Welcome!

We have had a very busy and exciting start to 2015, Alzheimer Europe’s 25th year in existence.

First of all, I am delighted to announce that Hilary Doxford, Vice-Chair of our European Working Group of People with Dementia (EWGPWD) has been appointed to the World Dementia Council and is the first council member living with dementia. The news has been received with great enthusiasm from other members of the working group as well as by our Board and member associations.

As to the work of the Council itself, it released a statement this month on dementia risk reduction and has made this one of its five priority areas of work in 2015. At the end of the month I met with World Dementia Council member, Raj Long - who leads its work on the development of an integrated regulatory pathway for dementia - to discuss AE’s involvement in the Global Action on dementia.

From the global stage to the European one, we are delighted to have secured our first two MEP signatures for the Glasgow Declaration this month and are grateful to Keith Taylor and Sirpa Pietikainen for their support in calling for the creation of a European Dementia Strategy and national strategies in every country in Europe, as well as calling on world leaders to recognise dementia as a public health priority and to develop a global action plan.

We are also delighted to welcome MEP Brando Benifei into our European Alzheimer’s Alliance and hope to welcome many more MEPs to the EAA this year and to work together to make dementia a European priority.

In terms of EU Projects, January has also been a very exciting month, with 35 project partners meeting in Paris, mid-month, to launch EPAD - the European Prevention of Alzheimer’s dementia Initiative. The five year project will establish a European-wide register of 24,000 participants, of which 1,500 will be invited to participate in a trial to test new treatments for prevention of Alzheimer’s dementia. EPAD has attracted a lot of media attention throughout Europe and we are very pleased to be involved in this interesting project. Also this month, EU researchers met in Stockholm for the launch of another project in which AE is involved, MIND-AD. This is a new JPND-funded project, aiming to identify effective prevention strategies for dementia.

As to our annual dementia conference, we are already working full steam ahead on our 25th annual conference, this year taking place in Ljubljana, Slovenia at the start of September. This year’s theme is “Dementia: putting strategies and research into practice” and registrations are now open via our website, as is the call for abstracts. For anyone interested in finding out more about our annual conferences, the official photos and videos of our Glasgow conference are now available on our website.

I look forward to seeing and working with many of you and hope that your year has started as well as ours!

Jean Georges
Executive Director
Alzheimer Europe

8 January: Government experts explore possibility of new European Joint Action on Dementia

Government experts met with European Commission representatives in Luxembourg on 8 January 2015 to assess the possibility of collaborating on a new European Joint Action on Dementia and building on the success of the previous ALCOVE Joint Action.

The new Joint Action would be led by the Scottish Government and four key areas were identified for collaboration (timely diagnosis and post-diagnostic support, dealing with behavioural and psychological symptoms of dementia at home, quality care in residential care, dementia-friendly communities).

The participants at the meeting expressed their interest in fully involving Alzheimer Europe in the development of the Joint Action to ensure that the views of people with dementia and their carers are adequately represented.

Jean Georges, Alzheimer Europe (AE)’s Executive Director, represented the organisation at the meeting.

13 January: Photos and videos from 24th AE conference are online

Alzheimer Europe (AE) held its 24th Annual Conference in Glasgow from 20 to 22 October 2014 under the motto “Dignity and autonomy in dementia”, co-organised with Alzheimer Scotland.

Photos and videos from the conference are now available on our website: http://alzheimer-europe.org/Conferences/Previous-conferences/2014-Glasgow/Conference-Photos-and-Videos

14-15 January: INTERDEM group works on outcome measures for psychosocial interventions

A team of researchers from the INTERDEM group met in London on 14 and 15 January to work on updating the important 2008 paper entitled “A European consensus on outcome measures for psychosocial intervention research in dementia care” and to consider new themes and concepts for psychosocial intervention outcome measures. This work is funded by JPND.

Alzheimer Europe will organise a consultation with carers and people with dementia in order to obtain feedback on the new themes and concepts proposed.

AE’s Director for Projects, Dianne Gove represented the organisation at the meetings.

15 January: GlaxoSmithKline organises its Health Advisory Board meeting

On 15 January, in Brentford (UK), British multinational pharmaceutical company, GlaxoSmithKline (GSK) organised its Health Advisory Board meeting.

The discussions were articulated around GSK’s goal to have a patient-centred approach in its operations.

The patient groups present at the meeting were: Alzheimer Europe, the Czech Coalition for Health, EGAN, Europa Donna, European Federation of Airway Diseases and Allergies, the European Patients Forum, the International Brain Tumors Alliance and Lupus Europe.

AE’s EU Public Affairs Advisor, Annette Dumas participated in the meeting on behalf of the organisation.

22 January: Registration is now open for our 25th annual conference

Alzheimer Europe (AE) and Alzheimer Slovenia (Spominčica) invite you to register for the 25th AE annual conference, this year to be held in Ljubljana, Slovenia from 2 to 4 September.

You can take advantage of the early bird registration fee (EUR 225 instead of EUR 350) via our website, until 31 May.

The full conference registration fee includes:

- Admission to all scientific sessions
- Delegate bag and final programme including the abstract book
- Opening ceremony and welcome reception
- Scheduled coffee breaks on 3 and 4 September
- Scheduled lunches on 3 and 4 September

AE and Spominčica provide reduced rates for students and for delegates from low and middle income countries (World Bank Categories). One day registrations are also available.

