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Editorial

We hope that you were pleasantly surprised by our new email design! It intends to provide easier access to your favourite newsletter, so we are eager to hear your comments.

In February, Alzheimer Europe held a lunch debate at the European Parliament and a Public Affairs meeting with our member associations. The lunch debate was very well attended and we were very glad to see seven MEPs present or represented. In the Public Affairs meeting, we discussed the 2013 Dementia in Europe Yearbook: our member associations will help us to collect information on national policies relating to care and support of people with dementia. We also launched our European Dementia Monitor, which will provide a benchmark of national policies. There again our members will provide invaluable support, along with our pharmaceutical partners.

The European Alzheimer’s Alliance (EAA) grew by two members in February: we welcome Arlene McCarthy and Rosa Estaràs Ferragut and look forward to seeing them at our next lunch debate in June.

Meanwhile, the Parliament adopted a resolution on active and healthy ageing which views ageing as an opportunity for the future. The Commission presented its progress in improving long-term care, including helping countries to develop strategies for independent living for older adults.

Our member associations are always sources of varied and interesting news, and February was no exception. The best news of all came from Bulgaria, where dementia drugs are at last eligible for reimbursement. Finland is celebrating 25 years of operation this year and Ireland has appointed a new CEO who will take office in May. Luxembourg won gold for a video clip about living with dementia and Portugal is pursuing an art therapy programme. In Italy, Alzheimer Uniti will research the effects of a multi-sensory room and Slovenia continues its successful series of Alzheimer Cafés.

In scientific news, two clinical trials have been announced: one will investigate whether inflammation speeds up the progress of Alzheimer’s disease and the other will test masitinib, an existing cancer drug.

Several new publications appeared in February, including a book on dementia released by the Maltese Ministry of Health. Helga Rohra, Chair of the European Working Group of People with Dementia, released a book in Romania and the UK Alzheimer’s Society published a report on life in care homes. The latest issue of Dementia in Europe magazine also appeared in February. The magazine, which is available for sale on the Alzheimer Europe website, features Italian MEP Roberta Angellini speaking about how the EU addresses dementia. It also investigates the health priorities of the Cypriot EU Presidency and the imminent launch of the Irish National Dementia Strategy. Finally, the magazine looks back at our Annual Conference in Vienna last year.

We are now accepting registrations for the 2013 Conference in Malta. You can register and submit abstracts via our website.

Jean Georges
Executive Director
The organisation also mentioned the following items:

stressed that early diagnosis also merits specific attention.

EPF’s paper aims to develop a comprehensive perspective on the needs and rights of older people. EPF and its members will also identify recommendations towards the EU institutions and Member States on how to better cooperate and work towards achieving the changes that are needed to meet the needs of older patients and uphold their rights across Europe.

The paper focuses on five priorities that have been identified by EPF and its members:

1. integrated care
2. an inclusive and holistic approach to health and social care
3. shared-decision making and empowerment for older people and their carers
4. equitable access to high quality and safe therapies for all older patients
5. making the meaningful involvement of older patients a reality.

Members were invited to answer questions relative to each topic and complete EPF’s proposals.

Alzheimer Europe agreed with these five priorities, but stressed that early diagnosis also merits specific attention. The organisation also mentioned the following items:

- promoting older peoples’ right to autonomy, including the right to choose one’s place of residence and care and the provision of adequate and varied healthcare options which are adapted to older people with specific medical conditions.
- offering community-based healthcare to older people, i.e. care in their own homes or in establishments which are an integral part of the community.
- developing quality principles on what a quality service should be.
- promoting shared decision making and patients’ rights to access information about their health status and any other information necessary to contribute towards making an informed decision. These will protect them from abuse in decisions about guardianship, mental capacity, informed consent and patients’ rights.
- including older people in clinical trials, while highlighting the ethical issues linked to the involvement of people with dementia in clinical trials.

In addition, the organisation pointed out that end-of-life care and the use of assistive technologies were missing from the paper. The organisation also invited EPF to consider the heterogeneity of older people, the Lesbian, Gay, Bisexual and Transgender (LGBT) community and people from minority ethnic groups.

Finally, Alzheimer Europe included some references to the organisation’s work in the field of ethics, advance directives and assistive technologies and some references to the recent developments of the European Innovation Partnership on Active and Healthy Ageing.

25 February: Alzheimer Europe holds Board meeting in Brussels

The Alzheimer Europe Board met on 25-26 February in Brussels. The Board members discussed various financial and operational matters, including:

- adoption of the 2012 financial accounts of the organisation.
- approval of the final report of the operating grant received by the EU health programme.
- approval of a memorandum of understanding for the collaboration with Alzheimer’s Disease International.
- discussion on the progress of various 2013 activities, such as the project on the ethical issues linked to perceptions and image of dementia, the 2013 Yearbook on dementia policies in the care and social sector, the European Working Group of People with Dementia, the project on good incontinence care and the Dementia Monitor.

The next meeting of the Board will take place on 17 and 18 June 2013.

26 February: Alzheimer Europe holds lunch debate at the European Parliament

On 26 February, Alzheimer Europe held a lunch debate at the European Parliament entitled “Clinical trials on Alzheimer’s disease: update on recent trial results and the new regulatory framework”. The debate was hosted by MEP Sirpa Pietikäinen (Finland), who is a member of the European Alzheimer’s Alliance (EAA) and also sits on the Alzheimer Europe Board. Sirpa welcomed the participants and introduced the two speakers.

The first speaker was Professor Alexander Kurz, Professor of Psychiatry at Munich’s Technische Universität. He gave a presentation on the evolution of Alzheimer’s disease (AD) in the brain, including the latest therapies available and results of various clinical trials.

Currently, the development of new AD medications focuses on the amyloid beta (Aβ) plaques that accumulate in the brain. Various approaches are being explored and the removal of Aβ using immunisation strategies is the most advanced. Even so, by the time treatment starts the disease has already progressed beyond the scope of any strategy. Prof Kurz noted that if we are able to intervene at the prodromal stage - a decade earlier than today - then we may be able to prevent damage caused by amyloid deposits. He also presented other research avenues that do not focus on amyloid deposits. These include approaches that block the aggregation of tau proteins and efforts to boost nerve growth and repair. It may be that some of these will be successful for the development of new treatments.
Prof Kurz was followed by Mr Fabio D'Atri, an expert from the European Commission’s DG Health and Consumers. Mr D'Atri presented the Commission’s proposal for a new “Regulation on Clinical Trials on medicinal products for human use”. He explained the proposed changes and highlighted the key provisions on the involvement of incapacitated adults and people with dementia in clinical trials.

There were more than 40 participants at the debate. The following Members of the European Parliament were present or represented by their assistants:

- Françoise Grossetête, MEP (France) - also EAA Chairperson.
- Margrete Auken, MEP (Denmark) - also Shadow Rapporteur for the revision of the Clinical Trials Directive in the ENVI Committee.
- Christian Ehler, MEP (Germany).
- Anneli Jäätteenmäki, MEP (Finland) - also EAA member.
- Angelika Werthmann, MEP (Austria) - also EAA member.
- Dan Dumitru Zamfirescu, MEP (Romania).

Other participants included representatives from 14 national Alzheimer associations and eight pharmaceutical companies.

26 February: Alzheimer Europe launches European Dementia Monitor

On 26 February, Alzheimer Europe held a meeting to launch discussions about the European Dementia Monitor. This monitor will be a benchmark of national dementia policies and will compare three key areas:

- Medical/scientific issues: prevalence, diagnosis, treatment.
- Care and social issues: social support, Alzheimer associations, care.
- Policy and legal issues: dementia strategies and research, guardianship.

The European Dementia Monitor aims to highlight the strengths and weaknesses of access to care and treatment between countries. It will also allow national associations to compare their own country to others.

