Wood, near Ascot in the United Kingdom.

The hosts provided an overview of the company, its research programmes in the field of Alzheimer's disease and the EU regulatory framework for clinical trials. This was followed by a tour of the chemistry and biology departments, where the visitors saw various processes in the development and initial analysis of potentially new medical compounds.

Staff and volunteers of the Alzheimer associations in Greece, Italy, Malta, Portugal, Sweden and the United Kingdom (Alzheimer's Society and Alzheimer Scotland) took part in the study visit.



2 November: AE signs collaboration agreement with Newsweaver

In order to improve its dissemination activities, Alzheimer Europe concluded an agreement with Newsweaver, which will provide e-mailing software free of charge to the organisation.

Alzheimer Europe gratefully acknowledges these in-kind contributions estimated at EUR 1,200 in 2012 and EUR 5,400 in 2013.

Based in Ireland, Newsweaver is one of Europe's leading email software providers. The company has a proven track record in working with EU funded projects, particularly in providing the tools and technology that allow the research team to communicate effectively with investigators, study personnel, participants and caregivers.

Currently, Newsweaver and Alzheimer Europe are partners in the NILVAD project, a three year clinical trial funded by the FP7 programme. Newsweaver is leading the dissemination and communication activities of the project: the company's email marketing service will be the primary tool used for disseminating information during the trial.



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www.newsweaver.com

15 November: New webspace for EWGPWD

The European Working Group of People With Dementia (EWGPWD) now has a presence on the Alzheimer Europe website. This includes the group's activities since its creation in 2012 and also biographies and pictures of the members.

www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia

Alzheimer Europe Networking

- On 1 November (Erl Wood, UK) Jean attended a study visit of Lilly's Erl Wood Research Centre.
- On 6 November (Brussels, Belgium) Annette attended a European Commission EIP AHA conference of partners.
- On 8 November (Brussels, Belgium) Annette had a meeting with Heather Clarke (EPDA).
- On 13 November (Brussels, Belgium) Annette attended a Pfizer stakeholders' day on clinical trials and IMI debate in the European Parliament.
- On 14 November (Brussels, Belgium) Annette attended the WeDO final conference.
- On 16 November (Luxembourg, Luxembourg), representatives of RedBurn Solutions and Invest Northern Ireland met with Jean to discuss possible project collaborations.
- On 19 November (Luxembourg, Luxembourg), Jean attended the 25th anniversary celebration of the Luxembourg Alzheimer's Association.
- On 20 December (Brussels, Belgium) Annette attended the AGE Platform thematic seminar on "Creating an age-friendly EU".
- On 22 November (Dublin, Ireland) Dianne attended the Autumn Conference 2012 of the Dementia Services Information Development Centre entitled "Ethics and Dementia Care".
- On 23 November (London, UK) Jean attended the GSK Advisory Board.
- On 27 November (Luxembourg, Luxembourg) Alex went to the 6th meeting of the Health-EU Editorial Board.
- On 29 November (London, UK) Jean and Alex attended an EMA training session on pharmaceutical legislation.
- On 30 November (London, UK) Jean attended a meeting of the EMA's Human Scientific Party with Patient and Consumer Organisation.
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Members of the European Alzheimer's Alliance

Currently, the total number of MEPs in the Alliance stands at 66, representing 22 Member States of the European Union and all 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), Werthmann Angelika (NI). **Belgium:** Brepoels Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tarabella Marc (S&D). **Bulgaria:** Parvanova Antonia (ALDE). **Cyprus:** Triantaphyllides Kyriacos (GUE-NGL). **Czech Republic:** Cabrnock 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), Juvin Philippe (EPP), Morin-Chartier Elisabeth (EPP), Pargneaux Gilles (S&D). **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:** Mauro Mario (EPP), 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), Busoi Cristian (ALDE), Sârbu Daciana Octavia (S&D). **Slovakia:** Mikolášik Miroslav (EPP), Zaborská Anna (EPP). **Slovenia:** Peterle Alojz (EPP). **Spain:** Badia i Cuchet Maria (S&D). **United Kingdom:** Ashworth Richard (ECR), Hall Fiona (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).

EU Developments

6 November: Commission organises first EIP-AHA conference

On 6 November, the European Commission organised the first European Innovation Partnership on Active and Healthy Ageing (EIP AHA) conference. This conference marked the official launch of the six actions identified in the Strategic Implementation Plan.

The Conference was headlined by Maire Geoghegan Quinn, Research Commissioner, Neelie Kroes, European Commission Vice President, Kathleen Lynch, Irish Minister of State from the Department of Health and Department of Justice, and María Pilar Farjas Abadía, Spanish Secretary General of Health and Consumers, Ministry of Health, Social Services and Equality.

High level representatives and Ministers from European regions and innovative projects discussed how to implement and scale up innovations for active ageing and what contribution they can make to regions. They were joined by leading figures in the field of active and healthy ageing from across Europe.

The six Action Groups presented their respective Action Plans: prescription adherence, fall prevention, frailty and

nutrition, integrated care, independent living and a horizontal approach to age-friendly environments.

The EIP AHA partners will now start implementing the plans. The European Commission with the Joint Research Centre is developing a monitoring framework to be able to report on the progress and impact of the Action Plans on European people, society and economy.

