Editorial

Welcome!

First of all, I would like to extend our deepest condolences to Alicja Sadowska’s family, friends and colleagues. Ms Sadowska, Chairperson of the Polish Alzheimer’s Association passed away on 18 March and will be sorely missed.

We were also saddened to hear of the passing of British author, Sir Terry Pratchett, who died on 12 March, aged 66, with Alzheimer’s disease.

With regards to Alzheimer Europe (AE)’s activities in March, we have been busy with conference abstracts coming in at a pace, especially towards the end of the month. The call closed on 31 March, with approximately 180 abstracts received. We will continue to accept abstracts for poster presentations and Slovenian sessions, however.

Our Glasgow Declaration campaign has already gathered nearly 1500 signatures from individuals, since its online launch last month. 40 organisations have also lent their support, as have 52 policy makers, including the 38 MEPs who signed in March alone. Among the 38, 14 are new European Alzheimer’s Alliance (EAA) members, meaning we now have over 100 MEPs (104 at the time of writing) supporting our campaign to make dementia a European priority.

March has been a huge month for dementia on the European and global stage, with the World Health Organisation (WHO)’s first Ministerial Conference on Global Action Against Dementia taking place mid-month in Geneva. I was delighted to be among the delegates, particularly since it was announced by Luxembourg’s Health Minister Lydia Mutsch during the conference that dementia would be a priority for Luxembourg’s EU Presidency later this year. Also during the conference, UK Health Secretary Jeremy Hunt announced a new USD 100 million global research fund for dementia.

At a European level, many of the projects AE is involved in have had a milestone month, with PredictND passing its first year European Commission review, Pharmacog - now in its final year – working on the final presentations of its preclinical work packages, NINADV having reached its recruitment target for its phase 3 trial of nilvadipine and PACE preparing for the first phase of its study. Last but not least, the Innovative Medicines Initiative (IMI) and its AETIONOMY, EMIF and EPAD projects announced the creation of an Alzheimer’s disease (AD) research platform to facilitate collaboration between the three projects.

Finally, a number of important research stories have emerged this month, including a Biogen drug trial showing promising early results, a study on the role played by tau in dementia, a new technique to identify early signs of AD, as well as a more worrying story emerging from the US, saying that only 45% of people diagnosed with dementia are actually told of their diagnosis by their doctors.

Our feet have barely touched the ground in March. Let’s hope April is just as productive for us all!

Jean Georges
Executive Director
Alzheimer Europe

6 March: Alzheimer Europe newsletter readership reaches 5000

Alzheimer Europe’s monthly dementia e-newsletter now reaches more than 5000 subscribers. We aim to keep our readers abreast of the latest developments in the dementia field, as well as sharing our own news and that of our member organisations.

16 March: AE joins new communications network launched by EPF

On 16 March, the European Patients’ Forum (EPF) welcomed communications people from a number of its member organisations, including Alzheimer Europe, to a new “Patients’ Comms Network”. The aim is to create a network that will work together to ensure patients’ voices are heard, by sharing news and activities with one another and helping support each other’s campaigns, and exchanging information that can benefit the entire patients’ community.

The network will meet on a monthly basis in Brussels, Belgium or via teleconference for groups and organisations based elsewhere.

19-20 March: Executive of the EWGPWD meets to prepare for the AE annual conference

On 19-20 March, the Executive of the European Working Group of People with Dementia (EWGPWD) met in Luxembourg to start preparations for the AE annual conference. They also discussed how best to take part in the various projects organised by Alzheimer Europe and how to expand EWGPWD membership. The Executive unanimously appointed Agnes Houston to the honorary position of board member of the recently created Alzheimer Europe Foundation.

23 March: Agnes Houston appears in “The Power of Words” dementia campaign video

On 23 March, the Joseph Rowntree Foundation (JRF) brought out a series of four short videos called “Dementia without walls”. The first in the series, “The Power of Words” is about the importance of the language used around dementia. It draws attention to the negative language used, in particular by the media and to the impact this has on people living with dementia.

European working Group of People with dementia (EWGPWD) Vice-Chair, Agnes Houston appears in the video, saying “I’m going about living my life well with dementia”. She refers to her diagnosis of dementia as “an added complication” to which she has to adapt and goes on to say that “words can empower people to live well”, urging people to choose their words with care.

“The Power of Words” emerged from a conference run by the JRF in late 2014 in Liverpool, UK, which brought together several groups of people with dementia. They put together a guide on appropriate/inappropriate language, which they have since made available to the UK media.

The other three videos in the series are: “It’s my life”, “Making our places and spaces dementia friendly” and “Day in the life of a dementia campaigner”.

http://www.jrf.org.uk/topic/dementia-without-walls

24 March: Series of seminars at the University of Leeds to explore advance decision making

On 24 March, the first of a series of seminars and workshops took place at the University of Leeds (UK) on the topic of advance decision making. This first seminar was entitled “advance decision making – the context, the promises and the pitfalls”.

A small group of experts from the UK, the EU and Norway presented papers and discussed issues related to the contexts in which advance decision making takes place, considering both advance decisions for the end of life and psychiatric advance decisions, the ethical principles implicated in advance decision making and the practical context within which advance decisions are implemented.

Dianne Gove, AE’s Director for Projects presented a paper on the practical and ethical issues linked to the use of advance directives by people with dementia.

The next seminar will be held in Leeds in September 2015 and will focus on the regulation of advance decisions and professional responses thereto, together with a consideration of the impact of physician attitudes on the implementation of advance decisions.

31 March: Glasgow Declaration signatures are mounting up

As at 31 March, the Glasgow Declaration – launched on 19 February - has already gathered nearly 1500 signatures from individuals and 40 organisations. Following an email campaign to all MEPs this month, we are delighted to have gained the support of 52 policy makers to date and are hoping for more in the coming months.

We are delighted with the support we have received so far on this campaign and are also very grateful for the work done by our members at events in their own countries, at which a good number of signatures have already been gathered.

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

AE is using the Twitter hashtags #GlasgowDeclaration and #dementiamatters for this campaign.
The deadline for signatures is 30 November 2015, after which we will present the results at the European Parliament in Brussels on 1 December.

Please sign the declaration and share it with your network.

31 March: Alzheimer Europe closes call for abstracts

The call for abstracts is now closed for the 25th Alzheimer Europe Conference in Slovenia from 2 to 4 September. We are pleased to have received approximately 180 abstracts. These will be reviewed by the Programme Committee during the first part of April and all submitting authors will be informed of the Committee’s decision shortly thereafter.

AE will continue to accept abstracts for poster presentations and for Slovenian sessions.

EU Projects

25 February: PharmaCog partners hold Steering Committee meeting

The members of the PharmaCog Steering Committee held a meeting in Lille, France on 25 February. The meeting was hosted by Prof Régis Bordet (Academic Coordinator) and mainly focused on the final presentations of the pre-clinical work packages. The delegates also discussed their input to the 2014 project report.

The PharmaCog partners are developing models to predict the efficacy of drug candidates by combining past and current data to define a series of biomarkers of dementia progression. The project began in 2010 and is now in its final year.

3-4 March: PredictND team meets in London to discuss progress

On 3-4 March, PredictND (“From patient data to clinical diagnosis in neurodegenerative diseases”) held a project meeting and a management board meeting in London to discuss progress so far. Dianne Gove presented the results of the survey carried out by Alzheimer Europe during the annual conference in Glasgow last year to assess user needs for the planned low-cost predictive games and tests. The PredictND team is currently preparing for a formal review meeting in Brussels at the end of the month for which Jean Georges will also present the results of the user survey. Attendees at the Glasgow conference provided valuable feedback which will contribute towards shaping the design of the future citizen portal containing the predictive games and tests.

http://www.predictnd.eu/

5-6 March: AFE-INNOVNET makes progress in making Europe age-friendly

On 5-6 March a consortium meeting was held for the AFE-Innovnet project whose aim is to create a thematic network for age-friendly environments in the European Union.

The various work package leaders gave a progress report and identified some of the problems they had encountered but also reported some promising age-friendly initiatives in certain regions. Anne-Sophie Parent presented a draft of the “EU covenant on demographic change: structure, governance and working methods” and Mireia Ferri presented work on the participatory approach.

http://www.afeinnovnet.eu/

9-10 March: European Summit on Innovation for Active & Health Ageing

On 9-10 March, Dianne attended the European Summit on Innovation for Active & Healthy Ageing organised by the European Innovation Partnership on Active and Healthy Ageing.