22 January: AE opens call for 2015 conference abstracts

Alzheimer Europe (AE) and Alzheimer Slovenia (Spominčica) are pleased to announce that the call for abstracts for the 25th AE Conference in Ljubljana, Slovenia from 2 to 4 September is now open.

Abstracts for oral and poster presentations are welcome in the following categories:

- **Dementia-friendly society** - Involving people with dementia, Perceptions and image of dementia, Art and dementia, Living in the community
- **Policies and Strategies** - Dementia strategies, Legal issues, Care pathways, Minority groups
- **Innovative care** – Psychosocial interventions, Post-Diagnostic support, Person-centred care, End-of-life aspect
- **Medical aspects** – Timely diagnosis, Risk factors and prevention of dementia, Behavioural and
psychological symptoms of dementia, Treatment of dementia.
The call for abstracts will close on 31 March 2015. Additional information is available on our website:
www.alzheimer-europe.org-Conferences/2015-Ljubljana/Call-for-abstracts

28 January: AE meets with World Dementia Council representative for exchange of views
On 28 January 2015, Raj Long, World Dementia Council member and UK Government Integrated Development Director paid a visit to Alzheimer Europe for an exchange of views.

Raj Long leads the World Dementia Council’s work on the development of an integrated regulatory pathway for dementia, which focusses on three areas:

- Bringing together an international team of key research and regulatory experts in dementia, to gain insights on critical learnings related to the development science of dementia drugs.
- Highlighting opportunities for innovative thinking and approach.
- Ensuring there is a transparent and effective approach to public policy-making governance.

28 January: Breakfast meeting at the EP on the topic of the care pathway for incontinence care
Age Platform Europe and Eurocarers held a breakfast meeting at the European Parliament (EP) on the future of health and social care: towards a new care pathway for Europe’s ageing societies, looking at the example of incontinence. Prof. Adrian Wagg provided an overview of the optimum continence service specification (the ideal organisation of care for people with incontinence), outlining the ten components of a high quality integrated continence service. He drew attention to a recent health economic analysis based on a population in the Netherlands, where it was found that this model would save money for payers, patients and carers even in a worst case scenario.

Archie Noone from the Scottish Dementia Working Group spoke of his experience of having dementia and incontinence. He stated that people should talk about incontinence in order to break down barriers. He felt that there was especially a need for men to be more open about incontinence. Archie drew attention to the possible negative impact of incontinence on relationships and how it can affect the perceptions that people have of themselves.

There was some discussion around the difficulty attracting sufficient attention to and funding for continence care. Anne-Sophie Parent from Age Platform Europe agreed that this was problematic and suggested the need to build on the innovative aspect of care, to show the socio-economic benefits and to focus on prevention.

Dianne Gove participated on behalf of AE.

29 January: Hilary Doxford becomes 1st World Dementia Council member living with dementia
On 29 January, we were delighted to hear that Hilary Doxford, Vice-Chair of the European Working Group of People with Dementia (EWGPWD) was appointed to the World Dementia Council. Ms Doxford, who was diagnosed with early onset Alzheimer’s disease in 2012, is the first council member living with dementia.

You can read more about Hilary Doxford here:

The announcement of her appointment on the UK Department of Health’s website is here:
http://dementiachallenge.dh.gov.uk/2015/01/29/world-dementia-council-hilary-doford/

EU Projects

14 January: EPAD partners launch a new AD prevention project

The five year EPAD project will establish a European-wide register of 24,000 participants, of which 1,500 will be invited to participate in a trial to test new treatments for prevention of Alzheimer’s dementia.

The project partners will initially develop a platform based on information from existing patient cohorts or register studies, which have already identified potential patients. Researchers will use these records to select a group of 1,500 people who are likely to develop dementia, but have not yet been diagnosed. This group will participate in a Phase 2 clinical trial in various European countries. At the end of the study, all data collected from the cohort and trial will become publicly available for analysis to improve disease models in the pre-dementia phase of Alzheimer’s disease.

There are 35 partners in the EPAD project, which is co-ordinated by Craig Ritchie, Professor of the Psychiatry of Ageing at the University of Edinburgh and Serge Van der Geyten, Director for Neuroscience External Affairs at Janssen Pharmaceutica.

During the meeting, the delegates learned more about how they will work together and identified priorities for the first year of deliverables. They also discussed how EPAD will...
Alzheimer Europe Networking

On 7 January (Luxembourg, Luxembourg) representatives of Association Luxembourg Alzheimer visited Alzheimer Europe for an exchange on good practices in the field of hospital care for people with dementia.

On 8 January (Luxembourg, Luxembourg) Jean attended a planning meeting of national government and European Commission representatives for the development of a new Joint Action on dementia.

On 14-15 January (Paris, France) Jean and Alex attended the launch meeting of the EPAD project.

On 15 January (London, UK) Dianne attended a meeting organised by Esme Moniz-Cook and funded by JPND to develop new themes and concepts for outcome measures in dementia care.

On 15 January (Brentford, UK) GlaxoSmithKline organised its Health Advisory Board meeting.

On 19 January (Brussels, Belgium) Annette met Amelia Ni Laoi (MEP Deirdre Clune’s assistant) and Ekaterina Karamfilova (MEP Andrey Kovatchev’s assistant).

On 19 January (Luxembourg, Luxembourg) Jürgen Scheftlein and Isabel Peny Rey Lorenzo visited Alzheimer Europe for an exchange on national dementia strategies and the new European Joint Action on Dementia.

