Editorial

With the European Parliament elections just around the corner, Annette and I were invited to join a discussion at the European Parliament in Brussels on the first day of the month. MEP Marina Yannakoudakis invited MEPs, NGOs, representatives from EU Health Commissioner Tonio Borg’s cabinet and other Commission officials to discuss the future of EU dementia policy.

As the campaign for the European elections picks up steam, so does our call for support to our European Dementia Pledge. 136 EP candidates now support greater EU collaboration on dementia, 71 of which signed the pledge in April alone!

We have been applying some of our tweeting skills picked up at Lilly’s “Twitter Academy” in Brussels on 8 April and our Twitter account has been busy with the strain of all the thank you tweets to pledgees and member organisations.

This month has also seen an important EU development in the area of clinical trials, with the new Clinical Trials Regulation receiving a landslide vote in favour at the European Parliament on 2 April. It will come into force mid-2016 and should ensure more open reporting of clinical trials results in Europe, as well as saving money and red tape for research institutions and companies conducting clinical trials in the EU.

On 8 and 9 April Dianné and I flew to Madrid for the Global Forum on Incontinence. Dianné presented the first draft of the guidelines on continence care for people with dementia living at home, which went down very well. The working group received plenty of feedback during and after the event, which it will consider prior to launching the guidelines at our annual conference later this year.

Our member organisations have been busy with their own campaigns and our Irish and UK colleagues are contacting politicians for both European and local elections.

Germany and France have been actively campaigning and managed to gather over 150,000 and 50,000 signatures respectively in support of their petitions in favour of healthcare reforms.

In our “dementia in society” section, we report on a recent UK survey into the impact of workers trying to juggle work and care. The results may give businesses pause for thought.

Also in the UK, our friends at the University of Worcester are looking for a new Head for their Association for Dementia Studies.

Last but certainly not least, the call for abstracts for our upcoming conference in Glasgow has now closed. They had been arriving in a steady stream since the call opened. The stream turned into a river in April and at the end of the month the flood barriers were really tested, the result being an impressive 331 abstracts (more than double the number of last year). All abstracts will be reviewed by the Programme Committee and authors will receive their decisions by the end of May. I would like to remind all accepted presenters that you must register for the conference by 30 June via our website.

Here’s to a May that promises to be just as eventful.

Jean Georges
Executive Director
Alzheimer Europe

8 April: AE staff attend Lilly’s Twitter Academy

On 8 April, Kate Ellis and Alex Telgadas attended a Twitter training session hosted by Lilly in Brussels. The “Twitter Academy” course was designed to increase understanding of the popular social medium amongst patient organisations and also Lilly employees. The course was led by two experts from communications agency Burson-Marsteller and focused on how the service helps organisations to communicate quickly and effectively with external audiences. The course sessions were very lively and interactive, with participants vying to produce a series of Tweets that gradually included all of the best features of the service.

@AlzheimerEurope thanks @LillyPadEU for the invitation to attend the recent Twitter Academy session held by @BMDigital in #Brussels!

8-9 April: Dianne Gove presents at Global Forum on Incontinence

On 8-9 April 2014, Dianne and Jean attended the Global Forum on Incontinence in Madrid, Spain. Dianne presented the first draft of the guidelines on continence care for people with dementia living at home. There was considerable interest from conference participants in these guidelines with some providing feedback and offering to be involved in the consultation process which will end in the middle of May.

Since the conference, several groups of people with dementia, informal carers, professional carers and some policy makers have been contacted and the working group (comprised of experts selected by SCA and Alzheimer Europe) will consider all feedback before finalising the guidelines which will be launched in October 2014 at the AE annual conference in Glasgow.

24 April: Dianne attends 22nd Ligue Alzheimer annual conference

On 24 April 2014, Dianne attended the 22nd annual conference of the Ligue Alzheimer asbl on the topic «L’Éthique à la recherche du bien-être» in Huy, Belgium. In the opening speech, Prof. Michel Longneaux described ethics as involving respecting each person as a person and warned against definitions of personhood based on cognitive capacity or self-awareness. He emphasised three points in relation to ethics and wellbeing: 1. The need to be realistic and to accept that everything is not possible. He pointed out that it can be frustrating when carers realise that what they would like to do for the person with dementia cannot be achieved, 2. Concerns about wellbeing should not focus solely on the person with dementia but should involve a compromise between his/her wellbeing and that of informal and formal carers and 3. The wellbeing of each person is influenced by a particular socio-economic and political context which also points towards the need for compromise. Interdependency and the need for carers to consider their own well-being were further developed during the session on “autonomy and interdependence” chaired by Sabine Henry and involving the members of the Groupe des Battants (the group of fighters). In the afternoon, a series of short presentations were made on a range of topics such as palliative care, new guardianship legislation, Alzheimer cafés and theatrical improvisation.

30 April: Alzheimer Europe closes call for abstracts

The call for abstracts for the 24th Alzheimer Europe Conference is now closed. We are delighted to have received more than 330 abstracts. These will be reviewed by the Programme Committee in May. All submitting authors will be informed of the Committee’s decision by 31 May 2014.

AE Projects

29 April: AFE-INNOVNET project holds first webinar

The first AFE-INNOVNET webinar, “A Solution to Demographic Change” was held on 29 April, moderated by Christina Dziewanska-Stringer (Council of European Municipalities and Regions - CEMR).

The aim was to present the project to interested stakeholders and 3 speakers were invited to do so: Anne-Sophie Parent, Secretary General of AGE Platform Europe, who made a general presentation of the project; Nhu Tram, Project Officer of the Council of European Municipalities and Regions (CEMR), who focused on the work package 3; Joan Martin, Responsible for the Louth Age-friendly portfolio, who introduced the various initiatives going on in Louth County and how it is involved in the AFE-INNOVNET project.