Günter Oettinger, European Commissioner for Digital Technology, opened the conference and provided an overview of ageing in Europe. He pointed out that Europe is the continent with the oldest population in the world and that everything must be done to ensure that people are able to live healthy, long and active lives. He drew attention to the need to modernise the healthcare system, ensure that older people remain in employment and continue to pay pension contributions but at the same time that a younger workforce is brought in. Mr Oettinger described today’s world as a digital society in which older people who cannot or do not want to use technology create a separation between themselves as technology is the entry card to today’s society. He stated that there was a need to ensure a dialogue with older people and to produce smart devices, hardware, software and IT services, all of which represent a chance for economic growth and employment.

Throughout the summit, themes which frequently occurred included the need for stakeholder involvement, to think in terms of prevention rather than cure and a community-based rather than hospital-centric approach to the healthcare of older people. The “silver economy” was frequently cited as a considerable opportunity for growth but the possible need to avoid segregating older people as a potential source of economic growth was briefly raised. There was also some degree of regret that positive change was not happening fast enough.
12-13 March: Researchers prepare for first phase of PACE study

On 12-13 March the partners of the PACE project (“Comparing the effectiveness of Palliative Care for Elderly people in long-term care facilities in Europe”) met in Volendam, Netherlands. During the consortium meeting, research partners presented the progress made to date and the planned activities for the coming months. In all the participating countries processes for obtaining ethical approval have started and the first study will start between March and April 2015. During this first phase of the project the consortium aims to describe and compare the effectiveness of health care systems with and without formal palliative care structures for long-term care facilities in six EU countries in terms of patient and family outcomes and in terms of staff knowledge, practices, and attitudes. In addition, during the meeting, the impact partners presented their work and discussed the methodology that will be used for setting up a User Forum involving different stakeholders, among others older people and their carers. Alzheimer Europe will contribute to this task. Dianne Gove and Ana Diaz attended this meeting.

http://www.endoflifeare.be/pace

19 March: IMI announces the creation of a new Alzheimer’s disease Research Platform

On 19 March, the Innovative Medicines Initiative (IMI) and its AETIONOMY, EMIF and EPAD projects are proud to announce the creation of the IMI Alzheimer’s Disease Research Platform. The platform will facilitate collaboration between the three projects, helping them to deliver results faster. At the same time, IMI and the Global Alzheimer’s Platform (GAP) are announcing their plans to sign a Memorandum of Understanding to accelerate Alzheimer’s drug development by building a global, standing, trial-ready platform for Alzheimer’s drug development.

The full text is available on the IMI website.

www.imi.europa.eu/content/press-release-imi-ad-platform

23 March: EMIF publishes its first 2015 newsletter

The EMIF partners published the first external 2015 project newsletter on 23 March. The main feature of this edition is the week-long series of meetings attended by 150 partners in all three EMIF topics - Platform, Metabolic and Alzheimer’s Disease - in December 2014. The delegates learned of significant progress in their own and in the other topics. EMIF week was an unprecedented opportunity for networking, which will foster further cross-topic collaboration.

Delegates also attended a public colloquium that initiated a dialogue between the EMIF community and the health care research community of Catalonia. Mr Jesús Rodrigo, Board member of Alzheimer Europe, was a speaker at this event; his presentation can be seen at http://goo.gl/rRmeIh

Newsletter: March 2015

The newsletter is available on the EMIF website and videos from the EMIF week are available on YouTube.


27 March: PredictND passes first year EC review

The PredictND team presented the progress of the first year on 27 March at a review meeting at the European Commission in Brussels.

The team was led by Jyrki Lötiönen (pictured), the project coordinator from VTT, Finland who introduced the project aims and objectives, as well as the management aspects of the project. Hilkka Soininen from the University of Eastern Finland presented the data acquisition and management plan, whereas Marie Brun from Rigshospitalet in Copenhagen updated the reviewers on the clinical validation plan and strategy. Daniel Rückert from Imperial College presented the first set of tools for prospective data acquisition and Timo Urhemaa from VTT the first prototype for prospective data analysis. Jean Georges from Alzheimer Europe gave a quick update on the dissemination strategy for the project, as well as the results of a small survey of clinicians and end-users on their views on the citizen portal to be developed as part of the project.

The reviewers were satisfied with the progress achieved in the first year of the project and made some useful suggestions for the further implementation in the following years.

More information on the project which has received funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration under grant agreement no 611005 can be found at: http://www.predictnd.eu/

31 March: NILVAD reaches the recruitment target for its phase 3 clinical trial

On 31 March, the NILVAD partners reached their recruitment target of 510 people for the project’s phase 3 trial of nilvadipine for mild to moderate Alzheimer’s disease.

Nilvadipine is an existing hypertension drug that has also been shown to block production of the amyloid protein, believed to be central to the Alzheimer’s disease process. The NILVAD trial is being conducted at 21 study sites in nine European countries.

www.nilvad.eu
In memoriam Alicja Sadowska, Polish Alzheimer's Association Chair

We were deeply saddened to hear that Alicja Sadowska, Chairperson of the Polish Alzheimer’s Association, passed away on 18 March after struggling with a painful disease for three months.

Ms Sadowska had been a part of the Alzheimer movement since 1993 and was elected as Chair of the Polish Alzheimer’s Association in 2005 - a position she retained until her death. She was a member of the Board of Alzheimer Europe (AE) from 2006 to 2014 and was on the organising committee of AE’s successful 2011 conference in Warsaw, under the banner of “European solidarity without borders”.

Her colleague and friend, Mirka Wojciechowska, wrote:

“Her unexpected death is such a terrible loss not only to her loved ones, her husband Maciej and two sons, but also to the cause we have been fighting for in Poland, Europe and the world. She believed that by working together we could change the world and help people with dementia have better opportunities to live, their problems understood and their needs met. She inspired and helped many people in Poland. I cannot believe she is no longer with us.”

Alzheimer Europe Networking

On 3 March (Brussels, Belgium) Alex attended a meeting organised by The Alzheimer Society of Ireland and hosted by MEP Nessa Childers in the European Parliament.

On 3 March (Brussels, Belgium) Annette had a meeting with representatives of The Alzheimer Society of Ireland.

On 3 March (London, United Kingdom) Dianne and Jean attended a workshop of the PredictND project.

On 4 March (London, United Kingdom) Dianne represented AE at the Management Board meeting of the PredictND project.

On 4-5 March (London, United Kingdom) Jean attended meetings of the Patients’ and Consumers’ Working Party of the European Medicines Agency.

On 9-10 March (Brussels, Belgium) Dianne attended the European Summit on Innovation for Active & Healthy Ageing organised in the framework of the European Innovation Partnership on Active and Healthy Ageing.

On 12-13 March (Volendam, Netherlands) Dianne and Ana attended a PACE (“Comparing the effectiveness of Palliative Care for Elderly people in long-term care facilities in Europe”) Consortium meeting.

On 16 March (Rotterdam, Netherlands) Alex attended the 4th General Assembly of the VPH-DARE@IT project.

On 16-17 March (Geneva, Switzerland) Heike and Jean attended the first WHO Ministerial Conference on the Global Action against Dementia.

On 18 March (Geneva, Switzerland) Jean attended a meeting of the CEO Initiative on Dementia to discuss the outcomes of the WHO Conference.

On 19 March (Nice, France) Jean attended the IMI Symposium for the launch of the IMI Alzheimer’s Platform.

On 19-22 March (Nice, France) Jean attended the AD/PD Conference.

On 19-20 March 2015 (Luxembourg, Luxembourg), the Executive of the European Working Group of People with Dementia (EWGPWD) had a meeting.

On 20 March (Nice, France) Jean met with representatives of Biogen Idec.

On 24 March (Amsterdam, Netherlands) Jean attended the Dementia Forum organised by Roche.

On 24 March (Leeds, UK) Dianne presented a paper on the practical and ethical issues related to the use of advance directives by people with dementia at the seminar “Towards a European understanding of advance decision-making: a comparative, interdisciplinary approach”.

On 24 March (Brussels, Belgium) Annette attended the first Think Tank of the year organised by EFPIA.

On 24 March (Brussels, Belgium) Annette had a meeting with EMSP to discuss access to employment for people with multiple sclerosis.

On 25 March (Brussels, Belgium) Annette met Elena Gentile, Italian MEP.

On 25 March (Brussels, Belgium) Annette had a meeting with Eurodiaconia that organised an informal exchange among stakeholders on the topic of long-term care.

