Welcome to the Alzheimer Europe

NEWSLETTER

May 2016

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Editorial

Welcome!

Well, it has certainly been another busy month! First off, we’ve been working through the abstract selection process for our 26th annual conference. I would like to thank everyone who submitted abstracts and am delighted to report that the Scientific Committee has approved 143 oral presentations and an additional 167 poster presentations, from the 357 abstracts submitted. If you have not yet been notified of the status of your abstract, you will be shortly.

Besides our own conference, we have been kept busy with a number of other international conferences this month, including the Dutch EU Presidency conference on dementia, which I was delighted to be a part of. During his opening speech, Deputy Minister for Health, Welfare and Sport in the Netherlands, Martin van Rijn called for a more dementia-friendly society and officially launched the Netherlands’ own Dementia Friends programme. I was also delighted to join the 69th World Health Assembly of the WHO in Geneva, which saw a number of Ministers of Health giving their support for the development of a resolution on dementia at the next World Health Assembly.

Our European Alzheimer’s Alliance (EAA) members have also been active, with 32 of them signing their support to the European Parliament Written Declaration 0027/2016 on the prioritisation of a European Dementia Strategy. Six members of the EAA, along with two other MEPs, also sent an open letter to the Dutch Health Minister and POLITICO, prior to the Dutch EU Presidency conference, calling for a collaborative approach from the European Commission, the European Commission Group of Government Experts in Dementia and all stakeholders to define a European Alzheimer Strategy.

There was more good news at the end of the month, with the announcement on 30 May that a Draft Decision on dementia, backed by 38 Member States and urging the WHO to take action on dementia was adopted at the 139th Executive Board meeting of the WHO. Last but not least on the policy front, I am delighted to be able to say “čestitke” (congratulations) to our friends at Alzheimer Slovenia for all their hard work on the National Dementia Strategy, which has paid off with the announcement that it has been signed by the Minister of Health Milojka Kolar Celarc and was presented at a press conference on 25 May.

All of this is excellent news for dementia policy in Europe and has our wholehearted support!

May has also been a good month for a number of the European projects in which we are involved, most particularly the European Prevention of Alzheimer’s Dementia (EPAD) initiative, which was delighted to announce the recruitment of its first research participant on 10 May. This news was enthusiastically welcomed at the EPAD General Assembly and Colloquium in Barcelona later in the month.

I wish you all a successful June and some better weather than Luxembourg has seen in recent days!

Jean Georges
Executive Director
25 May: AE presents its work on national care pathways at ICIC 2016

The 16th International Conference on Integrated Care (ICIC 2016) took place in Barcelona on 23 - 25 May 2016. The conference was organised by the International Foundation of Integrated Care (IFIC) and was co-hosted by the Catalan Government’s PIAISS, Hospital Clinic Barcelona (HCB), Forum ITESSS, and the TIC Salut Foundation.

The event brought together researchers, clinicians, managers and patient representatives from around the world who are engaged in the design and delivery of integrated health and social care. More than 1,000 delegates participated in the event and some additional 200 people followed it live stream.

The conference addressed the topics of integration across the care continuum, person-centred and integrated care, mental health and the use of mobile and digital health and care solutions. In addition, the final results of some relevant EU projects, such as the FP-7 European project INTEGRATE and EMPATHIE (Empowering patients in the management of chronic diseases) were presented during the conference.

On 25 May, AE Project Officer Ana Diaz presented Alzheimer Europe’s work on national care pathways for people with dementia living at home and participated in the kick-off meeting of the Special Interest Group on Values and Principles of integrated care.

The 2017 Conference on Integrated Care (ICIC 2017) will take place in Dublin, Ireland on 8-10 May 2017.

27 May: AE will continue as a member of the PCWP for another three years

On 27 May, Alzheimer Europe (AE) was accepted as a continuing member of the European Medicines Agency’s PCWP - the Working Party with Patients' and Consumers' Organisations - for the period 2016-2019.

The PCWP provides recommendations to the European Medicines Agency and its human scientific committees on all matters of interest to patients in relation to medicinal products. The working party is composed of representatives from patients’ and consumers’ organisations that fulfil the eligibility criteria, as well as the Agency’s human scientific committees and the Agency secretariat.

30 May: Alzheimer Europe finalises abstract selection for 26th annual conference

Alzheimer Europe would like to thank everyone who submitted abstracts for its 26th annual conference (26AEC) in Copenhagen from 31 October to 2 November 2016. The Scientific Committee has reviewed all 357 submitted abstracts and has approved 143 oral presentations and an additional 167 poster presentations.

Notifications are currently being sent out to all applicants. Selected presenters for poster and oral presentations must register by 30 June, when Early Bird registration closes.

http://alzheimer-europe.org/Conference/2016-Copenhagen

EU projects

10 May: Bid to prevent Alzheimer’s dementia signs up first study recruit

A major study to find interventions that prevent the onset of Alzheimer’s dementia has recruited its first participant.

The GBP 50 million (EUR 64 million) Europe-wide initiative aims to improve understanding of the early stages of Alzheimer’s disease and how it leads to dementia.

Julie Duffus (pictured) from near Edinburgh in Scotland is the first person to take part in the project, which aims to recruit 6000 volunteers from across Europe.

Participants will have regular health checks including blood tests and brain scans. Researchers will also track their thinking skills over time using tests of mental agility.

The team hopes to develop tests to identify early signs of Alzheimer’s disease that may indicate when a person is at risk of dementia before symptoms appear.

They will then invite these people to take part in clinical trials aimed at testing interventions that could delay, or even prevent, the onset of dementia.

The study is called the European Prevention of Alzheimer’s Dementia initiative (EPAD) and involves 36 organisations including universities, commercial partners and patient organisations.

Professor Craig Ritchie, of the University of Edinburgh, is jointly leading the study and has recruited the first participant.

Professor Ritchie said: “This is an important milestone in our quest to better understand the earliest stages of Alzheimer’s dementia. Early signs of Alzheimer’s disease are often present for up to twenty years before a person develops any symptoms. We believe that if we can identify these people sooner, early intervention may have greater success at tackling the disease.”

11 May: PACE project publishes its first paper

The EU-funded project PACE - Palliative Care for Older People in care and nursing homes in Europe - is delighted to announce that it published its first paper in a scientific journal. The paper “Comparing Palliative Care in Care Homes Across Europe (PACE): Protocol of a Cross-sectional Study of Deceased Residents in 6 EU Countries” appeared in the Journal of the American Medical Directors Association (JAMDA) on 11 May.

In it, PACE explores the growing challenges associated with aging in all European countries, concluding that there is “an urgent need to build a robust international comparative evidence base that can inform the development of policies to target improved palliative care in care homes.”

PACE hopes this paper will help inform international research in care homes on how to perform representative end-of-life care research in these settings and better understand which systems are associated with better outcomes.


17 May: EPAD partners hold General Assembly and Colloquium

On 17-19 May, the EPAD partners held a General Assembly in Barcelona, Spain under the banner “Initiation and Delivery”. The first day began with project leaders Craig Ritchie, Serge van der Geyten and José Luis Molinuevo...
welcoming some 120 delegates to the meeting. The delegates then joined working sessions to discuss their progress toward the project deliverables. Alzheimer Europe, along with Novartis, is co-leading the work package on dissemination activities and AE is also involved in the work package entitled “Ethical, Legal and Social Implications”.

The EPAD Colloquium also took place on the first day, with a focus on dissemination and how some trial centres have been successful in motivating people to become involved in research by developing local alliances and keeping these people informed and interested in ongoing research projects. The first speaker was Jean Georges (Alzheimer Europe) who presented current and upcoming EPAD communication activities. Prof Ritchie (University of Edinburgh) described the activities of the PREVENT project and Prof Miia Kivipelto (Karolinska Institutet, Sweden) showed the results of the FINGER study. In addition, Ms Maria Escrivà, Communication Specialist at the BarcelonaBeta Brain Research Center (BBRC), presented the ongoing activity around the ALFA study.

The second day focused on the development of EPAD’s longitudinal cohort study (LCS), which is in the final stages of preparation before approval. The project recently received positive feedback from the European Medicines Agency (EMA) on the LCS methodology. The delegates also discussed legal issues around data sharing and sample access, the ethical considerations of disclosing the risks of developing dementia and the setting up of participant panels at the European and local level, as well as future communication activities. In addition, a poster session showcased all the recent achievements of the project partners. The second day concluded with a visit to the new premises of the BBRC, which conducts research among adult children of people with Alzheimer’s dementia.

Day 3 focused on addressing issues to be resolved and a presentation on how the EPAD partners are cooperating with other dementia research projects. These include the current AETIONOMY and EMIF consortia and the upcoming AMYLPAD (Amyloid Imaging to Prevent Alzheimer’s Disease) project, all of which are funded by IMI - the Innovative Medicines Initiative. The delegates also held work package meetings to prioritise their upcoming activities and these were presented in the final session of the conference. The next EPAD General Assembly will take place in Stockholm, Sweden in 2017.