On 21 January (Luxembourg, Luxembourg) Kristina Niedderer from the University of Wolverhampton visited Alzheimer Europe to discuss a joint project application under the Marie Curie programme.
On 23 January (Stockholm, Sweden) Jean participated in the launch event of the JPND funded MIND-AD project.

On 28 January (Brussels, Belgium), Dianne attended a breakfast meeting at the European Parliament entitled “the future of health and social care: towards a new care pathway for Europe’s ageing societies – the example of incontinence”, organised by Age Platform Europe and Eurocarers.


On 29 January (Luxembourg, Luxembourg) Charlotte Nortvedt from Sandoz visited Alzheimer Europe to discuss joint projects.

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 87, representing 26 Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer’s Alliance:

**Austria**: Heinz K. Becker (EPP); Belgium: Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brentem (EPP); Bulgaria: Andrey Kovatchev (EPP); Croatia: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomalić (ECR); Czech Republic: Eleni Theocharous (EPP); Croatia: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP); Denmark: Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D), Finland: Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Miapetra Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EFP); France: Nathalie Griesbeck (ALDE); François Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D); Germany: Angelika Niebler (EPP); Greece: Kostas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Hungary: Ádám Kősa (EPP); Ireland: Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Séan Kelly (EPP); Mairead McGuinness (EPP); Liahd Ni Riada (GUE/NGL); Italy: Brando Benifei (S&D); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Patrizia Tola (S&D); Lithuania: Vilija Blinkėvičiūtė (S&D); Luxembourg: Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP); Malta: Therese Comodini Cachia (EPP); Roberta Metsola (EPP); Netherlands: Esther de Lange (EPP); Lambert van Nistelrooij (EPP); Poland: Elżbieta Lukacijewska (EPP); Portugal: Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Romania: Daciana Octavia Sarbu (S&D); Claudiu Ciprian Tanaseanu (S&D); Renate Weber (EPP); Slovakia: Miroslav Mikolásik (EPP); Anna Záborská (EPP); Slovenia: Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricia Šulin (EPP); Romana Tomc (EPP);ivo Vaigl (ALDE); Milan Zver (EPP); Spain: Soledad Cabezaón Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estarás Ferragut (EPP); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Pablo Zabal Bidegain (EPP); Sweden: Cecilia Wikström (ALDE); United Kingdom: Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Ian Hudgion (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Glenis Willmott (S&D).

European Alzheimer’s Alliance

8 January: Two MEPs sign our Glasgow Declaration

On 8 January, MEP Keith Taylor (Greens/EFA, UK) became the first MEP to sign the Glasgow Declaration. MEP Sirpa Pietikäinen (EPP, Finland) followed shortly afterwards, signing on 29 January. Both Mr Taylor and Ms Pietikäinen are Vice-Chairs of the European Alzheimer’s Alliance.

Alzheimer Europe launched the Glasgow Declaration on 20 October 2014. It calls for the creation of a European Dementia Strategy and national strategies in every country in Europe. The signatories also call upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

http://alzheimer-europe.org/Policy-in-Practice2/Glasgow-Declaration-2014

19 January: AE meets Amelia Ni Laoi and Ekaterina Karamfilova

On 19 January, AE’s EU Public Affairs Advisor, Annette Dumas met Amelia Ni Laoi (assistant to Irish MEP Deirdre Clune), to discuss the Glasgow Declaration, Alzheimer Europe’s work and MEP Clune’s interest in further raising awareness about dementia, with a specific interest in dementia and tourism.

On the same day, Annette met Ekaterina Karamfilova, the assistant of Bulgarian MEP Andrey Kovatchev, to discuss the Glasgow Declaration, Alzheimer Europe’s work and the MEP Access to Health group that MEP Kovatchev will launch in the European Parliament in January.

29 January: MEP Benifei joins the European Alzheimer’s Alliance

The European Alzheimer’s Alliance is very pleased to welcome Brando Benifei, MEP (Italy) as of 29 January 2015.

Mr Benifei is a member of the Group of the Progressive Alliance of Socialists and Democrats in the European Parliament (S&D). He sits on the Committee on Employment and Social Affairs and is a substitute on the Committee on Foreign Affairs.


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EU Developments

11 December: European Parliament intergroups announced

At its meeting on 11 December 2014, the Conference of Presidents of the European Parliament approved the list of intergroups to be established under the current legislative term of Parliament. The list includes an intergroup on Active ageing, intergenerational solidarity & family policies and another on Disability.

Intergroups consist of Members of the European Parliament (MEPs) from any political group and any committee and aim to hold informal exchanges of views on particular subjects and to promote contact between MEPs and civil society. They are not Parliament bodies and may not express Parliament’s opinion.


1 January: EPF publishes position paper on discrimination in healthcare

The European Patients’ Forum (EPF) has published its Position Paper on discrimination in healthcare, “Healthcare for all”. The paper was adopted following two member consultations and input from two EPF focus groups.

The aim is to promote the development of EU and national policies that tackle discrimination faced by patients. Key points are:

- Right of access and equal treatment in healthcare for all;
- Right to be protected from discrimination on health status;
- Right to respect and to dignity in healthcare facilities;
- Right to information and support;
- Right for vulnerable groups to participate in anti-discrimination policies.

EPF members are encouraged to disseminate the paper within their network.