On 27 March (Brussels, Belgium) Jean participated in the first year review for the PredictND project.
Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 104, representing 27 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); Kappel Barbara (NI); Rübig Paul (EPP)

**Belgium:** Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE)

**Bulgaria:** Andrey Kovatchev (EPP)

**Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomšić (ECR)

**Cyprus:** Costas Mavrides (S&D); Elena Theocarous (EPP)

**Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP)

**Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D)

**Estonia:** Urmas Paet (ALDE); Liis Jakonsaari (ALDE); Anneli Jäätteenmäki (ALDE); Miep Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP)

**France:** Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D)

**Germany:** Angelika Niebler (EPP); Udo Voigt (NI); Greece: Konstad Chrysoginos (GUE/NGL); Manolis Kefalogiannis (EPP)

**Hungary:** Ádám Kósa (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); Seán Kelly (EPP)

**Ireland:** Mairéad McGuinness (EPP); Liadh Ní Riada (GUE/NGL)

**Italy:** Elzbieta Lukacijewska (EPP)

**Lithuania:** Vilija Binklevičiute (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); Marek Plura (EPP)

**Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP)

**Romania:** Cristian Silviu Busuioc (MEP); Daciana Octavia Sârbu (S&D); Claudia Ciprian Tanasescu (S&D); Renate Weber (EPP)

**Slovakia:** Miroslav Mikolášik (EPP); Anna Záborská (EPP)

**Slovenia:** Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patrizia Toia (S&D)

**Spain:** Soledad Cabezón Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estarás-Ferratagut (EPP); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Ernest Maragall (Greens/EFA); Pablo Zabal Bidegain (EPP)

**Sweden:** Cecilia Wikström (ALDE), United Kingdom: Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Anneliese Dodds (S&D); Ian Hudgemon (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D); Glenis Willmott (S&D)

**European Alzheimer’s Alliance**

**4 March: MEP Marek Plura meets with AE, joins EAA**

On 4 March (Brussels, Belgium), Annette met Polish MEP Marek Plura. This was an opportunity for Alzheimer Europe to present its political priorities in dementia featured in the Glasgow Declaration. Mr Plura kindly signed the Declaration and joined the European Alzheimer’s Alliance. Mr Plura is a Vice-Chair of the Disability Intergroup in the European Parliament. He is currently working on a European Disability Card and will keep us informed about progress in this area as this may be interesting to follow with regards to the Dementia Friendly Communities. He also mentioned a conference in Latvia on this topic, during the Latvian Presidency of the EU.

**24 March: European Multiple Sclerosis Platform meeting hosted by EAA MEP Estarás-Ferratagut**

On 24 March the European Multiple Sclerosis Platform (EMSP) organised a meeting in the European Parliament in Brussels, Belgium on ‘breaking down the barriers access to employment and the economics of brain health’. The event was hosted by Rosa Estarás Ferragut, MEP, with the participation of Jeroen Lenaers, MEP. The aim of the meeting was to raise awareness about the discrimination people with neurodegenerative diseases like multiple sclerosis face on the work place, the difficulty to retain a job and the low quality of life these people have to endure.

After a vivid intervention by Shana Pezaro, a person with multiple sclerosis, Panos Kanavos from the London School of Economics deplored that Health Technology Assessment did not take into account the direct non medical costs (such as loss of productivity) of a given disease nor the qualitative value for the patient (the example of fatigue not being captured was mentioned). Maria Cabral, European Commission Employment and Social Affairs reminded that most employment policies were dealt with at Member State level. Nevertheless, European law prohibits discrimination at work and recent employment guidelines specifically address people with disabilities. The EU Semester looks at employment gaps between people with disabilities and people without disabilities. The implementation of the UN Convention on the Rights of People with Disabilities will be under scrutiny and the EU will need to show what has been done at EU level. By 2016, the EU will review its disability strategy and focus on action actions that add value at EU level. Emma Rogan, EMSP Project Coordinator, talked about the need to produce a Pact for Employment for people with multiple sclerosis and other neurodegenerative conditions. The Pact that will be officially presented later on this year calls for a healthier working environment and identifies areas where employers could make a significant difference.

This event is a follow-up of a panel discussion Alzheimer Europe co-organised alongside the European Parkinson’s...
Disease Association and EMSP and hosted by MEP Angelikas Werthmann in the European Parliament in 2013 on ‘The challenges of neurodegenerative diseases in the workplace’.

Annette Dumas attended the meeting, representing AE.

**25 March: 100th MEP joins the European Alzheimer’s Alliance**

On 25 March, MEP Sofia Ribeiro (EPP, Portugal) became the 100th member of the European Alzheimer’s Alliance (EAA).

The EAA is a non-exclusive, multinational and cross-party group that brings together Members of the European Parliament (MEPs) committed to supporting Alzheimer Europe and its members in making dementia a public health priority in Europe.

http://alzheimer-europe.org/Policy-in-Practice2/European-Alzheimer-s-Alliance

**25 March: MEP Elena Gentile meets with AE, joins EAA**

On 25 March (Brussels, Belgium), a meeting was organised between Italian MEP Elena Gentile and Alzheimer Europe, represented by Annette Dumas.

This was an opportunity for Alzheimer Europe to present its political priorities in dementia featured in the Glasgow Declaration. Ms Gentile kindly signed the Declaration and joined the European Alzheimer’s Alliance. Some areas for further collaboration were also explored at the meeting.

**31 March: 38 MEPs sign Glasgow Declaration and 14 join EAA**

During the month of March, 39 policy makers signed the Glasgow Declaration, 38 of whom are MEPs. The other was EU Commissioner for Transport, Violeta Bulc.


14 of these MEPs are also new members of the European Alzheimer’s Alliance (EAA), bringing the number of EAA members to 104. The 14 new members for the month of March are (in order of joining):

1. Marek Plura (EPP, Poland)
2. Barbara Kappel (NI, Austria)
3. Udo Voigt (NI, Germany)
4. Alyn Smith (Greens/EFA, UK)
5. Costas Mavrides (S&D, Cyprus)
6. Julie Ward (S&D, UK)
7. Anneliese Dodds (S&D, UK)
8. Urmantas Paet (Alde, Estonia)
9. Catherine Stihler (S&D, UK)
10. Sofia Ribeiro (EPP, Portugal)
11. Remo Sernagiotto (EPP, Italy)
12. Paul Rübig (EPP, Austria)
13. Elena Gentile (S&D, Italy)
14. Damiano Zoffoli (S&D, Italy)

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

**EU Developments**

**4-5 March 2015: EMA organises meetings with patients’ and consumers’ organisations**

The Patients’ and Consumers’ Organisations Working Party (PCWP) of the European Medicines Agency (EMA) met in London on 4 and 5 March 2015 together with the Agency’s Healthcare Professionals’ Organisations Working Party (HCPWP).

On the first day, the Agency presented its Roadmap to 2020 and updated the participants about the planned activities to mark the Agency’s 20th Anniversary. A survey of patients and healthcare professionals involved in EMA activities showed a high degree of satisfaction with their interaction. Additional agenda items were dedicated to paediatric clinical research, an update on Ebola, as well as progress reports on PROTECT and WEBRADR, two projects of the Innovative Medicines Initiative.

The second day was dedicated to an in-depth information session on biosimilars. In addition to providing an overview to PCWP and HCPWP members of the science behind biosimilars and how they are evaluated by regulators, the session explored how to bridge the scientific evaluation with clinical reality and public acceptability of biosimilars and discussed the role of communication in promoting better understanding of biosimilars.

Jean Georges represented Alzheimer Europe, a full PCWP member, at the meeting.

**11 March: Commission replies to MEPs’ question about prevention and treatment of brain disorders**

On 11 March, European Health and Food Safety Commissioner, Vytenis Andriukaitis (pictured) replied to a written question of 6 January, from Spanish MEPs, Juan Carlos Girauta Vidal and Javier Nart - both from the Group of the Alliance of Liberals and Democrats for Europe (ALDE).

The MEPs drew the Commission’s attention to the rising prevalence and cost of brain disorders in Europe and the “increasingly urgent” need for effective treatment. They
highlighted the need for increased investment and for reducing regulatory barriers and increasing patient involvement. Their overall question was:

"Has the Commission considered promoting specific measures aimed at improving the prevention and treatment of brain disorders?"

The answer sent by Commissioner Andriukaitis on 11 March drew the MEPs’ attention to the 2014 report on the 2009 EU initiative on Alzheimer’s disease and other dementias, which concluded the initiative had already prompted "significant action at EU-level". He reminded them that over half of EU Member States had adopted national plans on dementia and he mentioned the recent ALCOVE Joint Action and the current Joint Action on Mental Health and Well-being (2013-2016).

The Commissioner noted that over EUR 1.9 billion had been dedicated to brain research within the 7th EU Framework Programme for Research and Innovation (2007-2013) and that the new Programme, Horizon 2020 is creating further opportunities for this research. He also mentioned the Human Brain Project – which he said will lay a new scientific and technical foundation for medical progress - and the European Innovation Partnership on Active and Healthy Ageing (EIPAAH).

Finally, he pointed out that the European Medicines Agency (EMA) and the Commission ran several projects in 2014, exploring ways to use the current regulatory framework for authorisation of medicines more effectively.