Executive Director Jean Georges, Director for Communication Alex Teligadas and Director for Projects Dianne Gove represented Alzheimer Europe at these meetings.

To keep up to date with EPAD’s progress follow @IMI_EPAD on Twitter and visit the website http://ep-adr.org

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20 May 2016: SMART4MD project adopts logo

On 20 May, the SMART4MD project announced it has chosen its logo.

The four year project is developing an app called Support, Monitoring and Reminder Technology for Mild Dementia (SMART4MD). The app is being designed to help people with mild dementia adhere to treatment regimens as well as allowing them to share health-related data with their carers and doctors.

23 May: PACE consortium meets Helsinki to discuss project progress

On 23-24 May in Helsinki, Finland, the EU-funded project PACE - Comparing Palliative Care in Care Homes Across Europe held a General Assembly and a Consortium Meeting, including an Impact and Dissemination meeting.

During the two-day Consortium Meeting, speakers from different Work Packages (WP1, WP2, WP4, WP6 and WP8) presented their progress so far, including some preliminary results. Interestingly, some such results showed that, in the countries surveyed so far, the majority of people dying in care homes have dementia, with statistics between 58% and 83%.

It was also mentioned during these meetings that PACE has recently published its first paper and that the project was also presented at the 31st Alzheimer’s Disease International (ADI) conference, in Budapest, where Dr Jenny van der Steen spoke during the Plenary session on 22 April, and at the Dutch EU Presidency conference “Living well with(out) dementia” on 10 May.

Alzheimer Europe (AE), a partner in PACE’s “Impact and Dissemination” Work Package (WP8), was represented by Director for Projects Dianne Gove and Communications Officer Kate Boor Ellis at these meetings. WP8 held its own meeting on 24 May, to discuss progress made and agree on some future plans. The group agreed on the important points to present to the full consortium meeting that afternoon, as well as agreeing on three future user fora, results from which will inform project deliverable 8.4, the Policy Recommendations, planned for January 2019. AGE Platform Europe held the first user forum in September 2015 and will hold a second one on 15 June 2016 - for which subscriptions are still open until 14 June - and a third in early 2017. AE will hold a user forum more specific to people with dementia in mid-2017, which will be followed by a meeting with the researchers and the Impact and
Dissemination group to develop the Policy Recommendations.

You can subscribe to the PACE newsletter to keep up to date with progress, and can find more information on the project website:

http://www.eupace.eu/

**24 May: NILVAD project nears completion as partners hold 5th General Assembly**

On 24-25 May, the NILVAD partners met in Dublin, Ireland to discuss progress of the project’s clinical trial of nilvadipine for mild to moderate Alzheimer’s disease. The phase 3 trial is now only a few months away from completion among more than 500 participants at 21 sites in nine European countries.

As of May 2016, 326 people had completed the trial. The delegates heard updates on the close-out of trial sites and discussed various aspects around data management, particularly the statistical analysis that will begin when the remaining participants finish the trial in the last months of 2016. The final results of the clinical trial will likely be announced in mid-2017.

The agenda also included updates on the blood biomarker, blood flow and frailty sub-studies within the project. These are being conducted among groups of volunteers at several study sites. An additional sub-study on the personal experiences of the trial participants and their caregivers is close to receiving final approval and some 230 people in three countries will be invited to participate. This study was originally conceived by Alzheimer Europe and the association is also a partner in the Dissemination and Communication work package.

**Alzheimer Europe networking 2016**

On 2 May 2016 (Bern, Switzerland), Jean attended an evaluation meeting of the Swiss dementia strategy convened by the Swiss Government.

On 9-10 May 2016 (Amsterdam, Netherlands), Heike and Jean attended the EU Presidency Conference “Living well with(out) dementia”.

On 12 May 2016 (Luxembourg, Luxembourg), a delegation of MSD met with Jean in the AE offices for an exchange of views.

On 13 May 2016 (Brussels, Belgium) Vanessa attended a meeting at Eurodiaconia with a coalition of organisations working on long term care and integrated care.

On 17 May 2016 (Brussels, Belgium) Vanessa attended a public hearing at European Economic and Social Committee (EESC), on the Concluding observations of the UN CRPD Committee to the EU.

On 17-19 May 2016 (Barcelona, Spain), Jean, Dianne and Alex attended the General Assembly of the European Prevention of Alzheimer’s Dementia (EPAD) project.

On 18 May 2016 (Smolenice, Slovakia) Honorary Treasurer Charles Scerri represented AE at the Slovak conference “National Programme: To Conquer Alzheimer’s disease and Other Forms of Dementia”.

On 20 May 2016 (Berlin, Germany) Sabine Jansen, Executive Director of DAzG represented AE at the World Congress of Psychiatry 2017 kick off-meeting.

On 23 May 2016 (Geneva, Switzerland), Jean participated in the ministerial panel on dementia organised in the framework of the World Health Assembly of WHO.

On 23 May 2016 (Helsinki, Finland), Dianne attended the General Assembly of the PACE project.

On 23-24 May 2016 (Helsinki, Finland) Dianne and Kate attended the Consortium Meeting of the PACE project.

On 23-25 May 2016 (Barcelona, Spain) Ana attended the 16th International Conference on Integrated Care.

On 24 May 2016, Jean participated by teleconference in the Steering Committee meeting of the AETIONOMY project.

On 24-25 May 2016 (Dublin, Ireland) Alex attended the 5th General Assembly of the NILVAD project.

On 25 May 2016 (Luxembourg, Luxembourg), Jean and Dianne had a meeting with the Luxembourg Institute of Science and Technology.

On 31 May (Amsterdam, Netherlands) Jean and Ana participated in a meeting for the Carers’ Survey.
Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 126, 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 for 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); Kathlene van Brempt (S&D); Hilde Vautmans (ALDE). Bulgaria: Andrey Kovatchev (EPP), Croatia: Biljana Borzan (S&D); Tonino Picula (S&D); Ruda Tomasić (ECR). Cyprus: Costas Mastrides (S&D); Eleni Theocharous (EPP). Czech Republic: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). Denmark: Ole Christensen (ALDE); Jens Rohde (ALDE); Christel Schaldemose (S&D). Estonia: Urmas Paet (ALDE); Finland: Lisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Miatpora Kumpula-Natri (S&D); Merja Yliluoma (GUE/NGL); Sirpa Pietikäinen (EPP). France: Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chuitier (EPP); Gilles Pargneaux (S&D). Germany: Angelika Niebler (EPP); Udo Voigt (NI). Greece: Kostas Chrysogonos (GUE/NGL); Manolis Kelafogianis (EPP); Kostadinka Kuneva (GUE/NGL); Kyriakos Mitsotakis (S&D); Dimitris Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyraiki (EPP); Eleftherios Synadinos (NI). 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); Seán Kelly (EPP); Mairead McGuinness (EPP). Italy: Brando Benifei (S&D); Elena Gentile (S&D); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D); Damiano Zoffoli (S&D). Latvia: Ineta Elfena Gentile (S&D); Roberta Metsola (EPP). Lithuania: Vilmija Blinkyviciute (S&D). Luxembourg: Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP). Malta: Therese Comodini Cachia (EPP); Roberta Metsola (EPP); Alfred Sant (S&D). Netherlands: Esther de Lange (EPP); Jeroen Lenaers (EPP); Lambert van Nistelrooij (EPP). Poland: Elżbieta Łukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Plura (S&D); Bogdan Wenta (EPP). Portugal: Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP); Daciana Octavia Sarbu (S&D). Romania: Cristian-Silviu Busoi, MEP (EPP); Daciana Octavia Sarbu (S&D); Claudiu Ciprian Tanasescu (S&D); Renate Weber (EPP). Slovakia: Miroslav Mikolášik (EPP); Ivan Stefanec (EPP); Anna Zábovská (EPP); Jana Žitňanská (ECR). Slovenia: Franc Bogovčič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Sulin (EPP); Romana Tomc (EPP); Ivo Vajgl (ALDE); Milan Zver (EPP). Spain: Iñaki Urteaga (S&D). Spain: Carles Puigdemont (S&D). Sweden: Ida Auken (S&D); Marie Solberg (EPP). The United Kingdom: Iain Duncan Smith (EPP); Ian Duncan (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claire Perry (EPP); Debbie Abrahams (GUE/NGL); Caroline Lucas (Greens/EFA); Peter Ward (EFD); Colin Cochrane (NI). United States: Michael.tokenize (EPP); C. Steve Daines (S&D). Wales: Carwyn Jones (Plaid Cymru). World: Sir Richard Atkinson (EPP); Jytte Guteland (S&D); Richard Ashworth (ECR); Anneliese Dodds (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D); Glenis Willmott (S&D).