Between 35 and 40 participants attended the interactive webinar.

A recording of it is available here:

www.youtube.com/watch?v=FGOrO3SfFeature=youtu.be

DONATE NOW!
Help us make dementia a priority

www.alzheimer-europe.org/Donation
Alzheimer Europe Networking

On 1 April (Brussels), Annette and Jean attended the meeting organised by MEP and European Alzheimer’s Alliance Vice-Chair, M. Yannakoudakis, ‘Hand in hand – fighting against Alzheimer’s and other forms of dementia together’.

On 3-4 April (Brussels), Annette attended the European Commission summit on chronic diseases.

On 7 April (Diegem, Belgium), Alex attended a meeting of the EMIF WP15 Communications team.

On 8 April (Brussels), Annette attended the meeting organised by A. Kovatchev, MEP, on ‘universal access to health: your voice in the European Union’.

On 8 April (Brussels, Belgium), Kate and Alex attended the “Twitter Academy”, a social media training session sponsored by Lilly.

On 8-9 April (Madrid, Spain), Dianne and Jean attended the Global Forum on Incontinence at which Dianne presented the first draft of the guidelines on continence care for people with dementia living at home.

On 9 April (Brussels, Belgium), Annette attended the Carers Interest Group in the EP meeting that explored the ‘carers and work/life balance’.

On 10 April (Luxembourg, Luxembourg), Jean met with representatives of the European Association for Homes and Services for the Ageing.

On 24 April (Huy, Belgium), Dianne attended the 22nd annual conference of the Ligue Alzheimer asbl on the topic ‘L’Éthique à la recherche du bien-être’.

On 25 April (Brussels, Belgium), Jean met with representatives of Novartis and Lundbeck.

On 30 April (Luxembourg, Luxembourg), Jean met with representatives of Association Luxembourg Alzheimer.

On 30 April (Diegem, Belgium), Alex attended a meeting of the EMIF WP15 Communications team.

European Alzheimer’s Alliance and European Dementia Pledge

The following candidates to the European Parliament are currently members of the European Alzheimer’s Alliance and/or have signed the European Dementia Pledge as at 2 May. In total, 133 representing 26 Member States of the European Union have pledged their support to our campaign to make dementia a European priority.

Austria: Heinz K. Becker, MEP; Angelika Worthington, MEP; Belgium: Mark Demesmaeker, MEP; Frédérique Ries, MEP; Bart Staes, MEP; Marc Tarabella, MEP; Kathleen van Brempt, MEP.

Bulgaria: Andrey Kovatchev, MEP; Antonia Panvanova, MEP.

Croatia: Milorad Pupovac, Ruža Tomašić.

Cyprus: Simos Angelidis; Androulla Eleftheriou; Yiorgos Lillakas; Alexandros Michailidis; Yiannis Panayiotou; Antigoni Papadopoulou, MEP.

Denmark: Lave K. Broch; Ole Christensen, MEP; Jean Rohde, MEP; Christel Schaldemose, MEP; Britta Thomsen, MEP.

Finland: Piirka Aaltto; Jari Andersson; Ole Christensen, MEP; Jean Rohde, MEP; Christel Schaldemose, MEP; Britta Thomsen, MEP.

France: Jean-Pierre Audy, MEP; Christine de Veyrac, MEP; Nathalie Griesbeck, MEP.

Germany: Angelika Niebler, MEP; Thomas Ulmer, MEP; Greece: Nikolaos Chountis, MEP; Maria Elena Koppa, MEP; Rodi Kratsa-Tsagaropoulou, MEP.

Hungary: Ádám Kósa, MEP; Ireland: Matt Camp; Norway: Nils Eldøen, MEP; Philip Gregory, MEP; Mariage Jorund, MEP; Peter van Calsnaere, MEP;

Ireland: Matt Camp; Norway: Nils Eldøen, MEP; Philip Gregory, MEP; Mariage Jorund, MEP; Peter van Calsnaere, MEP; all candidates for the 2014 European Parliament elections to sign the Pledge, showing their commitment to people with dementia and their carers.

The list of signatories to date can be found here: gwee.alzheimer-europe.org/Policy-in-Practice2/European-Parliament-Elections-2014/EP-candidates-supporting-greater-EU-collaboration-on-dementia

European Alzheimer’s Alliance

1 April: MEP Marina Yannakoudakis hosts discussion on the future of EU dementia policy

MEP Marina Yannakoudakis invited fellow MEPs as well as NGOs, representatives from EU Health Commissioner Tonio Borg’s cabinet and other Commission officials to a meeting on 1 April at the European Parliament in Brussels. With the European Parliamentary elections fast approaching, the topic on the agenda was European policy regarding Alzheimer’s disease and other dementias during the next parliamentary term.

At the event, entitled “Hand in Hand: Fighting against Alzheimer’s and other forms of dementia together”, Ms Yannakoudakis who is the European Conservative Party’s health spokesperson and a vice-president of the European Alzheimer’s Alliance (EAA), expressed the
importance of ensuring that Alzheimer’s disease remains a real priority after the elections. She also stressed that the new Commission Presidency should place this issue at the top of its agenda.

“There is still so much more research to do and Member States need to ensure they have effective strategies in place for dealing with dementia”, she said.

Jean Georges, Executive Director of Alzheimer Europe commented, “not only do we need research into a cure for Alzheimer’s disease to give hope to future generations, but we need to find concrete solutions and approaches for the 8.7 million Europeans living with dementia today.”

