May was another busy month for us. We attended various project meetings and conferences and finalised the programme for the 23rd Alzheimer Europe Conference in Malta.

The NILVAD project is on track and the clinical trial has already begun in Ireland. EMIF is also proceeding smoothly and the partners have made progress in the first few months of the project.

Our top news item in May is the launch of the national dementia plan in Luxembourg. This long-awaited strategy is now in place and will benefit all people who are living with dementia, their families and caregivers. Portugal has also made progress by clearing a major hurdle on the way to its own plan.

In our other member countries, Norway’s Health Association is this year’s recipient of a large grant and Scotland continues to turn out new Dementia Champions. The Greek and Bulgarian associations have launched a new e-learning tool and there is also a new online forum from our Danish colleagues. Spain’s CEFAA issued a stern proclamation against austerity and the Ligue Alzheimer in Belgium held a very successful annual conference.

On the scientific front, Baxter’s immunoglobulin trial failed to meet its goals, even as TauRx began recruiting for global phase 3 trials for both Alzheimer’s disease and fronto-temporal dementia. The European Commission is also interested in clinical trials and is producing new rules to make them as safe and transparent as possible.

In other EU news, the Irish Presidency highlighted the European Month of the Brain by hosting a conference on brain research and healthcare. IMI held a forum to evaluate its current projects. The Commission appointed an expert panel for health issues while the EMA is calling for opinions on making safer medicines for older people.

Many interesting publications appeared in May, including an EU brochure on Joint Action projects and the first newsletter of the European Brain Council. The UK Alzheimer’s Society re-issued a popular activity book for people with dementia and the NHS launched an online e-learning course for dementia workers.

Our next lunch debate will take place on 18 June and will focus on the results of the ALCOVE project. The new issue of Dementia in Europe Magazine will appear on the same day. Issue 14 features Minister Kathleen Lynch speaking about Ireland’s national dementia strategy and MEP Alojz Peterle outlining the challenges of living with dementia in Slovenia. We also report on the latest meeting of the European Working Group of People with Dementia and many activities of our partners and member associations.

There are now only three weeks left to take advantage of the Early Bird registration rates for our 23rd Conference. We encourage delegates to visit our website and sign up early. The final conference programme will be published very soon.

We’ll also be doing our best to address the backlog of updates for the website. We are grateful to receive your suggestions and promise to implement them as soon as we can!

Jean Georges
Executive Director
31 May: Alzheimer Europe finalises programme for 23rd Annual Conference

Alzheimer Europe would like to thank all the people who submitted abstracts for its 23rd Annual Conference in Malta. The Scientific Committee has approved 95 oral and 67 poster presentations and notifications have been sent out to all applicants.

We are very pleased to have a wide variety of interesting and relevant topics for our delegates. The final Conference programme will soon be available on our website.

If you have not yet registered for the Conference, our “Early bird” reduced rates are still available up to 30 June.

13 May: NILVAD project team holds General Assembly

The NILVAD project partners held a General Assembly on 13-14 May in Hohenkammer near Munich, Germany.

This project will conduct a Phase 3 clinical trial of the drug nilvadipine in 500 subjects with mild to moderate Alzheimer’s disease in nine European countries. During the conference, the partners discussed the preparation of the trial sites and compared notes on the progress of the first months of recruitment. This included presentations on site initiation, randomisation training and adverse effect reporting.

According to the project team leaders, recruitment has already commenced at the lead site in Dublin (St. James’s Hospital) and recruitment will start shortly in the other sites across Europe. The delegates also looked at potential strategies to exploit the NILVAD study and patient data, such as new partnering proposals and funding applications.

The NILVAD project (2012-2017) has received support from the European Commission’s Seventh Framework Programme.

13 May: NILVAD project team holds General Assembly

AE Projects

13 May: NILVAD project team holds General Assembly

Alzheimer Europe Networking

On 13-14 May, Alex attended the NILVAD General Assembly (Hohenkammer, Germany).

On 14 May, Annette attended the European Commission "Month of the Brain" conference "European brain research: successes and next challenges" (Brussels, Belgium).


On 16 May, Dianne presented the ethics work on restrictions of freedom at the Identity and Belonging workshop at the Edinburgh School of Law (Edinburgh, United Kingdom).

On 16 May, Alex attended an EMIF project meeting (Barcelona, Spain).

On 21 May, Luisa Bartorelli, head of Alzheimer Unit Italy, visited the premises of Alzheimer Europe and ALA’s day care centre (Luxembourg, Luxembourg).

On 22-24 May, Annette attended the European Patients’ Forum General Assembly Meeting, EPF Annual conference “10 Years of active involvement: how far have we come, what do we need to go?” and EGAN conference on “Effective healthcare requires good nutritional care” (Dublin, Ireland).

On 27-28 May, Julie attended the conference "Healthy Brain Healthy Europe - A new horizon for brain research and healthcare" (Dublin, Ireland).

On 28 May, Alex attended the 22nd Annual conference of La Ligue Alzheimer (Libramont, Belgium).

On 29 May, Annette went to the European Commission D4 Action Group meeting of the European innovation partnership on active and healthy ageing (Brussels, Belgium).

On 29 May, Jean attended the negotiation meeting for the IMI funded AETIONOMY project (Brussels, Belgium).