The launch meeting was attended by 28 people and included representatives from national Alzheimer associations and pharmaceutical companies. The delegates agreed to provide existing information that will be compiled and developed by Alzheimer Europe. The final report will be presented at the European Parliament by the end of 2013.

27 February: Alzheimer Europe holds Public Affairs meeting

Alzheimer Europe and eight of its member associations held a Public Affairs meeting on 27 February. The aim of the meeting was to discuss AE’s 2013 Dementia in Europe Yearbook project. This year’s topic will be national policies relating to care and social support of people with dementia.

The yearbook will cover training of social and health care professionals in residential and home care. It will also cover the organisation and quality of care and support, such as staffing levels, standards of care, needs assessments and access to care and support. Another section will examine the provision and organisation of care and support. Finally, the yearbook will address carer support, such as for respite, training and consultation.

The yearbook will also include the latest dementia prevalence figures in the EU counties and Iceland, Jersey, Norway, Switzerland and Turkey. There will also be a directory of national Alzheimer’s associations, including number of staff, budgets and types of services provided.

The 2013 Dementia in Europe Yearbook will be published in December 2013.

Impressions from the Lunch Debate

Prof Alexander Kurz, Technische Universität München
Heike von Lützau-Hohlbein (Alzheimer Europe) with Sirpa Patikäinen, MEP (Finland)
Fabio D’Atri, European Commission
European Alzheimer’s Alliance

February: Two MEPs join the European Alzheimer’s Alliance (EAA)

The European Alzheimer’s Alliance is pleased to welcome two new members: Ms Rosa Estarás Ferragut, MEP (Spain) and Ms Arlene McCarthy, MEP (UK).

Rosa Estarás Ferragut is from Palma de Mallorca and a member of EPP, the Group of the European People’s Party. She sits on the Committee on Regional Development and is a substitute on the Committees on Transport and Tourism and Women’s Rights and Gender Equality. She joined the EAA on 8 February.

Arlene McCarthy hails from Belfast, Northern Ireland and joined the EAA on 21 February. She is affiliated with S&D, the Group of the Progressive Alliance of Socialists and Democrats in the European Parliament. Ms McCarthy, an MEP since 1994, is the Vice-Chair of the Committee on Economic and Monetary Affairs. She also sits on the Delegation for relations with Switzerland and Norway and on the EU-Iceland Joint Parliamentary Committee and the European Economic Area (EEA) Joint Parliamentary Committee.

4 February: EAA Vice-Chair Yannakoudakis emphasises the need for research funding

Marina Yannakoudakis, MEP (UK) and new Vice-Chairperson of the European Alzheimer’s Alliance (EAA), recently published an article on the Public Service Europe website. She explains that research funding – be it in the field of medical or technological innovation – is one of the few areas where EU funding should be increased. The article is reproduced here and can also be seen online (see link below). Marina is a Conservative Party MEP for London and sits on the European Parliament’s Environment and Public Health Committee.

The elusive cure for Alzheimer’s and battling dementia

I am pleased to have been named the new vice-chairwoman of the European Alzheimer’s Alliance this month, taking over from Belgian MEP Frieda Brepoels - who has stood down from the European Parliament to become Mayor of Bilzen. As a member of the European Parliament’s Environment and Public Health Committee, who follows the European health portfolio for the Conservative Party, I been monitoring the issue of dementia - including Alzheimer’s - for some time.

We have long supported the activities of the European Alzheimer’s Alliance and we commend its work on exchanging best practice between European Union member states in the care of Alzheimer sufferers as well co-ordinating transnational projects on the disease. While Alzheimer’s is a disease and not a natural part of ageing, dementia is still growing more prevalent as our population ages. Dementia not only affects those who are suffering from the disease but also their family and friends, many of whom devote their lives to caring for their loved ones.

Member states need to work together on tackling and treating Alzheimer’s while respecting the sovereignty of national health policies. Research is one area where pooling resources has value-added and I am pleased that the European Commission’s seventh framework programme has made more than €600m available to study neurodegenerative diseases, including Alzheimer’s. We need a multifaceted approach to address the challenge. This means looking at the four themes of
prevent, diagnosis, treatment and cure. One of the areas which we are looking at in more detail in the United Kingdom is early identification of the disease.

In my London constituency alone, 68,000 people are suffering from the dementia. And yet, another 40,000 people in the capital do not realise they have the condition. On average fewer than 50 per cent of cases of dementia are diagnosed in Britain and this figure is woefully low. We must encourage families to be alert for the signs of dementia. A scientist for Alzheimer’s Research UK once described the difference between absent-mindedness and the onset of the disease as “not forgetting where your keys are but forgetting what keys are for”.

Just because there is currently no cure for Alzheimer’s does not mean we can be complacent about diagnosis. Medication can help stave off the condition for several years and I encourage those who think their loved ones may be at risk to take them to their local doctor and request a memory test. That way, sufferers can access the support, care and medicine which can help them live well with the condition. Until we do have a cure, we need to increase funding for scientific studies into the disease.

I have already mentioned European research. Research – be it in the field of medical or technological innovation – is one of the few areas where I think EU funding should be increased. In the UK we have also boosted our dementia funding. British Health Secretary Jeremy Hunt announced at the end of last year that the UK government is going to invest £22 m in 21 pioneering dementia research projects. The projects cover all areas of scientific activity relevant to dementia including care, cure, cause and prevention.

Dementia may be the largest healthcare challenge, which we shall face this century. We need a comprehensive, multinational approach and the European Alzheimer’s Alliance has an important role to play here. I hope that I can do the alliance justice and live up to the expectations of the 10 million Alzheimer sufferers across the EU - as I take on my new role as vice-chairwoman.

On 19-20 February (Brussels, Belgium) Annette attended the European Voice Health Check Briefing on Alzheimer’s disease. On 19-20 February (Brussels, Belgium) Annette attended the EFNA workshop on the “European Month of the Brain”. On 21 February (Brussels, Belgium): Annette met A. Werthmann (MEP and member of the European Alzheimer’s Alliance) to discuss an EP event (EPP), Lulling Astrid (EPP).

On 28 February (Brussels, Belgium): Annette met E. Zafeiratou (Vodafone) to exchange information on our respective activities and explore collaboration opportunities.

On 28 February-1 March (Brussels, Belgium) Alex attended the launch of the European Medical Information Framework project. On 28 February (Brussels, Belgium) Annette attended the EFNA workshop on the “European Month of the Brain”. On 22 February (Rome, Italy) Alex attended the final workshop of the DECIDE project on neurodegenerative diseases under the banner of the European Month of the Brain.

On 12 February (Luxembourg, Luxembourg) Jean attended a meeting with Nutricia’s Steve Graves. On 18 February (Brussels, Belgium) Annette attended the European Voice Health Check Briefing on Alzheimer’s disease. On 27 February, Françoise Grossetête, MEP (France) and Chair of the European Alzheimer’s Alliance, received the EURORDIS MEP Award. The Awards were distributed on the occasion of the 6th Rare Disease Day.

The EURORDIS Awards recognise excellence and promotes leadership and achievement in the field of rare diseases. This year, the Awards acknowledge the outstanding contributions of patients’ advocacy groups, volunteers, scientists, companies, media and policy makers toward reducing the impact of rare diseases on people’s lives.

Ms Grossetête has been a tireless advocate for rare diseases in Europe. This Award recognises her work in a series of EU legislations in the field of rare diseases, cross-border healthcare and the third EU public health framework programme.

Photo credit: Vivian Hertz

http://www.eurordis.org/news-and-events

Alzheimer Europe Networking 2013

On 12 February (Luxembourg, Luxembourg) Jean attended a meeting with Nutricia’s Steve Graves. On 18 February (Brussels, Belgium) Annette attended the European Voice Health Check Briefing on Alzheimer’s disease. On 19-20 February (Brussels, Belgium) Annette attended the EFNA workshop on the “European Month of the Brain”. On 21 February (Brussels, Belgium): Annette met A. Werthmann (MEP and member of the European Alzheimer’s Alliance) to discuss an EP event on neurodegenerative diseases under the banner of the European Month of the Brain.