EU Developments

2 April: European Parliament votes for more transparent clinical trial rules

On 2 April, MEPs voted 594 to 17 in favour of new rules that will ensure more open reporting of clinical trials results in Europe.

The new legislation is expected to take effect in mid-2016 and will require results of all new clinical trials to be published online for open access within a year of the trial ending.

In addition to ensuring greater transparency, the new law will also reduce the red tape surrounding the approval process for studies on medicines, including simplifying rules for running multinational trials.

EU Health Commissioner Tonio Borg made a statement saying that these measures should save research institutions and companies conducting clinical trials in the EU some EUR 800 million per year in regulatory costs.

4 April: Commission recommendations on challenges faced by EU healthcare systems

In the face of what it calls “the demographic challenges and the pressure on age-related expenditure” for Europe’s healthcare systems, the European Commission adopted a new communication on 4 April, outlining recommendations to make these systems more robust.

Making reference to the 2013 Annual Growth Survey (AGS), it highlights to Member States that reforms of their healthcare systems “should be undertaken to ensure cost effectiveness and sustainability, assessing the performance of these systems against the twin aim of a more efficient use of public resources and access to high quality healthcare”.

The main emphasis is put on measures to be taken by the Member States in order to make their own healthcare systems “more resilient, more capable of coping with the challenges that lie ahead” all the while “remaining cost-effective and fiscally sustainable”.

The communication also mentions some measures which the EU can take to help and reminds Member States to make good use of European funding instruments in implementing the recommended reforms as well.


8 April: EMA announces final steps for its clinical-trial data policy

In light of the new Clinical Trials Regulation receiving such a strong vote in favour in the European Parliament on 2 April, the European Medicines Agency (EMA) announced on 8 April that it will launch a final round of targeted consultations with key stakeholders on its draft policy on proactive publication of and access to clinical-trial data at the beginning of May. The objective being to make every effort to be ready to comply with the new regulation which is expected to come into force mid 2016.


11 April: EMA opens registration for AD drug workshop

The European Medicines Agency (EMA) is inviting expressions of interest in attending its workshop on the clinical investigation of new medicines for the treatment of Alzheimer’s disease on 24-25 November 2014.

This workshop follows the public consultation of the agency’s concept paper on the need for revision of the guideline on medicinal products for the treatment of Alzheimer’s disease and other dementias. Based on the comments received, the Agency is currently revising the guideline and expects to release a first draft for public consultation within the next few months.

The main goal of the workshop is to make sure that, while revising its guideline, the EMA can take the most up-to-date scientific developments in understanding and treating Alzheimer’s disease into consideration, as well as the positions of experts in the field on the main topics covered in the guideline.

The workshop will bring together representatives of patients, regulators, pharmaceutical industry and independent experts.

Expressions of interest should be sent to achworkshop@ema.europa.eu by 1 July 2014 including name, company or affiliation, telephone number and e-mail address.


11 April: EUR 80 million EU co-funding call opens

A call for research programme proposals competing for a total of EUR 80 million in EU co-funding opened on 11 April.

The Marie Skłodowska-Curie co-funding scheme COFUND, financed under Horizon 2020, financially supports
regional, national and international programmes for research training and career development, to encourage the mobility of researchers both across borders and across sectors of activity.

Organisations funding or managing such programmes can apply by 2 October 2014.


14 April: EU Council adopts new rules on clinical trials

On 14 April, the EU Council approved a draft regulation aimed at facilitating and speeding up the authorisation procedure of clinical trials, meaning that the regulation is now adopted. It will enter into force 20 days following its publication in the Official Journal of the European Union and apply six months after a EU portal for the submission of data on clinical trials and an EU database identifying each clinical trial have become fully functional. The main objective of the regulation is to make the European Union more attractive for clinical research and to invert the decreasing number of investigations of medicines in humans conducted in the EU, while maintaining the high standards of patient safety. Between 2007 and 2011, the number of applications for clinical trials decreased by 25% in the EU. While member states will continue to make their independent assessment of notably ethical issues, the draft regulation provides for a uniform application of common rules.


Members’ News

23 March: Alzheimer Uniti Italy Fun Run in Rome during marathon

As in previous years, Alzheimer Uniti organised and participated in the Fun Run Rome (5km run/walk during the Rome Marathon) on March 23 taking advantage of one of the few opportunities to raise public awareness for Alzheimer’s disease. Participants ran and walked with their families by the great monuments of Rome including the Coliseum, the Circus Maximus, the Palatine hill and the Baths of Caracalla and a fun time was had by all.

1 April: Alzheimer Scotland launches “Big Idea” competition

On 1 April, Alzheimer Scotland launched a competition to encourage innovation in dementia.

In early June, as part of the organisation’s “Innovation, Research and Technology in Dementia” conference, it will be running a “Dragons’ Den” style competition to find an idea that could help to transform care and/or support for people with dementia and their families.

To submit an entry email Mark Leiper at: mleiper@alzscot.org and for further information about the competition visit: www.alzscot.org/news_and_community/news/2901_do_you_have_the_next_big_idea_for_dementia

4 April: France Alzheimer has a new logo

France Alzheimer and its 94 regional components have adopted a new, shared logo as of 4 April. The newly-designed, hexagonal logo represents the hexagonal shape of France and therefore the organisation’s unity and presence throughout the land.

4 April: Royal attention for dementia village in the Netherlands

On 4 April, Queen Maxima of the Netherlands hosted Sweden’s Queen Silvia on a visit to a special care facility for elderly people with dementia near Amsterdam.

“De Hogeweyk” is a gated community that is built like a small town, with its own town square, pub, theatre and shops. During their visit, the monarchs where shown around by Eloy van Hal, facility manager of De Hogeweyk. He said: “I felt the sincere attention of the queens. They took the time to really experience our special community.” The queens toured the entire facility and spoke to several residents.