On 30 May, Annette attended the EBC/ESF/FENS event in the European Parliament: "The prospects of brain research with Horizon 2020: responding effectively to carers’ social needs" (Brussels, Belgium).
Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 70, representing 23 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:** Demesmaeker Mark (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tarabella Marc (S&D), **Bulgaria:** Panvanova Antoniya (ALDE), **Cyprus:** Triantaphyllides Kyriacos (GUE-NGL), **Czech Republic:** Cabrnoch Milan (ECR), Kohlicek Jaromir (GUE-NGL), Roithova Zuzana (EPP), **Denmark:** Christensen Ole (S&D), Rohde Jens (ALDE), Schaldemose Christel (S&D), **Finland:** Jaakonsaari Lisa (S&D), Jäättenehmä Anneli (ALDE), Pietikäinen Sirpa (EPP), **France:** Audy Jean-Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Grossetête Françoise (EPP), Jooin Philippe (EPP), Morin-Charrier 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 Elieni (S&D), Kratsa-Tsagarakopoulou Rodi (EPP), **Ireland:** Aylward Liam (ALDE), Childers Nessa (S&D), Crowley Brian (ALDE), McGuinness Mairead (EPP), Mitchell Gay (EPP), **Italy:** Panzeri Pier Antonio (S&D), Toia Patrizia (S&D), **Luxembourg:** Engel Frank (EPP), Lulling Astrid (EPP), **Malta:** Simon Buusitil (EPP), Joseph Cuschieri (S&D), **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), Tanasescu Claudiu Ciprian (S&D), **Slovakia:** Mikolášik Marioslav (EPP), Zaborska Anna (EPP), **Slovenia:** Peterle Aleš (EPP), **Spain:** Bada i Cuchet Maria (S&D), Estarás Ferragut Rosa (EPP), **United Kingdom:** Anderson Martina (GUE-NGL), Ashworth Richard (ECR), Hall Fiona (ALDE), Mckean Linda (S&D), McCarthy Arlene (S&D), Morris 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

5 April: EMA invites comments about safer medicines for older people

The European Medicines Agency (EMA) has opened a consultation for a concept paper to investigate the quality aspects of medicines for older people.

Currently, there is no specific legal requirement for the development of medicines for geriatric use. Nevertheless, there is a need to ensure that medicines are fit for use by patients of all ages within the indicated patient populations. Given the growing older population, the EMA recognises that it should ensure that the specific needs of the elderly are integrated during the development, approval and use of medicines.

The EMA is seeking opinions and comments on this topic, especially from regulators, pharmaceutical industry, pharmacists, medical practitioners, academic groups, patient associations and national bodies responsible for medicines’ reimbursement. The deadline for submissions is 30 June 2013.

It is anticipated that the drafting of the reflection paper will start in Q3 2013 and that it will be finalised in Q3 2014, with an external consultation in Q1/Q2 2015 and finalization by the end of that year.

On 21 May, the European Commission nominated an independent expert panel to provide advice on effective ways of investing in health.

The panel will advise on health planning, budget prioritisation, health services research, hospital and healthcare management, healthcare provision and health education and promotion. The Commission will circulate this advice to Member States on an informal and non-binding basis.

The 12 panellists are Pedro Pita Barros, Margaret Barry, Helmut Brand, Werner Brouwer, Jan de Maesener, Bengt Jonsson, Fernando Lamata, Lasse Lehtonen, Dorjan Manusic, Clifford Martin McKee, Gualtieri Ricciardi and Sarah Thomson.

On 13 May, the Innovative Medicines Initiative (IMI) held its annual meeting in Brussels. The conference focused on how IMI projects are increasing our understanding of brain disorders and leading to the development of better trials and new drugs for these disorders.

The morning was dedicated to brain research, an area where IMI is particularly active and where there is an urgent need for new drugs. Researchers are currently investigating schizophrenia, depression, chronic pain, autism and Alzheimer’s disease. The latter is being addressed in the PharmaCog and EMIF-AD projects, which both include Alzheimer Europe as a partner.

The afternoon session concentrated on IMI’s place in the European Research Area. IMI is currently the largest public-private partnership in healthcare research, covering all aspects of science, research, health, regulatory aspects and clinical practice. Existing projects have shown tangible deliverables within two years, which has never been achieved by other funding schemes.

On 27-28 May, the Irish EU Presidency hosted a conference entitled “Healthy Brain, Healthy Europe: a new horizon for brain research and healthcare” in Dublin.
The aim of the conference was to showcase achievements in brain research, raise awareness of brain disorders and encourage EU countries to coordinate and optimise resources allocated to brain research and healthcare. It was also the last of a series of events carried out under the “European Month of the Brain”.

Dr. James Reilly, Irish Minister for Health, opened the conference by saying that the most effective way of addressing brain disorders is to work together and that research must be translated into policy.

Delegates were able to attend five plenary sessions that explored scientific progress in brain research, the socio-economic costs of brain-related care and the new approaches that will be needed for effective brain care in the future. There was also a panel discussion that identified recommendations for action on brain research and healthcare throughout Europe.

A conference report will soon be available on the Irish EU Presidency website.

http://eu2013.ie/

29 May: Parliament committee endorses new rules on clinical trials

On 29 May, the Public Health Committee in the European Parliament endorsed draft EU rules for clinical trials of new medicines. The new regulation is designed to encourage research while protecting patients’ rights and making simpler, more uniform rules. The new text makes specific provision for low-risk trials, clarifies the duties of ethics committees and details how to obtain informed consent from patients. It also simplifies reporting procedures and empowers the Commission to conduct checks. Finally, it stipulates that member states must respond to applications from clinical trial sponsors within fixed deadlines.

Transparency will be improved by requiring that detailed summaries be published in a publicly accessible EU database. This includes full Clinical Study Reports, once a decision on authorisation is complete. Fines would be imposed on sponsors who do not comply with this requirement.