24 March: IMI announces new Board

The Innovative Medicines Initiative (IMI) announced its new Governing Board on 24 March, with five members from the European Commission and five members from (EFPIA).

The new Chair is Marc de Garidel of French pharmaceutical company, Ipsen Group. He brings more than 30 years of pharma experience to the role.

Find out who the other board members are here: http://www.imi.europa.eu/content/marc-de-garidel-gb-chair

24 March: EFPIA Think Tank takes place in Brussels

On 24 March, the European Federation of Pharmaceutical Industries and Associations (EFPIA) held a Think Tank in Brussels, Belgium. Participants discussed the state of play of the EU Regulation on Data Protection and areas of common concern, the programme of the EFPIA Healthcare Collaboration Summit (a meeting where industry and patient representatives meet to increase their mutual understanding and debate on shared policy concerns), the Riga conference organised by EFPIA, EPF, EGA and EPHA, the Patient Access Partnership, patients and industry attitudes to media, patients access to medical congresses. EPF presented its role in PISCE, an EU-funded project on self-care.

Annette Dumas took part on behalf of AE.

25 March: Eurodiaconia holds stakeholder meeting on topic of long-term care

On 25 March Eurodiaconia held an informal exchange among stakeholders on the topic of long-term care in Brussels, Belgium.

The aim was to share information, initiatives and advocacy priorities and see if areas of cooperation and joint action could be identified. Alongside Alzheimer Europe, the other organisations to participate were : AGE Platform EU, COFACE (Confederation of Family Organisations in the European Union), EASPD (European Association of Service Providers for Persons with Disabilities), ENNHRI (European Network of National Human Rights Institutions), ESN (European Social Network), Eurocarers and Eurohealthnet. The participants agreed to stay in contact, monitor the EU initiatives dealing with long-term care or having an impact on long-term care provision, and keep the group informed about their activities and priorities on long-term care.

Annette participated the meeting for AE

2 February: Jersey Alzheimer’s Association welcomes new educator

Michala Graham BSc/QTS was appointed as full-time Educator of the Jersey Alzheimer’s Association on 2 February 2015.

She has experience teaching Health and Social Care for the past seven years and has also completed in-depth training with a qualified dementia trainer in the UK.

She will help to raise awareness of dementia in the community and promote the services and activities provided by the Jersey Alzheimer’s Association. She will also offer educational workshops and visit many different groups of people of all ages in schools and colleges, businesses and services and care settings to improve people’s knowledge and understanding of dementia.

Michala is particularly interested in championing person-centred dementia care. She is keen to make a positive difference to the lives of those living with dementia and their families and carers by challenging stigma and improving island wide understanding and knowledge of the disease.

Michala Graham said:

“I am thrilled to have been offered the opportunity to work for Jersey Alzheimer’s Association. I am very much looking forward to raising awareness and ultimately enhancing the well-being and lives and experiences of those living with dementia. It is important to challenge attitudes which reinforce stigma and raising awareness at all levels and within all sectors, will help service providers
fully understand and appreciate what people living with dementia need.”

The Chair of Jersey Alzheimer’s Association, Jim Hollywood, said:

“We are delighted to have Michala Graham join us at Jersey Alzheimer’s Association. We are confident that with her enthusiasm, energy and determination, she will contribute enormously to our committed focus on public education concerning Alzheimer’s disease and the other dementias.”

For further information please contact Michala Graham by

E-mail: michalagrahamja@gmail.com

Phone: 07700 803756

22 February: Article in popular Croatian newspaper helps Alzheimer Croatia’s case for a National Dementia Strategy

Alzheimer Croatia reports on the recent publication of an article about living with Alzheimer's disease, by one of Croatia’s most popular newspapers.

The article attracted a lot of attention and helped to boost Alzheimer Croatia’s member numbers.

It describes the life of a retired architect (92 years old) and his wife who is also his carer (80 years old), who struggle alone with Alzheimer’s disease, which was diagnosed some years ago with help of Alzheimer Croatia.

The writer's portrayal of their lives draws attention to the problems shared by the majority of the 85,000 Croatian families affected by the disease. Alone, without significant help from the Croatian Government and for the most part with very low income (pensions), their only solace and advice comes from Alzheimer Croatia. This is why the organisation continues to put pressure on the Government to recognise the urgent need to develop a National Dementia Strategy.

Recent awareness-raising activities during World Alzheimer’s Month in Croatia, as well as subsequent appearances in the media have already helped to reduce stigma around dementia in Croatia. As a result of these activities, the number of families seeking help from Alzheimer Croatia has doubled, Alzheimer cafés are now taking place in eight Croatian cities and there has been an increase in the number of local Alzheimer’s associations.


28 February: Alzheimer Bulgaria publishes report on services for people with dementia

In February 2015, Alzheimer Bulgaria released a new report on services for people with dementia.

For more information about the new 21-page report, please email Alzheimer Bulgaria at office@alzheimer-bg.org

An English translation of the Executive Summary can be found here:

http://alzheimer-europe.org/Policy-In-Practice2/National-Dementia-Plans/Bulgaria#fragment-1

1 March: Jersey Alzheimer’s Association moves into new offices

Earlier this year, the Jersey Alzheimer’s Association moved into new offices. Their new address is: de Carteret House, Hilgrove Street, St Heller, Jersey JE2 4SL.

3 March: Nessa Childers hosts Alzheimer Society of Ireland MEP event

Nessa Childers, MEP and European Alzheimer’s Alliance (EAA) Vice-Chair (Ireland), hosted The Alzheimer Society of Ireland at an information session for Irish MEPs in the European Parliament in Brussels, Belgium on 3 March. The aim of this event was to update MEPs on Ireland’s first National Dementia Strategy and to discuss how to make dementia a national and European priority.

MEPs Deirdre Clune, Mairead McGuinness and Matt Carthy all took part in the event, while Marian Harkin was represented by her assistant. Helen Rochford-Brennan, Chair of the Irish Dementia Working Group and a Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD), addressed MEPs and spoke about her experience living with dementia and about her role as an advocate. MEPs also heard from Gerry Martin, CEO of The Alzheimer Society of Ireland, who spoke about Ireland’s first National Dementia Strategy and asked those present to raise the issue of dementia in their work as MEPs, not only as a health issue, but also as a community and social issue.

Alex Teligadas, Director for Communications of Alzheimer Europe (AE), presented on AE’s campaign to make dementia a European priority and on the Glasgow Declaration. Additional contributions were made by Joanna Joyce, Advocacy Officer of The Alzheimer Society of Ireland.

Since this information session seven Irish MEPs have signed the Glasgow Declaration.
11 March: Alzheimer Portugal calls for Health Minister to move forward with National Dementia Plan

On 11 March, Alzheimer Portugal sent a letter to the Portuguese Prime Minister, expressing concerns about the issue of dementia in Portugal and in the world, drawing attention to the World Health Organisation (WHO) Global Action Against Dementia conference, which took place in Geneva, Switzerland on 16 and 17 March. Alzheimer Portugal believes Portugal should be represented at the highest level in order to help make dementia a global priority.

The letter also aimed to draw attention to the urgency of moving forward with a National Dementia Plan. A draft plan was submitted in 2013 but has not yet been passed. Alzheimer Portugal has previously offered to cooperate in the creation and subsequent implementation of such a plan, being well placed to do so, given their considerable experience on the ground, supporting people with dementia and their carers.

They believe the four fundamental bases of the Plan should be:

- **Improving** the quality of life of people living with dementia and their carers - including pharmacological and non-pharmacological interventions, social support and equipment - by creating and implementing specific health and social policies.
- **Investigating** the causes of Alzheimer’s disease, looking at prevention and diagnosis and collecting epidemiological data.
- **Creating** a legal framework, defining the rights of people with disabilities, covering care, intervention and research issues.
- **Defining** the support and healthcare network clearly, based on present resources and the real needs of people living with dementia and their carers.

12 March: Czech Alzheimer’s Society has new logo

On 12 March, the Czech Alzheimer’s Society announced that it has adopted a new logo (pictured).

13 March: The Alzheimer Society of Ireland co-organises EP event on healthy ageing in Europe

The Alzheimer Society of Ireland (ASI) was one of several organisations that organised an event with the European Parliament Office in Ireland on 13 March. This event was titled “Promoting Good Health in Older Age: Engaging with Europe”.

MEP Nessa Childers, EAA Vice-Chair, and MEP Lynn Boylan represented the European Parliament at the event and took part in a discussion on the future of health issues in Europe. Tina Leonard, ASI’s Head of Advocacy presented on the work of ASI and on Ireland’s first National Dementia Strategy. During this presentation she highlighted the fact that dementia is a major constituency issue and must be seen as a political priority. Ms Leonard also used this opportunity to highlight the action that is being taken on dementia at a European level, including the Dementia Pledge and the Glasgow Declaration.