On 22 February (Rome, Italy) Alex attended the final workshop of the DECIDE project. On 25-27 February (Brussels, Belgium) Annette attended the Board meeting, members and staff attended the Board meeting, the Company round table, the Dementia Monitor meeting, the Lunch debate on “Clinical trials on AD” and EU Public Affairs meeting. On 28 February (Brussels, Belgium): Annette met E. Zafeiratou (Vodafone) to exchange information on our respective activities and explore collaboration opportunities.

On 28 February-1 March (Brussels, Belgium) Alex attended the launch of the European Medical Information Framework project.

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 67, 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. Hein (EPP), Verthamn Angelika (NI). **Belgium:** Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tarabella Marc (S&D).

**Bulgaria:** Parvanova Antonia (ALDE). **Cyprus:** Triastaphyllides Kyriacos (GUE-NGL). **Czech Republic:** Cabnec Milan (ECP), Kohlick Jaromir (GUE/NGL), Roithova Zuzana (EPP).

**Denmark:** Christensen Ole (S&D), Rohde Jens (ALDE), Schaldemose Christel (S&D). **Finland:** Jaakonsaari Liisa (S&D), Jäättmannki Anneli (ALDE), Pietikäinen Sirpa (EPP). **France:** Audy Jean-Pierre (EPP), De Vayrcrin Christine (EPP), Grisbeck Nathalie (ALDE), Grossetête Françoise (EPP), Juviv Philippe (EPP), Morin-Chartier Elisabeth (EP), Pargneaux Gilles (S&D), GERMANY: Niebler Angelika (EPP), Roth-Behrendt Dagmar (S&D), Ulmer Thomas (EPP), Weigerber Anja (EPP). **Greece:** Chounts Nikolaos (GUE-NGL), Koppa Maria Elena (S&D), Kratsa-Tsararopoulou Rodi (EPP). **Ireland:** Aylward Lian (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 Binkkeviciute (S&D). **Luxembourg:** Engel Frank (EPP), Lulling Astrid (EPP). **Netherlands:** De Lange Esther (EPP), van Nistelroo Lambert (EPP), Wortmann-Kool Corien (EPP). **Poland:** Lukaciewska.
EU Developments

6 February: Parliament adopts resolution on the European Innovation Partnership on Active and Healthy Ageing

On 6 February, the European Parliament adopted Kartika Liotard’s (NL, GUE/NLG) resolution on the European Innovation Partnership on Active and Healthy Ageing on behalf of the Committee on the Environment, Public Health and Food Safety.

This resolution was drafted in response to a Communication from the Commission “Taking forward the Strategic Implementation Plan of the European Innovation Partnership on Active and Healthy Ageing” of 29 February 2012. The European Parliament agreed with the Commission’s proposal which views aging as an opportunity for the future rather than a burden on society.

The resolution seeks to reinforce the Commission’s proposals under three pillars:

Pillar 1: Prevention, screening and early diagnosis

The resolution invites the Commission and Member States to tackle structural issues, including health illiteracy. It states that serious efforts are needed with regard to prevention and the promotion of a healthy lifestyle, to delay or reverse the progression of disease in the early stages. While supporting the Commission’s approach with regard to health promotion through integrated programmes, the resolution emphasizes the need to investigate if illnesses are linked to individual behaviour or environmental conditions.

The resolution also supports the Commission’s approach in regard to increasing physical activity levels of the population. Industry and business are asked to get involved in this area.

Pillar 2: Care and cure

The resolution supports the Commission’s objective to further develop integrated care and cure systems. Member States and competent authorities are invited to develop national, regional and local care and cure systems that incorporate a holistic and integrated approach to the management of age-related diseases.

The resolution adds that the costs of such an approach should not be met solely by the individual but should be considered as a societal responsibility, guaranteeing inter- and intra-generational solidarity. eHealth services and their impact on the costs of healthcare are also discussed.

The resolution acknowledges that the continuous increase in overall healthcare and social support costs cannot be attributed to an ageing population alone. Where the burden of healthcare costs is increasingly borne by the individual, this being likely to create a vicious circle whereby people’s health and wellbeing are put at risk as they might be compelled to reallocate their often limited resources or abandon treatment.

The resolution also stresses the need to achieve equal opportunities for all European citizens in the field of healthcare.

Pillar 3: Active ageing and independent living

The resolution addresses how to encourage older people to live independently in their own homes for as long as is viable, stressing that the solution is inter-generationally and comprehensively active neighbourhoods.

The resolution considers that the Ambient Assisted Living Joint Programme is an important instrument for the deployment of technical resources to facilitate daily life and the provision of decent and safe housing in both rural and urban areas.

The resolution concludes with a discussion of issues such as age-friendly innovations and services. It also stresses the importance of facilitating intergenerational volunteering and the need to establish support systems for family carers.


20 February: Commission presents Working Document on long-term care

On 20 February, the European Commission (DG Social Affairs and Employment) presented its Staff Working Document on “Long-term care in ageing societies - Challenges and policy options”. This paper accompanies the Commission’s Communication “Towards Social Investment for Growth and Cohesion”, which was presented on the same day.

The paper demonstrates that even late in life there are strong arguments for a social investment approach to social protection. The arguments presented focus on the economic and social returns that a strategy of social investment can achieve through a combination of reduced disability in old age, improved capacity of older people to manage functional limitations and higher productivity in care delivery.

This paper examines how long-term care (LTC) needs may develop given the trends in demography and health. It also describes the diversity of LTC provision across the EU and discusses the strengths and limits of present LTC approaches both from a social protection perspective and in view of future challenges. It then analyses policies and gives examples of good practices that could help Member States meet the challenges and provide better protection against LTC risks.

The paper highlights the need for a longer-term strategy of social investment combining policies of 1) prevention, health promotion and rehabilitation with 2) systematic productivity drives in care delivery and 3) measures that raise the capacity of frail older people to manage self-care and independent living.
The paper also mentions a new JRC-IPTS project for 2013-14 that aims to support the Commission in helping Member States to develop LTC strategies promoting independent living of older adults through technology-based solutions, better organise the provision of care or increase the productivity and quality of LTC delivery. The main objective is to produce guidelines for the Member States to design LTC strategies than can increase the capacity of older adults for independent living.

http://ec.europa.eu/social/main.jsp?catId=89&langId=en&newsId=1807&mo reDocuments=yes&tableName=news

20 February: Commission presents Communication on social investment

On 20 February, the European Commission (DG Social Affairs and Employment) presented its "Social Investment Package" in a Communication entitled "Towards Social Investment for Growth and Cohesion". The Communication calls on Member States to prioritise social investment and to modernise their welfare states through active inclusion strategies and a more efficient and more effective use of social budgets. It also offers guidance to Member States on how best to use EU financial support - such as the European Social Fund - to implement the outlined objectives.

The Social Investment Package is an integrated policy framework that addresses the social, economic and budgetary divergences between Member States. It aims to respond to the significant challenges Member States currently face: high levels of financial distress, increasing poverty and social exclusion and record levels of unemployment, especially among young people. These challenges are combined with that of ageing societies and smaller working age populations, which test the sustainability and adequacy of national social systems.

The Package focuses on ensuring that social protection systems respond to people's needs at critical moments throughout their lives. It also calls for simplified and better targeted social policies, to provide adequate and sustainable social protection systems. Finally, it aims to upgrade active inclusion strategies in the Member States.