20 January: European Brain Council reports on EP Interest Group meeting

In its newsletter of 29 January, the European Brain Council (EBC) reported, on a meeting of the European Parliament Interest Group on Mental Health, Well-Being and Brain Disorders on 20 January. Participants discussed, among other things, the potential implications of President Juncker’s Investment Plan on Horizon2020 and brain-related research:

“The European Parliament Interest Group on Mental Health, Well-Being and Brain Disorders, facilitated by the Global Alliance of Mental Illness Advocacy Networks (GAMIAN-Europe) held their first meeting of the year on January 20, in the European Parliament, Brussels. The interest group is co-chaired by MEPs Nessa Childers (S&D – Ireland), Marian Harkin (ALDE – Ireland), Jean Lambert (Greens – UK) and Cristian Silviu Busoi (ALDE – Romania).

The title of the meeting was “Sound Mental Health Policy Development – the Need for Focused Research” and had focus on the ROAMER project and mental health in Horizon2020.

ROAMER (“Roadmap for Mental Health Research in Europe”) is an EU-funded project that EBC is taking part in. EBC Vice-President, Patrice Boyer, was therefore asked to take part in the panel discussion on ROAMER together with David McDaid, from the London School of Economics, and Paul Arteel, Executive Director of GAMIAN-Europe. The interest group had also invited Commission officials, Barbara Kerstiens, Head of Sector Public Health, DG Research & Innovation, and Jürgen Scheftlein, Policy Officer, DG Santé (formerly DG SANCO) to talk about the Commission’s approach and projects in the field of mental health, such as the Joint Action on Mental Health and Well-Being and how the project findings from ROAMER could be included in it. Barbara Kerstiens talked about EU-funded projects such as DEVELAGE and EUROSPIN as well as more generally on Horizon2020. The latter did receive much attention, especially after it was announced that funding streams within Horizon2020 might be reduced in order to contribute to financing President Juncker’s Investment Plan. Among others, Horizon2020’s “Societal Challenges” pillar funds projects including research on understanding health, ageing and disease and active ageing and developing and comparing new models for safe and efficient, prevention oriented health and care system.

However, no answer could be provided as yet on EBC’s question as to what concrete implications Juncker’s Investment Plan would have on Horizon2020 and brain related research. The EBC will though remain watchful as regards the potential developments in this regard and calls on its member organisations to continue advocating for the need for sustained brain research in Europe.”

27 January: Launch of the Interest Group on Patient Access to Healthcare

On 27 January (Brussels, Belgium), Bulgarian MEP Andrey Kovatchev officially launched the Interest Group on Patient Access to Healthcare in the European Parliament. This platform will identify what needs to be done and can be done at European and national level to address the inequalities in access to health across Europe and within the Member States. The platform will provide Member States with the tools to offer equal quality services.

Health Commissioner V Andriukaitis recognised the challenges and barriers patients can face when accessing the health services. Access to healthcare must be part of all policies and must be centred around three Ps: Prevention, Promotion, Protection and Participation in the first three Ps. The Interest Group will help identify the barriers and propose solutions that the Commission will use in its work.

The Commissioner then identified some complementary actions that could support the Interest Group work: the Commission Communication on effective, accessible and resilient health systems, the Directive on cross-border healthcare, the European reference network (a Commission priority for 2015), the European Semester, social inclusion through the OMC, Joint Actions on chronic diseases and the third Health Programme.
Andrey Kovatchev shared the announcement made by the Health Minister of Bulgaria that he supported the work of the Interest Group, and will engage with stakeholders in the implementation of the recommendations of the European Semester. He will also call on other Member States to support this initiative in the Council. He also mentioned the interest of the UK Health Minister who has indicated he would meet representatives of the Interest Group during his next visit in Brussels.

The Interest Group Vice-Chairs are: Biljana Borzan (Slovenia), Cristian Silviu Busoi (Romania), Marian Harkin (Ireland), Karin Kadenbach (Austria), Katerina Konecna (Czech Republic), Andrey Kovatchev (Bulgaria).

Annette participated in the meeting for AE.

Members’ News

13 December: Finnish society holds elections for Council and Board

The Council meeting of the Alzheimer Society of Finland (Muistiliitto) elected Pirkko Lahti (pictured) as the new Chairperson of the Council. Ms Lahti is a psychologist and former Executive Director of the Finnish Association for Mental Health, as well as former President of the World Federation for Mental Health. She has a vast experience of NGOs and a personal connection to dementia, being her husband’s informal carer.

“I want to work towards the equal rights of the people with dementia and their families, as well as influence the decisions concerning them”, Ms Lahti states.

MEP Sirpa Pietikäinen will continue as the Vice-Chairperson of the Council. In 2015, the Board will be run by three strong advocates of Muistiliitto’s work: MP Merja Mäkisalo-Ropponen as Chair; MP Sari Sarkanmaa as 1st Vice-Chair and MP Annika Saarikko as 2nd Vice-Chair. Jouni Rasi, a member of Muistiliitto’s dementia working group, will serve the board as a permanent advisor from 2015 to 2016.

31 December 2014: France Alzheimer public awareness videos released

In December, France Alzheimer (FA) released a series of videos under the title “Pas si compliqué de comprendre la recherche...” (It’s not that hard to understand research...).

The four animated episodes are about scientific research on Alzheimer’s disease, the idea being to explain, in layman’s terms, four research projects financially supported by FA.

The videos, in French, can be seen here:
https://www.youtube.com/user/francealzheimer

19 January: Alzheimer’s Society launches Care and cure magazine

The first issue of the Alzheimer’s Society (UK) research magazine, Care and cure was published on 19 January.