This was followed by a meeting with Gea Broekema-Procházka, director of Alzheimer Nederland, where they discussed the care of people with dementia in the Netherlands. After speaking to Queen Silvia about her personal experience with dementia, Ms Broekema-Procházka said: “It was very special to discover that we share similar experiences.”


7 April: Alzheimer Scotland has a new logo

As of 7 April, Alzheimer Scotland has adopted a new logo as part of its new branding policy, which aims to be “collaborative, enabling, personalised, influential, innovative, a part of life”:
7 April: German Alzheimer Society petition surpasses target

The German Alzheimer Society’s campaign for the rapid implementation of a fundamental reform of long-term care, launched on 25 March in partnership with social association VdK has surpassed the organisations’ expectations in terms of public response.

As at 7 April more than 150,000 people had pledged their support for the petition demanding a “grosse Pflegereform jetzt!” (“big care reform, now!”), thus exceeding by some margin the 50,000 signature target.

This means that their petition will now lead to a public hearing at the German National Petitions Committee.

German Health Minister, Hermann Gröhe recently presented a proposal for changes in long-term care starting from 1 January 2015 but plans for a larger and more comprehensive reform were postponed to the end of the current parliamentary term. Heike von Lützau-Hohlbein, chairperson of the German Association believes that the large number of signatures received clearly reflects that such a delay is not in the interest of people who need help today. “We believe that the policy has to take the voices of so many citizens seriously.” More information can be found at: www.grosse-pflegereform-jetzt.de

9 April: Alzheimer café in Croatia hosts speaker from Spominčica

Alzheimer’s Disease Societies Croatia organised an Alzheimer café at the Hotel Dubrovnik in Zagreb on 9 April.

The President of the Croatian organisation, Dr Ninoslav Mimica invited Stefanija Lukic Zlobek from Slovenia’s national dementia association, Spominčica to present their successful run of more than 40 Alzheimer cafés throughout Slovenia in the past year.

9 April: France Alzheimer campaign collects 50,000 signatures

Earlier this year, France Alzheimer launched a national campaign for the French government to pass a law making better provisions for the needs of people who have lost their autonomy.

About 100 people attended a FA gathering in Paris on 9 April in support of this campaign. The timing was symbolic since the law was to be presented to the council of ministers simultaneously. Sadly, the latter was postponed to a later date but FA was able to use the occasion to gather more signatures.

Having now surpassed the target of 50,000, the organisation has sent the signatures, along with a chest of “souvenirs” (photos of Alzheimer’s patients and their carers) to the President, the idea being to remind Mr Hollande of the campaign promises he made.

For more information about the petition and to sign it: www.lemanifeste.francealzheimer.org/

14-15 April: Romanian Alzheimer Society attends ELMI project kick-off meeting

On 14 and 15 April the Romanian Alzheimer Society attended a kick-off meeting for a project called ELMI (Enhancing Labour Market Integration of Elderly Family Carers through Skills Improving) in Capri, Italy.

One of the project’s main aims is to implement an e-learning course for informal carers, “cercigriverfamiliarei” in Romania. Developed in Italy, the course is designed to provide informal carers with skills that can support them in their regular activities as carers. ELMI also aims to develop a strategy to support the transition from informal to formal care so that carers can re-enter the labour market after their initial professional activity has ended. It also aims to draft an ECVET (European Credit System for Vocational Education and Training) Memorandum of Understanding (MoU). Finally, the project will seek to analyse the possible rollout of the training tool and of the overall strategy to Poland and the Czech Republic.

Policy Watch

20 March: University of Luxembourg hosts ALGG dementia forum

A forum about care prospects for people with dementia, organised by ALGG (the Luxembourg Association of Gerontology / Geriatrics) took place at the University of Luxembourg on 20 March.

At the forum, the Luxembourg Minister for Family and Integration, Corinne Cahen, stressed the importance of people with dementia and their families having the best possible quality of life.

Mrs Cahen spoke of the concerted effort made in recent years in Luxembourg and detailed the Dementia Action Plan, adopted in 2013 and whose objectives are to improve caregiver support and to champion the autonomy and rights of patients.

1 April: UN Council holds Social Forum on Human Rights of Older Persons

With the ageing of the world’s population in mind, the United Nations Human Rights Council held a Social Forum on the rights of older persons, from 1 to 3 April at the Palais des Nations in Geneva, Switzerland. The aim of the session was the implementation of Human Rights Council resolution 24/25, the mandate of which is to consider the existing framework, identify possible gaps, consider how
best to address them and ultimately to promote and protect the rights and dignity of older persons.

During the opening of the forum the Chairperson-Rapporteur, Dr Monica Roqué spoke of the “systematic violation of human rights of older people around the world” in developed and developing countries and Navi Pillay, UN High Commissioner for Human Rights spoke of a “fragmented, uneven and incomplete landscape” due to the lack of an overarching international framework to protect the rights of older persons.

Among the many, distinguished speakers was Matthias Kloth, Administrator, Directorate General of Human Rights and Rule of Law for the Council of Europe. Mr Kloth presented the Council’s new recommendation on the promotion of human rights of older persons, unanimously adopted by the Committee of Ministers on 14 February 2014. He described it as “a new soft law standard for the protection of older persons in all 47 member states of the Council of Europe”. It consists of a set of 54 principles to “promote, protect and ensure the full enjoyment of all human rights by all older persons, and to promote respect for their inherent dignity.”

The recommendation foresees a voluntary follow-up process 5 years after its adoption.