The event was very well attended, with over 100 people participating on the day. Presentations are available on the European Parliament Office website: [www.europarl.eu](http://www.europarl.eu)

17 March: Alzheimer Nederland and Alzheimer Society intensify their cooperation

Alzheimer Nederland and the Alzheimer’s Society (UK) will intensify their cooperation to stimulate research into dementia. The organisations have signed a memorandum of understanding to this effect.

The first concrete product of the collaboration is a fellowship program. This program makes it possible for scientists to exchange knowledge, ideas and expertise across the borders of the two countries. Both organisations have expressed their intention to support the cooperation, each investing EUR 60,000 over the course of the next two years.

Gea Broekema, Director of Alzheimer Nederland said:

“Alzheimer Nederland and the Alzheimer’s Society are two organisations with a long and proud history in funding research. It was a very logical decision to join our efforts.”

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

“We hope that our cooperation will stimulate other Alzheimer’s organisations to join us, so we can create new opportunities for researchers”.

19 March: France Alzheimer announces new online resource for carers


The new version, says France Alzheimer, is more user-friendly and is better adapted to the specific needs of each person.

20 March: Monaco’s AMPA holds press conference ahead of April’s “Rallye des Gazelles”

On 20 March, the Monaco Alzheimer’s Association (AMPA) held a press conference, announcing its participation in the 25th “Rallye Aicha des Gazelles” – the only female rally raid in the world - along with the Moroccan Alzheimer’s Association (MAA) and Sud Maroc Alzheimer, this April.

AMPA announced three actions:

1. Participation in the medical fleet, “Coeur de Gazelle” (Federico Palmeriti and Salomé Nicaise), to help raise dementia awareness in Moroccan communities.

2. Participation in the rally itself (Kate Williams and Laura Bougarne).

3. Inauguration of Morocco’s first platform to host support and research for Alzheimer’s disease, which will be operational in Essaouira from April, with the support of AMPA.

This year the rally will have 320 participants driving 4x4s, quads, SUVs and motorcycles.

Rally trailer in English: http://www.dailymotion.com/video/xoxcqc_coeur-de-gazelle


Rally website: http://www.rallyeaichadesgazelles.com/

21 March: Alzheimer Slovenija hosts public auction and football match

On 21 March in Ljubljana, Alzheimer Slovenia (Spomnica) hosted a public auction and football match for retired footballer, Zoran Ubavič, who was diagnosed with dementia aged 42. Now at age 50, his quality of life and financial situation have deteriorated considerably. The event made more than EUR 11,000 and was reported on Slovenian television and in national newspapers.

Mr Ubavič was a forward, who spent his entire career playing for Slovenian clubs. He was capped once for the Slovenia national football team in 1992 and was the Slovenian PrvaLiga top scorer in its inaugural 1991–92 season.

24 March: FAE now provides a neuropsychological evaluation service

On 24 March, the Spanish Alzheimer Foundation, Fundación Alzheimer España (FAE) announced its new Neuropsychological evaluation service, with the aim of encouraging the early diagnosis and treatment of dementia.

FAE believes that neuropsychological intervention programs must be applied from the beginning of the first symptoms, to be effective and so, has decided to offer neuropsychological assessments “to those that have subjective memory complaints, mood changes, little mistakes that occur more and more frequently, etc.” FAE offers to perform “a scan of cognitive status, behavioral, emotional and functional in order to address the situation; the sooner, the better.”

FAE psychologist, Luis García Sánchez wrote, described the new service:

“Neuropsychologists administer tests that have been developed through rigorous research in order to study people’s short and long term memory, attention, concentration, reasoning, ability to solve problems and learn new information...A variety of tests are available that can narrow the range of possible diagnoses by identifying patterns indicative of Alzheimer’s, head injury,
stroke, or other conditions that could be causing symptoms like depression”.

However, he warned "Despite the great utility of neuropsychological tests, they are not one tool sufficient for the diagnosis of dementia and must be interpreted as a complement to other diagnostic strategies.”

http://www.alzfae.org/

Policy Watch

16-17 March: Participants of WHO dementia conference launch a global Call for Action

On 16 and 17 March Switzerland played host to the World Health Organisation (WHO)’s first Ministerial Conference on Global Action Against Dementia, which brought together ministers from around the world and experts from the research, clinical and NGO communities, to discuss global issues surrounding dementia. 80 countries were represented at the event, which was supported by the UK Department of Health and the Organisation for Economic Cooperation and Development (OECD).

There was a clear consensus among delegates on the need for globally coordinated efforts to track the evolution of dementia and to create policies to address the impact of the condition and to conduct research for treatment and improved, cost-effective care.

The WHO committed to leading and coordinating efforts and also pledged to establish a Global Dementia Observatory that will monitor disease prevalence and dementia care resources in Member States and track the establishment of national dementia policies and plans. According to the WHO, priority actions in such plans should include raising awareness, working towards timely diagnosis, commitment to good quality continuing care and services, caregiver support, workforce training and research.

On day two of the conference, the UK Government’s announcement that it is investing over EUR 94 million into a pioneering global Dementia Discovery Fund was welcomed.

As the conference drew to a close, participants adopted a Call for Action, aiming to strengthen global efforts. The “Call for Action of the First WHO Ministerial Conference on Global Action Against Dementia” highlights the importance of, among others:

Empowering and engaging the full and active participation of people living with dementia, their caregivers and families, as well as overcoming stigma and discrimination.

Fostering collaboration between all stakeholders to improve prevention and care, and to stimulate research.

Balancing prevention, risk reduction, care and cure so that whilst efforts are directed towards finding effective treatments and practices and risk reduction interventions, continuous improvements are made on care for people living with dementia and support for their caregivers.

Emphasising that policies, plans, programmes, interventions and actions are sensitive to the needs, expectations and human rights of people living with dementia and their caregivers.

It calls for the following actions, among others, to be taken by governments the world over:

Raising the priority accorded to global efforts for dementia on the agendas of relevant high-level forums and meetings of national and international leaders.

Promoting a better understanding of dementia, raising public awareness and engagement, including the respect for their human rights, reducing stigma and discrimination, and fostering greater participation, social inclusion and integration of people living with dementia.

Advancing prevention, risk reduction, diagnosis and treatment of dementia, consistent with current and emerging evidence.

Facilitating technological and social innovations to meet the needs of people living with dementia and their caregivers.

Supporting a gender-sensitive approach in the elaboration of plans, policies and interventions aimed at improving the lives of people living with dementia.

Supporting the efforts of the World Health Organisation, within its mandate and work plans, to fulfill its leadership role in full collaboration with national and international partners, to promote and monitor global efforts on dementia.

In closing, WHO Director General, Dr Margaret Chan (pictured) applauded participants for adopting the Call for Action, which she called “a very strong showing of solidarity”. Dr Chan shared her hope that this Call could channel the momentum started by the G8 Legacy event in December 2013. “WHO is here to support this effort”, she pledged.

Dr Chan also paid special thanks to Luxembourg, whose Health Minister Lydia Mutsch announced during the conference that it would prioritise dementia under its EU Presidency (July to December 2015).

Alzheimer Europe’s Executive Director, Jean Georges attended the conference.


16 March: Global Dementia Framework document and website launched

As part of the 1st WHO Ministerial Conference on Global Action Against Dementia, the “Global Dementia Framework” was launched on 16 March. The Framework brings together pledges on dementia from different countries and organisations and collates information about dementia-related activities, allowing countries and organisations to promote their work to a global audience and identify other organisations, nations and regions they might collaborate with.
Activities and pledges are listed under the headings of: Care, Cure, Leadership, Open Science & Data, Research, Rights and Risk Reduction.

https://globaldementiaframework.wordpress.com/

17 March: UK Health Secretary announces USD 100m dementia discovery fund at WHO conference

On 17 March, during the first WHO Ministerial Conference on Global Action Against Dementia, UK Health Secretary Jeremy Hunt announced financial commitments made by several big pharmaceutical companies to the UK Government -run “Dementia Discovery Fund”.

Commitments made by GlaxoSmithKline, Pfizer, Johnson & Johnson, Lilly and Biogen – along side previous commitments from the UK government and Alzheimer’s Research UK - have brought the fund up to a total of USD 100 million (EUR 92.4m).


17 March: Luxembourg announces dementia as a priority of its EU Presidency in 2015

Lydia Mutsch, Luxembourg’s Health Minister attended the World Health Organisation (WHO)’s first Ministerial Conference on Global Action Against Dementia, with Luxembourg’s Permanent Representative in Geneva, Jean-Marc Hoscheit.