The magazine was created in response to feedback from Alzheimer’s Society readers, who wanted to find out about the latest in dementia research and the background information to understand it better. Care and cure magazine will have regular sections for news, features and insights into research.

Issue 1 - winter 2014 can be downloaded here, for free:

23 January: Alzheimer’s Society reports on dementia guide milestones and awards

On 23 January we received the following article from Dr Tim Beanland, Knowledge Manager at the Alzheimer’s Society (UK), reporting on some of the milestones achieved and awards received for the Alzheimer’s Society’s dementia guide:

Since its launch in July 2013, ‘The dementia guide: living well after diagnosis’ has proven very popular in the UK where there is inevitably great demand for comprehensive information shortly after a diagnosis. We have now distributed over 250,000 copies of the guide in print, and recently launched a film that delivers the same content through experts and people living with dementia who share their experiences. The guide offers practical information and advice on topics people say they want covered soon after diagnosis.

The dementia guide is endorsed by the Royal Colleges of Psychiatrists and GPs and initial funding from the Department of Health meant it could be developed in numerous accessible formats including Braille and language translations, including BSL. Generous subsequent support from Lloyds Banking Group has allowed us to make the guide freely available to NHS services – many copies have been distributed through memory clinics – as well as Alzheimer’s Society staff.

We were also delighted that the guide won a highly commended prize in the British Medical Association Patient Information Awards in September 2014. To read the dementia guide or watch the film, visit
www.alzheimers.org.uk/dementiaguide

25 January: Luxembourg runs new awareness campaign on buses

From 12 December to 25 January the Association Luxembourg Alzheimer (ALA) ran an advertising campaign on the back of buses in the north, south and centre of the
country. Posters asked the simple question: “Dementia?” and gave the number of the ALA helpline.

ALA is considering extending the campaign for a further four weeks.

28 January: Slovenia gears up to host two international dementia conferences in 2015

Alzheimer Slovenia (Spominčica) is in the middle of intensive preparations for the 25th annual Alzheimer Europe (AE) conference. The conference is about “Dementia: putting strategies and research into practice” and will be held in Ljubljana, Slovenia from 2 to 4 September. Spominčica’s President, Štefanija Lukic Zlobek says “we are doing our best to make your stay in our country as pleasant as possible”.

This year’s Mediterranean Alzheimer Alliance conference will also be held in Ljubljana, dedicated to the memory of Prof. Aleš Kogoj, gerontopsychiatrist and founder of Spominčica.

Policy Watch

15 January: UK Screening Committee upholds position against dementia screening for over 65s

On 15 January, the UK National Screening Committee (UK NSC) upheld its recommendation against screening everyone aged 65 and over for dementia. The UK NSC reviewed the current evidence extensively and concluded that the current test for dementia, which is a form of questionnaire, does not accurately identify those people who have dementia and those who do not.

To recommend screening, the Committee would need to be confident that by acting early, treatments would slow or even prevent this serious disease. At the moment these treatments do not exist.

Dr Anne Mackie, Director of Programmes for the UK NSC, said: “The evidence shows us that for every 100 people aged 65 tested, 18 would test positive, but only six of these would have dementia and one case would be missed. This means we cannot recommend universal screening."

Alzheimer Europe’s member for England, Wales and Northern Ireland, the Alzheimer’s Society (UK) has said it opposes routine population screening for now, as there is not enough evidence to support it.

Jeremy Hughes, Chief Executive at Alzheimer’s Society said: “Everyone with dementia has the right to know about their condition and tackle it head on, but the UK National Screening Committee are right that until tests are more accurate and the right treatments are available, population screening for dementia amongst all over 65s remains inappropriate."

The UK NSC will next consider introducing the programme in three years, or earlier “if significant new evidence becomes available”.

29 January: World Dementia Council issues risk reduction statement

The World Dementia Council (WDC) has issued a statement about dementia risk reduction and has made this one of their five priority areas of work:

“The WDC considers dementia risk reduction to be a critical element of the global dementia agenda. At their third meeting in October 2014, members of the Council concluded that, while further research in this area is still clearly needed, the growing evidence base strongly suggests that cognitive decline at the population level could be affected by behaviour changes that reduce cardiovascular risk factors.

The WDC is calling on governments around the world to focus on dementia risk reduction (or risk management) alongside work on finding a cure or disease-modifying therapy and continuing to improve diagnosis, care and quality of life for people with dementia.”


Science Watch

2 January: Stanford University suggests a new therapeutic target for AD

Researchers at Stanford University, California have completed a study concluding that Alzheimer’s disease (AD) could be prevented and possibly cured by boosting the brain’s own immune response. They discovered that nerve cells die because microglia - cells which are supposed to clear the brain of bacteria, viruses and dangerous deposits - stop working. Their results were published in the Journal of Clinical Investigation on 2 January.

Microglia function well in young people but as people age, the protein EP2 stops them operating efficiently. The researchers found that by blocking the protein in mouse models, the microglia were able to function normally again, thus resuming their normal cleaning duties; “hoovering up” amyloid-beta plaques.

The scientists discovered that in young mice, the microglia kept the sticky plaques under control. But when experiments were done on older mice, the protein EP2 swung into action and stopped the microglia producing enzymes which digested the plaques.

Similarly mice which were genetically engineered not to have EP2 did not develop AD, even when injected with a solution of amyloid-beta, suggesting that their cells were disposing of the protein naturally.
Study author, Dr Katrin Andreasson said their experiments show that keeping microglia on the right track “counters memory loss and preserves healthy brain physiology”.