The Council of Europe’s recommendation and other related documents for the Forum can be found here:


4 April: US bipartisan bill encourages global action on Alzheimer’s Research

A bipartisan bill was unveiled in the US House of Representatives on 4 April, calling on the US Secretary of Health and Human Services to enter into negotiations with the World Health Organization with the aim of developing a Global Alzheimer’s disease and dementia action plan.

The bill’s co-authors, US Congressmen Chris Smith (Republican) and Chaka Fattah (Democrat), both of whom are actively involved in various areas related to dementia research and policy, also call on their government to encourage and facilitate partnerships with the private sector, such as the current partnership between the National Institutes of Health and 10 pharmaceutical companies to identify new approaches to treat Alzheimer’s disease.

Congressman Fattah said “The US is in a position to incite action and we must not only lead, but engage our partners around the world. This legislation and the creation of a Global Alzheimer’s Fund would be the most significant step to date in our response to Alzheimer’s and its growing toll on our ageing population and fiscal health.”

24 April: UK care bill to protect those receiving state-funded homecare

Following six months of campaigning by pressure groups supporting the interests of elderly people, UK MPs agreed to amend the care bill to reflect that people receiving state-funded care in their own homes should be given additional protection by the Human Rights Act. The amendment was announced on 24 April and represents a U-turn from a previous decision to specifically exclude home-care recipients from this section of the bill.

The care bill will go onto the statute book in the UK in 2015 and will consolidate more than a dozen different laws into a single modern framework for care and support.

The amendment will now be tabled in the House of Lords. It will not apply to self-funded, privately provided care.

Science Watch

6 March: Poor fitness and IQ at 18 may increase risk of early-onset dementia

Research conducted at Gothenburg University, Sweden tracked the health of 1.1 million 18-year-old men who were conscripted into the Swedish army between 1968 and 2005. The study, published on 6 March in the journal Brain, found that men with poorer cardiovascular fitness and/or lower IQ aged 18 more often developed early-onset dementia.

More specifically, men with lowest levels of cardiovascular fitness at the time of conscription were 2.5 times more likely to develop dementia before the age of 60 than those with the highest fitness levels. Those who performed poorly on cognitive tests as teenagers were at four times greater risk, and a combination of both poor cardiovascular fitness and cognitive performance lead to a seven times greater risk.

Dr Doug Brown, Director of Research and Development for Alzheimer’s Society commented:

“These research findings suggest that having lower cardio fitness earlier in life may substantially increase your risk of developing early-onset dementia. Much of the research on early-onset dementia to date has been on genetic factors, but this study suggests lifestyle factors should be a focus of future research.”

www.ncbi.nlm.nih.gov/pubmed/24604561

10 March: Alzheimer’s disease could be linked to fungal infections

Scientists from Barcelona’s Severo Ochoa Centre for Molecular Biology and from the Carlos III University of Madrid have published a study in the Journal of Alzheimer’s Disease on 10 March, analysing a possible link between fungal infections and AD.

The researchers carried out tests on brain samples from deceased patients with AD and found “compelling evidence” to suggest that these patients had a species of fungus in their blood that may have impacted on their central nervous systems.
Further polymerase chain reaction (PCR) analyses revealed a variety of fungal species in the tested samples. The various different species of fungus were present depending on how advanced the disease was, according to the researchers.

They concluded that future studies could help determine the role of fungal infections in the development of Alzheimer’s disease.

www.i-alz.com/vol41-1

31 March: New study into effects of caffeine on Alzheimer’s disease

A research team led by Prof. Christa E. Müller from the University of Bonn, Germany and Dr David Blum from the University of Lille, France has completed a study into the effects of caffeine on tau deposits in Alzheimer’s disease. The project spanned two years and results were published in the online edition of the “Neurobiology of Aging” journal on 31 March.

In a prior study, the team of researchers had found that a specific receptor for the neurotransmitter adenosine might play an important role in the loss of memory. Since caffeine blocks adenosine receptors in the brain, they suspected that this might underlie the chemical's apparent effects against Alzheimer’s disease.

The research team elected to develop an adenosine receptor subtype A2A antagonist in ultrapure and water-soluble form (designated MSX-3) similar to caffeine rather than caffeine itself, as they found it worked in a more targeted manner and had fewer side effects.

Over the course of several weeks, the team of researchers tested MSX-3 on mouse models bred with an altered tau protein. As compared with a control group, the treated mouse models achieved significantly better results on memory tests, in particular where spatial memory was concerned. Improvement of the pathogenic processes in the hippocampus was also observed.

The researchers now want to test the A2A antagonist in additional animal models. If the results are positive, a clinical study may follow.

www.neurobiologyofaging.org/article/10.1016/j.neurobiolaging.2014.02.008- abstract

31 March: Prana drug fails Alzheimer’s disease study

On 31 March Prana Biotechnology announced the failure of its experimental drug, PBT2 in a mid-stage study to treat Alzheimer’s disease.

The trial enrolled 42 patients who either received the drug or placebo over a period of 52 weeks. Prana said that the drug was safe and well-tolerated and 40 patients completed the treatment period, but that there was no statistically significant reduction in the levels of beta-amyloid plaques in the brain of patients with a mild form of the condition when compared with placebo results. Prana also said the drug did not improve brain metabolic activity, cognition nor function in the study.

3 April: Mechanics of sewing machines give insight into AD

On 3 April, Alzheimer’s Society wrote an online report of a study completed by researchers at Lancaster University, which may provide some insight into the origins of Alzheimer’s disease. The study was published in the Scientific Reports section of the "Nature" Journal.

Existing techniques are not sufficient to get a proper look at the oligomers thought to trigger these diseases; optical microscopy does not provide enough resolution at this scale and electron microscopy gives the resolution but not the contrast. To overcome this problem, Physicist Dr Oleg Kolosov and his team developed an imaging technique called Ultrasonic Force Microscopy (UFM). This technique was inspired by the motion of a sewing machine.