The Action Groups include 261 commitments by over 3000 stakeholders from all Member States, and the Action Plans aim to improve the quality of life of four million European senior citizens between now and 2015.

http://ec.europa.eu/health/ageing/events/ev_20121106_en.htm

14 November: WeDO: European Quality Framework for Long-Term Care Services

On 14 November, AGE Platform EU presented its "European Quality Framework for Long-Term Care Services". The framework highlights principles and guidelines for the well-being and dignity of older people in need of care and assistance.

It is the result of the two-year WeDO project, coordinated by AGE Platform Europe with the help of 18 partner organisations. It aims to improve the quality of life for older people in need of care and assistance with a set of

11 quality principles and seven areas of action, recommendations for policy makers and a methodology on how to implement them with a participatory approach. It gets inspiration from the "European Charter of the rights and responsibilities of older people in need of care and assistance" launched in 2010.

The Framework was presented at the final WeDO conference, which was hosted and chaired by Heinz K. Becker, Member of the European Parliament, Co-chair of the Intergroup on Ageing and Intergenerational Solidarity and Member of the European Alzheimer's Alliance.

The other deliverable of the project was the development of an "EU strategy for the well-being and dignity of people in need of care and assistance". This strategy was developed with the input of a wide range of stakeholders supporting the WeDO initiative. It identifies EU legislative areas that can support the adoption of the European Quality Framework, Age-Friendly Environments in Europe, the elimination of all forms of discrimination in care, ageism and elderly abuse, the promotion of adequate protection and support to elderly people in need of care, informal and formal carers and volunteers in the EU.

Alzheimer Europe participated in the development of this strategy and is a firm supporter.

<http://wedo.ttp.eu/wedo-events>



16 November: Commission and OECD publish new health report

On 16 November, the European Commission and the OECD published "Health at a Glance: Europe - 2012". This report presents a set of key indicators of health status, determinants of health, health care resources and activities, quality of care, health expenditure and financing in the 27 EU Member States, 5 candidate countries and 3 EFTA countries.

The selection of indicators is based largely on the European Community Health Indicators (ECHI) shortlist. This is a set of indicators that has been developed to guide the reporting of health statistics in the European Union. It is complemented by additional indicators on health expenditure and quality of care, building on the OECD expertise in these areas.

Some of the key findings include:

- Growth in health spending per capita slowed or fell in real terms in 2010 in almost all European countries
- Life expectancy at birth in EU member states has increased by over six years between 1980 and 2010
- Spending on disease prevention fell by 3.2% in 2010
- The number of doctors per capita has increased in almost all EU member states over the past decade, from an average 2.9 per 1,000 people in 2000 to 3.4 in 2010.

- There are now many more specialists than GPs in nearly all countries, due to lack of interest in traditional "family medicine" practice and a growing remuneration gap.

http://europa.eu/rapid/press-release_IP-12-1217_en.htm
www.oecd.org/els/healthpoliciesanddata/HealthAtAGlanceEurope2012.pdf

23 November: Commission launches consultation on European Reference Networks

On 23 November, the European Commission's DG Health and Consumers launched a public consultation on the implementation of European Reference Networks (ERNs). This Directive on the application of patients' rights in cross-border healthcare requires the European Commission to support Member States in the development of ERNs between healthcare providers and centres of expertise.

The main added value of the ERNs is to facilitate improvements in access to diagnosis and delivery of high-quality, accessible and cost-effective healthcare for patients who have a medical condition requiring a particular concentration of expertise or resources, particularly in medical domains where expertise is rare. ERNs could also be focal points for medical training and research, information dissemination and evaluation, especially for rare diseases.

The Directive asks the European Commission to adopt a list of criteria that the networks will have to fulfil and list the conditions and criteria which providers wishing to join networks will have to meet. The Commission is also required to develop and publish criteria for establishing and evaluating ERNs. Finally, the Commission is asked to facilitate the exchange of information and expertise on the establishment of the networks and of their evaluation.

The consultation seeks opinions and contributions based on evaluated experiences, regional or national models, technical and professional standards, criteria or recommendations which could provide inputs and facilitate the definition of technical and quality criteria (scope, general and disease specific elements). It is targeted at patient organisations, health professionals' organisations and healthcare provider organisations, academics, public health institutions, public authorities and other similar bodies. A conceptual paper and a questionnaire to be completed on-line are provided in support to the consultation.

The consultation will run between 23 November 2012 and 24 January 2013. A report will be provided after closure of the consultation.

<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:EN:PDF>
http://ec.europa.eu/health/cross_border_care/docs/cons_implementation_ern_concept_paper_en.pdf
http://ec.europa.eu/health/cross_border_care/docs/cons_implementation_ern_questionnaire_en.pdf

28 November: Tonio Borg appointed new Commissioner for Health and Consumer Policy

On 28 November, the European Council appointed Tonio Borg as the new Commissioner for Health and Consumer Policy for the remainder of the current term of office of the Commission.

The official nomination came after a majority of Members of the European Parliament backed him in a vote on 21 November (386 votes in favour, 281 against and 28 abstentions).

Tonio Borg is a Maltese national and has been Deputy Prime Minister of his country since 2004 and minister for foreign affairs since 2008. He replaces John Dalli.