The Social Investment Package is accompanied by:

- a Commission Recommendation on "Investing in Children: breaking the cycle of disadvantage" that contains an integrated policy framework to improve children's opportunities.
- a Staff Working Document containing evidence on demographic and social trends and the role of social policies in responding to the social, economic and macro-economic challenges in the EU.
- a Staff Working Document following up on the 2008 Commission Recommendation on Active Inclusion for people excluded from the labour market.
- the 3rd Biennial Report on Social Services of General Interest to help public authorities and stakeholders understand and implement the revised EU rules on social services.
- a Staff Working Document on Long Term Care, presenting challenges and policy options.
- a Staff Working Document on confronting homelessness, explaining the situation of homelessness in the European Union and possible strategies to consider.
- a Staff Working Document on Investing in Health, containing strategies to improve the efficiency and effectiveness of health systems in a context of tighter public healthcare budgets and discussing how health can contribute to increasing human capital and social inclusion.
- a Staff Working Document outlining how the European Social Fund will contribute to implementing the Social Investment Package.

The Commission will closely monitor the performance of individual Member States’ social protection systems through the European Semester and formulate, where necessary, Country Specific Recommendations.

http://ec.europa.eu/social/main.jsp?catId=89&langId=en&newsId=1807&herNews=yes

www.alzheimer-europe.org/Donation

21 February: Parliament will re-distribute seats after 2014 elections

On 21 February, the Constitutional Affairs Committee adopted a Report proposing a redistribution of seats in the European Parliament after the elections that will take place in May or June 2014. This redistribution was made necessary both by the Lisbon Treaty and Croatia’s accession to the EU in July 2013. The proposed solution is in three parts:

- no Member State gains seats.
- the following all lose one seat: Austria, Belgium, Bulgaria, Croatia, Czech Republic, Greece, Hungary, Ireland, Latvia, Lithuania, Portugal, Romania.
- Germany loses three seats.

The European Parliament will vote on this proposal in March. The European Council will then decide the distribution of seats by unanimous vote. The European Parliament can approve or reject the Council’s decision but it cannot change the content of the proposal.

The committee also agreed to submit a new proposal before the end of 2015 to establish a durable and transparent system for allocating seats among EU member states before each European election. This should take into account demographic developments and include the possibility of reserving a number of seats to members elected on transnational lists.

27 February: President Barroso launches a Science and Technology Advisory Council

On 27 February, José Manuel Barroso, European Commission President, announced the creation of a Science and Technology Advisory Council. This is an independent and informal group of science and technology experts from academia, business and civil society. It covers a broad range of disciplines and unites expertise from across the European Research Area.

The creation of the Council is another building block that will support the development of research and innovation, as well as the goal to deliver smart, sustainable and inclusive growth in Europe. It will operate alongside the Innovation Union, the European Research Area and Horizon 2020.

The main aim of the Council is to advise the President on how to create the proper environment for innovation by shaping a European society that embraces science, technology and engineering. The Council will advise on the opportunities and risks stemming from scientific and technological progress and how to communicate these in order to foster an informed societal debate and ensure that Europe does not “miss the boat” and remains a global leader in cutting-edge technologies.

The Council members have been selected by the President in consultation with Prof Anne Glover, the first Chief Scientific Adviser. The Science and Technology Advisory Council held its first meeting in Brussels on 27 February 2013.


Policy Watch

31 January: Amyvid faces hurdles in US reimbursement process

In April 2012, the American FDA approved the use of florbetapir (Amyvid) as a test agent for PET scans in detecting amyloid. However, the new scan is not yet eligible for reimbursement by Medicare; it must first pass through a national coverage analysis. A recent panel meeting was part of this process, with panelists expressing doubts about the procedure.

Specifically, the 12-member panel expressed little support for the idea that an imaging technology can change health outcomes. Some of the panelists questioned the lack of data on how a positive scan would enable clinicians to affect outcomes and the course of care. Others were concerned that the benefit of having a positive test result was outweighed by potential false positives and other issues that come with that knowledge. Dr. Rita Redberg, Professor of Cardiology and Chairperson of the panel, asked: “What’s the value to the patient if a scan establishes a diagnosis after the process of cognitive decline from Alzheimer’s disease has started?”

The panelists heard comments from several invited speakers, including Dr. William Thies, Chief Medical and Scientific Officer of the US Alzheimer’s Association. Dr. Thies remarked that a positive diagnosis for Alzheimer’s disease could better a patient’s care later in life. It would allow doctors to build a care plan and team, while improving documentation and communication among healthcare providers and payers. Other positive comments were that the imaging agent could reduce the number of people treated for Alzheimer’s disease if the disease is confirmed. Also, Amyvid could hasten the understanding of the disease and finding a cure. Finally, if physicians did not see signs of accumulated amyloid through a scan, they might be able to rule out Alzheimer’s disease as a reason for cognitive decline.

1 February: Bulgarians will be reimbursed for dementia drugs

Bulgarians with dementia received excellent news last month, as the government passed legislation that makes it possible for dementia drugs to be reimbursed by national insurance.

Members’ News

25 January: Clinicians discuss Ireland’s national dementia strategy

On 25 January, the Alzheimer Society of Ireland (ASI) hosted a forum for clinicians in order to engage them in an open discussion around the forthcoming National Dementia Strategy.

The "Clinicians Roundtable on the National Dementia Strategy" was attended by 27 specialists in Old Age Psychiatry, Geriatric Medicine, Neurology and Psychology. The principal aim of the event was to gauge the doctors’ opinions on the Irish national dementia plan, which will launch later this year. Another objective was to explore how ASI can support the active involvement of clinicians in the plan. Finally, the roundtable sought to develop clear messages about the core clinical elements of the dementia plan toward other clinical areas.

Discussions were structured around three thematic areas: Clinical Leadership and Developing a Dementia Register; People with Younger Onset Dementia and Early Diagnosis and Memory Clinics/Services. The clinicians were very active in proposing suggestions and improvements, both for the dementia plan and ASI’s continuing efforts to support them.

The full report is available from the Alzheimer Society of Ireland website.

www.alzheimer.ie

1 February: Gerry Martin is the new CEO of The Alzheimer Society of Ireland

On 1 February, Gerry Martin was appointed as the new CEO of The Alzheimer Society of Ireland. He will take office on 1 May. This appointment seeks to continue the strong leadership of the organisation under former CEO Maurice O’Connell.

Newsletter: February 2013
Gerry Martin joins The Alzheimer Society of Ireland from Permanent TSB where he has held leadership roles for the past 15 years, and is currently General Manager responsible for the bank’s branch network. Gerry holds an MSc (Management Practice) from The Smurfit Graduate School of Business (UCD).

Speaking of this appointment, Kevin Norton, Chairman of The Alzheimer Society of Ireland says, “We are very pleased to welcome Gerry Martin to the team at what is a critical time for those living with dementia. There are currently more than 40,000 people living with dementia in Ireland, and this figure is set to treble over the next 30 years. With these challenges in mind, we will be working with the Government and other stakeholders in the development and implementation of the National Dementia Strategy.

Furthermore, I would like to take this opportunity to thank Maurice O’Connell for his significant contribution to The Alzheimer Society of Ireland over the last 14 years. During this time Maurice led the organisation through a period of substantial growth and development. In addition to providing over 1 million hours of service, the Society is the recognised voice of people with dementia,” says Norton.

1 February: Researchers seek information on tablet computer apps for people with dementia

The German Alzheimer Society and the Charité dementia care home in Berlin are conducting a study to determine which tablet computer applications (apps) are the most appropriate for care home residents.

Tablet computers are increasingly popular in dementia care homes, as they are portable, light and easy to use. The Charité researchers are looking for apps that are used by people with dementia. They are particularly interested in how the apps are used and how the residents are reacting to them.

To participate in this study, please send an email to sabine.hamm@charite.de http://medsoz.charite.de/forschung/demographie_und_alter/tablet_gestuetzte_aktivierung_von_demenzpatienten_im_pflegeheim/

Muistiliitto wants to build a safer life for people with memory-related diseases by raising awareness about safety issues and basic human rights. The society is challenging all Finns to TAKE CARE! of themselves and the people around them. We all need each other occasionally and no one should have to survive alone.