For low-risk trials, compensation for damages would be covered by the general compensation system established under the national security or health care system. For other clinical trials, the sponsor would be deemed liable for damages, but could make use of a national indemnification system which all Member States should set up to reduce high insurance costs.

The regulation also clarified the role of ethics committees in authorising a clinical trial. The rules on obtaining a person’s informed consent to taking part in a trial are laid down in detail, so as to ensure proper access to information and compensation for damages. Specific rules would also apply to clinical trials on pregnant or breastfeeding women, on persons deprived of liberty and on people with specific needs.

Glenis Willmott, MEP (UK) is the lead Rapporteur for this piece of legislation. Her report was adopted unanimously by the Public Health Committee and she has received a mandate to negotiate an agreement with EU ministers.


29 May: Commission publishes report on public health capacity

On 29 May, the European Commission presented its “Public Health Capacity in the EU - Final report”.

The report provides an overview of capacity for public health in EU Member States, with a view to identifying areas of action which can be taken at national and EU levels to strengthen public health capacity and improve population health. It is based on the results of a 2010-11 study by the Executive Agency for Health and Consumers.

It includes literature research, a quantitative and qualitative assessment at country level by national public health experts, case studies, policy dialogues and interviews with national stakeholders. There is also a new conceptual model for public health capacity, which was developed after assessing six key domains: leadership and governance, organisational structures, workforce, financial resources, partnerships and knowledge development.

The report also makes recommendations for improvements to Member States’ public health capacity. These include the need for additional resources, a stronger focus on the behavioural, socio-economic and environmental determinants of health and more “good governance”, i.e. strengthening the competences for public health at various levels of government as well as better processes policy formulation, implementation and evaluation.


29 May: Parliament issues recommendations for effective 2014 elections

The Constitutional Affairs Committee of the European Parliament has prepared a report of recommendations on how EU Member States and political parties can improve the organisation of the 2014 European elections. The report, drafted by Andrew Duff, MEP (UK) follows recent decisions to bring forward the polling date and to nominate party political candidates for the Commission Presidency.

The report recommends that election ballot papers should list European political parties as well as national ones. European parties should name their candidates for European Commission President well in advance, to allow them time to run an EU-wide campaign on EU issues. National parties should say which European party they are affiliated with and announce their candidate for Commission President.
Political parties should also ensure that the names of candidate MEPs are made public at least six weeks before the start of polling. Parties should also field more female candidates and encourage equal representation wherever possible. Finally, parties are encouraged to include EU citizens residing in member states other than their own and registered to vote there.

Candidates should be expected to pledge that if elected to serve as an MEP, they will do so - unless they become ineligible by being appointed to a government or Commission post.

To reverse the low turnout across the Member States, the Committee calls on Member States to conduct campaigns that encourage citizens to vote. On the day, Member States should not publish election results until the close of polling in the member state whose electors are the last to vote on 25 May 2014.

This non-legislative resolution is to be put to a vote by the full House in July.


DONATE NOW! Help us make dementia a priority

www.alzheimer-europe.org/Donation

Policy Watch

14 May: Luxembourg launches national dementia plan

On 14 May, Luxembourg’s Health and Family Ministries presented the country’s first national dementia plan during a press conference.

The two Ministries will work in concert to carry out the plan. The Ministry of Health will be responsible for the areas of prevention, diagnostic standards, medical reimbursement and education. Meanwhile, the Family Ministry will develop a dedicated website and conduct an awareness campaign that includes a psycho-geriatric training course for health workers.

At the beginning of the conference, both Ministers made the personal comment that one of their parents was afflicted with Alzheimer’s disease. Family Minister Marc Spautz likened awareness of dementia today to that of AIDS 20 years ago: the general public had little or no knowledge about it, so the disease was feared and its sufferers were stigmatised. Mr Spautz is confident that the campaign and the training course will help to eliminate these issues in Luxembourg.

There are an estimated 6,500 people living with dementia in Luxembourg - of which 60% with Alzheimer’s disease - and they are expected to reach 8,500 by 2025.


15 May: G8 countries will collaborate on dementia research

On 15 May, Prime Minister David Cameron announced that the UK will use its Presidency of the G8 to identify and agree a new international approach on dementia research, in recognition that the condition is fast becoming the biggest pressure on care systems around the world.

The Group of Eight (G8) is a forum for the governments of the world’s eight wealthiest countries: Canada, France, Germany, Italy, Japan, Russia, UK and USA. The EU is also part of the group. This year, the UK holds the Presidency and can therefore arrange summits.

In September 2013, there will be a specific G8 dementia summit in London. This will bring together the members’ Science and Health Ministers, dementia experts and industry figures in an effort to secure more coordination and collaboration on dementia globally.

According to Mr Cameron, the UK and the US are also exploring opportunities to advance thinking on dementia research and identify opportunities for more international collaboration. This joint leadership will help to tackle key issues such as facilitating the discovery and development of drugs and to advance thinking on future treatments and therapies.

www.gov.uk/government/news/uk-to-use-g8-to-target-global-effort-on-dementia

20 May: Portuguese dementia plan takes a major step forward

A recent meeting held under the auspices of the Portuguese Health Ministry proved to be an important step forward in the preparation of the national dementia plan in Portugal.

On 20-21 May, a group of some 40 dementia experts persuaded the Portuguese government that existing dementia prevalence figures are sufficiently accurate to allow the next phase of the plan to proceed right away. The original government plan called for a dedicated epidemiological study - an expensive and lengthy process.

The group included psychiatrists, neurologists, general practitioners, researchers, members of the municipalities and representatives of Alzheimer Portugal. Their work was coordinated by Prof Joel Menard, one of the architects of the original French Alzheimer Plan. They put forward a prevalence figure of 160,000 people with dementia in Portugal.