European Alzheimer’s Alliance

1 May: EAA member Deirdre Clune has initiated the Written Declaration on prioritisation of a European dementia strategy

Irish MEP Deirdre Clune, along with ten other MEPs, has initiated a Written Declaration on the prioritisation of a European Dementia Strategy. Launched on 4 April, the Declaration calls upon the Council and the Commission to make combatting Alzheimer’s and other types of dementia a top priority of the European Union (EU), and to put further emphasis on cooperation among Member States in the areas of research, care and prevention.

In her past contributions to Alzheimer Europe (AE)’s campaign to make dementia a European priority Ms Clune has:

- Participated in an AE lunch debate in Brussels on 30 June 2015, on the Global Action against Dementia.
- Signed the Glasgow Declaration on 18 March 2015.
- Participated in an AE lunch debate in Brussels on 2 December 2014, on the topic of dementia prevention.
- Signed AE’s European Dementia Pledge, thus becoming a member of the EAA and affirming her support for greater EU collaboration on dementia, in May 2014.

Ms Clune sits on the Transport and Tourism Committee. She is a substitute on the Employment and Social Affairs Committee.


11 May: EAA member Carlos Coelho promotes Written Declaration on prioritisation of a European dementia strategy

MEP Carlos Coelho (Portugal) has been a member of the European Alzheimer’s Alliance (EAA) since February 2008. In his contributions to Alzheimer Europe’s campaign to make dementia a European priority he recently signed the ongoing European Parliament Written Declaration 27/2016 calling for the prioritisation of a European dementia strategy. Mr Coelho belongs to the EPP group in Portugal, who took the opportunity to spread the word about the Declaration online following his signature.

- Signed EP Written Declaration 80/2008 on the priorities in the fight against Alzheimer’s disease.
- Attended Alzheimer Europe annual conference in Lisbon in 2007 and signed the Paris Declaration.

Mr Coelho sits on the Internal Market and Consumer Protection Committee. He is a substitute on the Committee on Civil Liberties, Justice and Home Affairs.
30 May: 32 EAA members sign Written Declaration on the prioritisation of a European Dementia Strategy

Alzheimer Europe would like to thank the 32 members of the European Alzheimer’s Alliance (EAA) who have signed Written Declaration 0027/2016 on the prioritisation of a European Dementia Strategy:

Martina Anderson (UK), Brando Benifei (Italy), Dominique Bilde (France), Franc Bogović (Slovenia), Cristian-Silviu Buoi (Romania), Soledad Cabezon Ruiz (Spain), Kostas Chrysogonos (Greece), Deirdre Clune (Ireland), Carlos Coelho (Portugal), Tanja Fajon (Slovenia), Marian Harkin (Ireland), Brian Hayes (Ireland), Anneli Jäätteenmäki (Finland), Barbara Kappel (Austria), Ádám Kösa (Hungary), Merja Kyllönen (Finland), Peter Lundgren (Sweden), Marisa Matias (Portugal), Linda McAllan (UK), Mairead McGuinness (Ireland), Roberta Metsola (Malta), Alojz Peterle (Slovenia), Sofia Ribeiro (Portugal), Sofia Sakorafa (Greece), Christel Schaldemose (Denmark), Igor Soltes (Slovenia), Ivan Štefanec (Slovakia), Pavel Svoboda (Czech Republic), Ivo Vajgl (Slovenia) Julie Ward (UK), Tomáš Zdechovský (Czech Republic), Milan Zver (Slovenia).

Written Declaration 0027/2016 is open for signatures until 11 July 2016: http://goo.gl/MbVebN

EU developments

21 April: European Commission holds Conference on Chronic Diseases - Towards better prevention and management of chronic diseases

The meeting outlined the EU approach towards chronic diseases and identified areas for EU added value in preventing chronic disease and reducing their health and economic impact.

European Commissioner for Health and Food Safety, Vytenis Andriukaitis gave the opening speech which can be read in full here.

Participants included representatives of Member States, international organisations, civil society and patient organisations active in the field of chronic diseases, as well as representatives of the medical and social sector, insurance and social security systems.

Chronic diseases have had an enormous impact on health systems. 70 to 80% of all healthcare costs in the EU - an estimated EUR 700 billion – is currently spent on chronic diseases. In addition, chronic diseases completely stop many people from being able to work

Many chronic diseases, like cardiovascular diseases and type 2 diabetes, are largely preventable through healthy lifestyle choices, and others illnesses, like multiple sclerosis or dementia, can be managed to help patients feel their best and remain active for longer. With better prevention and management it could also be possible to reduce their impact.

At the conference, all the participants were invited to work jointly on the implementation of activities with a potential to reduce the impact of chronic diseases, improve health outcomes and reinforce the stability of health systems.

During the conference, the Commission launched The Health Policy Platform - the successor to the Health Policy Forum. It will be an online tool for communicating and working collaboratively between the European Commission and EU and national health stakeholders but also amongst health stakeholders themselves. This platform should be a better way of advancing work via online and face-to-face discussions, sharing best practices, drafting joint statements and promoting events. It will also give access to a library of relevant materials.

25 April: European Economic and Social Committee (EESC) holds Public Hearing on long-term care sector

A public hearing held on 25 April will contribute to the European Economic and Social Committee (EESC) opinion on the subject – “Long term social care labour supply and mobility”. This own initiative opinion from the EESC will elaborate on the human and social rights of “live-in” care workers in the context of labour supply and mobility issues that face the long-term care (LTC) sector as a whole.

The organisation and provision of LTC is a challenge many Member States are facing. The sector is underpaid, highly feminised and often employs undocumented migrant workers. It suffers from workforce imbalances and skills shortages. Situations of undeclared work and poor working conditions affect mainly live-in carers.

Proactive measures to encourage the creation of quality, well-paid jobs in the sector with decent working conditions are needed, to ensure an adequate labour supply for the LTC sector.

It is important that the needs of carers be made more visible and for carers to have their rights recognised. They need professional growth with access to ongoing training - for example elderly people have changing needs and may require specialised care, particularly if they are diagnosed with a form of dementia. Care should be seen as an investment and should be valued, and elderly care should be based on national service with a co-ordinated action plan.

The European Union (EU) has various tools at its disposal but the needs of carers are spread across many different sectors including health, employment and justice, among others. In essence, there is a need for long and short-term care solutions, but the focus should also be on quality of jobs for the workforce.

The discussion explored these issues in the context of labour and migration policies at European and national levels and will put forward relevant recommendations for
action. The speakers included MEPs and representatives from the European Commission, civil society and NGOs. All presentations from the hearing can be viewed here. A preliminary draft opinion will be available by 5 July.

27 April: IMI holds Patient Engagement Workshop

The Innovative Medicines Initiative Joint Undertaking (IMI JU) organised an exploratory workshop on how to foster patient engagement in medicines’ Research and Development (R&D) and discuss how IMI themselves can support this endeavour in future calls for proposals.

The overarching objective was to facilitate a discussion to assist IMI in further developing its patient engagement strategy and in particular to:

- Identify appropriate levels and mechanisms of involvement of patients in IMI and its projects.
- Discuss the strategy for optimisation and coordination of patient engagement practice in different projects and realization of the patient centric aspiration of the IMI Strategic Research Agenda.
- Identify possible topics for future IMI research projects on enabling patient involvement in medicines lifecycle, including collaboration opportunities with similar and complementary initiatives in various countries and regions.

There was general agreement that patient involvement is required, but that there is a need to articulate it better, e.g. better therapies, better outcomes and better life after treatment.

One concrete idea put forward was the setting up of an independent patient advisory board to ensure input at the topic definition stage, and a platform to coordinate input from relevant stakeholders. Appropriate framework is needed to avoid potential conflict of interest. This group should be linked to IMI’s governance structure. Alzheimer Europe Policy Officer Vanessa Challinor participated in this workshop.

A full summary of the workshop along with the presentations is available here: http://www.imi.europa.eu/events/2016/05/19/patient-engagement-strategy-workshop

28 April: European Parliament will recognise new rights for people who have to take care of a family member

Members of the European Parliament (MEPs) have voted for a resolution calling on the European Commission to urgently propose a new European Union (EU) law, which offers carers remuneration and minimum standards of social protection during the time they perform their care tasks.

Today, 2.5 million people work in the care sector or as household employees, of which 88% are women and migrants. It is important for them to be protected by labour law and be granted a status.

MEPs have called for a “professionalisation” of domestic work to turn precarious and undeclared female work into recognised jobs, which would give domestic workers and carers social protection rights. They also urge the European Commission to propose a framework for recognition of the status of non-professional carers.

The vote arises from a Parliament women’s rights committee report, adopted in February, calling on the European Commission to encourage EU countries to take initiatives to protect the rights of domestic workers and care staff in the EU.

"If we regulate this profession, we will be able to reduce trafficking and the abuse of women," said report author MEP Kostadinka Kuneva (GUE-NGL, Greece), who is also a member of AE’s European Alzheimer’s Alliance (EAA).