Members' News

21 September: Ireland celebrates World Alzheimer's Week



To mark World Alzheimer's Week 2012, the Alzheimer Society of Ireland held a record 29 events nationwide with attendance figures much increased on previous years.

In Dublin, approximately 200 people attended an awareness evening featuring the following speakers: Dr. Frank Marmion, Samantha Taylor, Information Manager with the Alzheimer Society of Ireland and family carer Gerry McGuinness. Helpline volunteers, ASI staff and legal experts also attended and answered queries from the public on the night.

In addition, information events were held in the day care centres in Monaghan, Donegal, Waterford and Limerick counties. Many Day Care Centres also held parties to celebrate World Alzheimer Day with staff, clients, family and friends.

21 September: Norway raises funds and awareness on World Alzheimer's Day



This year, as every year, the Norwegian Health Association held a national fundraising drive for dementia during World Alzheimer's Day. The 500 local chapters of the association collected more than EUR 600,000 for research, information and local initiatives.

The local chapters arranged open meetings and gatherings, all focusing on dementia. Health personnel, researchers and relatives spoke about experiences, research and daily challenges. For many, these open meetings are the first real sources of information about dementia. The two Oslo chapters held lectures for secondary school students and also screened a new film, Pyramiden, which focuses on younger relatives of people with dementia.

The Regional Dementia Awards were also presented on World Alzheimer's Day. These awards are tributes to extraordinary efforts by an individual, a local chapter or the public sector. This year, the prizes went to relatives who work for better dementia services in their region, to dedicated health personnel and to a nursing home that offers services beyond the ordinary for those with dementia and their relatives.

21 September: Finland values memory on World Alzheimer's Week



The Finns marked World Alzheimer's Week with numerous activities organised by the 42 member associations of Muistiliitto, the Alzheimer Society of Finland.

This year, "Memory is a valuable thing" was the main theme during the biggest campaign week of 2012. Activities included public seminars, memory marches and memory cafes, averaging two events per week for each association.

Muistiliitto does not participate directly in World Alzheimer's Week, but the association did launch the latest issue of its member magazine. This issue emphasised the theme of nutrition and featured research results about the first year of life with a dementia diagnosis. Both of these studies received excellent media coverage – as did the activities of the regional associations.



www.muistiliitto.fi

21 September: Poland organises dementia debate on World Alzheimer's Day



On World Alzheimer's Day, the Polish Alzheimer's Association and the Alzheimer Coalition - which was initiated and founded by the association - organised a debate entitled "People with Alzheimer's disease are still waiting for the European standards of care in Poland".

Attendees included representatives from the Ministries of Health and Labour, the Ombudsman's Office and the Spokesperson for Patients' Rights Office, as well as members of local and regional Alzheimer's associations and journalists.

Members of the Coalition presented the description of the current state of medical support and for patients in Poland, as well as the foundations and goals of the Polish Alzheimer's Plan - which the Coalition had prepared. As a result, there was wide press coverage on both Alzheimer's disease and the Polish Alzheimer's Plan. Unfortunately, no decisions have been made as to when and how the Polish Alzheimer's Plan could be implemented.



21 September: World Alzheimer's Day activities in the Netherlands



Alzheimer Nederland celebrated World Alzheimer's Day with over 55 activities across the country's 52 regional branches. Each branch planned and carried out their own activities, which included Memory Walks, boat trips, a charity golf tournament, symposia and special Alzheimer Café evenings. In all, the activities attracted some 6,000 people nationwide.



21 September: Alzheimer Scotland presents Dementia Awards on World Alzheimer's Day



Alzheimer Scotland - along with NHS Education for Scotland, NHS Health Scotland and the Scottish Social Services Council - held the first ever award ceremony for "Scotland's Dementia Awards" on World Alzheimer's Day.

These awards celebrate the work of both professionals and community groups who are committed helping people with dementia and their families. They showcase the creativity, innovation and dedication that make a real difference to the daily lives of people with dementia and their families across Scotland when organisations, groups and teams work together. There are six awards:

- Best acute care initiative
- Best innovation in continuing care
- Best community support initiative
- Best dementia friendly community initiative
- Best educational initiative
- Most innovative partnership.

www.ScotlandsDementiaAwards.org.uk

21 September: Swiss Alzheimer societies present awards to local heroes



On World Alzheimer's Day, the various chapters of the Swiss society held award ceremonies to recognise exceptional people in their local communities. The winners were cited as role models for how we can all get involved to make life better for people with dementia. They received the "Focus" glass sculpture along with a cash prize.



20 October: Italian dementia centre re-opens after earthquake



On 20 October, Alzheimer Uniti Italy re-opened the headquarters of its affiliate ASDAM in Mirandola (Modena), a town that suffered heavy damage during an earthquake in May 2012.



Following the earthquake, the association managed to continue its work with people with Alzheimer's disease and their families by

operating in tents for five months. On 20 October, they moved into a more stable structure, a trailer that has been outfitted as a proper office and meeting room.

The opening ceremony was attended by the mayor and included a ribbon-cutting and other festivities. In another trailer nearby, the town also opened a new Alzheimer Evaluation Unit, complete with two doctor's surgeries.