The next phase of the national plan is a study to determine the needs of people with dementia. This study is already prepared and can begin very quickly. It will begin in the north of Portugal and will return results within six to nine months. According to a government spokesperson, the rest of the country will follow in turn.

Alzheimer Portugal was represented by Fátima Brito, Vice Chairperson and Celso Pontes, Coordinator of the Scientific Committee. The association is very pleased that its role as an active stakeholder has been acknowledged and praised by the participants of this working group.
Members’ News

5 April: Norwegian broadcaster raises funds for dementia research

The Norwegian Health Association has been elected by the Norwegian National Broadcaster (NRK) as the organisation that will benefit from their annual fundraising event in October 2013.

The total sum is estimated at EUR 30 million. This will enable the Association to enhance and structure Norwegian dementia research. In particular, the Association will play a facilitating role in establishing a national dementia network. One third of the funds raised will be used to create and run a national coordinated research program focusing on causes, prevention, diagnostics and treatment of dementia and also initiate a national research network amongst dementia researchers in Norway.

As a preparatory step, the association organised a one day seminar that was attended by 50 Norwegian dementia researchers - including 18 of the most prominent actors in the field. Participants were informed of the latest developments in dementia research and also mid- and long-term future topics and strategies.

This was the first time a conference of this kind was organised in Norway. Feedback showed that this was an interesting and informative day. The setting allowed the organisation of the research program. This will include enabling the Association to enhance and structure their annual fundraising event in October 2013.

The next step is to formalise, structure and establish the organisation of the research program. This will include interactive workshops with a smaller group of researchers to prioritise the content of the programme.

1 May: Denmark encourages inclusion and launches new dementia forum

The Danish National Board of Social Services has launched a campaign that focuses on the importance of maintaining sporting and cultural activities for people who live with dementia. The campaign was organised in cooperation with the Danish Alzheimer Association and numerous leisure clubs and associations.

The campaign is in line with the Association’s activities to encourage physical and cultural activities for people with dementia. According to Nis Nissen, Director of the Danish Alzheimer Association, people with dementia may be forced to withdraw from activities because they can no longer cope, but a club mate or a volunteer can easily help by helping with transportation and guiding them through the activities.

The Association has also launched a new online dementia forum called Demensnet. The forum at www.demensnet.dk is a safe digital meeting place for people with dementia and their relatives. They can blog with other people or get advice from others in the same situation or experts, e.g. doctors, nurses, psychologists, lawyers and social workers. The Association hopes that the new site will attract many young people, who are used to seeking information and help on the internet.

2 May: Scotland gains 210 new Dementia Champions

On 2 May, 210 healthcare and social services professionals graduated from the second and third cohorts of Scotland’s Dementia Champions Programme. This is the first cohort to include social services staff who will take their skills into local communities. The new Dementia Champions will work closely with Alzheimer Scotland’s Nurse Specialists/Consultants across all NHS Boards in Scotland.

The graduation ceremony took place in Edinburgh, with a keynote address delivered by Alex Neil, Cabinet Secretary for Health and Wellbeing. He said: “It is essential that both health and social care staff are well equipped to understand the care people with dementia and their families are entitled to, in order to ensure that services are of the highest standards. Today’s graduates will be supported to apply what they have learned in their workplaces so that they can improve dementia services right across the country.”

The original 100 healthcare graduates from 2012 are already making a measurable difference in how people with dementia are cared for in Scotland’s acute hospitals.

3 May: CEFA protests against austerity measures

On 3 May, CEFA (Spanish Confederation of Associations of Families of People with Alzheimer’s and other dementias) issued a press release that decries the worsening economic situation of many people with dementia and their caregivers.

The article explains that most of these people are elderly pensioners living on fixed incomes. The government recently froze these incomes, but also raised insurance co-payment rates and imposed a new co-payment for drugs. Further austerity measures have also been announced, such as eliminating the Social Security contributions of family caregivers.

CEFA strongly protests these measures and warns that they are stifling the quality of life and dignity of many individuals. These people have been paying into insurance and retirement schemes all of their lives, but now their needs are being ignored. The austerity measures are condemning many families to poverty, forcing them to choose between paying for access to health services and buying the basic necessities of life. The association is convinced that there are better alternatives to get out of the economic crisis than limiting the resources of those who already have the least.

www.ceafa.es
28 May: Belgian Ligue Alzheimer holds 21st Annual Conference

On 28 May, Belgium’s Ligue Alzheimer held a successful 21st Annual Conference entitled “Living with Alzheimer’s disease today” in Libramont.

The conference included an update on scientific research and dementia prevalence in the country. These were followed by presentations on the activities of the Ligue’s regional chapters and a session with three people with dementia. This was conducted informally - in the style of an Alzheimer Café meeting - and was much appreciated by the audience and participants alike.

There was also a round-table discussion featuring caregiver experiences, the role of general practitioners and the development of training programmes in the region. Finally, representatives from the Association Luxembourg Alzheimer provided an overview of their activities.

The conference was very popular, with some 450 delegates filling the hall to capacity. These included people with dementia and their carers, health and care professionals, representatives from the Alzheimer Associations in Belgium and Luxembourg as well as Alzheimer Europe. There was a remarkably large contingent of local residents, including students, who did not necessarily have dementia in their lives or families. This group was very active during the Q&A sessions and is testament to the efforts of the Ligue Alzheimer to raise dementia awareness in Wallonia.

31 May: Athens AD association presents new e-learning tool for carers

On 7 June, the Athens Association of Alzheimer’s Disease and Related Disorders and various partners will host an information day for the SET CARE project at the University of Athens.