29 April: MEPs send open letter to Dutch Health Minister and POLITICO regarding challenges of dementia

On 29 April, eight members of the European Parliament (MEPs) sent an open letter to the Dutch Health Minister and POLITICO, prior to the Dutch EU Presidency conference, summing up the challenges dementia raises and providing some recommendations for future action.

The letter - co-signed by MEPs Heinz K. Becker (Austria), Philippe de Backer (Belgium), Nessa Childers (Ireland), Françoise Grossetête (France), Karin Kadenbach (Austria), Jeroen Lenaers (Netherlands), Miroslav Mikolášik (Slovakia) and Frédérique Ries (Belgium) - applauds the Netherlands’ organisation of the EU Presidency conference on dementia and calls for a collaborative approach from the European Commission, the European Commission Group of Government Experts in Dementia and all stakeholders to define a European Alzheimer Strategy.

“The European Parliament is keen to support all initiatives that will address the challenges of society and the needs of people with AD, professionals, researchers and industry”, it concludes.

Six of the eight MEPs are members of Alzheimer Europe’s European Alzheimer’s Alliance (EAA),

29 April: Expert Group on Health Systems Performance Assessment (HSPA) publishes report

The expert group on health systems performance assessment (HSPA) composed of European countries’ health authorities and international organisations, and co-chaired by Sweden and the Commission, has published its first report: "So What? Strategies across Europe to assess quality of care”.

This first report focuses on quality of care. It is based on the exchange of experiences and knowledge among countries and with international organisations between 2014 and 2015. It sets out a selection of country cases, analyses them and draws general conclusions. The aim is to provide useful recommendations for policy makers who want to design, set up, run and evaluate a system to assess quality of care.

http://ec.europa.eu/health/systems_performance_assessment/key_document/index_en.htm#anchor0

3 May: Web accessibility will now be the law of the land in Europe

On 3 May, after more than three years since its proposal, it was agreed that web accessibility will now be the law of the land in Europe. This is a victory not only for persons with disabilities, but all of us, said MEP Dita Charanzová (Czech Republic, ALDE), the rapporteur of the Directive on Web Accessibility for Public Sector Websites.

The Directive requires:

- All new public sector websites and apps will have to be accessible and current websites will have to be updated.
- Older content, like old videos or word documents, will be available to citizens in accessible form on demand.
- Government videos will have to have captioning or another accessible alternative, including live streaming within a maximum of 14 days of broadcast.
- Online services, like paying fines or fees, will have to be accessible.
- A clear statement on each website to explain if a part of a website is not accessible.

More than 80 million Europeans have disabilities and with an ageing society (there are currently 87 million persons over the age of 65 in Europe) this number is growing. This legislation is therefore vital, even for those without disabilities today, said Ms Charanzová.

This result has been reached through the hard work and dedication of Ms Charanzová alongside several other MEPs, as well as the good will of the Dutch EU Presidency. It is an important first step towards full equality for all in our digital world, but it cannot be the last, concluded Ms Charanzová.


9 May: Dutch EU-Presidency organises two-day conference on “Living well with(out) dementia”

As part of their programme for the rotating Presidency of the European Union, the Netherlands dedicated a two-day conference to dementia entitled “Living well with(out) dementia” on 9-10 May.

The conference was opened with introductory statements by Martin van Rijn, State Secretary for Health, Welfare and Sport of the Netherlands, John F. Ryan, Acting Director of the European Commission, Public Health Directorate, Shekhar Saxena from the World Health Organisation, Yves Joanne from the World Dementia Council and Chris Lammers, a Dutch person with dementia. The introductions highlighted the importance of dementia as a public health priority and the need for European and global collaboration to promote research and exchange good practices.

The following keynote presentations updated the audience on the latest research:

- Tiia Ngandu (Finland) on the scientific evidence on prevention
- Anne Margriet Pot (Netherlands) on the prevention of carers’ stress
- Myrra Vernooij-Dassen (Netherlands) on the support of people with dementia and their carers
- Philip Scheltens (Netherlands) on the latest insights on the diagnosis of Alzheimer’s disease
- Iva Holmerová (Czech Republic) on improving institutionalised care
- Lieve vanden Block (Belgium) on end-of-life care

The event, which was moderated by Marijke Vos from the Dutch Dementia Plan, was broken down into three key sections focusing on living well without dementia and the growing importance of prevention and risk reduction, on living well with dementia at home and on living well with dementia in care homes. During each session, important dementia projects were presented which are funded by the Innovative Medicines Initiative, the Joint Programme for Neurodegenerative Diseases Research (JPND) or the Horizon2020 programme of the European Union: ABIDE, ACTIFCare, EPAD, IN-MINDD, PACE and RHAPSODY.

At the closing session, Dirk Pilat gave an update on the latest OECD activities on dementia and Ruxandra Draghia-Akli provided an overview of the different research activities supported by DG Research and Innovation of the European Commission. The importance of dementia as a European priority was further stressed by Michal Novak who announced that the issue would remain a priority of the forthcoming Slovak Presidency of the European Union which would organise a conference entitled: “Alzheimer’s disease, the epidemic of the third millennium” in November 2016.
Heike von Lützau-Hohibein, Chairperson, Jean Georges, Executive Director, Iva Holmerová, Vice-Chairperson and Charles Scerri, Honorary Secretary (all pictured) represented Alzheimer Europe at this conference.

http://english.eu2016.nl/

9 May: Dutch Deputy Minister for Health calls for a more dementia-friendly society at EU Presidency conference

Martin van Rijn, Deputy Minister for Health, Welfare and Sport in the Netherlands, opened the Dutch EU Presidency conference on 9 May, with a speech imploring delegates, researchers, policy makers, medical professionals, carers and wider society to become more involved in creating a dementia-friendly society. Mr van Rijn said that while it is indeed of great importance to search for a cure for, and causes of Alzheimer’s and other dementias, it is also of vital importance that we work together to try and ensure that people living with dementia have as good a quality of life as they possibly can, both in terms of care and day-to-day living experience.

Mr van Rijn drew delegates’ attention to an exhibition of portrait paintings around them at the conference. The portraits of people with dementia living their final years in a nursing home, were painted by the artist Herman van Hoogdalem in honour of his mother, who also had dementia.

There are more than seven million people living with dementia across Europe, a number that is increasing exponentially as societies age. Searching for a cure is firmly on the political and scientific agenda, which, Mr van Rijn stressed, can only be a good thing. However, “we want both more research into a cure, and better care which leads to a more meaningful life right now” he said.

“This is the job for medical care, for the specialist and family doctor and nurse. However is it not also the task of the partner, the family and friends and the neighbours the bus driver, the community policeman and shopkeeper? It is the job of us all.”

Mr van Rijn’s opening speech marked the official launch of the Netherlands’ “Dementia-Friendly Together” campaign. The campaign - for which EUR 10 million has been made available over the next five years - will be run by Alzheimer Nederland and pension administrators PGGM as part of the Deltaplan Dementie and includes a short online training course, available to everyone.

Supermarket chain Albert Heijn, Connexxion Taxi Services and Amsterdam city council will all join the effort to make the Netherlands more dementia-friendly. They were all represented at the launch.

You can download Mr van Rijn’s full speech here: http://goo.gl/USbk2E

11 May: Council of Europe adopts new Recommendation on research on biological materials of human origin

On 11 May, the Committee of Ministers of the Council of Europe adopted a new Recommendation on research on biological materials of human origin.

Biomedical research on materials of human origin is a powerful tool to improve health and healthcare systems, the new legal instrument acknowledges, and the development of collections and cross-border flow of such research materials is increasing. However, this raises questions of the risk for private life of the persons concerned, as well as of the autonomy that these individuals have over their biological materials once they have been removed.

The purpose of this new Recommendation is to spell out and safeguard fundamental rights of the persons whose biological materials are intended for biomedical research. Their dignity, integrity and privacy must be guaranteed, while at the same time the researchers should benefit from the access to biological materials.

The Recommendation takes into account new developments in the field of biobanking, such as the increasingly diverse origin of biological materials stored in collections, the difficulty to guarantee non-identifiability of such samples, the increasing amount of research involving materials coming from different collections, and the importance of research on biomaterials removed from persons not able to consent.

This new legal instrument sets out the conditions for obtaining and storing materials for future research as well as for using them in specific research projects, in particular regarding appropriate information and consent of the persons concerned.

The governance of collections is an important theme covered by the document. Taking into account the trend of developing collections of biological materials of human origin at national level, the Recommendation stresses in particular that their governance should be guided by the principles of transparency and accountability.

The current Recommendation succeeds the Recommendation[2006]4; it was developed following a public consultation process involving all the stakeholders, in particular medical associations, scientists, ethics bodies, and patient organisations.

https://search.coe.int/cm/Pages/result_details.aspx?ObjectId=0900001680644817

17 May: EESC holds Public Hearing on Concluding Observations of the UN CRPD Committee to the European Union

On 17 May, the European Economic and Social Committee (EESC) held a Public Hearing on the Concluding Observations of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) Committee to the European Union –
“A new strategy for persons with disabilities in the European Union”.