1 November: Bulgarian GPs petition government for dementia plan



Alzheimer Bulgaria has launched a campaign to persuade the government to enact the EU's Written Declaration 80/2008. This calls on national governments to recognise Alzheimer's disease as a public health priority and to develop a national dementia plan.

The declaration was adopted by the European Parliament on 6 February 2009 - including signatures from 16 Bulgarian delegates - but the government has yet to act upon it. During a recent national conference of Bulgarian GPs, Alzheimer Bulgaria began collecting signatures for a petition to revive government interest and action toward this goal.

www.alzheimer-europe.org/Policy-in-Practice2/EU-Action-on-Dementia/2009-European-Parliament-Written-Declaration#fragment-1

8 November: France Alzheimer launches new website



France Alzheimer has launched a new website with an updated look, enhanced features and fresh content. The home page includes a short movie

to introduce the site and showcases the association's new report on how Alzheimer's disease affects intimate relations.



www.francealzheimer.org

9 November: Czech Alzheimer Society celebrates 15th anniversary



On 9 November, the Czech Alzheimer Society celebrated its 15th anniversary with a conference at the Ministry of Health in Prague.

The conference, entitled "1997-2012: 15 years with you. What we have achieved & what we are expecting", was opened by Ms Irena Kohlerova, representing the Minister of Health. She informed delegates about the progress of the National Dementia Strategy: the government has approved much of the proposed content, which should lead to the launch of a national dementia plan by 2014.

This was followed by a presentation of the society's activities, which include promoting and defending the rights of people with dementia. A notable accomplishment was the society's involvement in the process to have dementia drugs reimbursed by health insurance, which became effective in 2001. The society is also very involved in the quality of care, especially the development of quality care criteria in long-term facilities and day care units. There are already 30 facilities around the country that are operating under this accreditation system.

Iva Holmerová, current Chairperson, is very pleased that the society is well known and respected both at home and internationally. The Czech Alzheimer Society participates in many of the activities of Alzheimer Europe (where Iva also serves as Vice-Chairperson of the Board) and Alzheimer's Disease International (ADI).

www.alzheimer.cz

9 November: Slovenian association holds Alzheimer Café



Alzheimer Slovenia held its latest Alzheimer Café on 9 November in Ljubljana. The main speaker was Prof Voyko Kavcic from the Institute of Gerontology at Wayne State University in Michigan, USA. He gave a presentation on the treatment of Alzheimer's disease.



12 November: Spanish journalist visits Greece on way to Jerusalem



Guillermo Nagore is walking from Spain to Jerusalem, in order to raise awareness for Alzheimer's disease. On 12 November, he reached Thessaloniki, Greece and visited the premises of Alzheimer Hellas.

Prof Magda Tsolaki, Chair of the Greek association, welcomed Guillermo to the Day Care Centre in Thessaloniki. He was able to meet many of the staff and observe their current activities. There was also a press conference, during which Guillermo spoke about his experiences. He discussed the need to make dementia a national priority and heard about the difficult situation Alzheimer Hellas is facing due to the economic crisis.

Guillermo is a Spanish journalist who began his quest on 16 February on behalf of the CEAFA Alzheimer association in Spain. The project is called "La memoria es el camino" (Memory is the path). Mr Nagore began his journey in Finisterre - the final destination for many pilgrims on the route to Santiago de Compostela.



<http://lamemoriaeselcamino.com/>

19 November: Association Luxembourg Alzheimer celebrates 25th anniversary



The Luxembourg Alzheimer's Association celebrated its 25th anniversary on 19 November.

The association's history and achievements were presented by two of the founding members and former chairpersons Paul Diederich and Jeannot Krecké (pictured).

In his presentation of the history of the Luxembourg Alzheimer's association, Jeannot Krecké also highlighted the setting up of the Alzheimer Europe secretariat in Luxembourg in 1996 as an important milestone of the organisation's commitment to greater European collaboration and the exchange of good practices.

Current chair Jules Geisen gave an overview of the care concept piloted and promoted by the association, as well as the many services provided by the organisation. He stressed the importance of the staff of the organisation who provide care to people with dementia with great dedication. On behalf of the many families affected by Alzheimer's disease and other forms of dementia, he took this opportunity to thank all staff members for their commitment.

Marie-Josée Jacobs, Minister for Family and Integration and Mars di Bartolomeo, Minister for Health, both congratulated the organisation for their relentless work in providing services and support to people with dementia

and their carers and promised their continued support in the years to come.

20 November: New German brochure for assistive technology



The German Alzheimer Society has published a new brochure entitled "Safety and independence: assistive technology for people with dementia".

The brochure is designed for people who live at home and are still mobile and active. It describes various assistive devices that are available in Germany, such as sensors that can switch off gas stoves or GPS-based tracking systems. The brochure also explains how these items are reimbursed by health insurance.

Heike von Lützu-Hohlbein, Chair of the German Alzheimer Society, said: "While technology can be helpful in many cases, it must never become a substitute for human contact and attention. Human dignity must always be the first priority."

The brochure is available for sale on the society's website.

www.deutsche-alzheimer.de/index.php?id=48&news=142

20 November: Danes "Break the Isolation" on World Alzheimer's Day



On 20 September, the Danish Alzheimer Association and the Alzheimer Research Fund marked World Alzheimer's Day with a scientific conference on the role of exercise in the development and treatment of Alzheimer's disease.