The 25th year of the society will be filled with activities: these have already begun and will run up to a climax on World Alzheimer’s Day on 21 September. On 1 February, Muistiliitto held a forum for policy makers, member associations and the media in the Parliament of Finland, so called Little Parliament. The audience first heard a moving speech from the daughter of the woman who died of exposure and inspired the TAKE CARE! motto. This was followed by presentations from Sirpa Pietikäinen (MEP and Vice Chairperson of Muistiliitto), Merja Mäkisalo-Ropponen (MP and Chairperson) and Eila Okkonen (Executive Director). Finally, Anna Mäki-Petäjä-Leinonen (Senior Lecturer in Family Law) introduced the new Alzheimer Europe report about ethical issues linked to restrictions of freedom of people with dementia.

Muistiliitto can be reached by email by Executive Director Eila Okkonen at eila.okkonen@muistiliitto.fi or Specialist Heidi Härma at heidi.harma@muistiliitto.fi

www.muistiliitto.fi

2 February: Norwegian Health Association holds seminars for caregivers

In early February, the Norwegian Health Association arranged a one day seminar where family carers shared their experiences of dementia with others. The aim of the seminar was to allow carers to share their knowledge and experience with other people who may be in the same situation. Participants were encouraged to share their stories and were also advised on presentation techniques, how to relate to media and how to help further educate and inform family members and caregivers.

The feedback from the participants showed that this was an informative and inspiring day that gave motivation to be open about dementia. All the lectures were filmed and will be available on the association’s website for those who were unable to attend.

This training event also served to support the family carers that participate as lecturers at one of Norway’s 250 municipal schools for family carers. These schools are part of the government’s educational programme for caregivers, aiming to give them knowledge about dementia and creating meeting points for others in the same situation. More than 75% of all Norwegian municipalities offer a 12 hour educational programme for family caregivers.

The Norwegian Health Association promotes the opportunity for all family caregivers to participate in their local communities and for greater transparency regarding dementia in our society.

1 February: Muistiliitto turns 25 and urges Finns to TAKE CARE!

Muistiliitto, the recognised voice of people with dementia in our society, celebrates its 25th birthday with the motto TAKE CARE!

The motto stems from a true recent story: a woman with Alzheimer’s disease wandered outside her home and got lost during a freezing winter day. She walked around for hours, but nobody stopped her and no one asked her if she needed help; she died later the same day in a hospital.

www.alzheimer-europe.org/Donation

1 February: Muistiliitto turns 25 and urges Finns to TAKE CARE!

In 2013, the Alzheimer Society of Finland celebrates its 25th birthday with the motto TAKE CARE!

The motto stems from a true recent story: a woman with Alzheimer’s disease wandered outside her home and got lost during a freezing winter day. She walked around for hours, but nobody stopped her and no one asked her if she needed help; she died later the same day in a hospital.
2 February: Alzheimer Uniti Italy will conduct a Snoezelen Room study

Alzheimer Uniti Italy will lead a controlled study to examine the therapeutic outcome of a new Snoezelen Room in an Alzheimer’s care home near Rome.

The Snoezelen Room is a multi-sensory room for people with dementia that offers a variety of sensory experiences through sounds, lighting effects, colours, scents and textures. It has been designed to fit both the cognitive status and behaviour needs of the care home residents. This soothing type of environment is known to improve the quality of life of people with dementia - even if it does not change the progress of the disease.

The word "Snoezelen" combines the Dutch words "snuffelen" (to seek/explore) and “doezelen” (to doze). This therapy originated in the Netherlands and has been throughout Europe for ten years. The Snoezelen Room is specifically designed for people with dementia in residential and semi-residential settings.

Previous trials have shown significant improvement in behaviour and communication. These results have met with great approval from caregivers, who claim that it also acts as a kind of “leisure time” for people with dementia.

"Spaces of Memory” is an on-going project and can be followed on the website below.

http://projetoespacosdememoria.blogspot.pt/

3 February: Alzheimer Portugal launches intergenerational art project

Alzheimer Portugal has launched a new intergenerational project called "Spaces of Memory" that aims to boost inclusion of people with Alzheimer’s disease in the local community.

The project, which is managed by Dr. Carlos Garcia, takes place in Alzheimer Portugal’s day care centre and pairs people with dementia with students from the local College of Arts Maria Amalia. The pairs are creating visual art forms based on meaningful moments in their lives. The resulting art works will become permanent fixtures in the centre, promoting expression, creativity and sharing among generations. They will also serve to enhance the physical space of the centre, both inside and outside the building.

On 9 February, the Icelandic Alzheimer Association (FAAS) attended the opening of a new Alzheimer’s disease diagnostic centre in Reykjavik.

The new centre is operated by Mentis Cura, a local company that has developed software for electroencephalography (EEG) statistical pattern recognition. This helps to diagnose and track the progress of early stage Alzheimer’s disease. FAAS is both a partner and a shareholder of Mentis Cura, which is also developing a diagnostic tool for attention deficit hyperactivity disorder (ADHD).

The opening ceremony was also attended by the President of Iceland, who congratulated Mentis Cura on what he called “a turning point for human understanding.” President Grímsson added: “We all know examples of individuals who have been written off or judged because of lack of understanding of their conditions. It will be exciting to watch the impact of the diagnostic for Alzheimer’s patients and children.”

Ms Fanney Proppé Eiríksdóttir (pictured), Chairperson of FAAS, also congratulated Mentis Cura on the opening and thanked them for their efforts. She said: “Even though the thought of there not being any cure for Alzheimer’s is difficult, the progress is remarkable and early diagnostic is a matter of human rights. It means that patients can fight their own battles, instead of having to rely on their partners or children, take care of their own matters and retire with dignity.”

A September 2012 paper about the effectiveness of the software can be downloaded from the website shown below.

www.karger.com/Article/Abstract/339996
20 February: Luxembourg's ALA wins top prizes for video clip

On 20 February, the Association Luxembourg Alzheimer (ALA) won the jury's top Gold Award for a video clip entitled "Living with dementia" at the Luxembourg Media Awards 2013. The video clip is part of ALA's latest awareness campaign and appears on local TV and in cinemas. The clip also won first prize among the public, who participated by casting e-votes.

The clip portrays a man who is wandering, apparently lost, in a busy neighbourhood. He seems unable to make any sense of his surroundings, even when he attempts to board a local bus. The man attracts various odd looks from people, but no one comes forward to help him find his way.

The video clip can be seen on ALA's website - www.alzheimer.lu/de/actualites/verschiedenes/alzheimer-spot.html - and pictures from the award ceremony are available on the website below.

http://kultur.rtl.lu/kulturpur/fotoen/11087/overview?back=/kulturpur/fotoen

25 February: New "Robalz" robot will assist Spanish caregivers

Spain’s Fundación Alzheimer España (FAE) has launched a project, along with UC3M Robotics Lab, to develop a personal robot that will help caregivers of people in the early stages of Alzheimer’s disease.

The "Robalz" robot is designed to ease some of the caregiver's burden by accompanying the ill person and providing help with entertainment, stimulation, personal assistance and security and safety. Some of the robot’s potential activities are described below:

- entertainment: the robot can be a companion and entertainer, e.g. by telling stories or broadcasting news, music and films. This may help avert feelings of loneliness and make the person feel wanted and looked after.
- stimulation: the robot can provide memory exercises and various art or music therapies as ways to delay cognitive decline. However, these scenarios require further study.
- personal assistance: the robot can help with daily tasks, such as reminding people of their daily activities and how to carry them out. It can also remind them of the location of various items or help with decisions on which clothes to wear.
- security and safety: the robot can have a surveillance function with an alarm to warn the caregiver of unusual behaviour. This is related to domotic applications, in which the robot can act as an interface with the caregiver.