The European Union (EU) has to periodically submit a report to the UN CPARD Committee detailing the measures taken to implement the convention. The first report was submitted in 2014, and in 2015 the UN Committee responded with a series of recommendations - Concluding Observations (COs) - on how the EU can, within its remit, promote and safeguard the rights of people with disabilities in Europe.

The EESC is currently drafting an own-initiative opinion focussing on the implications of the COs for future EU disability policy. The hearing was an opportunity to debate and gather contributions from relevant stakeholders-the point of view of EU Institutions, including the European Commission, the Council of the EU, the European Ombudsman and European Parliament and the point of view of civil society, which will feed directly into the work of the drafting group.

The conclusions of the this hearing, from the point of view of EU Institutions - including the European Commission, the Council of the EU, the European Ombudsman and European Parliament – and from the point of view of civil society, will feed directly into the work of the drafting group. A draft opinion is planned for 28 June 2016.

18 May: Major new report reveals socio-economic impact of IMI projects

A major new analysis shows Innovative Medicines Initiative (IMI) projects are generating socio-economic impacts on a number of fronts. The report produced by a panel of independent, high-level experts from the fields of health economics and research and innovation policy shows how the first projects launched by IMI are making concrete improvements to pharmaceutical research and development (R&D).

Importantly the report notes that many of the projects’ achievements would not have been possible without IMI.

The group analysed in detail the outputs and impacts of the first nine IMI projects to finish. Between them, they have a total budget of EUR 217.6 million, and cover areas such as diabetes, medicines safety, schizophrenia and depression, education and training, chronic pain, and severe asthma.


20 May: Commission publishes European Semester 2016 Country-Specific Recommendations

The European Commission has published its annual analysis of the economic and social challenges in the EU Member States - the Country Reports (CRs). These reports are a tool under the streamlined European Semester of economic policy coordination to monitor policy reforms and to point early on to challenges that Member States should address.

In May 2016, based on the analysis presented in the country reports and the dialogue held with Member States, the Commission presented country-specific recommendations for the next 12 to 18 months.

In the area of health the country reports highlight, among other things, issues relating to health status and healthcare systems in EU Member States, albeit from a financial and economic point of view.

http://ec.europa.eu/social/main.jsp?langId=en&catId=699&consultId=22&visitId=0&furtherConsult=yes

24 May: Commission launches consultation on European Pillar of Social Rights

The European Commission has launched a consultation to get feedback on the role of the European Pillar of Social Rights as part of a deeper and fairer Economic and Monetary Union. The consultation is open until 31 December 2016.

The consultation process has three main aims:

- To make an assessment of the present EU social "acquis": Which existing rights are practiced and remain relevant for today’s and tomorrow’s challenges? Should we consider new ways to deliver on these rights?
- To reflect on new trends in work patterns and societies: What has been the impact of new technologies, demographic trends and other factors on our working life and social conditions? Which best practices and lessons from social innovation should be actively encouraged?
- To gather views and get feedback on the outline of the European Pillar of Social Rights itself and help Member States outside the euro area to determine whether to opt in: What will be the role, scope and content of the Pillar as part of the social dimension of EMU? What are the euro area’s needs? What are the challenges related to the principles put forward under the Pillar?

http://ec.europa.eu/social/main.jsp?langId=en&catId=699&consultId=22&visitId=0&furtherConsult=yes

30 May: Commission launches public call for members of the European Group on Ethics

On 30 May, the European Commission launched a public call for candidates for membership of the European Group on Ethics in Science and New Technologies (EGE), an independent advisory body.

The EGE will consist of up to 15 members who are experts in natural and social sciences and humanities, philosophy, ethics or law and who collectively reflect the breadth of perspectives across Europe and a balance of disciplinary backgrounds.

The EGE is a multi-disciplinary body addressing all aspects of Commission policies and legislation where ethical, societal and fundamental rights dimensions intersect with the development of science and new technologies. Since its inception in 1991, the EGE has provided the Commission with high quality and independent advice on these ethical issues.

The call for expression of interest in membership of the EGE closes on 26 June 2016.

2 April: Athens Association organises Caregiver’s Day 2016

On 2 April, the Athens Association of Alzheimer’s Disease and Related Disorders organised a full day event dedicated to caregivers of people with dementia.

“Caregiver’s Day 2016” consisted of interactive seminars, during which caregivers had the chance to learn more about various dementia-related issues. An introductory speech titled “Alzheimer’s disease in Greece nowadays” was given by Dr Paraskevi Sakka, President of the Athens Association.

A total of 350 caregivers participated in the event and 180 new members joined the Association in order to benefit from its wide range of services.

26 April: BMW heiress donates almost EUR 1 million to German Alzheimer society

On 26 April, it was announced at a press conference in Berlin that BMW heiress Susanne Klatten will make an unprecedented donation of almost EUR 1 million to the German Alzheimer Society, Deutsche Alzheimer Gesellschaft (DAiZG).

Ms Klatten will donate a total of EUR 100 million to various “social projects” in Germany. Her three first selected charitable donations, totalling EUR 1.77 million were presented at the press conference. The largest chunk goes to the DAiZG, which will receive EUR 915,000 over the next five years for its “Dementia partners” projects (Germany’s Dementia Friends programme).

EUR 371,000 euros will go to the pilot project “Fit and Smart: from the start” for vulnerable children in Berlin Neukölln and EUR 482,000 will go to the project “Welcome Work” by Perspektiv gGmbH, which will help give young refugees job prospects.

The DAiZG is delighted to receive this donation, particularly as it had been struggling to find the capital to finance this project.

"It is important that as many people as possible know how great the resulting limitations of the disease are and how they can support people with dementia and their families, when they encounter them” said Sabine Jansen, Executive Director of DAiZG.


2 May: Alzheimer Albania reports on artistic initiative “The Forgetfulness”

Alzheimer Albania is pleased to report on an initiative by six artists in Durres: an exhibition called The Forgetfulness (Harresa). There are beautiful paintings, an installation called the Grandfather’s Clocks, poetry on the topic of Alzheimer’s disease - the artist’s perception.
The city is

The Forgetfulness is the first artistic exhibition dedicated to Alzheimer’s disease (AD) in Albania. It ran from 2 May until 28 May 2016, open every day of the week. In the evening the program included music and dance for older people and on Thursday afternoons a doctor was also present, to talk about the disease and how to manage it better.

The Nursing Home of Durres organised a visit to the gallery during this initiative and students from the University of Durres “Aleksander Moisiu” also viewed the exhibited works and learned more about AD.

Alzheimer Albania made information leaflets available at the exhibition. The association enthusiastically promoted the exhibition, in the hope that as many people as possible would visit, as it believes this kind of initiative is a good start in helping create a dementia-friendly society.

5 May: Alzheimer Scotland reports on its Election 2016 Pledge on Dementia campaign

5 May 2016 saw Scotland voters go to the polls to elect 129 Members of the Scottish Parliament – our devolved legislature. The Scottish Parliament’s responsibilities include health and social care, and, new from this year, aspects of social security including benefits for carers – so, the majority of legislative responsibility that affects people with dementia and carers in Scotland sits with the Scottish Parliament in Edinburgh.

Alzheimer Scotland was therefore keen to engage as many candidates as possible in the run-up to the election. We wanted to make sure that as many as possible of those elected as Members of the Scottish Parliament (MSPs) were aware of the most important issues affecting people with dementia and had signed up to doing something about it.

We used email and Twitter to ask every candidate to sign up to a six point pledge that reflects the areas Alzheimer Scotland has identified a key to transforming the lives of people living with dementia.

Alzheimer Scotland’s staff, members, activists and supporters all got on board, because we know that candidates are most likely to respond to an ask from someone living locally, who may potentially vote for them!

217 candidates signed up to say they supported our pledge – about 36% of the total. Of the 129 successfully elected candidates, 60 had signed – not far off half of the new parliament. This gives us a great base to build from.

Over the summer, we are now going to make sure we are engaging with all the MSPs so that they know about what Alzheimer Scotland does in their area, and how working with us on the six priorities outlined in the pledge will help people living with dementia near them.

9 May: Alzheimer Nederland officially launches Dementia Friends programme at EU Presidency dementia conference

On 9 May, at the opening of the Dutch EU Presidency’s conference “Living well with(out) dementia”, the Netherlands’ Dementia Friends programme was officially launched.

The five-year Dementia Friends programme, from Alzheimer Nederland and social partner PGGM (Dutch pension asset manager), is similar to Dementia Friends programmes in other countries such as the UK, Japan and Canada.

The aim is to have 1 million Dementia Friends in the Netherlands by 2020.