The conference included lectures and presentations of research results from Danish and American scientists. In particular, a Danish researcher gave an overview of her work on how exercise influences cognition. There was also a presentation of a prospective Danish study to see if intensive exercise can slow down the rate of cognitive decline in people with a recent diagnosis of Alzheimer's disease.

Meanwhile, volunteers from the association ran fundraising and awareness campaigns all over the country, under this year's "Break the Isolation" theme. They distributed information packs and sold "Remember Cakes", which were also very popular last year. The association also gathered support to present a Remember Cake to the Danish Prime Minister – part of the continuing effort to put dementia on the national agenda.

The campaign received very good media coverage - including interviews with people with dementia on national TV and radio - as well as coverage on national stations and newspapers.

25 November: Alzheimer Nederland recognises professional case managers



On 25 November, Alzheimer Nederland held a ceremony to congratulate the Dutch Association of Case Managers for the launch of their professional profile. The number of these dedicated professionals is

growing quickly, with a corresponding increase in their activities to help people with dementia and their carers in the Netherlands.



In October, Alzheimer Nederland and the National Care Institute started seven pilot programmes for the implementation of the national standard for integrated dementia care. Health insurance providers and departments of Alzheimer Nederland will use the national standard to make regional integrated dementia plans.

www.casemanagersdementie.venvn.nl

27 November: Czech region wins award for services to the elderly



On 27 November, the South Moravian region of the Czech Republic won second place in the international competition "Living with Alzheimer's disease, and despite her".

This initiative advocates the inclusion and active participation of people with dementia in urban life, so that they may remain active and productive citizens after diagnosis. It also recognises the significant role of qualified caregivers. The award and a EUR 4,000 cash prize were accepted by Mr. Jiří Altman, a South Moravian politician.



The event was sponsored by Foundation Médéric Alzheimer ELISAN, together with the European network for local inclusion and social action. South Moravia won the award for the project "Provision of Gerontology and organisational supervision in facilities for the elderly run by the South Moravian Region."

The project, which started in 2010, aims to increase the quality of services for the elderly in South Moravia in accordance with the criteria of the Czech Gerontological and Geriatric Society and the Czech Alzheimer Society.



www.alzheimer-europe.org/Donation

Policy Watch

20 November: Bulgaria to start reimbursing dementia drugs



During a recent session of the UN Economic and Social Council, a spokesman for the Bulgarian government announced that dementia medicines would be partially reimbursed in Bulgaria as of January 2013.

The announcement came during the 49th session of the council in Geneva, which included a review of Bulgaria. Foundation Compassion Alzheimer Bulgaria had submitted a special report on the problems affecting people with dementia in Bulgaria for this review. The report, along with lobbying activity, prompted questions to the Bulgarian delegation about dementia policies and treatments. The Bulgarian state representatives responded that medicines for dementia will be covered partially by the public health system from January 2013.



<http://www2.ohchr.org/english/bodies/cescr/docs/E.C.12.BGR.CO.4-5.pdf>

Science Watch

1 November: Janssen and Shionogi to collaborate on BACE inhibitors

Janssen and Shionogi have begun research collaboration for the development and commercialization of oral beta-secretase ("BACE") inhibitors for the treatment of Alzheimer's disease.

BACE inhibitors are a class of compounds that can enter the brain and block the activity of BACE 1, an enzyme needed for the generation of beta-amyloid.

Under the terms of the agreement, the oral BACE inhibitor compounds discovered by Shionogi will be licensed to Janssen. Inhibition of BACE activity is expected to reduce the progression of dementia associated with Alzheimer's disease.

Shionogi and Janssen will also jointly conduct research on back-up oral small molecules. In the event that one or more of these back-up compounds are selected for clinical studies, Janssen will conduct the development in accordance with mutually agreed plans.

www.shionogi.co.jp/ir_en/news/detail/e_121031.pdf

7 November: New CPEC cell may boost CSF production

Researchers at the University of California in Irvine (UCI) have used stem cells to create a new cell type called CPEC, or choroid plexus epithelial cell.

CPECs are critical for the proper functioning of the choroid plexus, the brain tissue that produces cerebrospinal fluid (CSF). Among their various roles, CPECs make CSF and remove metabolic waste and foreign substances from the fluid and brain. In neurodegenerative diseases, the choroid plexus and CPECs age prematurely, resulting in reduced CSF formation and decreased ability to flush out such debris as the plaque-forming proteins that are a hallmark of Alzheimer's.

According to Dr. Edwin Monuki, Associate Professor of Neuropathology at UCI, CPECs could be part of neurodegenerative disease treatments in at least three ways. First, they're able to increase the production of CSF to help flush out plaque-causing proteins from brain tissue and limit disease progression. Second, CPEC "superpumps" could be designed to transport high levels of therapeutic compounds to the CSF, brain and spinal

cord. Third, these cells can be used to screen and optimize drugs that improve choroid plexus function.