Finally, the robot can generate periodic reports about the person’s favourite activities, in order to help caregivers and professional design and adapt daily routines.

Science Watch

31 January: Women with heart disease are more prone to vascular dementia

A recent study shows that older women with heart disease are at greater risk of developing vascular dementia.

The study, conducted at the Mayo Clinic in Rochester, Minnesota, followed 1,450 men and women in their 70s and 80s. They were free of cognitive impairment at the start of the study and underwent tests to measure brain function every 15 months.

After four years, 348 people had developed some form of mild cognitive impairment (MCI). Amongst this group, 94 had the type of MCI linked to vascular dementia. The link was particularly strong in women: those with heart problems were about three times more likely to develop it than women without heart concerns.

Dr. Rosebud Roberts, Professor of Epidemiology at the Mayo Clinic, said: "If we reduce the risk of the conditions that lead to cardiac disease, hopefully we can reduce the risk of developing MCI, and thereby reduce the risk of developing dementia.”


4 February: New clinical trial will study brain inflammation in AD

The University of Southampton has just launched a three-year study to see whether inflammation caused by infections also speeds up progress of Alzheimer's disease.

The research team, led by Dr. Delphine Boche, Lecturer in Clinical Neurosciences, believes that the Alzheimer's immune system goes beyond its role as protector of the body and starts causing damage, like it does in an autoimmune disease.

The study will use brain tissue from people who lived with Alzheimer's disease. Scientists will compare the brains of those who had infections when they died with those who did not. They are particularly interested in microglia, immune cells that remove cellular debris. Dr. Boche believes that microglia may produce chemicals that are harmful to surrounding cells and make Alzheimer's worse.

She said: "There is already evidence that the immune system is on high alert in people with Alzheimer's and we think that an extra trigger, like an infection, could tip the balance and make immune cells switch from being protective to harmful."
4 February: Cerebrolysin improves cognitive function in vascular dementia

Researchers from Sichuan University in China have shown that Cerebrolysin can help improve cognitive and global function in patients with mild to moderate vascular dementia.

Cerebrolysin is a peptide-based drug that supports the survival, stability and function of neurons. The drug decreases amyloid production, promotes synaptic repair and improves cognitive and behavioural performance. It is marketed by Ebewe Pharmaceutical and is already used in 44 countries for stroke, dementia, and traumatic brain injury.

For this study, researchers looked at data from six randomized controlled trials involving 597 people. All participants received Cerebrolysin intravenously in different daily concentrations and for different treatment periods from a few weeks to three years. The combined results showed significant improvement in cognitive function compared to standard care alone or placebo. Participants were tested on their recall, arithmetic or other cognitive abilities. The drug also had a small positive effect on patients’ overall clinical state. There was also some suggestion that long-term treatment was associated with greater benefits.

The study was led by Dr. Li He, Neurology Researcher at Sichuan University. He said: “The results are promising but due to low numbers of trials, inconsistencies between trials, risk of bias in the way some of the trials were conducted and lack of long-term follow-up, we cannot yet recommend Cerebrolysin as a routine treatment for vascular dementia.”


5 February: CD36 protein is linked to amyloid build-up

Scientists from Weill Cornell Medical College have shown that the CD36 protein is linked to amyloid build-up in mouse models.

Dr. Costantino Iadecola, Professor of Neurology, led the team that investigated whether lowering amyloid burden can reduce signs of Alzheimer’s disease. The researchers removed a receptor called CD36 that appears on the surface of immune cells from the mouse brains. They found that mice without CD36 had less amyloid in their brain vessels and performed better on cognitive tests, suggesting that removing protein from arteries can reduce symptoms of the disease.

Dr. Iadecola said: “Our findings strongly suggest that amyloid, in addition to damaging neurons, also threatens the cerebral blood supply and increases the brain’s susceptibility to damage through oxygen deprivation.

“If we can stop accumulation of amyloid in these blood vessels, we might be able to significantly improve cognitive function in Alzheimer’s disease patients. Furthermore, we might be able to improve the effectiveness of amyloid immunotherapy, which is in clinical trials but has been hampered by the accumulation of amyloid in cerebral blood vessels.”

www.pnas.org/content/108/12/5063.abstract?sid=449533bb-d922-4e19-be8c-3fadb93f340d

5 February: The amyloid protein is not transmissible

A new study from the University of the Pennsylvania School of Medicine suggests that the amyloid protein does not transmit itself from one cell to another, nor can it be transmitted from one person to another.

Previous studies have suggested that amyloid proteins might act as prions, which pass from cell to cell in diseases such as Creutzfeldt-Jakob disease. Prions can spread from contaminated food and through blood transfusions and tissue transplants.

In this study, led by Dr. John Trojanowski, Professor of Geriatric Medicine and Gerontology, scientists investigated whether similar prions were at work in neurodegenerative diseases such as Alzheimer’s or Parkinson’s disease. They studied people who had received human growth hormone from 1963 to 1985 derived from cadavers. In the mid-1980s, over 200 of these patients developed Creutzfeldt-Jakob disease after being inadvertently infected with prion proteins from affected donor tissue. Since then, this group of patients has been closely monitored with extensive medical records to track for further cases.

The researchers looked for signs of an elevated risk of Alzheimer’s, Parkinson’s, fronto-temporal lobar degeneration and amyotrophic lateral sclerosis (ALS) among the recipients. They found three cases of ALS but no cases of Alzheimer’s or Parkinson’s.

Dr. John Trojanowski said: “People wonder if it will be possible for a person with Alzheimer’s disease to infect another individual without Alzheimer’s disease, if a kidney transplant came from an Alzheimer’s patient.

“Our findings argue there is no evidence in this large cohort of human-to-human transmission. The likelihood of a transplant conveying the disease would be very low.”


8 February: New clinical trials of masitinib for Alzheimer’s disease

French biotech company AB Science has begun recruitment for two new studies of its masitinib molecule for Alzheimer’s disease.

The first is a phase 3 study in people with mild to moderate Alzheimer’s disease. This will compare the safety and efficacy of masitinib or placebo during 24 weeks, in addition to a stable dose of cholinesterase inhibitors and/or memantine. During a phase 2 study, Masitinib demonstrated statistically significant improvement on the ADAS-Cog scale (see weblink below).

The other trial is a phase 1 pharmacokinetics study that will evaluate the impact of masitinib on the pharmacokinetic profile of galantamine and donepezil.

Masitinib is a tyrosine kinase inhibitor (TKI) that is typically used in cancer drugs. AB Science is also running
There is ample evidence. The nerve cells. We haven’t formally proven toxicity, but therefore, they tend to aggregate and seem to damage proteins that aggregate into clumps.

Mutation also causes the production of three different proteins that aggregate into clumps. It is already known that the mutated C9orf72 gene contains a repetition of a certain DNA sequence. This study, led by Dr. Dieter Edbauer, Neuroscientist at the Ludwig Maximilian University in Munich found that the mutation also causes the production of three different proteins that aggregate into clumps.

Dr. Edbauer said: “These are very extraordinary proteins that usually don’t show up in the organism. As far as we know, they are completely useless and scarcely soluble. Therefore, they tend to aggregate and seem to damage the nerve cells. We haven’t formally proven toxicity, but there is ample evidence.

“As the mechanism of their production is so unusual, we may find ways to inhibit their synthesis without interfering with the formation of other proteins. One could also try to block their aggregation and accelerate their decomposition.”

12 February: Vascular brain injury causes more cognitive aging than plaque

A recent study from the University of California at Davis (UC) shows that vascular brain injury is a far greater risk factor for cognitive impairment than the deposition of amyloid plaque.

The scientists were led by Dr. Bruce Reed, Professor of Neurology at UC. They tested 61 participants who ranged in age from 65 to 90 with an average age of 78. 30 participants had no dementia diagnosis, 24 were cognitively impaired and seven were diagnosed with dementia. The participants underwent both MRI and PET scans, in order to determine whether there was a correlation between vascular brain injury and the deposition of beta amyloid plaques.