Dr Kolosov said: “By using a vibrating scanner, which moves quickly up and down like the foot of a sewing machine needle, the friction between the sample and the scanner was reduced - resulting in a better quality, and high contrast nanometre scale resolution image.”

To enable clearer images they needed to increase the contrast and used poly-L-lysine (PLL) which kept the proteins stuck to the slides as the vibrating scanner was passed over them.

The team intends to use their technique to test the effects of inhibitors of oligomer formation, working towards what they hope will be a possible new treatment for Alzheimer’s disease.

www.nature.com/journal/v41/440206c/full/jep4004.html

3 April: Cardiff University launches global Alzheimer’s disease study

A team of scientists at Cardiff University in Wales has embarked on a GBP 6M (EUR 7.3M approx) project on 3 April with the aim of exploring the combined influence of genetics and lifestyle in the development of Alzheimer’s disease across a global sample group of one million people. The team hopes to gain a comprehensive understanding of the disease’s various risks to people and to give a fuller picture of what triggers the condition.

Project leader, Professor Julie Williams, Head of Neurodegeneration at the University’s Medical Research Council Centre on Neuropsychiatric Genetics and Genomics says that their ultimate goal is to help create more personalised treatments for the disease and treatments that offset it altogether.

Professor Williams believes that the insights gleaned by her researchers will mean that it is possible to distinguish those at a high risk from those at lower risk of developing the disease and could, in the long term, provide an opportunity for early intervention.
9 April: Cerebain Biotech announces progress on medical device for AD


The aim of the device is to “provide continuous omentum stimulation, enabling substantial advancements in the treatment efficiency and the quality of life of Alzheimer’s patients”.

Omentum is a naturally occurring tissue in the abdominal space and has been shown in previous clinical studies to possess regenerative qualities in several areas of the human body, including the brain.

The results of research conducted by Cerebain’s prototype manufacturer and project partner, Sonos Models, Inc. suggests that they have three options for implantable devices.

Cerebain’s President, Eric Clemons, stated that it was now the objective of the company to test various methods and modalities, “with the aim of developing an enormous matrix of input to direct us to the best solution. Our goal is to be less invasive, as small as possible and as simple as possible to reach the broadest patient base.”

14 April: High levels of copper combined with MCI may lead to AD

In a new study published on 14 April in Annals of Neurology, researchers at Fatebenefratelli Hospital in Rome claim that people with mild cognitive impairment (MCI) and high levels of copper in their bloodstream are at an increased risk of developing Alzheimer’s disease.

The team of researchers tested 141 people, all of whom had MCI, for levels of copper. They found that those with high levels had a 50% chance of developing Alzheimer’s disease within four years, while those with low levels of this type of copper were less than 20% likely to progress to Alzheimer’s disease.

Based on these findings, a blood test was developed to test copper levels in people with MCI with the aim of predicting who is at greater risk of developing Alzheimer’s disease. This test is currently only available in Italy.

Alzheimer’s Society is currently funding research to help unravel the complex relationship between copper and dementia by studying brain scans. Their Head of Research, Dr James Pickett, said of the study:

“This small study alone is not strong enough to suggest that a blood test for copper could reliably predict those who will go on to develop Alzheimer’s disease...For people living with mild cognitive impairment, there is not enough evidence that cutting out copper – which is a vital mineral for the body - will stave off Alzheimer’s disease”.


20 April: New class of compounds may help in treatment of AD

A study, published online in the journal Nature Chemical Biology on 20 April, claims to have found a way of stabilising the retromer protein complex which previous studies had shown to play a role in reducing the risk of Alzheimer’s disease and late-onset Parkinson’s disease.

Led by Dr Scott Small, director of the Alzheimer’s Disease Center at Columbia University Medical Center in New York, the team completed their study using computer-based virtual screening to identify new “pharmacological chaperones” that were able to bind to retromer’s weak points and stabilise the entire protein complex.

By screening known chemical compounds the researchers identified 100 potential candidates of which they noted that 24 showed promise. One in particular, R55 significantly increased retromer’s stability, including during heat stress testing.

After further investigation of R55 using cultured neurons of both healthy mice and those of an Alzheimer’s mouse model the researchers found it greatly increased retromer levels and decreased amyloid-beta levels. They also found R55 to be “relatively non-toxic.”

The team is now conducting preclinical research on the compound and its analogs, to see if they are stable in serum, can cross the blood-brain barrier, and whether they are safe in animal models.

www.nature.com/nchembio/journal/vaop/ncurrent/full/nchembio.1508.html

23 April: Study claims to reverse loss of memory in AD mouse models

Researchers from the Institute of Neuroscience at the Universitat Autònoma de Barcelona claim to have reversed memory loss in Alzheimer’s disease mouse models, using gene therapy. Their research appears on the cover of the 23 April edition of The Journal of Neuroscience.

The team of researchers discovered the cellular mechanism involved in memory consolidation and were able to inject the hippocampus with a gene which causes the production of a protein blocked in patients with Alzheimer’s, Crtp1 (CREB regulated transcription coactivator-1). Once restored, the protein allows free passage to signals needed to activate the genes involved in long-term memory functioning.
Dementia in Society

1 March: “Head Games” movie premieres in London

An American documentary examining the rise in injuries in rugby union and other sports that can cause brain damage in later life premiered in London on 1 March. “Head Games: The Global Concussion Crisis” focuses on what it calls a “silent, global epidemic” of head injuries triggered by contact sports. The documentary warns that these injuries are becoming increasingly robust and are leaving more and more former players suffering from dementia and the effects of brain damage in their middle years.