The next steps are to develop an effective drug screening system and to conduct proof-of-concept studies to see how these CPECs affect the brain in mouse models of Alzheimer's disease.

www.jneurosci.org/content/32/45/15934.abstract?sid=443baa7c-bc81-4356-8b5c-9952ba69b56c

8 November: Scientists predict the progression of Alzheimer's disease

Scientists at Tel Aviv University (TAU) have developed predictor models that use metabolic information to pinpoint the progression of Alzheimer's disease, with a reported 90% accuracy in predicting the stage of the disease.

The researchers collected data from the hippocampal region of the brain, which controls memory and learning and is damaged as Alzheimer's progresses. By counting the number of metabolic genes found in the neurons and surrounding tissue, they built a predictive model that relates abnormalities in these genes to the progression of the disease.

Out of almost 1,500 genes, the researchers were able to select 50 that were the most predictive of Alzheimer's disease. They compared the findings from these 50 genes among people with Alzheimer's disease, healthy controls and primates. It emerged that, in all but the Alzheimer's group, the number of the specific genes was tightly limited with little difference between individuals. This implies that these genes are significant to normal brain functioning, and their strict regulation in healthy patients is compromised by Alzheimer's disease.

This research was conducted by Shiri Stempler, PhD candidate at TAU, along with TAU Professors Eytan Ruppim and Lior Wolf. They will next try to identify biomarkers in the blood that are associated with these metabolic changes.

www.ncbi.nlm.nih.gov/pubmed/23029292

9 November: Contraceptive pill maintains cognition later in life

A research team from the University of Wisconsin (UW) found that women who used a hormonal contraceptive earlier in life performed better on cognitive tests compared to those who did not. These beneficial effects increased the longer the women had taken "the Pill".

The team was led by Kelly Egan, researcher, and Dr. Carey Gleason, Assistant Professor of Geriatrics at WU, who surveyed 261 women aged 40 to 65.

It is believed that oestrogen, the main hormone in the Pill, helps maintain the function of the brain in two ways. Firstly, it may prevent the arteries from hardening and becoming blocked, which keeps a steady flow of blood to the brain. Oestrogen may also encourage the growth of certain cells in the brain and spinal cord.

<http://online.liebertpub.com/doi/abs/10.1089/jwh.2012.3522?journalCode=jwh>

11 November: Dopamine improves long-term memory

The “feel-good” hormone dopamine improves long-term memory: this is the finding of a team led by Prof Emrah Düzel, neuroscientist at the German Center for Neurodegenerative Diseases and the University of Magdeburg.

The researchers investigated test subjects ranging in age from 65 to 75 years who were given Levodopa (L-DOPA), a precursor of dopamine. The treated subjects performed better in a memory test than a control group who took a placebo.

Dopamine is a neurotransmitter, i.e. it provides communications between nerve cells as well as between nerve and muscle cells. If this transmission becomes disturbed, symptoms of Parkinson’s disease can occur. Dopamine is also known to play a role in the formation of long-lasting memories, as rewarding incidents and other important events can usually be remembered for a long time. The current study confirms this effect in older people.

Prof Düzel said: “Our investigations for the first time prove that dopamine has an effect on episodic memory. This is the part of long-term memory which allows us to recall actual events. Episodic memory is that part of our capacity to remember, which is first affected in Alzheimer’s dementia.

“Dopamine contributes to anchoring memories in the brain on a permanent basis. You might say it improves the survival chances of memory content. Our study also shows that the survival of memories can be regulated, regardless of how strong these were originally encoded. This is a new finding.”

www.sciencedirect.com/science/article/pii/S0149763409001298

12 November: Regulation of apoptosis may reduce neuronal death

Researchers have discovered a mechanism that causes neuron degeneration, triggered by the apoptosis protein. Apoptosis helps the body make heme - a molecule that carries iron in the blood - but is also known to be present at extremely high levels in Alzheimer’s disease.

This study shows that excess heme leads to the overproduction of ROS molecules, which in turn triggers the process of cellular suicide called apoptosis. ROS molecules are active in cellular communications, but can also cause damage at high concentrations. This means that more apoptosis and more heme cause neurons to die.

When the scientists reduced apoptosis in lab cell cultures, they noticed that the neurons didn’t die. This suggests that apoptosis might be a new therapeutic target for neurodegenerative disorders. The team is now researching the function of apoptosis in mouse models.

The research team was led by Prof. Huaxi Xu from the Sanford-Burnham Medical Research Institute in California. He said: “Since the upregulation of apoptosis is important for cell death in diseases such as Alzheimer’s, we’re now searching for small molecules that modulate

apoptosis expression or activity. We’ll then determine whether these compounds may be potential drugs for Alzheimer’s or other neurodegenerative diseases.”

www.jneurosci.org/content/32/44/15565.abstract?sid=4de3af14-74e7-4aa8-97bd-2b12d828456e



www.alzheimer-europe.org/Donation

15 November: TREM2 gene variant is linked to higher risk of Alzheimer’s disease

An international research team headed by University College London (UCL) has linked a rare variant of the TREM2 gene to a higher risk of Alzheimer’s disease.

Researchers studied data from more than 25,000 people in order to identify the gene mutation known as R47H. The mutation is extremely rare, but increases the likelihood of developing Alzheimer’s disease roughly three-fold – similar to ApoE, the only other gene known to have a significant impact.