9 May: Alzheimer Albania reports on its “AWAREness days” this month

Alzheimer Albania joined the launch of Sea Hero Quest, helping researchers to fight dementia. At the same time, activities were used as an awareness-raising campaign for dementia in Albania. We had the pivotal contribution of Jera Kruja, Professor of Neurology, Head of Neurology Service at Mother Theresa University Hospital Center (UHC Mother Teresa), Tirana, Albania and Mira Rakacoll, Professor of Neurology and neurologist at UHC Mother Teresa. They contributed by explaining the first signs of dementia, the situation in our country and the multidisciplinary treatments for people with dementia following diagnosis.

There were four important dates: 9 May, 15 May, 19 May and 21 May. The first date was a social event hosted by Telekom Albania with participants from Health Care Authorities, neurologists, family friends of people with dementia, journalists and medical students. The others were appearances on national television programs with large audience.

Norketa Merkuri, Executive Director of Alzheimer Albania, was also part of the panel. She presented the objectives and vision of the organisation, the importance of having information about dementia, the need for tailored care and support during all the stages of the disease, and the social impact it has. She also introduced the webpage www.alz.al to the public, which is a useful source of up to date information in Albanian, for people with dementia, family members and caregivers.
Alzheimer Albania organised two testimonials, anonymously talking about what it is like to live with and take care of a family member with dementia. They were part of the programs, as another approach to be better understood and heard.

These awareness activities are helping the Albanian society to reduce the stigma which surrounds all types of dementia and to help people understand that dementia is not a normal part of aging. Dementia should be the focus of Health Care and Social Care Authorities in Albania.

11 May: Alzheimer Iceland holds Annual Meeting and adopts new name and logo

Alzheimer Iceland held its Annual Meeting on 11 May. The existing Board was re-elected, meaning no change for the coming year on that front.

There was one important change in the Association’s legislation - namely the name itself. The previous name was FAAS - Felag áhugafólks og aðstandenda Alzheimersjúklinga og annarra skyldra sjúkdóma - a long explanation of the purpose of the Association in Icelandic.

To simplify things, the new full name is the Alzheimer Association of Iceland, but to go even further in simplifying things, the name Alzheimer Iceland will be used in the association’s external communications. The association has also adopted a new logo reflecting this name change (pictured).

Unfortunately, the association has not yet made much progress in convincing the Icelandic government to create a national dementia plan, nor to support the association in documenting the statistics concerning dementia diagnosis in the country, but Alzheimer Iceland believes the number of diagnosed people to be around 2500 and around the same undiagnosed.

Alzheimer Iceland is now working on a new website, to be launched on 21 September – World Alzheimer’s Day. Arni Sverisson, Chairman of Alzheimer Iceland said “It looks promising so far, and we believe that we can be very proud of it when it is finished”.

The association has also recently moved its headquarters to bigger and better premises, allowing more room for meetings with people with dementia and their relatives.

15 May: UK Alzheimer’s Society hosts successful Dementia Awareness Week 2016

Dementia Awareness Week (DAW) is the Alzheimer’s Society’s annual flagship awareness-raising campaign, and it took place from 15 to 21 May. Here is the Society’s report on this year’s successful DAW events:

This year’s theme was “confronting dementia”. We wanted people to confront their worries by addressing dementia directly. By treating dementia as something separate to them, we hope people feel more empowered to express their fears and do something about it. We also wanted to show people who are worried about dementia that they can come to the Alzheimer’s Society for information and support.

In the build up to this week we created specific resources for our supporters and volunteers to use, we asked our Dementia Friends Champions to get involved by delivering Dementia Friends Information Sessions and we also built up some coverage with national and regional media.

Successes

- #DAW2016 was no.1 trending on Twitter – with support tweets from celebrities and politicians.
- Over 7,000 YouTube views of our Rhod Gilbert awareness raising video - www.youtube.com/watch?v=lyLoBA6sFyY.
- Over 51,298 website visits and 153,904 page views - our third busiest day ever on the website.
- Over 400 local events took place during the week.
- Over 940 pieces of media coverage.
- Dementia Awareness materials were distributed to over 1,000 external partners/supporters.
- We were involved in the production of BBC1 documentary “The Truth About Dementia” which aired on Thursday 19 May.
- We had the first ever dementia-friendly cricket match.
- One news story which had incredible coverage across broadsheets, tabloids and broadcast, stated that “people with dementia symptoms put off visiting their GP over fears that being diagnosed with the condition means their life is over. A poll for The Alzheimer’s Society found 62% would delay seeking help. This Dementia Week Alzheimer’s Society is urging people to act on early warning signs to have a better chance of living well for longer”.

18 May: Alzheimer Croatia will support optimal health care program for people with mental health disorders

On 18 May, Alzheimer Croatia hosted the first meeting of the EU Twinning project working group to protect and improve mental health and more accessible treatment for people with mental disabilities in Croatia. The holder of this EUR 670,000 project is the Ministry of Health of Republic of Croatia. It will be carried out in cooperation with the Croatian Institute for Public Health and the Netherlands Institute of Mental Health and Addiction (Trimbos Institute).

The aims are: improving early recognition of mental health problems and disorders, improving patient care, better treatment options and to increase public awareness of the problems caused by mental disorders.
Alzheimer Croatia was invited to share its experience and knowledge, to help the working group in the development of its quality programme for the early detection of dementia, and appropriate care for patients with neurodegenerative diseases, as well as the training of professional and family caregivers.

It will be an opportunity to more strongly promote the proposal of the National Strategy to combat dementia, developed by Alzheimer Croatia.

22 May: Alzheimer Croatia promotes mobile game Sea Hero Quest

Croatian Telecom and the Alzheimer Croatia, during its recent Alzheimer Café together presented the global initiative #gameforgood within which the mobile game Sea Hero Quest was launched. The game collects data on the spatial orientation abilities of healthy people to help those who have lost such skills through dementia. In the first two weeks, the game collected more data than would be achieved during 10 years of classic laboratory research.

Croatian Telecom will support “World Alzheimer’s Month” (September), when it will further promote the game, supporting the efforts of Alzheimer Croatia regarding de-stigmatising dementia.

23 May: Jersey Alzheimer’s Association reports on Dementia Awareness Week 2016

The week went very well, with lots of support from the island’s media. The week kicked off with a Clergy Breakfast hosted by Trinity Church to share the work which we have been doing together regarding Dementia Friendly Churches and those who attended ended with a “Meals for Memories” fry up.

You may have heard Jim (Hollywood) on the radio and seen him in the paper talking about dementia and the services we provide.

A dozen people attended the Memory Box Workshop lead by Angela Francey and hosted at the Jersey Library. Angela provided an engaging talk on how to create a box and had examples of items to share.

A reminiscence session with “men in mind” was held on Thursday and it was great to see a number of professionals across the different sectors looking at how we can plan activities to better support the needs of gentlemen in our community living with dementia.

Two public talks were given on dementia and the work of JAA as part of the Library Lunchtime Talks Series which allowed people the opportunity to learn about dementia and chat to JAA staff.

Finally, we ended the week with an awareness stall and group of keen bag packers at Grand Marche, St Helier. The group was made up of Friendship Group members, Crestbridge and Barclays staff, JAA staff, trustees, volunteers and family and friends.

24 May: Federazione Alzheimer Italia reports on dental care for people with dementia

In May 2016, the Associazione Alzheimer Milano, which is part of Federazione Alzheimer Italia (FAI) - the biggest Italian non-profit organisation for people with dementia and their families in Italy - in collaboration with Luigi Sacco Hospital in Milan launched a new project called "Dental Care for People with Alzheimer’s". The aim is to ensure priority is given during outpatient visits and, in severe cases, home visits in Milan from a professional dentist specialised in care of people with dementia.

This service operates in collaboration with regional health service and is free of charge for people with a dementia diagnosis.

With the progression of the disease, people with dementia may gradually reduce their level of oral hygiene, which can cause pain and can even affect their ability to speak, as well as decreasing their interest in food.

Gabriella Salvini, Chairperson of FAI said:

“A healthy mouth positively influences the quality of life of people with dementia and their families. It would be desirable to include in the multidisciplinary team of doctors and specialists involved in the diagnosis also the dentist, in order to establish prevention protocols and educate patients and their families in good oral hygiene”. In the early stages of dementia, dental care should be emphasised as being of primary importance, to ensure a stable oral condition, leading to less difficulties in the later stages of the disease. A lack of good oral hygiene and care can lead to bigger problems and even the need for dental surgery, which can be painful and stressful.

FAI hopes this initiative will lead to the creation of dental care best practices, within a multidisciplinary team. It intends to help similar projects nationwide.

24 May: Alzheimer Portugal presents “First Date” campaign

Do you dream of having a first date like Corinne and Paul? (See below video link) If not, make the most of your next meeting with those you love.

It is with the “First Date” that the international agency BBDO and the association Alzheimer Portugal met. Together they have worked to raise awareness of the best known form of dementia, but still too often
underestimated compared to the exponential growth of its cases on a global scale.