Dr. Reed said: “The first question was whether those two pathologies correlate to each other, and the simple answer is ‘no’. Earlier research, conducted in animals, has suggested that having a stroke causes more beta amyloid deposition in the brain. If that were the case, people who had more vascular brain injury should have higher levels of beta amyloid. We found no evidence to support that.

“The second was whether higher levels of cerebrovascular disease or amyloid plaques have a greater impact on cognitive function in older, non-demented adults. Half of the study participants had abnormal levels of beta amyloid and half vascular brain injury, or infarcts. It was really very clear that the amyloid had very little effect, but the vascular brain injury had distinctly negative effects. The more vascular brain injury the participants had, the worse their memory and the worse their executive function.”

14 February: HRT may delay the onset of Alzheimer’s disease

A recent study from Stanford University shows that hormone replacement therapy (HRT) could delay the onset of Alzheimer’s disease in women. HRT is used to relieve the symptoms of menopause and has also been shown to cut the incidence of heart attacks.

Researchers tested 70 healthy women aged 45-65 who had been on hormone therapy since menopause. The women were divided into two groups, of which one remained on hormones and the other discontinued therapy. All the women underwent periodic blood testing over a two year period.

The researchers found that about 20% of the women carried the ApoE4 gene, a major genetic risk factor for Alzheimer’s disease. Within this group, the women who had undergone HRT were six times less likely to develop cognitive impairment than those who had not.

The study team was led by Dr. Natalie Ragon, Professor of Psychiatry and Behavioral Sciences at Stanford, who said: “This shows that ApoE4 is contributing to aging at the cellular level well before any outward symptoms of decline become apparent. Yet, estrogen appears to have a protective effect for middle-aged women who are carrying this genetic risk factor.”

26 February: Scientists map pathway for brain waste clearance

Researchers at New York’s Stony Brook University have developed a new method to image the brain’s entire glymphatic pathway. This is the process where cerebrospinal fluid (CSF) filters through the brain and exchanges with interstitial fluid (ISF) to clear waste, similar to the way lymphatic vessels clear waste from other organs.

The researchers were led by Dr. Helene Benveniste, Professor of Anesthesiology and Radiology at Stony Brook. They used contrast agents and molecular tracers with MRI to develop the imaging tools. Using these tools, they imaged major regions in the brain and produced a map of the entire glymphatic pathway. The images show the CSF-ISF interchange throughout the whole brain, including pathways parallel to major arteries that are also involved in the waste clearing process.

Dr. Benveniste said: “Our experiments showed proof of concept that the glymphatic pathway function can be measured using a simple and clinically relevant imaging technique. This technique provides a three-dimensional view of the glymphatic pathway that captures movement of waste and solutes in real time. This will help us to define the role of the pathway in clearing matter such as...
amyloid beta and tau proteins, which affect brain processes if they build up.”

www.jci.org/articles/view/67677

Dementia in Society

6 February: Americans with AD will nearly triple by 2050

A new study predicts that the number of Americans with Alzheimer’s disease will almost triple by 2050.

Numbers are projected to rise from about 5 million now to 13.8 million. Lead author Jennifer Weuve describes this as if “everyone in the state of Illinois had Alzheimer’s”. In European terms, this is more than the entire current population of Greece or some 80% of all Dutch people.

Dr. Weuve, Assistant Professor of Medicine at Chicago’s Rush Institute for Healthy Aging, also pointed out: “We’ve had great success in this country when we’ve decided to focus on a condition. We’ve done it with good research in heart disease, cancer and HIV, but we are in our infancy when it comes to Alzheimer’s research.”

In 2012, US funding for Alzheimer’s disease was USD 606 million (EUR 455 million), compared to HIV’s USD 3 billion (EUR 2.2 billion) and USD 6 billion for cancer. An additional USD 100 million (EUR 75 million) for Alzheimer’s research for 2013 is awaiting approval.

The study was financed by the National Institute on Aging. National Institutes of Health and the US Alzheimer’s Association.

www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abs
tract?sid=cfef1e67-2463-4d7e-a59f-133f737a5b0a

New Publications & Resources

2 February: Maltese Ministry publishes a book on dementia

"X'ћin hu?"

The Malta Department of Health, the Elderly and Community Care has recently launched the book "X'ћin hu? Fatti dwar id-dimensja" ("What time is it? Facts about dementia").

The book is authored by Charles Scerri, Secretary of the Malta Dementia Society with the collaboration of the well-known local author Trevor Zahra. It provides important information about the various aspects of dementia and ways with which individuals with dementia can have a better quality of life at home.

Dr. Scerri (pictured) also serves as Honorary Secretary on the Board of Alzheimer Europe.

6 February: New video series provides insights for carers

A new online video series from the Caregiver Action Network (CAN) paints a picture of the common experiences of America’s diverse Alzheimer’s disease family caregivers. The video series reveals common struggles and stresses, and provides insights.

The video series responds to needs identified in a 2012 survey of more than 600 Alzheimer’s family caregivers in America. Results showed that many caregivers are not getting the stress relief they need, with many seeking tips on how to be a more effective caregiver and on ways they can better communicate with family and friends about the person they are caring for.

The new videos are a series of short segments that can be watched all at once or individually, to help provide caregivers with inspiration, perspective and advice whenever they can find a few minutes throughout the day.

http://caregiveraction.org/resources/alzheimer-videos/

11 February: European Commission publishes “Active and Healthy Ageing - For you & with you”

On 11 February, the European Commission (DG Digital Agenda) published a new brochure: “Active and Healthy Ageing - For you & with you”.

The brochure highlights the challenges and opportunities related to demographic ageing in Europe. It also presents a selection of EU-funded IT solutions developed to improve the health and quality of life of seniors.

The publication particularly calls upon society to be active and proactive towards change and innovation and support healthy ageing and smart innovation with ICT technology.

http://europa.eu/ey2012/ey2012main.jsp?langId=en&catId=970&newsId=1806&furtherNews=yes

26 February: UK Alzheimer’s Society releases report on life in care homes

On 26 February, the UK Alzheimer’s Society published a report entitled: "Low expectations - Attitudes on choice, care and community for people with dementia in care homes". The report provides new evidence on the key issues affecting people with dementia living in care homes. It summarises evidence from surveys of family members, care home staff and people with dementia about their views on care in care homes.

"Low Expectations" finds evidence of a deep-seated pessimism about life in care homes. Only 41% of relatives surveyed by Alzheimer’s Society reported that their loved ones enjoyed good quality of life. Despite this, three quarters of relatives would recommend their family member’s care home.

The report also reveals the severe image crisis facing the care sector. According to a poll commissioned by the charity, 70% of UK adults say they would be fairly or very scared of going into a care home. In addition, two thirds do not feel the sector is doing enough to tackle abuse in care homes.

The Society argues that public attitudes and scepticism about whether people with dementia enjoy a good quality
of life in a care home is leading to a failure to drive up standards of care.

Jeremy Hughes, Chief Executive at Alzheimer’s Society, said: “When you walk into an excellent care home it’s full of warmth, activities and interaction. But between these best examples and the worst, which often dominate headlines, there is a forgotten scandal of people with dementia who are failed and left living a life that can only be described as ‘OK’.

“Society has such low expectations of care homes that people are settling for average. Throughout our lives we demand the best for ourselves and our children. Why do we expect less for our parents? We need the government and care homes to work together to lift up expectations so people know they have the right to demand the best.”

The report is available on the Alzheimer’s Society website.

www.alzheimers.org.uk/lowexpectations

27 February: New book on dementia published in Romania

On 27 February, a new book about dementia was published in Romania. “Stepping out of the shadow” describes the personal experience of receiving a dementia diagnosis and the ensuing consequences. The book was written by Ms Helga Rohra, who was diagnosed with Dementia with Lewy bodies five years ago. Ms Rohra is an ardent dementia activist and also the Chairperson of the European Working Group of People with Dementia (EWPWD).