Study leader Dr. Rita Guerreiro of UCL said: “These findings are particularly exciting because they give us a clear signal about what could be going wrong in Alzheimer’s disease.”

Dr. Eric Karran, Director of Research at Alzheimer’s Research UK, said: “This is a landmark finding and reveals important new clues about the genetic causes of Alzheimer’s disease. We’re pleased to have supported this pioneering study, which will have major implications for understanding how Alzheimer’s develops - an important step towards designing new treatments.”

www.nejm.org/doi/full/10.1056/NEJMe1213157

18 November: Vitamin E may help delay onset of Alzheimer’s disease

A study led by Prof Patrizia Mecocci, professor of Gerontology and Geriatrics at the University of Perugia in Italy, shows that vitamin E can help prevent the onset of neurodegenerative diseases that lead to dementia.

In these diseases, damage to neurons and synapses is caused by oxidative stress. Vitamin E, the main antioxidant in the human body, can help protect the brain from such damage.

The term “vitamin E” encompasses eight natural elements: four tocopherols and four tocotrienols. Today, most vitamin E supplements in the market contain only mixed tocopherols. However, it is increasingly becoming accepted that the tocotrienols are also necessary: when all eight elements are present, vitamin E is in its strongest antioxidant condition.

Prof Mecocci said: “Our studies have shown that subjects with mild cognitive impairment (MCI) have reduced blood levels of all natural tocopherols and tocotrienols, compared to individuals with normal cognition. MCI often represents prodromal Alzheimer’s, thus different vitamin E forms could be relevant in preventing or delaying the onset of Alzheimer’s in individuals with MCI.

"While no compound has been proven to have the ability to reverse the effects of Alzheimer's once it has been established, studies have shown that all eight compounds of vitamin E may be able to interfere with the cascade of events that lead to brain damage in Alzheimer's."

[www.neurobiologyofaging.org/article/S0197-4580\(11\)00498-2/abstract](http://www.neurobiologyofaging.org/article/S0197-4580(11)00498-2/abstract)

19 November: Cancer protein may protect the brain

Danish scientists at the University of Copenhagen have found that the S100A4 protein plays an active role in brain protection and repair. They also found that it activates previously disabled signalling pathways in the brain.

The protein is already known as a key factor in metastasis (the spread of cancer) and is not found in the brains of healthy individuals.

The team was led by Oksana Dmytriyeva, a post-doctoral researcher in pharmacology. She said: "When we deleted the protein in mice, we discovered their brains were less protected and less able to resist injury. We were surprised to find this protein in this role as we thought it was purely a cancer protein."

www.nature.com/ncomms/journal/v3/n11/full/ncomms2202.html

20 November: Clusterin activity causes formation of plaques and tangles

Researchers from King's College London have discovered that the clusterin protein plays an active role in the formation of amyloid plaques and tangles.

Clusterin is already known to be active in late-onset Alzheimer's disease, as human blood levels are elevated from an early stage in the disease. The research team led by Simon Lovestone, Professor of Old Age Psychiatry, wanted to find out what role the protein plays in the progression of the disease.

Their first finding was that the presence of amyloid alters the amount of clusterin in mouse neurons. Clusterin acts to switch on a signalling pathway that drives the changes in tau that are associated with the formation of tangles. When this signalling pathway was chronically switched on in an Alzheimer's mouse model, the researchers saw an increase in tangle formation and evidence of cognitive defects.

The researchers also investigated clusterin in humans: they detected clusterin activation in Alzheimer brains, but not in those with other forms of dementia.

Prof Lovestone said: "We have shown that we can block the toxic effects of amyloid when we stop this signalling pathway in brain cells grown in the lab. We believe that if we could block its activity in the brains of Alzheimer's patients too, we may have an opportunity to halt the disease in man. Indeed, we have already begun our own drug development programme to do just that and are at the stage where potential compounds are coming back to us for further testing."

www.nature.com/mp/journal/vaop/ncurrent/full/mp2012163a.html

25 November: Psoriasis drug reduces plaque in rodents

Researchers at the University of Zurich and the Charité University Hospital in Berlin found that ustekinumab - an existing medicine for treating psoriasis - reduces plaque and memory loss in Alzheimer mouse models. The study involved two proteins of the immune system known to boost inflammation: interleukin-12 and interleukin-23, known collectively as IL-12/23.

The team first established that accumulation of beta-amyloid in the human brain sets off an immune reaction, including the release of IL-12/23. In turn, this activates a molecule called P40 that increases inflammation across the brain. The presence of P40 also tends to encourage more single beta amyloid particles to form into plaques.

The scientists then injected mouse and rat models with antibodies that shut down P40. The result was a significant reduction in amyloid plaque and higher performance in memory and cognitive function tests. In addition, the treated rodents still had amyloid plaques, but there were less single particles available to form new ones.

Drugs which target the same system have already been tested on people with psoriasis. The study leaders, Prof Frank Heppner from Berlin and Prof Burkhard Becher from Zurich, said: "Based on the safety data in patients, clinical studies could now be implemented without delay. Now, the goal is to bring the new therapeutic approach to Alzheimer patients quickly."