25 March: UK survey analyses impact of dementia care on business

At the Carers UK business forum, “Employers for Carers” on 25 March, the results of a recent survey into the challenges faced by UK workers trying to juggle their professional activities with caring were presented.

One in five of the survey respondents said they had to cut working hours and one in ten had to accept a less senior role than they were qualified for in order to exercise their caring activity.

From a business perspective, 90 per cent of businesses who participated in the survey believed that dementia was an increasingly big issue for their organisations.

George McNamara, Head of Policy & Public Affairs at Alzheimer’s Society comments that “dementia is a national challenge and businesses are not immune. Employers must respond in order to retain staff and stay competitive.” He concluded that “only those employers who fully understand and recognise the need to provide support and the benefits will succeed in the future.”

The full survey report can be found here:

www.carersuk.org/component/cck/?task=download&file=policy_file&id=447

5 April: Music festival in Luxembourg raises funds for National Alzheimer Association

On 5 April in Esch-sur-Alzette, Luxembourg, a fundraising music festival took place at the “Kulturfabrik”. Luxembourgish rap and rock artists shared the stage, performing for a 400-strong audience, whose ticket fees will be donated to the Association Luxembourg Alzheimer (ALA).

The “MooFest” played host to half a dozen local artists, invited by local heavy metal headliners, MooF.

9 April: Kristen Stewart receives charitable birthday gift from fans

A number of Kristen Stewart’s fans gave the Hollywood actress a surprise for her 24th birthday on 9 April. They donated over USD 20,000 (EUR 15,000 approx.) for a cause close to the actress’ heart: Alzheimer’s disease research.

In the upcoming movie “Still Alice” (to be released in 2015) Ms Stewart plays teenager Lydia Howland whose mother, Dr Alice Howland, played by actress Julianne Moore, learns that she has early onset Alzheimer’s disease.

Newsletter: April 2014

“Grace and Mary”, published on 13 March, tells the story of Mary and her son, John. The latter tries to hold on to the remaining slivers of his mother’s identity as her dementia progresses. All the while, he navigates the choppy waters of family politics as he uncovers some difficult truths about Mary and her mother, Grace.

The story is, as Mr Bragg said himself in a recent newspaper interview, written largely about his own struggle with his own mother, Mary’s death from dementia in 2013.

www.jneurosci.org/content/34/17/5776.short?sid=c3086afe-f4f39b411a1e

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When the Crtc1 protein is altered, the genes responsible for the synopsis or connections between neurons in the hippocampus cannot be activated and the individual cannot perform memory tasks correctly”, explained Carlos Saura, head of the research team.

The study authors suggest that a cure for AD lies in developing pharmacological therapies, which can activate the Crtc1 protein thus preventing, slowing down or reverting cognitive changes.

www.headgamesinthefilm.com/
17 April: Nobel laureate Gabriel Garcia Marquez dies with dementia

Columbian author and Nobel laureate, Gabriel Garcia Marquez, has died on 17 April, aged 87, in Mexico City of dementia-related complications.

Marquez wrote the 1967 magical-realism landmark novel, “One Hundred Years of Solitude”, which has been translated into three dozen languages and sold more than 30 million copies worldwide.

Garcia Marquez had all but disappeared from public view in his final year as he suffered from dementia and cancer treatments, according to his brother Jaime Garcia Marquez.

18 April: Sporting Memories and Bristol Rugby tackle dementia together

Bristol Rugby’s final home league fixture of the 2013-2014 season celebrated the history and heritage of the club and also aimed to raise awareness of dementia. Bristol Rugby Community Foundation held activities at the Memorial Ground for the game against London Welsh on 18 April, which Bristol won 25 points to 21.

Fans were interviewed by “Memory Makers” around the ground, sharing their favourite memories of watching Bristol Rugby over the years. These memories are to be used to help tackle social isolation for people with dementia in the local area, with help from the Sporting Memories Network project.

There was a special match day programme distributed to the crowd, recounting memories from former players and fans too, and information was made available about the national Dementia Friends initiative by Alzheimer’s Society.

22 April: Vacancy for Head of ADS at University of Worcester

The University of Worcester has announced a vacancy for “Head of the Association for Dementia Studies”.

Since it came into being five years ago, the Association for Dementia Studies has focused on the active inclusion of people living with dementia and their families in all programmes of research, education and in the strategic direction of its work; a strong person-centred ethical framework; active partnerships with local, regional and national organisations; working as part of a global network of person-centred dementia care practice. All staff are experts in dementia care.

The successful candidate will be joining a team of thirty educators and researchers all committed to working in this way.

A value base that aligns with ADS is more critical in this post than in-depth dementia care knowledge and expertise. Proven operational management skills are more important than sector specific knowledge.

All the formal details are on the link below and the closing date is 23 May.

www.worcester.ac.uk/community/job-vacancy-head-of-ads.html

New Publications & Resources

1 April: Alzheimer Nederland launches the “Alzheimer Assistent”

Alzheimer Nederland has developed an app for people who care for someone with dementia: the Alzheimer Assistent. In The Netherlands there are more than 300,000 people who care for a family member or friend with dementia. Ninety percent of them are overburdened or run health risks as a result. This group of people, therefore asked Alzheimer Nederland to develop a digital application for and by family caregivers and experts.

Living with someone with dementia brings new challenges every day, such as behavioral changes. At such a moment there is an immediate need for support and advice from fellow carers and experts. The Alzheimer Assistent provides information on more than sixty topics in text and video. Since users can share their own tips and suggest further topics also, the information supply will continue to grow.