Stanford University is now hoping to produce a compound which only blocks EP2 to prevent unnecessary side effects.

http://www.jci.org/articles/view/77487

5 January: Dementia may increase risk of criminal behaviour

Researchers at Lund University, Sweden and the University of California, San Francisco (UCSF), have completed a study into the prevalence of criminal behaviour in people with diagnosed neurodegenerative disorders, such as Alzheimer’s disease (AD) and the behavioural variant of Frontotemporal dementia (bvFTD). Their study was published in the journal, JAMA Neurology on 5 January.

AD and FTD can prevent the proper functioning of areas of the brain involved in decision making, emotional processing, judgment, self-awareness, sexual behaviour and violence. The study authors note that dementia can lead to people with no history of antisocial activities exhibiting behaviour that is “antisocial”, some of which is classified as criminal by law and society.

The medical records of 2,397 patients – all of whom attended the UCSF Memory and Aging Center between 1999 and 2012 – were reviewed to assess the frequency of criminal behaviour. This was done by screening for specific keywords identifying criminal behaviour among patient notes. Criminal behaviour was defined by the study as “acts that violate the law as well as those that deviate from social decorum and could potentially lead to legal ramifications”.

Criminal behaviour that emerged during a patient’s illness was observed in 8.3% of the patients. In particular, the following percentages of patients were found to have documented criminal behaviours: AD 7.7%; bvFTD 37.4%; semantic variant primary progressive aphasia (svPPA) 27%; Huntington disease (HD) 20%.

Types of criminal behaviour observed most frequently varied between diseases and patient gender: Patients with bvFTD were most likely to have committed acts of theft, traffic violations, sexual advances, trespassing and public urination. In general, traffic violations, many of which were linked to memory loss, were most frequently committed by patients with AD.

The study notes that new criminal behaviours are far more prevalent in association with disorders affecting the frontotemporal or fronto-subcortical circuits of the brain.

In conclusion, the authors emphasise the importance of vigilance among carers for patients with neurodegenerative conditions that begin to affect their normal behaviours, particularly if the patients find themselves within legal settings. They acknowledge, however, that prospective studies designed to specifically evaluate criminality will need to be conducted.

http://archneur.jamanetwork.com/article.aspx?articleid=2088872&resultCid=k3

6 January: GliaCure completes Phase 1a of experimental AD drug trial

On 6 January, privately-held biotechnology company, GliaCure announced the successful completion of a Phase 1a clinical trial of its experimental Alzheimer’s disease (AD) drug candidate, GC021109, which both promotes the clearance of amyloid and stimulates anti-inflammatory actions through a single target.

The Phase 1a trial, which began in September of last year, involved single dosing of 44 healthy volunteers to investigate the drug’s safety, tolerability and pharmacokinetic properties.

A Phase 1b trial, testing the same features in people with mild to moderate AD, is currently underway and first dosing is planned in the first quarter of 2015.

Glia cells, which the company targets in the development of therapies for neurological and neuropsychiatric disorders, are non-neuronal cells that maintain homeostasis, form myelin and provide support and protection for neurons and peripheral nervous system.

12 January: Worldwide AD license agreement struck between J&J and AC Immune

On 12 January Swiss biotech firm, AC Immune announced an exclusive worldwide license agreement with Johnson & Johnson to develop “anti-Tau vaccines” for Alzheimer’s disease (AD).

AC Immune said that it would receive an upfront sum and further payments based on scientific and commercial progress under the worldwide exclusive license agreement and research collaboration with J&J’s Janssen Pharmaceuticals unit.

J&J will further develop AC Immune’s lead therapeutic vaccine, ACI-35, which is currently in an early-stage Phase 1b clinical trial. ACI-35 is designed to stimulate the patient’s immune system to produce a response against tau protein, so targeting AD in its early stages.

AC Immune’s Chief Executive, Andrea Pfeifer said the company plans to start testing the vaccine on people with Down’s syndrome (DS) – around 75% of adults with DS develop dementia – during the course of 2015.

13 January: Compounds in blood may be linked to Alzheimer’s disease

A new study, funded by the Alzheimer’s Society (UK) and conducted by King’s College London (KCL), has found that the number of molecules formed from cholesterol and found in the blood, could be linked to a higher risk of Alzheimer’s disease (AD).

The study looked at fatty molecules in blood samples from 124 individuals including 36 with AD and 48 with Mild Cognitive Impairment (MCI) and was published on 13 January in the journal, Translational Psychiatry.

Ten molecules were identified, whose levels in the blood were found to predict AD with an accuracy of 79%. Six of the ten molecules were by-products formed from the
breakdown of cholesterol in the body, though the researchers found no overall correlation between cholesterol in the blood and AD.

Alzheimer’s Society Research Fellow and lead study author, Dr Petroula Proitsi was pleased with the results but stressed that the team’s findings would need to be expanded and replicated in larger cohorts:

“The false positive rate of 23.1 per cent would mean that using these molecules for diagnosis would see nearly a quarter of healthy people wrongly diagnosed with Alzheimer’s. This highlights that these molecules cannot be used for diagnostic purposes and that the important message from this study is the identification of new interesting lipid molecules to be associated with Alzheimer’s disease”, she concluded.