Ustekinumab is marketed by Janssen as Stelara.

www.nature.com/nm/journal/vaop/ncurrent/full/nm.2965.html

New Publications & Resources

1 November: New resources for intellectual disability and dementia



Karen Watchman, a trainer and consultant in Scotland, has developed a new website that provides information about intellectual (learning) disability and dementia. The website offers access to further information, resources, training and conference presentations. It also hosts a discussion forum for the exchange of suggestions, information and updates from those working in this growing field.

The number of adults with an intellectual disability (ID) who are affected by dementia will continue to rise. This presents a significant challenge to everyone and is referred to by Karen as a "ticking time-bomb that is now starting to go off". The onset of dementia changes how support needs to be provided for people with ID. It requires a shift from supporting long-term independent living skills to maintaining and maximising existing abilities. It also involves urgent consideration of how we talk to people with ID about dementia, in order for informed choices to be made.

Karen has a PhD in Down's syndrome and dementia and an MSc in Dementia Studies. She is also the former Director of Down's Syndrome Scotland. In 2012, she

developed a part-time online MSc degree in “Dementia: International Experience, Policy and Practice” whilst Programme Director at the University of Edinburgh. This Masters programme includes the first online postgraduate course in intellectual disability and dementia. The online course, tutored by Karen, will begin in January 2013.

Finally, Karen is the co-author of “Supporting Derek”, a training resource pack, and has also developed a series of training courses for staff on intellectual disability and dementia which can be accessed through the new website.

karenwatchman@hotmail.com

www.learningdisabilityanddementia.org

1 November: New website dedicated to people with dementia



“A Dementia Voice” is a new interactive website that gives people with dementia a friendly space to express themselves freely, make new contacts, and tell their own story. It’s based around the blogs, or diaries, of people with dementia, but

also includes links to other dementia-friendly websites.

The website is hosted by Dementia Friendly Communities, a new social enterprise based in Sutherland, England.

www.adementiaivoice.com

Contact Alzheimer Europe at:

Alzheimer Europe, 145 route de Thionville, L-2611, Luxembourg
info@alzheimer-europe.org, www.alzheimer-europe.org

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AE Calendar

Date	Meeting	AE Representative
7 December	Meeting with Stefania Lukic Zlobec from Alzheimer Slovenia (Brussels, Belgium)	Annette
10 December	PharmaCog Steering Committee meeting (Lille, France)	Alex
11 December	EFPIA Think Tank (Brussels, Belgium)	Annette
12 December	Meeting with Integrated BioBank of Luxembourg (Luxembourg, Luxembourg)	Jean
13-15 December	ELTECA meeting on long term care (Prague, Czech Republic)	Jean
17 December	Vodafone Accessibility Awards Ceremony (Brussels, Belgium)	Annette
17 January 2013	Meeting with Alzheimer’s Disease International (Luxembourg, Luxembourg)	Jean
21-22 January 2013	Kick-off meeting of European Medical Information Framework project (Amsterdam, Netherlands)	Jean

Future Conferences

Date	Meeting	Place
7-10 December 2012	8 th International Winter Conference on Alzheimer’s Disease, www.ad-zuers.com	Zuers, Austria
25-27 January 2013	5 th European Neurological Conference on Clinical Practices: Neurovascular and Neurodegenerative Diseases, www.enccp.net	Krakow, Poland
29-30 January 2013	EFGCP Annual Conference: Virtual future: what are the ethical dimensions of using emerging technologies in clinical trials and research?, www.efgcp.eu	Brussels, Belgium
6-10 March 2013	11th 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
28 March 2013	ALCOVE Final Symposium, www.alcove-project.eu/index.php?option=com_content&view=article&id=46&Itemid=184	Paris, France
11-14 April 2013	The 7th World Congress on Controversies in Neurology (CONY), www.comtecmed.com/cony/2013/	Istanbul, Turkey
18-20 April 2013	28th International Conference of Alzheimer’s Disease International: Dementia: Action for global change, www.adi2013.org	Taipei, Taiwan
18-21 April 2013	9th International Congress on Mental Dysfunction & Other Non-Motor Features in Parkinson’s Disease and Related Disorders – MDPD 2013, www.kenes.com/mdpd2013	Seoul, Korea
4-12 May 2013	Neural Stem Cells in Development and for Brain Repair, www.nsas.it/neural-stem-cells-for-development-and-repair	Cortona, Italy
23-24 May 2013	3 rd International Conference on Neurodegenerative Disorders: Immunotherapy and Biomarkers, http://eventus.trippus.se/immunotherapy_uppsala2013	Uppsala, Sweden
23-27 June 2013	The 20th IAGG Congress of gerontology and geriatrics, www.iagg2013.org	Seoul, Korea
10-12 October 2013	23 rd Alzheimer Europe Conference: “Living well in a dementia-friendly society”, www.alzheimer-europe.org/EN/Conferences	St. Julian’s, Malta
17-20 October 2013	8 th International Congress on Vascular Dementia – ICVD 2013, www.kenes.com/icvd	Athens, Greece
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 th International Congress of Clinical Neurophysiology (ICCN), www.iccn2014.de	Berlin, Germany

23rd Alzheimer Europe Conference
Living well in a dementia-
friendly society
St. Julian's, Malta, 10-12 October 2013
Mark the dates!

www.alzheimer-europe.org/conferences



The Alzheimer Europe newsletter arises from the 2012 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.