Job opportunities

28 February: Stirling University seeks lecturer and offers PhD opportunity

The University of Stirling is seeking to appoint a full-time lecturer to the team delivering qualifying social work education. Applications are invited from potential candidates with a strong commitment to social work education and research; to team working; and to enhancing the contribution of Social Work to Applied Social Research.

The successful candidate will contribute to the range of duties associated with the successful delivery of qualifying social work education. The post holder will also be expected to contribute to the School’s research strategy in terms of both publication and income generation.

The University is also offering a fully funded PhD studentship to investigate services and support for people with alcohol related brain damage. The student will work closely with the University’s School of Applied Social Science and the Salvation Army. The project is titled: “Understanding the experiences and support needs of people with cognitive impairment and alcohol problems among users of Salvation Army services in Scotland.”

Interested applicants are invited to contact louise.mccabe@stir.ac.uk by 15 March.

www.stir.ac.uk/about/jobs/details/index.html?id=QUUFXD26D3F3VQXB7V79W7N&nPostingID=551&nPostingTargetID=144&nmask=extstirling&lg=UK
www.stir.ac.uk/impact/partnership-projects

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

Alzheimer Europe Board
Chairperson: Heike von Lützau-Hohlbain (Germany); Vice-Chairperson: Iva Holmrova (Czech Republic); Honorary Secretary: Charles Sceri (Malta); Honorary Treasurer: Maria de Rosario Zincke dos Reis (Portugal); Members: Patrick Maugard (France), Maurice O’Connell (Ireland), Sirpa Pietikainen (Finland), Helga Rohra (Germany), Alicja Sadowska (Poland), Henry Simmons (UK - Scotland).

Alzheimer Europe Staff
Executive Director: Jean Georges; EU Public Affairs Officer: Annette Dumas; Administrative Assistant: Kate Ellis; Editor – Dementia in Europe Magazine: Julie Fraser; Information Officer: Dianne Gove; Conference and Event Coordinator: Gwladys Guillory; Communications Officer: Alex Teligadas; Administrative Assistant: Grazia Tomasini.

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www.alzheimer-europe.org/Donation
### AE Calendar 2013

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<tr>
<td>1 March</td>
<td>European Innovation Partnership on Active and Healthy Ageing action group meeting on ‘age-friendly communities’ (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>4 March</td>
<td>Meeting with representatives of the Parliament Magazine to discuss event in the EP with A. Werthmann on Neurodegenerative diseases (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>5 March</td>
<td>CEO Initiative on Alzheimer’s disease in European Parliament (Brussels, Belgium)</td>
<td>Jean</td>
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<tr>
<td>7 March</td>
<td>Innovative Medicines Initiative Symposium “Collaborating for cures” (Brussels, Belgium)</td>
<td>Jean</td>
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<tr>
<td>8 March</td>
<td>F2F AETIONOMY meeting at the Fraunhofer Institute for Algorithms and Scientific Computing (Sankt Augustin, Germany)</td>
<td>Dianne</td>
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<tr>
<td>12 March</td>
<td>RightTimePlace Care Project Meeting (Brussels, Belgium)</td>
<td>Dianne</td>
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<tr>
<td>13 March</td>
<td>Meeting with Michael Habel, European Commission (Luxembourg, Luxembourg)</td>
<td>Jean</td>
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<tr>
<td>14 March</td>
<td>European Commission ‘European Month of the Brain’ conference: ‘European brain research: successes and next challenges’ (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>21 March</td>
<td>Kick off meeting for the “Good incontinence care project” (Luxembourg, Luxembourg)</td>
<td>Dianne, Jean</td>
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<td>28 March</td>
<td>ALCOVE Final Symposium (Paris, France)</td>
<td>AE staff</td>
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<tr>
<td>12 April</td>
<td>EWGPD meeting (Brussels, Belgium)</td>
<td>Helga, AE staff</td>
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### Future Conferences

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<tr>
<td>21-23 March 2013</td>
<td>57. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), <a href="www.dgkn-kongress.de">link</a></td>
<td>Leipzig, Germany</td>
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<tr>
<td>28 March 2013</td>
<td>ALCOVE Final Symposium, <a href="www.alcove-project.eu/index.php?option=com_content&amp;view=article&amp;id=46&amp;Itemid=184">link</a></td>
<td>Paris, France</td>
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<tr>
<td>11-14 April 2013</td>
<td>The 7th World Congress on Controversies in Neurology (ICCN), <a href="www.comteemed.com/cone/2013/">link</a></td>
<td>Istanbul, Turkey</td>
</tr>
<tr>
<td>18-20 April 2013</td>
<td>28th International Conference of Alzheimer’s Disease International: Dementia: Action for global change, <a href="www.ad2013.org">link</a></td>
<td>Taipei, Taiwan</td>
</tr>
<tr>
<td>18-21 April 2013</td>
<td>9th International Conference on Mental Dysfunction &amp; Other Non-Motor Features in Parkinson’s Disease and Related Disorders – MOPD ’13, <a href="www.kenes.com/mopd2013">link</a></td>
<td>Seoul, Korea</td>
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<tr>
<td>4-12 May 2013</td>
<td>Neural Stem Cells in Development and for Brain Repair, <a href="www.neuralsc-metrics.de">link</a></td>
<td>Cortona, Italy</td>
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<tr>
<td>5-6 June 2013</td>
<td>Pioneers in healthcare, <a href="info@researchmedia.eu">link</a></td>
<td>Brussels, Belgium</td>
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<tr>
<td>8-11 June 2013</td>
<td>23rd INS 2013 meeting, <a href="www.congrex.com">link</a></td>
<td>Barcelona, Spain</td>
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<tr>
<td>13-14 June 2013</td>
<td>EU Summit on active and healthy ageing: An action agenda for European cities and Communities, <a href="http://www.ahacconference2013.eu">link</a></td>
<td>Dublin, Ireland</td>
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<tr>
<td>20-23 June 2013</td>
<td>The 20th IAGG Congress on gerontology and geriatrics, <a href="www.iaag2013.org">link</a></td>
<td>Seoul, Korea</td>
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<tr>
<td>21-26 September 2013</td>
<td>20th World Congress of Neurology, <a href="www.wwcn.at">link</a></td>
<td>Vienna, Austria</td>
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<tr>
<td>5-9 October 2013</td>
<td>26th ECNP (European College of Neuropsychopharmacology), <a href="www.ecnp-congress.eu">link</a></td>
<td>Barcelona, Spain</td>
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<tr>
<td>17-20 October 2013</td>
<td>8th International Congress on Vascular Dementia – ICVD 2013, <a href="www.kenes.com/icvd">link</a></td>
<td>Athens, Greece</td>
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<tr>
<td>11-14 December 2013</td>
<td>The 16th Asia Pacific regional Conference of Alzheimer’s disease international, <a href="www.aprc2013-hongkong-macau.com">link</a></td>
<td>Hong Kong &amp; Macau</td>
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<tr>
<td>20-22 March 2014</td>
<td>58th Annual meeting of the German society for clinical neurophysiology and functional imaging (DGKN), <a href="www.dgkn-kongress.de">link</a></td>
<td>Berlin, Germany</td>
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<tr>
<td>20-23 March 2014</td>
<td>30th International Congress of Clinical Neurophysiology of the IFCN (ICCN), <a href="www.iccn2014.de">link</a></td>
<td>Berlin, Germany</td>
</tr>
<tr>
<td>5-9 July 2014</td>
<td>9th FENS Forum of Neuroscience, <a href="http://forum.fens.org/2014">link</a></td>
<td>Milan, Italy</td>
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</table>
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