It is from here that was born the spark for BBDO’s idea: “we wanted to transfer to all the emotions and the feelings of family members and through this feeling of empathy, invite them to donate. This means a first date, precisely, where a girl is talking about herself without restraint, but unfortunately the one who is listening is not a new flame, but her dad”.

The aim of “First Date” is not only to tell a story that gives the public something to think about, but also to draw attention to how frustrating it can be not to remember even the things and people you are most fond of, of your own life experiences... and how much pain this can cause family members in particular.

The awareness campaign and fundraising is done via Alzheimer Portugal’s Youtube channel, website and Facebook page.

The film was completed with the executive creative direction of Stefania Siani and Federico Pepe, working with two creative directors, Pas Frezza and Luca Iannucci. It was produced by Riot, with Andrea Vavassori and directed by Alessio Fava and photography by Alessandro Dominici. The music that accompanies the story is a beautiful cover of “Have You Ever Seen the Rain” by Bettex.

See the campaign video here: https://www.youtube.com/watch?v=Cu_NslcmeA

25 May: Alzheimer’s Society reports on the UK’s first dedicated Dementia Research Institute

In the UK, the Alzheimer’s Society has partnered with the government-run Medical Research Council and fellow charity Alzheimer’s Research UK to create the country’s first dedicated Dementia Research Institute.

The Alzheimer’s Society and Alzheimer’s Research UK have both pledged GBP 50 million (EUR 65.9 million) towards the work of the UK Dementia Research Institute, in the single biggest financial commitment to dementia research in the history of both charities. A further GBP 150 million (EUR 198 million) will be given by the Medical Research Council, bringing the total investment to GBP 250 million (EUR 329 million).

The Institute will bring together leading international scientists and experts to transform the landscape of dementia research in the UK and across the globe.

Set to be fully up and running by 2020, the Institute will have a central UK hub with a network of regional centres and is expected to engage hundreds of scientists. This research will help to drive new approaches to diagnosis, treatment, care and ultimately prevention of the disease.

As well as increasing the amount of fundamental biomedical research taking place in the Institute, the funding from the Alzheimer’s Society allows the vision and strategy of the UK Dementia Research Institute to be broadened to include clinical, care, technology and public health research.

The direct experience of people with dementia and their carers will help to inform the work of the Institute, which the Alzheimer’s Society is uniquely placed to ensure. By enabling people living with dementia to define what high-quality, evidence-based care and support means to them, we can reduce disability and distress, limit harmful practices and improve the inclusion of people with dementia in society.

Jeremy Hughes, Chief Executive Officer of the Alzheimer’s Society, said:

“The UK Dementia Research Institute heralds an exciting era for global dementia research, as it launches an unprecedented collaboration of world-leading dementia expertise and provides the largest single investment in dementia research to date.”

Policy watch

13 April: Spain’s first national strategy for neurodegenerative diseases, including AD

On 13 April, the Ministry of Health, Social Services and Equality in Spain approved the country’s first National Health System strategy for Neurodegenerative Diseases (NDs). The main lines of action in the new Strategy are to improve diagnosis, give personal attention to patients and establish programs that facilitate respite for those who care for those affected by NDs.

In his speech, the Minister stressed the importance of adopting this Strategy, as the incidence of NDs is increasing due to an aging population. Although there are over 600 such pathologies, the main diseases because of their high prevalence and severity, are Alzheimer’s disease (AD), Parkinson’s, Huntington’s and Amyotrophic Lateral Sclerosis (ALS). According to different prevalence studies regarding these and other diseases, it is estimated that around a million Spaniards may be living with an ND.

The first line of the Strategy refers to preventing disease and improving early diagnosis, for which states must develop processes for referring patients to hospital care from health centres and monitoring programmes for people at high risk, genetically.

Second in the Strategy is care for people with NDs. It determines that the communities should develop plans that integrate social and health care. It is also anticipated to create an individualised plan of care for each person diagnosed with an ND.

This new Strategy also puts special emphasis on community carers and respite programmes established to facilitate relaxation, as well as emotional support programmes such as self-care training activities (stress management, relaxation, etc.).

Other strategic areas addressed by the Strategy are increasing awareness of NDs to reduce stigma, training professionals and promoting research in areas such as epidemiological studies, risk factors, new drug therapies or...
2 May: Swiss Government evaluates progress of national dementia strategy

Representatives of the Swiss Ministry of Health met in Berne to discuss the progress of the national dementia strategy (2014-2017). The attendees were welcomed by Pascal Strupler, the Director of the Ministry of Health and the discussions were followed by Margret Duetz Schmucki, the head of the unit “National Health Policy”.

Introductory statements were made by invited experts:

Jean Georges, Executive Director of Alzheimer Europe compared the priorities of the Swiss dementia strategy with those of national dementia strategies in other European countries,

Armin von Gunten of the Department of Psychiatry at the University of Lausanne provided an overview of current prevention strategies and the relevance of a timely diagnosis of dementia,

Sandra Oppikofer of the Centre for Gerontology of the University of Zurich highlighted the importance of providing an ethical framework for providing care for people with dementia to allow them to live in dignity and autonomy,

Stefanie Becker, the Executive Director of the Swiss Alzheimer’s Society focused on the importance of “living well with dementia” and suggested the development of minimum standards for “dementia-friendly” initiatives.

After the discussions, Pascal Strupler welcomed the progress to date of the Swiss dementia strategy and highlighted the importance of including the dementia dimension also in strategies for non-communicable diseases, mental health and active ageing.

16 May: DAI launches booklet advocating for the Human Rights of people with dementia

On 16 May, Dementia Alliance International (DAI) launched a new booklet “The Human Rights of People Living with Dementia: from Rhetoric to Reality”. The booklet aims to be an important source of information for people with dementia and a helpful tool for addressing national and global policy affecting people with dementia.

The publication follows demands by DAI - at the first World Health Organisation (WHO) Ministerial Conference on Dementia in 2015 - that access to the UN Convention on the Rights of People with Disabilities (UN CRPD) should explicitly guarantee the rights of people with dementia, who are affected by many of the articles contained within, but not explicitly recognised by the document.

18 May: Irish Government Promises Progress in Dementia Care

Ireland’s new Programme for Government was published this month and states “We will implement the Irish National Dementia Strategy”.

These eight short words have the power to substantially improve the lives of the 55,000 people living with dementia in Ireland. In the lead up to Ireland’s general election The Alzheimer Society of Ireland (ASI) ran a campaign titled Vote to Remember. This campaign asked all political parties and election candidates to commit to Renew, Reform and Resource the National Dementia Strategy so ASI has warmly welcomed the Government’s renewed commitment to the implementation of Ireland’s first dementia strategy. ASI will continue to work closely with the Irish Government to ensure this is achieved.

Pictured: Staff and branch members of The Alzheimer Society of Ireland with Senator Lorraine Clifford-Lee during Election 2016.

For further information on ASI’s election campaign please visit:

http://alzheimer.ie/Get-Involved/Campaigning/Past-Campaigns/Election-2016-Vote-to-Remember.aspx

18 May: AE Honorary Secretary Charles Scerri reports on Slovak dementia conference

On 18 May, Alzheimer Europe (AE) Honorary Secretary Charles Scerri attended the conference “National Programme: To Conquer Alzheimer’s disease and Other Forms of Dementia” in Slovakia. This event was organised by the Institute of Neuroimmunology of the Slovak Academy of Sciences MEMORY Centre, under the auspices of the Ministry of Education, Science, Research and Sport of the Slovak Republic. The main aim was to discuss the recent progress made in the field of dementia in Slovakia and the challenges the country faces in developing a National Dementia Plan.

During his intervention, Mr Scerri gave an overview of why AE believes dementia should be a national and European priority, including epidemiological data from the European Cooperation in Dementia [EuroCode] study and the increasing public health impact of dementia in the European Union. This was followed by a short presentation of the Paris Declaration, which was adopted ten years ago, as well as key achievements that followed, with a particular focus on EU research collaboration programmes and the recent expansion in the number of dementia strategies and plans in various European countries. AE’s contribution to the generation of data through its comparative reports, the European Dementia Ethics Network, involvement in Innovative Medicines Initiative (IMI) and the EU’s Seventh Research Framework Programme (FP7) projects and the
workings of the European Working Group of People with Dementia (EWGPWD) was also discussed. The Glasgow Declaration campaign, launched in 2014 was then presented and the need of future EU action on dementia.

AE welcomed Slovakia’s commitment in making dementia a priority of its upcoming EU Presidency, beginning 1 July.

23 May: Health ministers call for greater WHO collaboration on dementia

During the 69th World Health Assembly (WHA69) of the World Health Organisation, the Swiss government convened a Ministerial Panel dedicated to “Alzheimer’s disease and other related diseases” in Geneva on 23 May 2016. The event was co-sponsored by the governments of Canada, Monaco, Panama and Zambia.