Further information as well as the download can be found at:

www.alzheimerassistent.nl

22 April: European Commission publishes health investments guide

On 22 April, the European Commission issued a guide for health investments under the ESIF (European Structural and Investment Funds) 2014-2020.

The guide can be found here:

www.ec.europa.eu/regional_policy/information/guidelines/index_en.cfm
Contact Alzheimer Europe:
Alzheimer Europe, 14 rue Dicks, L-1417, Luxembourg
info@alzheimer-europe.org; www.alzheimer-europe.org

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

Alzheimer Europe Staff
Executive Director: Jean Georges; Project Officer: Ana Diaz; EU Public Affairs Advisor: Annette Dumas; Communications Officer: Kate Ellis; Director for Projects: Dianne Gove; Conference and Event Coordinator: Gwladys Guilloty; Finance Officer: Stefanie Peulen; Director for Communication: Alex Teligadas; Administrative Assistant: Grazia Tomavini.

AE Calendar 2014

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tbody>
<tr>
<td>9 May</td>
<td>Meeting with Lily (Brussels, Belgium)</td>
<td>Jean</td>
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<tr>
<td>29-31 May</td>
<td>EU-VD NO General Assembly (Ulle, France)</td>
<td>Alex</td>
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<tr>
<td>12-13 May</td>
<td>EPF’s annual meetings (Brussels, Belgium)</td>
<td>Annette, Jean</td>
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<tr>
<td>12-14 May</td>
<td>Action Group Synergies (in the subgroup “patient empowerment (Athens, Greece)</td>
<td>Dianne</td>
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<tr>
<td>19 May</td>
<td>WHO Launch of Global Alzheimer’s and Dementia Action Alliance (Geneva, Switzerland)</td>
<td>Jean</td>
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<tr>
<td>20-21 May</td>
<td>AFE-innovet/age Platform (Brussels, Belgium)</td>
<td>Dianne</td>
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<tr>
<td>22-23 May</td>
<td>EWGPWD meeting (Luxembourg, Luxembourg)</td>
<td>EWGPWD and AE Staff</td>
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<tr>
<td>23 May</td>
<td>“Caregiving at a Crossroads: Bridging the Gap between Science and Practice” (Dublin, Ireland)</td>
<td>Ana</td>
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<tr>
<td>5-6 June</td>
<td>Lilly Advisory Board (Stockholm, Sweden)</td>
<td>Jean</td>
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<tr>
<td>5-6 June</td>
<td>IMPACT project meeting (Ibiza, Spain)</td>
<td>Dianne</td>
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<tr>
<td>18 June</td>
<td>“Frailty in old age, identifying priorities for an EU policy” conference (Brussels, Belgium)</td>
<td>Dianne</td>
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<tr>
<td>24-25 June</td>
<td>ADI University (Geneva, Switzerland)</td>
<td>Jean</td>
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<tr>
<td>25 June</td>
<td>JPNO workshop on palliative and end-of-life care research</td>
<td>Dianne</td>
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</tbody>
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Future Conferences

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>8-11 May</td>
<td>8th World Congress on Controversies in Neurology (COnNy), <a href="http://www.comteumed.com/conyg/2014/">www.comteumed.com/conyg/2014/</a></td>
<td>Berlin, Germany</td>
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<tr>
<td>16-17 May</td>
<td>The Alzheimer’s Show, <a href="http://alzheimershow.co.uk/">http://alzheimershow.co.uk/</a></td>
<td>London, UK</td>
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<tr>
<td>31 May-3 June</td>
<td>EFNS-ENS Joint Congress of European Neurology 2014, <a href="http://www.jointcongressofeuropeannurology.org">www.jointcongressofeuropeannurology.org</a></td>
<td>Istanbul, Turkey</td>
</tr>
<tr>
<td>6 June</td>
<td>Dementia Awareness Conference, <a href="http://daw.dementiascotland.org/Registration">http://daw.dementiascotland.org/Registration</a></td>
<td>Glasgow, UK</td>
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<tr>
<td>14 June</td>
<td>12ème Réunion francophone sur la maladie d’Alzheimer et les syndromes apparentés</td>
<td>Montpellier, France</td>
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<tr>
<td>26-27 June</td>
<td>International Dementia Conference, “Risky Business 2 - this time it’s personal”, <a href="http://www.dementiaconference.com/call-for-papers">www.dementiaconference.com/call-for-papers</a></td>
<td>Sydney, Australia</td>
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<tr>
<td>5-9 July</td>
<td>9th FENS 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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<tr>
<td>12-17 July</td>
<td>AAC Conference 2014, <a href="http://www.aac.org/aac">www.aac.org/aac</a></td>
<td>Copenhagen, Denmark</td>
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<tr>
<td>25-26 September</td>
<td>Innovation in Aging Services-Pathways to the Future, <a href="http://unproject.nl/aahsa/home">http://unproject.nl/aahsa/home</a></td>
<td>Amsterdam, Netherlands</td>
</tr>
<tr>
<td>20-22 October</td>
<td>24th Alzheimer Europe Congress “Dignity and autonomy in dementia”, <a href="http://www.alzheimer-europe.org/conferences">www.alzheimer-europe.org/conferences</a></td>
<td>Glasgow, United Kingdom</td>
</tr>
<tr>
<td>20-23 June 2015</td>
<td>1st Congress of the European Academy of Neurology (EAN), <a href="http://www.eanurology.org/berlin2015">www.eanurology.org/berlin2015</a></td>
<td>Berlin, Germany</td>
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</tbody>
</table>
24th Alzheimer Europe Conference
Dignity and autonomy in dementia
Glasgow, Scotland, UK
20-22 October 2014
Mark the dates!

www.alzheimer-europe.org/conferences