The SET CARE partners have developed a self-study e-learning tool for caregivers of elderly people, including people with dementia. The original content of the course was created in Italy; the partners translated and adapted the material for use in both Greece and Bulgaria.

During the information day, the organisers will present the SET CARE materials to Greek organisations such as job centres, the local Alzheimer’s association chapters, NGOs and other public bodies that can help promote and disseminate this tool. There will be a demonstration of the SET CARE tool, followed by a discussion with experts on its usability in an educational framework. The information day will also feature presentations on dementia, the burden of care, projects for older people in Greece and distance learning.

The other Greek partners of the SET CARE project are the Centre of Family and Child Care, 01 plirofoki ekpaideftiki, the Greek-Bulgarian Cultural Association and the Municipality of Korydallos. The partners outside of Greece are Anzianienonsoi in Italy and Balkanplan Ltd. and NPO in Bulgaria.

A similar information day is being organised in Bulgaria to present the SET CARE tool to Bulgarian carers.

For more information, please contact Ms Areti Efthymiou (Greece) at kentroalz@otenet.gr or Ms Denitza Topchiyska (Bulgaria) at denitza.t@gmail.com

Science Watch

1 May: Anaesthesia is not a risk factor for dementia

A new study from the Mayo Clinic shows that receiving anaesthesia after the age of 45 is not a risk factor for dementia.

According to Dr. David Warner, Pediatric Anaesthesiologist at Mayo, some elderly people have problems with cognitive function for weeks or months following surgical procedures. There has been concern that exposure to anaesthesia may be associated with long-term cognitive changes, including dementia. “It’s reassuring we’re adding to the body of knowledge that there is not an association of anaesthesia and surgery with Alzheimer’s. There are a lot of things to worry about when an elderly person has surgery, but it seems that developing Alzheimer’s isn’t one of them.”

The study analysed thousands of patient records from the Rochester Epidemiology Project, which gave researchers access to the medical records of nearly all residents of Olmsted County, Minnesota. Researchers studied about 900 patients older than 45 who had dementia and lived in Olmsted County from 1985 to 1994. They compared that group to people of similar ages in Olmsted County who did not develop dementia during that time. They found that about 70% of the patients in both groups needed surgery requiring general anaesthesia - meaning those who had dementia and underwent surgery that included general anaesthesia did not get worse, and those who did not have dementia and had surgery did not develop dementia as a result.

www.mayoclinicproceedings.org/article/S0025-6196(13)00124-9/abstract

6 May: Family longevity delays onset of dementia

A joint Danish-American study has shown that dementia starts later in families with exceptional longevity.

Researchers followed more than 1,800 participants (1,510 family members and 360 spouses as controls) in the Long Life Family Study, which is evaluating genetic and non-genetic factors associated with extreme longevity. They looked at the onset of Alzheimer’s disease among blood relatives within long-living families and compared that with similar data on their spouses.

Results showed that older family members (average age 88) had similar rates of mental decline as their spouses. However, sons and daughters (average age 70) of exceptionally long-lived people had less than half the risk of Alzheimer’s disease than their similarly aged spouses.

Toptchiyska (Bulgaria) at denitza.t@gmail.com

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Results showed that older family members (average age 88) had similar rates of mental decline as their spouses. However, sons and daughters (average age 70) of exceptionally long-lived people had less than half the risk of Alzheimer’s disease than their similarly aged spouses.

The research team was led by Dr. Stephanie Cosentino, Assistant Professor of Neuropsychology at New York’s Columbia University Medical Center. She said: “Overall, a
higher proportion of family members than their spouses were dementia-free until age 90. After 95 years of age, however, exceptionally long-lived individuals had a high prevalence of dementia, pointing to a delayed onset of mental impairment in families with exceptional longevity.

7 May: Baxter’s immunoglobulin trial fails to meet endpoints

On 7 May, Baxter announced that its Phase III clinical study of immunoglobulin (IG) did not meet the co-primary endpoints of reducing cognitive decline and preserving functional abilities in patients with mild to moderate Alzheimer’s disease.

After 18 months of treatment, participants taking the IG treatment did not demonstrate statistically significant differences in the rate of cognitive decline or functional ability as compared to placebo.

However, one sub-group showed a positive, numerical difference in change from baseline versus placebo in cognition as measured by the ADAS-Cog and 3MS tests. These participants included people with moderate Alzheimer’s disease and carriers of the ApoE4 genetic marker, while the differences ranged between 16-29%.

Ludwig Hantson, President of Baxter’s BioScience business, said: “The study missed its primary end-points, however we remain interested by the pre-specified sub-group analyses, particularly among patients with moderate disease and those who carry a genetic risk factor for Alzheimer’s disease, two patient groups that are in great need of advances in care. A detailed analysis of the results from the GAP study continues, and we look forward to a greater understanding of the full data set.”

10 May: Depression after age 50 is a risk factor for dementia

Analysis conducted by scientists at the University of Pittsburgh’s school of Medicine in the US and the Federal University of Minais Gerais in Brazil found that vascular dementia rates are significantly higher in people who have previously suffered from depression.

Dr. Breno S. Diniz, a psychiatrist at Minais Gerais who led the study, said that late-life depression is one of the most common psychiatric conditions in older people. It has long been associated with the development of other conditions and higher death rates.

The study looked at people aged over 50 who did not have dementia to begin with and analysed them in follow-up periods of 6.1 years. The results showed that depression after the age of 50 increased the risk of all-cause dementia by 1.85 times. For Alzheimer’s disease, the risk factor is 1.65 while vascular dementia is the most likely form of dementia at 2.52.