The next stage of the team’s research will be to look into whether changes in the identified metabolites are also associated with disease initiation and progression.

http://www.nature.com/tp/journal/v5/n1/full/tp2014127a.html

14 January: French study claims donepezil slows brain atrophy in prodromal AD

Dr Bruno Dubois and colleagues at Salpêtrière Hospital in Paris, France have completed a study into the effect of the drug donepezil on the rate of hippocampal atrophy. 216 patients with suspected prodromal Alzheimer’s disease (AD) were involved in the study, which was published on 14 January 14 in the journal of the Alzheimer’s Association, Alzheimer’s and Dementia.

In patients with suspected prodromal AD, treatment with a daily dose of 10mg of donepezil for one year reduced the rate of hippocampal atrophy by 45%, as compared with placebo, the researchers report.

Despite the positive effects the researchers found on hippocampal atrophy, however, there were no significant between-group differences in any neuropsychological tests.

The researchers concluded that longitudinal studies are needed to evaluate the association between reduced rate of hippocampal atrophy and any protective effects on cognition.

http://www.alzheimersanddementia.com/article/S1552-5260%2814%2902856-8/abstract

14 January: Study into hibernation claims to have found new AD target

Researchers at the MRC Toxicology Unit in Leicester, UK have completed a study looking into the “regenerative power of hibernation” and how it might halt the progression of neurodegenerative diseases. Their study, which claims to have identified a new therapeutic target for Alzheimer’s disease (AD), was published on 14 January in the journal, Nature.

In the early stages of AD and other neurodegenerative disorders, synapses stop working, leading to brain cell death. Synaptic connections in bears, hedgehogs and mice are naturally culled as they enter hibernation, but are automatically repaired as they wake up the following spring, with no apparent damage to memory. Observing this process, the research team discovered “cold-shock” chemicals that triggered the process.

They used such a chemical - RBM3 – in their experiments, managing to prevent brain cells dying in mouse models. In the experiments, non-hibernating mice with AD and prion disease were cooled from a body temperature of 37°C to between 16 and 18°C.

Young, diseased mice lost synapses during the cold shock process, but regained them as they warmed up. Older mice, however, were unable to re-establish these connections as they awoke.

In a further set of tests, the team showed the brain cell deaths from prion disease and AD could be prevented by artificially boosting RBM3 levels.

They concluded that their results indicated a new drug target, as well as claiming that memories could one day be restored, “because a lot of memory decline is correlated with synapse loss, which is the early stage of dementia, so you might get back some of the synapse you’ve lost."

Dr Doug Brown, the director of research and development at the Alzheimer’s Society said: “While we don’t think body cooling is a feasible treatment for long-term, progressive conditions like Alzheimer’s disease, this research opens up the possibility of finding drugs that can have the same effect. We are very much looking forward to seeing this research taken forward to the next stage.”

http://www.nature.com/nature/journal/vaop/ncurrent/full/nature14142.html

19 January: Decade-old cancer drug to be tested as AD treatment

A new US study, administrated by Yale University and the Alzheimer’s Disease Cooperative Study (ADCS) is looking at the drug, saracatinib as a possible treatment for Alzheimer’s disease (AD). Saracatinib was developed in the 2000s with the aim of treating cancer and although it failed in trials, it was shown to be effective in blocking a protein that is associated with the damage of brain cells.

As much of the research required into the safety of the drug has already been completed, things can progress quickly.

The study, which will run for a year, will follow 152 participants with mild AD, 76 of whom will receive the drug and the remainder of whom will be on placebo.

Funding of USD 13M has been granted by the National Institutes of Health, to allow the study to run in approximately 20 laboratories throughout the US and one in Vancouver, Canada.

21 January: Health Canada issues safety warning on donepezil

Alzheimer’s disease (AD) drug, donepezil has been linked to rare but serious side effects, Health Canada announced on 21 January. They added two rare but serious side effects to the prescribing information for the drug and
warned that health professionals should assess patients for risk factors for rhabdomyolysis before prescribing.

The side effects in question are a muscle breakdown called rhabdomyolysis and a neurological disorder, neuromyelitis, which have occurred in some patients.

Internationally, there were 88 cases of rhabdomyolysis and 67 cases of NMS linked with donepezil, with some patients having both conditions. Three deaths were associated with rhabdomyolysis and nine deaths with NMS, most of them in Japan.


26 January: Study says long-term use of anticholinergics increases dementia risk

The long-term use of certain medications with anticholinergic effects, such as sleep aids and hayfever treatments, could be linked to an increased risk of dementia, according to a study published in the journal JAMA International Medicine on 26 January.

Researchers at the University of Washington in the US studied 3,434 participants aged 65 and over for a period of at least seven years, during which time 797 participants developed dementia.

The researchers compared the length of use of different anticholinergic drugs with the incidence of dementia to calculate the risk over time. The link, they said was only clear for participants who took the drugs for three years or more. It was not clear, however, whether this applied only to people taking the drugs for three years in one continuous block, or whether it was also true of those taking the drugs for a total of three years, in shorter increments.


Dementia in society

31 December: Depression in dementia more common in those living at home, study finds

Residents of long-term care homes, living with dementia are less likely to suffer from depressive symptoms than those living in the community, according to research done at the University of Manchester. The study findings were published in the journal International Psychogeriatrics in December.

The study involved 414 people with severe dementia and their carers in eight EU countries – England, Estonia, Finland, France, Germany, the Netherlands and Spain. Information on quality of life, activities of daily living such as bathing, feeding and dressing was gathered, as well as information on the presence of depressive symptoms using standardised measures. The data showed that 37% of people living in the community showed signs of depression, as compared with 23% of those in care homes.