Speaking during a ministerial round table on day two of the conference, Minister Mutsch presented Luxembourg’s National Dementia Plan, the results of concerted action between several ministries and the upcoming secondary prevention programme, to “tackle multi-dimensional secondary dementia prevention from a wide ranging angle, including counselling for social issues, disease information, life-style advice, family and financial matters and legal aspects.” The programme is planned for July this year, coinciding with the start of Luxembourg’s EU Presidency.

Minister Mutsch declared that “dementia will be one of the main health related topics during the upcoming Luxembourg EU Presidency” and went on to make a number of commitments on dementia for the 6 month period (July to December):

Luxembourg’s aim, she said, is to increase public awareness at EU level and to launch a “common reflection process” among health ministers around the importance of secondary prevention and post-diagnostic support.

Together with the European Commission, Luxembourg will also discuss the possibility of formalising a permanent governmental expert forum at EU level, to “enable governmental authorities to exchange best practices and identify areas where European cooperation would make a difference.”

Minister Mutsch also spoke of the possibility of an EU wide Dementia Strategy to be tested among Member States.

In closing, she welcomed the Global Dementia Framework elaborated by the UK and expressed Luxembourg’s support for the global “Call for Action” adopted by conference participants.

Luxembourg’s commitments were received with great enthusiasm and, in particular, to be acclaimed by WHO Director General, Dr Margaret Chan during her closing speech later the same day.

26 March: Gibraltar pushes ahead with dementia strategy

On 26 March Gibraltar’s Health Minister, Dr John Cortes confirmed that the drafting of a Dementia Strategy is nearing completion and that the new Dementia Residential Home and Day Centre should open its doors in autumn of this year.

Gibraltar Alzheimer’s and Dementia Society (GADS) – which has already raised over GBP 100,000 (EUR 136,000) for use in the new premises with the help of the local community – had previously raised concerns about delays over the completion date.

Dr Cortes told the Chronicle that the delays were the “usual building contractors’ delays, with completion dates being reviewed. We are hoping the building works will be finished in the summer and that they will open in autumn.”

The workforce and model of care provision, he assured, was under active consideration.

Dr Cortes also assured that the Dementia Strategy would soon be under discussion with GADS and confirmed that the introduction of screening for dementia for over 60s and 65s was being considered as part of the strategy.

The announcement came on the same day that the film “Still Alice” made its debut on Gibraltar – or “the Rock” as it is affectionately known by locals.
Science Watch

7 February: Study looks at cognitive deterioration with suspected non-Alzheimer disease pathology (SNAP)

According to the widely accepted model of Alzheimer’s disease (AD), the brain begins to accumulate deposits of beta-amyloid 10 to 15 years prior to diagnosis, about 5 years before neurodegeneration involving the formation of tau aggregates, shrinkage of the hippocampus and slowing down of brain metabolism. This model and the assumption that beta-amyloid triggers neurodegeneration have been examined in recent studies.

Scientists at the IRCCS Istituto di Ricerche Farmacologiche Mario Negri in Bergamo, Italy conducted a study looking at predictors of progressive cognitive deterioration in patients with suspected non-Alzheimer disease pathology (SNAP) and mild cognitive impairment (MCI). Their results were published in the journal, Neurology on 7 February.

The team measured markers of amyloid pathology and neurodegeneration in 201 patients with MCI followed for up to 6 years - with 2.5 years being the average follow-up period - to detect progressive cognitive deterioration. People with MCI were categorised in four subgroups based on the presence or absence of amyloid pathology and neurodegeneration.

The highest rate of progression of cognitive deterioration amongst MCI patients was in the group with amyloid pathology and neurodegenerative markers. It was almost always the case that a clear progression of cognitive deterioration within two to three years occurred only when there were obvious neurodegenerative markers. An amyloid pathology seems to accelerate the process but does not seem to indicate an increased risk of progression.

The researchers suggest that from a clinical perspective, it may be interesting to look for neurodegenerative markers amongst MCI patients in order to estimate their risk of developing dementia. Their findings also support the notion that neurodegeneration in AD is not always necessarily induced by beta-amyloid in the brain and this raises the question of whether dementia without amyloid should be treated as Alzheimer’s dementia or rather whether there are different underlying pathological processes which resemble Alzheimer’s dementia.

http://www.neurology.org/content/early/2015/01/08/WNL.000000000001209.abstract

11 February: MIND diet could help protect against dementia

A study published in Alzheimer's & Dementia: The Journal of the Alzheimer's Association on 11 February, details the potential a new diet - developed by researchers from Rush University Medical Center in Chicago, US – has for reducing the risk of Alzheimer’s disease (AD).

The Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet was created by nutritional epidemiologist Dr Martha Clare Morris and her colleagues, using aspects of the DASH (Dietary Approaches to Stop Hypertension) diet and the Mediterranean diet.

Unlike the DASH and Mediterranean diets - in which high consumption of all fruits is recommended - the MIND diet focuses specifically on berries. Dr Morris explains that blueberries and strawberries in particular have been hailed for their “brain benefits” in past research.

The researchers analysed the food intake of 923 Chicago residents between the ages of 58 and 98 who were part of the Rush Memory and Aging Project - an ongoing study that aims to identify factors that may protect cognitive health.

Dietary information was gathered from food frequency questionnaires the participants completed between 2004 and 2013. The researchers scored participants on how closely their food intake matched either the MIND diet, Mediterranean diet or DASH diet. Incidence of AD was then assessed over an average follow-up period of 4.5 years.

The researchers found that participants whose food intake closely followed either of the three diets were at lower risk of AD. Participants who followed the Mediterranean diet were at 54% lower risk, those who followed the MIND diet were at 53% lower risk, while followers of the DASH diet had a 39% reduced risk.

However, the team found that participants who had a moderate adherence to the Mediterranean or DASH diets showed no reduced risk for Alzheimer’s, while moderate adherence to the MIND diet still put participants at 35% lower risk of developing the disease.

http://www.alzheimersanddementia.com/article/S1552-5260%2815%2900017-5/abstract

20 February: Diabetes and depression linked to progression from MCI to dementia

According to research published in the American Journal of Psychiatry on 20 February, a team led by Professor Gill Livingston at University College London conducted a systematic review of 62 research studies looking at the rates of conversion to dementia in almost 16,000 people with Mild Cognitive Impairment (MCI).

Amongst the factors investigated, the study revealed that:

• Diabetes significantly increased the risk of progression from MCI to dementia.

• Those with symptoms of depression were more likely to convert from MCI to dementia.

• Heavy alcohol use predicted greater likelihood of progressing from MCI to dementia. Evidence looking at moderate alcohol use was inconsistent, however.

• Following a Mediterranean diet decreased the risk of developing dementia in people with MCI.

• Lower vitamin B12 levels predicted a greater risk of conversion from MCI to dementia.

28 February: Study validates new technique to identify early signs of AD

A new study led by researchers from the University of California-Los Angeles (UCLA) has validated a new technique to measure atrophy - loss of tissue - in the hippocampus of the brain. Atrophy is one of the earliest indicators of Alzheimer's disease (AD). The study - led by Dr Liana Apostolova, director of the neuroimaging laboratory at the Mary S. Easton Center for Alzheimer’s Disease Research at UCLA - was published in February’s issue of the journal, Alzheimer’s and Dementia.

In AD, loss of memory is one of the first symptoms to show. Through structural magnetic resonance imaging (MRI) examinations, this has been found to be caused by atrophy in the hippocampus.

The European Alzheimer’s Disease Consortium-Alzheimer’s Disease Neuroimaging Initiative (EADC-ADNI) was set up in an attempt to create a clear-cut structural MRI technique to measure hippocampal atrophy in relation to AD.

From an in-depth analysis of the most commonly used structural MRI techniques for AD, the EADC-ADNI developed the Harmonized Hippocampal Segmentation Protocol (HarP). Dr Apostolova and colleagues set out to validate the technique in their study.

Using a powerful 7 Tesla MRI scanner, the team analysed the brains of nine deceased AD patients and seven “cognitively normal” deceased patients for around 60 hours each, which Dr Apostolova says provided “unprecedented visualization” of their hippocampal tissue.

The researchers then used HarP to measure the hippocampal volumes of all patients, before assessing the accumulation of tau proteins in each brain and the loss of brain cells - two key indicators of AD.

From this, the team found there was a strong correlation between hippocampal volume and tau protein accumulation and brain cell loss. The researchers say this provides "pathological confirmation" that hippocampal morphometry is a valid biomarker for AD and that HarP is an effective technique to measure it.

http://www.alzheimersanddementia.com/article/S1552-5260%2815%2900002-3/abstract

2 March: Alzheimer’s disease protein found in young brains

US scientists have found evidence of amyloid protein in the brains of people as young as 20. Their study was published in the journal, Brain on 2 March.