10 May: Leukemia drug may help reduce Lewy bodies

A leukemia drug called nilotinib has been found to slow the production of tau and alpha-synuclein proteins in the brain. Alpha-synuclein is the main component of Lewy bodies and thus mainly associated with Parkinson’s disease.

Researchers affiliated with Georgetown University administered nilotinib to mouse models and found that it eliminated abnormal protein build-up in their brains. The treated mice saw improvements in both cognitive and motor functions and also lived longer compared to mice treated with placebo.

The research team was headed by Dr. Charbel Moussa, Assistant Professor and Head of Laboratory for Dementia and Parkinsonism at Georgetown. He is now planning clinical trials for Dementia with Lewy Bodies and hopes to later include Alzheimer’s and Parkinson’s diseases as well.

Nilotinib is marketed as Tasigna by Novartis in the USA and the EU.

14 May: New synthetic drug improves memory in mice

A new synthetic compound called J147 has been shown to reverse memory loss and reduce amyloid levels in aged mouse models.

Researchers from the Salk Institute for Biological Studies in California administered the drug to 20-month-old mice with advanced Alzheimer’s disease pathology for three months. They observed reductions in memory loss and levels of amyloid, as well as an increase of the BDNF protein.

BDNF (brain-derived neurotrophic factor) protects neurons from toxins, helps new neurons grow and connect with other brain cells and is involved in memory formation. Post mortem studies show lower than normal levels of BDNF in the brains of people with Alzheimer’s disease.

The team was headed by Prof David Schubert, Head of the Cellular Neurobiology Laboratory at Salk. He said: "In addition to yielding an exceptionally promising therapeutic, both the strategy of using mice with existing disease and the drug discovery process based upon aging are what make the study interesting and exciting.” He added that this study “more closely resembles what happens in humans, who have advanced pathology when diagnosis occurs and treatment begins.”

In a separate experiment, the researchers tested J147 directly against Aicrpet and found that it performed as well or better in several memory tests.

This study was supported by the Alzheimer’s Drug Discovery Foundation, the Bundy Foundation, the Fritz Burns Foundation, the George E. Hewitt Foundation, the Alzheimer’s Association, and the National Institutes of Health.

http://alzres.com/content/5/3/25/abstract

http://hmg.oxfordjournals.org/content/early/2013/05/09/hmg.dtt192.abstract?sid=0b253505-3e4-4319-9350-cloneb9347d6
21 May: Vitamin B slows atrophy of brain areas affected by dementia
A research team from Oxford University has shown that a treatment based on Vitamin B can slow atrophy of the brain areas affected by dementia.

Previous studies have shown that a large daily dose of three types of vitamin B (B12, B6 and B9 or folic acid) can slow mental decline in elderly people who suffer from mild memory problems. This study was a re-examination of the previous results. It showed that high doses of the vitamins (particularly B12) can lower the levels of an amino acid called homocysteine, which is associated with an increased risk of cognitive impairment and Alzheimer’s disease.

The analysis was led by Dr. David Smith, Professor of Pharmacology at Oxford University and carried out by Dr. Gwenaëlle Douaud, researcher at the Functional Magnetic Resonance Imaging of the Brain Centre in Oxford. Her team showed that the atrophy of the brain regions was linked to cognitive decline among the 156 participants in the study. In 77 participants with high homocysteine levels, treatment with B vitamins lowered these levels. In turn, this slowed the shrinkage of the brain regions and thus resulted in less cognitive decline.

Professor Hugh Perry, chairman of the MRC’s Neurosciences and Mental Health Board, said: “We already know that low levels of B vitamins are associated with cognitive impairment. This study adds to that knowledge and shows that high doses of these vitamins - particularly B12 - can lower homocysteine levels and reduce the rate of atrophy of those specific parts of the brain related to Alzheimer’s. The challenge now is to identify the mechanisms by which lower homocysteine influences brain atrophy and to study larger cohorts of patients in trials to confirm that progression to dementia really can be slowed down.”

The MRC, or Medical Research Council, funded the original study.

www.pnas.org/content/early/2013/05/16/1301816110.abstract?sid=4704b5bd-4b74-427f-9677-49265a8b6b4e
http://users.fmrib.ox.ac.uk/~douaud/VB_vbm.pdf

22 May: TauRx begins recruitment for Phase 3 trial
TauRx Therapeutics has begun enrolment of participants for its Phase 3 trial of the drug LMTX for mild to moderate Alzheimer’s disease. The first enrolments were in the UK, with a goal of more than 100 participants at 16 trial centres. Globally, TauRx is recruiting more than 1,500 patients in some 20 countries in trials for both Alzheimer’s disease and fronto-temporal dementia (FTD).

According to the company, LMTX targets a process in the brain whereby a normal form of tau protein begins to self-aggregate due to binding neuronal waste-products. Once the process has started, the aggregates are able to propagate themselves indefinitely, using up normal tau protein and converting it into the toxic aggregates. After destroying the nerve cells where they are initially formed, the aggregates go on to infect nearby healthy neurons, progressively spreading and accelerating the destruction throughout the brain. LMTX stops this aggregation process and releases the trapped tau protein in a form which can be easily cleared by nerve cells.


24 May: 2012 bexarotene study results are called into question
The findings of a March 2012 study on bexarotene have been partially called into doubt by a team of scientists who were not involved in the original study.

Amongst other conclusions, the original paper stated that the drug eliminated a substantial amount of amyloid plaque in a very short time period. However, when the current team re-created the trial, there was no reduction in plaque burden in any of the three mouse models that were treated.