Overall, Finland (15%) and the Netherlands (21%) had the lowest rates of depression in people with severe dementia, compared to 23% overall.

The study also looked at the rates of anti-depressant prescribing across the different countries. It found that England and Spain had the highest rates, while Germany had the lowest.

https://www.escholar.manchester.ac.uk/uk-ac-man-scw-239493

12 January: Julianne Moore wins Best Actress Golden Globe for Still Alice

Actress Julianne Moore won the accolade of Best Actress in a Drama at the Golden Globes award ceremony on 12 January, for her leading role in the film, Still Alice.

Ms Moore, who beat Jennifer Aniston, Felicity Jones, Rosamund Pike and Reese Witherspoon to the award, plays a professor with early onset Alzheimer’s disease.

New Publications & Resources

31 December: King Baudouin Foundation publishes “Osez le Dialogue”

In December 2014, the King Baudouin Foundation brought out “Osez le Dialogue”, a publication about setting conditions to start a dialogue between a person with cognitive impairment and their carer, concerning a care pathway.

Particular attention is paid to Alzheimer’s disease.

The King Baudouin Foundation is an independent, pluralistic foundation in Belgium, seeking social justice and change at a European and international level.

“Osez le Dialogue” is available here: http://goc.gi/WHbMsF

1 January: Registrations open for KU Leuven’s Ethics in Dementia Care course

Registrations opened this month for KU Leuven’s Ethics in Dementia Care course at KU Leuven, Belgium.

The objective of the course is to foster exchanges on foundational, clinical-ethical and organisational-ethical approaches to dementia care.

The course’s Keynote Speaker will be Fabrice Gzil of the Fondation Médéric Alzheimer, Paris, France and the Course Coordinator is Professor Chris Gastmans, President of the European Association of Centres of Medical Ethics and Professor of Medical Ethics at KU Leuven.

For more information and to register:

19 January: Applications open for second EUPATI Expert Patient Training Course

The second EUPATI Expert Patient Training Course on medicines’ Research and Development opened for applications on 19 January.

Offering patients and patient advocates expert-level training in medicines research and development, it will run from September 2015 until the end of November 2016 and will contain a mixture of independent e-learning coursework and face-to-face training events.

Contact Alzheimer Europe:

Alzheimer Europe, 14 rue Dicks, L-1417, Luxembourg info@alzheimer-europe.org, www.alzheimer-europe.org

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AE Calendar 2015

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tbody>
<tr>
<td>9 February</td>
<td>Preparatory meeting for IM call (Munich, Germany)</td>
<td>Jean</td>
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<tr>
<td>12-13 February</td>
<td>EPAD WP6 meeting (Barcelona, Spain)</td>
<td>Jean, Alex</td>
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<tr>
<td>22-25 February</td>
<td>Board meeting, Company round table and Public Affairs meetings (Luxembourg, Luxembourg)</td>
<td>AE Board, staff members</td>
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<tr>
<td>27 February</td>
<td>Incontinence working group meeting (Brussels, Belgium)</td>
<td>Dianne, Jean</td>
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Future Conferences 2015

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tr>
<td>25-28 February</td>
<td>5th National Alzheimer Conference in Bucharest - “National and international policies in dementia - timely diagnosis, care and research”, <a href="http://www.alzcongres.ro">www.alzcongres.ro</a></td>
<td>Bucharest, Romania</td>
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<td>16-17 March</td>
<td>First Ministerial Conference on Dementia at the World Health Organization, <a href="http://www.ahl.co.uk">www.ahl.co.uk</a></td>
<td>Geneva, Switzerland</td>
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<td>18-22 March</td>
<td>AD/PD 2015, The 12th International Conference on Alzheimer’s and Parkinson’s Disease, <a href="http://www.sknex.org/adpd/pages/home.aspx">www.sknex.org/adpd/pages/home.aspx</a></td>
<td>Nice, France</td>
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<tr>
<td>27-28 March</td>
<td>19th annual meeting of the German Society of Neurogenetics (DGfN), <a href="http://www.dgfn.de">www.dgfn.de</a></td>
<td>Bonn, Germany</td>
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<td>20-23 June</td>
<td>1st Congress of the European Academy of Neurology (EAN), <a href="http://www.eaneurology.org/budapest2015">www.eaneurology.org/budapest2015</a></td>
<td>Berlin, Germany</td>
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<td>1-3 July</td>
<td>Summer Course on Ethics in Dementia Care, <a href="https://gbiomed.kuleuven.be/english/research/50000687/50000697/summer-course">https://gbiomed.kuleuven.be/english/research/50000687/50000697/summer-course</a></td>
<td>Leuven, Belgium</td>
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<td>2-4 September</td>
<td>25th Alzheimer Europe Conference - “Dementia: putting strategies and research into practice”</td>
<td>Ljubljana, Slovenia</td>
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<td>9-12 March</td>
<td>14th International Athens/Springfield Symposium on Advances in Alzheimer Therapy, <a href="http://www.ae-springfield.com">www.ae-springfield.com</a></td>
<td>Athens, Greece</td>
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25th Alzheimer Europe Conference
Dementia: putting strategies and research into practice
Ljubljana, Slovenia / 2–4 September 2015
Mark the dates!

www.alzheimer-europe.org/conferences

The Alzheimer Europe newsletter arises from the 2014 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.