When study lead, Professor Changiz Geula, Cognitive Neurology and Alzheimer’s Disease Center at Northwestern University Feinberg School of Medicine, Chicago compared autopsy brains from normal people between ages 20-66 years, older people without dementia between 70-99 years, and people with AD between 60-95 years, they found evidence of amyloid in a particular part of the brain in all of them – a region that is not normally studied in AD, but it plays roles in memory and attention.

“There is some characteristic of these neurons that allows amyloid to accumulate there more than in other neurons,” says Geula. “At least in this cell population, the machinery to form aggregates is there.” Reducing the amount of amyloid in the brains of young people might help halt the formation of AD, the research concludes.

http://brain.oxfordjournals.org/content/early/2015/03/15/brain.awv024

4 March: Gout may help prevent AD, study concludes

People who suffer from gout may be less likely to develop Alzheimer’s disease (AD), according to surprising new research. The study was published in the journal, Annals of Rheumatic Disease on 4 March.

Scientists have previously suggested uric acid might play a role in slowing down the progress of brain conditions such as Parkinson’s disease (PD), but now researchers from the Boston University Medical Center and Massachusetts General Hospital in the US say AD risk might also be affected.

Researchers compared 59,204 British men and women with gout to 238,805 without the condition, finding a lower Alzheimer’s risk among gout sufferers, even when factors such as age, sex, socio-economic status and lifestyle factors were taken into account. The average age of patients in the study was 65. They researchers calculated that people with a history of gout had a 24 % lower risk of developing AD.

Gout is a painful condition, caused by higher levels of the waste product, uric acid in the blood and the formation of sodium urate crystals in the joints (pictured). It is usually caused by consuming high quantities of fatty foods and too much alcohol, particularly beer and spirits.

http://ard.bmj.com/content/early/2015/02/11/annrheumdis-2014-206917

5 March: NIH backs AD drug development with Open Science Portal

The National Institutes of Health (NIH) in the US has launched the Accelerating Medicines Partnership-Alzheimer’s Disease (AMP-AD) Target Discovery and Preclinical Validation Project. Under this initiative, teams of scientists will generate molecular and clinical data (genomic, epigenomic, RNAseq, proteomic) from more than 2,000 human brains. To enable the sharing of the resulting datasets, the NIH has funded the AMP-AD Knowledge Portal, an environment where massive amounts of data can be stored, accessed, and collaboratively analysed.

The portal will allow researchers from different labs to analyse and integrate data produced by molecular analysis of the 2,000 human brain samples (at every stage
11 March: Ultrasound may help treat AD, animal study suggests

New research carried out by a team at the University of Queensland in Australia has found high-energy sound waves helped remove abnormal clumps of proteins from the brains of mouse models, as well as improving their memory. Results were published in the peer-reviewed journal, Science Translational Medicine on 11 March.

There was a 50% reduction in plaques in mouse models whose brains were exposed to ultrasound once a week for five to seven weeks. Memory also improved to the extent that the mice were able to negotiate a maze just as well as healthy mice after the treatment and were also better able to avoid a section of a spinning wheel that would give them an electric shock.

The authors pointed out several important differences between this mouse study and the ability to use the technique in humans, however:

- The human brain is much larger, and the skull thicker, so the ultrasound would need to be stronger to penetrate all areas of the brain. This could have negative consequences, such as causing damage to healthy brain tissue.
- There are concerns that the level of immune response that might be activated in the human brain could be too high. To counter this, the researchers suggest the potential treatment regimen could focus on giving ultrasound to smaller sections at a time.
- The mice in the study already had plaques when the ultrasound was started. The researchers do not know at what point Alzheimer’s disease (AD) it would be appropriate to start treating humans. They are concerned that if they gave ultrasound to people with very early AD when there are few amyloid plaques, it may damage brain tissue.
- The study did not look at the long-term effects of the treatment.

Further animal studies will now be required, progressing to primates, before any human trials can take place.

http://stm.sciencemag.org/content/7/278/278ra33.abstract?sid=526a559-3565-41bc-8ed1-40b20d525a87

12 March: Epilepsy drug could be useful in AD treatment

A common epilepsy drug may reverse a condition that impairs memory in older people and increases the risk of developing Alzheimer’s dementia, suggests a study published on 12 March in the journal, NeuroImage: Clinical.

The small-scale study - carried out by US researchers at Johns Hopkins University in Baltimore, Maryland - found that low doses of the epilepsy drug, levetiracetam improved performance on an image recognition task for people with amnestic mild cognitive impairment (aMCI). This condition causes memory problems, and people who have it are at an increased risk of developing dementia.

The study involved 84 participants with an average age of 70. All participants were over 55 years old. 17 were healthy, while 67 had symptoms of aMCI. In a double-blind, randomised trial, researchers administered different doses of the drug and a placebo, and observed brain changes using MRIs during memory tasks. Even low doses of the drug improved memory performance and reduced hyperactivity in the brain, the researchers said.

“What we want to discover now is whether treatment over a longer time will prevent further cognitive decline and delay or stop progression to Alzheimer’s dementia,” said lead investigator, Dr Michela Gallagher.

The UK’s National Health Service (NHS) advised caution in interpreting the results of the study, commenting that the research had focused on the short-term impact of the drug on a single test and on brain activity scans. “It is also important to note that the effect of taking the drug for two weeks was not lasting. It is not possible to say from this study whether continuing to take the drug would reduce a person’s chances of developing dementia. Larger and longer-term trials would be needed to assess this”, they said, concluding that “the benefits and risks still need to be weighed up for each new condition a drug is used for. For now, levetiracetam remains a prescription-only medication that is only licensed for the treatment of epilepsy.”


16 March: VPH-DARE@IT partners hold 4th General Assembly

The VPH-DARE@IT partners held their 4th General Assembly on 16-17 March at Erasmus Medical Center in Rotterdam.

The agenda included updates from all the work packages and a poster exhibition. In addition, delegates broke out into working groups to examine specific topics and prepared their input for the annual project report. They also heard a presentation about the activities of Alzheimer Europe by Alex Teligadas, AE’s Director for Communication.

The partners also released their third project newsletter, which features progress and developments, partner activities and events, global news items about dementia-related research and articles and current research papers.
from the consortium. The newsletter can be downloaded at the project website.

The “Virtual Physiological Human: Dementia Research Enabled by IT” project aims to provide a modelling approach to understanding dementia onset and progression. This will enable earlier and more individualized diagnoses and prognoses of dementia.

VPH-DARE@IT has been funded by the European Commission within the 7th Framework Programme.

www.vph-dare.eu

18 March: Antipsychotics are more dangerous for people with dementia than previously thought, study finds

A recent study has found that antipsychotic drugs used to manage “behavioural problems” - such as delusions, hallucinations, agitation and aggression, which are experienced by some people living with dementia - may be leading to earlier deaths than previously thought. The study appeared in the journal, JAMA Psychiatry on 18 March.

Recognition has grown over the past ten years of the adverse events — including pneumonia, cardiac failure and cerebrovascular disorders — associated with the treatment of behavioural and psychological symptoms of dementia (BPSD). With this in mind, researchers from the University of Michigan Medical School and VA Center for Clinical Management Research looked at nearly 91,000 American veterans over the age of 65 with dementia, to clarify the absolute effect of these drugs on the risk of earlier death, as compared with no treatment or an alternative psychotropic.

Data from each patient who took a psychiatric medication was matched to data from a similar patient who didn’t take the drugs. The main outcomes of the study showed that those taking antipsychotics had a disproportionate risk of death and that among those taking the more commonly used antipsychotics, the risk climbed along with the dosage.

Lead author, Dr Donovan Maust commented that the harm associated with using such drugs for people with dementia is clear and that clinicians likely continued to use them due to the distressing nature of the symptoms they are used to quell, but that the study result ought to raise the threshold for prescription further.

Dr Doug Brown, director of research & development at the Alzheimer’s Society, said that in light of the risks, antipsychotic drugs should only ever be used as a last resort for people living with dementia. “Although they are important for a minority of people with dementia, disturbingly they are still often prescribed inappropriately or unnecessarily,” he said.

“Training professionals in safe alternatives for managing distressing behaviour can reduce the need for antipsychotic medication,” added Dr Brown.


20 March: Biogen drug trial shows promising early results

An experimental Alzheimer’s disease treatment - BIIB037 or aducanumab - being developed by biotechnology firm Biogen, slows cognitive decline, according to a study published on 20 March. The positive results of the small, preliminary study, involving 166 participants, were presented at 12th International Conference on Alzheimer’s and Parkinson’s Diseases and Related Neurological Disorders (AD/PD) in Nice, France.