The new study was a joint effort by researchers at the University of Chicago, Northwestern University, Massachusetts General Hospital, Washington University in St. Louis and the University of Tübingen in Germany. They were led by Dr. Sangram Sisodia, Professor of Neuroscience at the University of Chicago.

The 2012 study was conducted by scientists at Case Western Reserve University. They also reported that bexarotene reduced the level of soluble amyloid beta in the mice and this conclusion was not disputed.

Bexarotene is currently in use as a cancer drug, marketed by Eisai as Targretin.

www.sciencemag.org/content/340/6135/924.6.abstract?sid=1b30fd89-98ed-405-975c-6444043c1a00a
www.sciencemag.org/content/335/6075/1503.abstract?sid=8617a2b-c531-427f-8b35-fc0c459f130a

Dementia in Society
17 May: MHE criticises American DSM-5 manual
Mental Health Europe (MHE) has issued a press release that criticises various elements of the new edition of the “Diagnostic and Statistical Manual of Mental Disorders (DSM-5)” published by the American Psychiatric Association (APA). DSM-5 was officially presented released on 18 May and is the fifth edition of this manual.

MHE contends that DSM-5 is excessively biased toward a biological approach to mental health issues. Conversely, psychological and social interventions are relatively downgraded - despite the fact that such therapies are in common use to support personal and social recovery.

Another concern is the inclusion of diagnostic categories with questionable reliability: the manual continues to medicalise normal reactions such as grief or shyness. This increases the risk of diagnosing psychiatric illness on
people who would fare much better without one - and the subsequent prescription of unneeded psychotropic drugs.

According to Karina Huberman, MHE Acting Director, "mental health problems are not black and white. They can be fleeting or permanent, stem from a multitude of causes, and, depending on the individual person, respond to different interventions. The biomedical approach in the DSM 5 is thus restrictive and harmful, and should definitely be rethought."

Dr. Irwin claims to have helped at least 25 people to die at the clinic. Assisted suicide is a criminal offence in the UK but is legal in Switzerland.

In previous cases, critics to assisted suicide have claimed that it carries the implication that those with dementia should consider killing themselves. They point out that dementia sufferers can live for many years with the condition. This man’s death is one more element in the debate over the circumstances in which assisted suicide should be permitted.

New Publications & Resources

1 May: EU publishes brochure on Joint Actions

The European Commission has published a new brochure entitled “Joint Actions: EU support for key public health initiatives 2008-2011”. The brochure explains how the Joint Actions (JAs) work, how they are funded and how they are monitored to ensure that they contribute European added value. There is a detailed overview of all 20 JAs funded between 2008-11, with particular attention to their results, outputs and impact on national health policies within the EU.

JAs are one of four types of actions funded by the EU Health Programme. They are designed to stimulate governments, academic and other non-profit organisations to join forces at the EU level in order to tackle problems shared by many EU Member States. JAs involve partner organisations from many different Member State and aim to jointly develop solutions that can be put into practice directly at national level. Further JAs are continuing up to 2015 and beyond.


15 May: UK reports on progress of Challenge on Dementia

The UK Department of Health has released an annual progress report on the first year of the Prime Minister’s Challenge on Dementia. The Challenge aims to deliver major improvements in dementia care and research by 2015. The report gives an overview of the plan and highlights various activities that have launched in the last 12 months.

Health & care

- A new service that rewards GPs for having a proactive approach to the assessment of patients who may be showing early signs of dementia.
- A "Dementia Care and Support Compact" with major care providers to improve care and support for people with dementia living at home and in care homes.
- A commitment by some 140 NHS trusts to become "dementia friendly", working in partnership with their local Dementia Action Alliance.
- The appointment of senior clinical leads to ensure that staff is trained in dementia care.

Support for carers

Some EUR 950,000 has been allocated to develop initiatives to increase awareness of carers’ needs among

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22 May: EPF holds General Assembly

On 22 May, the European Patients’ Forum (EPF) held a General Assembly meeting in Dublin.

The presentation of the 2012 Annual Report showed that EPF has been active in various EU legislative proposals or consultations. These include Clinical Trials, Transparency, Data Protection, Medical Devices, Rights and Needs of Older Patients, Professional Qualifications, Health for Growth and Horizon 2020. EPF is also involved in 12 EU projects.

In 2013, EPF continues to implement the elements of its 2007-2013 Strategic Plan, with particular emphasis on the following:

- reinforcing EPF capacity through its capacity building programme, regional advocacy seminar, youth involvement, reinforced membership and the Policy Advisory Group.
- strengthening the influence and impact of the patients’ perspective in the field of chronic diseases, e-health, access to healthcare, health literacy, structural funds, cross border healthcare, pharmacovigilance and falsified medicines.
- feeding project and patient evidence into policy and consolidating the EPF communication strategy.

Delegates also adopted the new Strategic Plan (2014-2020) during the meeting. The new plan is likely to introduce discrimination as a key priority for the EPF, especially working with other groups that are already active in this field.

28 May: Dementia sufferer ends life at the Swiss Dignitas clinic

An unnamed 83-year-old man with dementia chose to die at the Dignitas “suicide clinic” in Switzerland rather than become an eventual burden to his family. He was apparently the first British citizen to use Dignitas’ services solely because of dementia.

Dr. Michael Irwin, retired GP and campaigner for assisted suicide, arranged beforehand for the man to see a psychiatrist to produce a report saying he was mentally competent. He said: “His wife said he was grateful. His family was 100 per cent behind him. I have spoken to his widow since and she felt that it was handled in a very dignified and proper manner.”

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www.eu-patient.eu/Events/EPF-10th-anniversary-celebration-and-Annual-General-Meeting/Presentations-agm/
An additional ten 30-minute sessions provide support for dementia. The introductory sessions of the course are available free of charge on the project website.

27 May: EBC publishes first newsletter

The European Brain Council (EBC) has published the first issue of its quarterly newsletter “EBC News”.

The EBC coordinates the interests of European organisations in neurology, neurosurgery, psychiatry, neuroscience, as well as patient organisations and industry. The newsletter aims to communicate all the different elements of brain diseases, including the science and challenges that European societies will face in the future.

EBC News can be downloaded from the Council’s website.

28 May: Alzheimer’s Society launches new activities book

The UK Alzheimer’s Society has launched a newly revised version of its popular activities book named “Taking part: activities for people with dementia”. The book is aimed at health and social care professionals and includes detailed breakdowns of more than 80 activity ideas that detail precisely "What you need" and "How it's done".

Each chapter is dedicated to a theme e.g. life history work, gardening, and computers and the internet. Chapters also include an overview of recent research findings in that area, practical tips and case studies of innovative and successful activity programmes from a range of different care settings that bring the ideas to life.

The book is available from Alzheimer’s Society online shop.

Job opportunities

27 May: DZNE is looking for a Research Group Leader

DZNE - the German Centre for Neurodegenerative Diseases - has a vacancy for a Research Group Leader to provide leadership to a research group that focuses on the provision, consultation, adaption, and development of analyses and research methods in the field of dementia-specific health services research. Scientific requirements are as follows:

- Excellent scientific expertise, preferably with a PhD preferably in an interdisciplinary context, e.g. social sciences, psychology, nursing science, medicine.
Alzheimer’s Disease International (ADI) has an immediate vacancy for an Administrator at its London office. Further details are available on the association’s website.

31 May: ADI is recruiting an Administrator

Alzheimer’s Disease International (ADI) has an immediate vacancy for an Administrator at its London office. Further details are available on the association’s website.

**AE Calendar 2013**

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE Representative</th>
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<tbody>
<tr>
<td>5 June</td>
<td>Alzheimer Scotland conference (Glasgow, UK)</td>
<td>Jean</td>
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<tr>
<td>4 June</td>
<td>EMA Scientific advice meeting</td>
<td>Jean</td>
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<tr>
<td>10-11 June</td>
<td>EMRI project meeting (Stages, Spain)</td>
<td>Alex</td>
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<tr>
<td>12 June</td>
<td>First meeting of the ethics working group on perceptions and the portrayal of dementia (Brussels, Belgium)</td>
<td>Dianne</td>
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<tr>
<td>17-18 June</td>
<td>Regional Symposium on Preventing Abuse and Neglect of Older Persons in Europe, organised by the Office of the United Nations High Commissioner for Human Rights (Brussels, Belgium)</td>
<td>Dianne</td>
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<tr>
<td>17-19 June</td>
<td>AE staff and Board, EFPIA Think Tank meeting and public affairs meeting (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>19 June</td>
<td>EFPIA Think Tank (Brussels, Belgium)</td>
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**Future Conferences**

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<tr>
<th>Date</th>
<th>Meeting</th>
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<tr>
<td>8-11 June</td>
<td>23rd ENS 2013 meeting, <a href="http://www.congres.org">www.congres.org</a></td>
<td>Barcelona, Spain</td>
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<tr>
<td>13-14 June</td>
<td>EU Summit on active and healthy ageing: An action agenda for European cities and Communities, <a href="http://www.aahcongress2013.ie">www.aahcongress2013.ie</a></td>
<td>Dublin, Ireland</td>
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<tr>
<td>1-2 July</td>
<td>NeuroConnection, <a href="http://www.neuroconnection.eu">www.neuroconnection.eu</a></td>
<td>Marseille, France</td>
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<tr>
<td>4-5 July</td>
<td>2nd symposium france roumain: l' Association, une approche interdisciplinaire, <a href="http://www.epum-illie-metropole.fr">www.epum-illie-metropole.fr</a></td>
<td>Lille, France</td>
</tr>
<tr>
<td>21-26 September</td>
<td>XIV World Congress of Neurology, <a href="http://www.wangst.at">www.wangst.at</a></td>
<td>Vienna, Austria</td>
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<tr>
<td>5-9 October</td>
<td>26th ECNP (European College of Neuropsychopharmacology), <a href="http://www.ecnp-congress.eu">www.ecnp-congress.eu</a></td>
<td>Barcelona, Spain</td>
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<tr>
<td>17-20 October</td>
<td>8th International Congress on Vascular Dementia – ICVD 2013, <a href="http://www.kenes.com/Cod">www.kenes.com/Cod</a></td>
<td>Athens, Greece</td>
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<tr>
<td>11-14 December</td>
<td>The 16th Asia Pacific regional Conference of Alzheimer’s disease international, <a href="http://www.apc2013-hongkong-macao.com">www.apc2013-hongkong-macao.com</a></td>
<td>Hong Kong &amp; Macau</td>
</tr>
<tr>
<td>20-22 March</td>
<td>50th Annual meeting of the German society for clinical neurophysiology and functional imaging (DGKN), <a href="http://www.dgkn-kongress.de">www.dgkn-kongress.de</a></td>
<td>Berlin, Germany</td>
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<td>20-23 March</td>
<td>30th International Congress of Clinical Neurophysiology of the IFCN (CCN), <a href="http://www.iccn2014.de">www.iccn2014.de</a></td>
<td>Berlin, Germany</td>
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<tr>
<td>5-9 July</td>
<td>5th ENS Forum of Neuroscience, <a href="http://forum.fens.org/2014">http://forum.fens.org/2014</a></td>
<td>Milan, Italy</td>
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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 2013 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.