In the trial, brain scans showed a reduction of amyloid plaques and the higher the dose of drug, the greater the reduction. Tests also showed that those people who took the drug had a slower rate of cognitive decline than those who did not – although the trial was not set up primarily to see whether there was any effect on cognition.

Based on these results, Biogen is advancing the aducanumab clinical program to Phase 3 with plans to initiate enrollment later this year.


24 March: Study concludes tau is more important than amyloid in AD

Researchers in the US have completed a study of more than 3,600 post-mortem brains, concluding that the progression of dysfunctional tau protein drives the cognitive decline and memory loss seen in Alzheimer’s disease (AD). Amyloid - the other toxic protein that characterises AD – builds up as dementia progresses, but is not the primary culprit, said the researchers at the Mayo Clinic in Florida and Minnesota. Their results were published in the journal, Brain on 24 March.

The study was conducted in two parts. Researchers studied brains donated to the Mayo Clinic over the course of more than a year; 1,375 of these brains were from patients who had been diagnosed with AD. These patients had died at different stages of dementia and at different ages. Researchers were, therefore able to evaluate AD progression on a timeline versus a snapshot in time, looking simultaneously at the impacts of tau and amyloid. This allowed them to evaluate the progressive, wide-ranging impacts of both proteins, using recommended scoring systems to examine the evolution of both in the brain tissue.

The findings showed that the severity of tau, but not of amyloid, predicted age onset of cognitive decline, disease duration, and mental deterioration.

The second part of the study examined amyloid brain scans taken of patients prior to death and compared the scans with measures of tau and amyloid brain pathology. It showed that amyloid can be found in the brains of older people who have not experienced cognitive decline.

Lead study author, Dr Melissa Murray said:

“The thought behind this is that tau is leading to the death of the neurons whereas amyloid may be causing a miscommunication between neurons. But it’s that death of the neuron that is really the extreme aspect of the
The challenges faced by older LGBT (lesbian, gay, bisexual and transgender) people in social care are the subject of a new report by The National Care Forum (NCF). NCF is working on the project with the National LGBT & Transgender Partnership, Sue Ryder and the Voluntary Organisations Disability Group under a Department of Health partnership. The partnership will disseminate practical case studies and create a toolkit for commissioners to support the specific needs of older LGBT people.

As the first part of the project, the partnership has published a paper, “The dementia challenge for LGBT communities”.

With approximately 1.2 million older lesbian and gay people currently living in the UK, the report stresses the importance of raising awareness for a population it describes as “an invisible population...rarely acknowledged by service providers and commissioners”.

There is currently no specific reference to LGBT issues in the UK’s National Dementia Strategy despite the fact that older LGBT people with dementia are more likely to be estranged from their relatives. With this potential lack of family support, formal care is likely to be important, the report suggests.

The issue of prejudice in care is also raised, which the authors point out may affect how someone perceives and experiences support. “It cannot be right that people from the generation that fought hard for equality are forced back into the closet when they receive social care”, they say.

In terms of proposed solutions to some of these issues, the report says that while some campaigners believe LGBT-specific residential care for people with dementia might work, this is both unlikely in the current financial climate and also many people do not want to live in LGBT-only care settings. What is preferable, they say, is “LGBT friendly” dementia support in mainstream settings – which relies less on funds and more on cultural change and staff training.

They suggest, rather, that developing better practices is the way forward, through training, discussion forums and by ensuring the Care Quality Commission regulator places pressure on commissioners to do more to address support for ageing LGBT communities.

12 March: Author, Sir Terry Pratchett dies with Alzheimer’s disease

British author, Sir Terry Pratchett, who wrote the famous Discworld series of novels, has died aged 66 with Alzheimer’s disease.

The announcement came in typically irreverent manner on the author’s Twitter feed, with a series of tweets beginning in the voice of his Discworld character, Death: “AT LAST, SIR TERRY, WE MUST WALK TOGETHER.”

Mr Pratchett’s publisher, Larry Finlay, paid tribute to one of the world’s “brightest, sharpest minds”:

“In over 70 books, Terry enriched the planet like few before him,” he said. “As all who read him know, Discworld was his vehicle to satirise this world: he did so brilliantly, with great skill, enormous humour and constant invention.”

Mr Finlay announced that the author died at his home "with his cat sleeping on his bed, surrounded by his family" on Thursday 12 March.

Terry Pratchett had publicly announced his diagnosis with early onset Alzheimer’s disease in 2007.

New Publications & Resources

13 March: World Dementia Council publishes first year progress report

The World Dementia Council (WDC) has published a report setting out the progress it has made on its five priorities in the past year, as well as calling for further action that is still needed to tackle dementia globally.

The full report can be read here:


16 March: Fondation Médéric Alzheimer publishes brochure for notaries with older clients with cognitive impairments

The Fondation Médéric Alzheimer has published a brochure called "Le Notaire face aux citoyens en situation de handicap cognitif – Repères pour la pratique" in partnership with the Conseil Supérieur du Notariat

The brochure is aimed at helping notaries with older clients with cognitive problems, who are buying or selling property or with making a will, for example. It gives practical and structured advice to the notary in order to better recognise potential risks and to decide whether a client may not be able to make and express decisions for themselves.

The brochure (in French) is free to download:

http://www.fondation-mederic-alzheimer.org/content/download/18763/83756/file/BrochureNotairesFondationMedericAlzheimer.pdf

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>1 April</td>
<td>Meeting with MEP Françoise Grossetête’s assistant (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>2 April</td>
<td>Meeting of the ethics working group looking at ethical dilemmas (Luxembourg, Luxembourg)</td>
<td>Dianne and Jean</td>
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<tr>
<td>9-10 April</td>
<td>Meeting of Dissemination working group (WP6) for EPAD project</td>
<td>Alex and Jean</td>
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<tr>
<td>21-24 April</td>
<td>Visiting potential venues for AEC 2016 (Tallin, Estonia)</td>
<td>Gwladys</td>
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<tr>
<td>23-24 April</td>
<td>Kick-off meeting of the MIAMI-MD project (Chelmsford, United Kingdom)</td>
<td>Dianne and Kate</td>
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### Future Conferences 2015

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>23-25 April</td>
<td>ICFSR 2015 International Conference on Frailty &amp; Sarcopenia research, <a href="http://www.jfrailtyaging.com">www.jfrailtyaging.com</a></td>
<td>Boston, USA</td>
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<tr>
<td>5 May</td>
<td>La démence à tous âges : enjeux et spécificités, <a href="http://www.alzheimer.be">www.alzheimer.be</a></td>
<td>Brussels, Belgium</td>
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<tr>
<td>14-17 May</td>
<td>9th Panhellenic Conference on Alzheimer’s Disease and 1st Mediterranean Conference on Neurodegenerative Diseases, <a href="http://9thconference25.med.auth.gr/conference/go/index.html">http://9thconference25.med.auth.gr/conference/go/index.html</a></td>
<td>Thessaloniki, Greece</td>
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<tr>
<td>1-7 June</td>
<td>Dementia Awareness Week: Let’s talk about dementia, <a href="http://daw.dementiascotland.org/">http://daw.dementiascotland.org/</a></td>
<td>Scotland, UK</td>
</tr>
<tr>
<td>5-6 June</td>
<td>The Alzheimer’s Show London, <a href="http://alzheimershow.co.uk/">http://alzheimershow.co.uk/</a></td>
<td>London, UK</td>
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<tr>
<td>11-13 June</td>
<td>7th Kuopio Alzheimer Symposium “From mechanisms to prediction and intervention of Alzheimer’s disease”, <a href="http://www.uw.fi/kuopiosymposium">http://www.uw.fi/kuopiosymposium</a></td>
<td>Kuopio, Finland</td>
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<tr>
<td>20-23 June</td>
<td>1st Congress of the European Academy of Neurology (EAN), <a href="http://www.eaneurology.org/berlin2015">www.eaneurology.org/berlin2015</a></td>
<td>Berlin, Germany</td>
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<tr>
<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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<tr>
<td>2-4 September</td>
<td>23th Alzheimer Europe Conference “Dementia: putting strategies and research into practice”, <a href="http://alzheimer-europe.org/conferences/2015-ljubljana">http://alzheimer-europe.org/conferences/2015-ljubljana</a></td>
<td>Ljubljana, Slovenia</td>
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<tr>
<td>31 October-5 November</td>
<td>XXII World Congress of Neurology, <a href="http://www.wcn-neurology.com">www.wcn-neurology.com</a></td>
<td>Santiago, Chile</td>
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<tr>
<td>9-12 March 2016</td>
<td>14th International Athens/Springfield Symposium on Advances in Alzheimer Therapy, <a href="http://www.ad-springfield.com">www.ad-springfield.com</a></td>
<td>Athens, Greece</td>
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</table>
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