After welcoming remarks by the Federal Councillor Alain Berset and an introductory statement by Director General Margaret Chan identifying dementia as one of the key health priorities of all governments, a number of Ministers of Health recalled the commitment of their respective governments to dementia and stressed the importance of greater global and European collaboration on dementia and gave their support for the development of a resolution on dementia at the next World Health Assembly. This approach was supported by:

• Sabine Oberhauser, Federal Minister of Health of Austria,
• Tedros Adhanom, Minister of Foreign Affairs of Ethiopia,
• Hermann Gröhe, Federal Minister of Health of Germany
• Lydia Mutsch, Minister of Health of Luxembourg
• Justyne Caruana, Parliamentary Secretary for Rights of Persons with Disabilities and Active Ageing of Malta
• Edith Schippers, Minister of Health, Welfare and Sport of the Netherlands
• Sylvia Mathews Burwell, Secretary of Health and Human Services of the United States of America.

Alzheimer Europe was represented by its Executive Director, Jean Georges, at this meeting.

25 May: Slovenia has a National Dementia Strategy

A strategy for coping with dementia in Slovenia for 2020 is the first document of its kind in this field in Slovenia and was signed by the Minister of Health Milojka Kolar Celarc and presented at a press conference on 25 May.

The strategy reflects the essential elements and commitments contained in the documents adopted at the EU and the World Health Organization (WHO), as well as strategies in the field of management of dementia in other countries. It provides a coordinated and integrated approach by all stakeholders in tackling dementia and related conditions. The aim of the strategy is to ensure preventive measures, early diagnosis and appropriate standard of health and social protection and medical care for people with dementia. It focuses on the individual and his/her needs, which require a coordinated and responsive operation of law and a multidisciplinary treatment approach.

The strategy also sets out strategic areas in relation to the treatment of people with dementia, namely:

• Raising awareness and reducing the stigma of the disease.
• Early diagnosis and subsequent comprehensive treatment of people with dementia.
• Access to treatment and therapy anti dementia.
• Ensuring access to social services and individual and holistic treatment.
• Palliative care for people with dementia, etc.

The strategy was prepared by a working group appointed by the Minister of Health, members in addition to the Ministry of Health were from the Ministry of Labour, Family, Social Affairs and Equal Opportunities, representatives of the psychiatric profession (Dr Aleš Kogoj, until his death as well as an external collaborator Dr Katarina Barbara Štrukelj) and other healthcare professionals, working both at the primary, secondary and tertiary levels of health care activities (Dr Zvezdan Pars, head of the Neurological Clinic UKC Ljubljana, Dr Dušan Flisar, Tatiana Cvetko, ZD Koper, Boštjan Zupan, SB Celje, Darnika Klančar US Cervenica), representatives of non-governmental organisations, including Štefanija L. Zlobec, Spominčica President of Alzheimer Slovenija (Spominčica) and Alzheimer Europe Board member, and the Director of a home for the elderly in Fužine.

Spominčica thanks the media for support in raising awareness, de-stigmatisation and recognising the first signs of dementia.

http://www.mz.gov.si/si/delovna_podroeba_in_prioritete/zdravstveno_varstvo/demenca/

30 May: WHO urged by 38 Members States to take action on dementia

A Draft Decision on dementia, backed by 38 Member States, urging the World Health Organisation (WHO) to take action on dementia was adopted on 30 May at the 139th Executive Board meeting of the WHO.

This paves the way for the Draft Global Action Plan on a public health response to dementia for consideration at the 70th WHO World Health Assembly (WHA70) meeting in 2017 and is a clear signal to the WHO to act on dementia.


Science watch

12 April: European mental health project targets biological roots of social withdrawal

Withdrawal from friends, family, and colleagues is of the most painful and debilitating symptoms of major depression. It can also be an early
sign of schizophrenia or Alzheimer’s disease. On 12 April, a large coalition of European researchers and pharmaceutical companies announced a new EUR 16.5 million research initiative, aimed at determining whether the social withdrawal in such disorders has a common biological cause.

“Inappropriate social integration is a common, but neglected, facet of the majority of neuropsychiatric disorders,” said neuroscientist Martien Kas of Utrecht University in the Netherlands, and coordinator of the new Psychiatric Ratings using Intermediate Stratified Markers (PRISM) project, funded by the Innovative Medicines Initiative (IMI). Using measures such as functional magnetic resonance imaging, electroencephalograms, and blood tests, as well as smartphone apps to track social behaviour, PRISM will compare groups of people with Alzheimer’s disease, schizophrenia, and major depressive disorder to determine which biological factors correlate with social withdrawal in the different groups and look for common factors.

This focus on social withdrawal is an unmet need in a variety of psychiatric and neurodegenerative diseases and in aging in general, according to neuroscientist John Cryan of University College Cork in Ireland.

29 April: Course of depression may predict dementia risk

People with late-life depression have an increased risk of dementia if their symptoms increase over time, whereas a single episode of depression, even if severe, does not carry a significant risk, a new study has found. The study, published in The Lancet Psychiatry on 29 April, was led by Dr Arfan Ikram, of Erasmus University Medical Center, Rotterdam, the Netherlands.

Dr Ikram and his research team studied five trajectories of depression characterised by low, decreasing, remitting, increasing or high using Centre for Epidemiology Depression Scale scores in 3,325 participants aged 55 years or older.

Studying trajectories of depression is likely to be a more accurate way of distinguishing patients at risk of dementia than single assessments, the researchers said. Indeed, the 255 individuals whose depressive symptoms started low and steadily increased over an 11 year-period had a 42% increased risk of dementia and a 44% increased risk of Alzheimer’s disease (AD) in the subsequent 10 years compared with the 2,441 individuals whose depressive symptoms started and remained low.

The researchers also note in The Lancet Psychiatry that the increasing depression course was associated with a 58% increased risk of dementia after censoring for incident stroke and a 45% increased risk after accounting for mortality as a competing risk.

The study answers the question of whether depression modifies the risk of dementia, but the question of how remains.

http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366%2816%2900097-3/abstract

3 May: Sea Hero Quest app aims to help researchers better understand dementia

A new, free game available in app stores for smartphones and tablets aims to help researchers better understand dementia. Sea Hero Quest was developed by experts from University College London (UCL), the University of East Anglia, Alzheimer’s Research UK and London-based graphic design outfit Glitchers and has been launched by Deutsche Telekom. Gamers who play for just two minutes will be able to provide the equivalent of five hours of lab-based research data, according to its creators.

Since its official launch on 3 May, Sea Hero Quest has been downloaded more than 7,000 times in the Google Play Store. The game tracks navigational data anonymously and pools together the information from users around the world. In turn, researchers are able to create benchmarks for spatial navigation.

"Every element of the game was carefully crafted to be as fun and exciting as it is scientifically valid," its creators write on the Sea Hero Quest website.

UCL Neuroscientist Hugo Spiers calls it “citizen science” and says that his research team is hoping to learn how well people do across different ages and demographics.


10 May: Australian researchers develop new theory for causes of dementia, involving out-of-control immune system

Australian researchers at the University of Adelaide have developed a new theory for the causes of dementia and other neurodegenerative diseases, involving an out-of-control immune system. Their work was published in the journal Frontiers in Neuroscience on 10 May.

The researchers assembled strong evidence that the neurological decline common to these diseases is caused by “auto-inflammation”, where the body’s own immune system develops a persistent inflammatory response and causes brain cells to die.

There are many distinct forms of neurodegeneration including Alzheimer’s, Parkinson’s and Huntington’s diseases. These conditions are distinguished by the different types of brain nerve cells that are first affected and by the symptoms that first appear. However, as all of these diseases progress, they become more similar.

Study lead Professor Robert Richards, from the University of Adelaide’s School of Biological Sciences, believes that instead of many different mechanisms, each disease has the same underlying mechanism, and common pathway of nerve cell loss.

“Our interest in the body’s own [innate] immune system as the culprit began when we discovered that immune system agents become activated in a laboratory model of Huntington’s disease,” he said. “Remarkably, researchers from other laboratories were at the same time reporting similar features in other neurodegenerative diseases. When we pulled the evidence together, it made a very strong case that uncontrolled innate immunity is indeed the common cause.”
The innate immune system is the first line of defence in cells, and normally distinguishes molecules that belong to the body from foreign, disease-causing, molecules. It is an alarm and response system with a self-destruct mechanism to contain and eliminate invaders or abnormal cells, like cancer.

Malfunctions can occur because of various triggers including genetic mutations, infection, toxins or physical injury, all of which have been linked with different forms of neurodegeneration. Initially the innate immune system protects the tissue against these triggers, but prolonged activation becomes self-perpetuating, causing brain cell death to occur.

“We hope this new way of understanding neurodegeneration will lead to new treatments,” Professor Richards said. “We now need to further investigate the immune signalling molecules, to identify new drug targets that will delay the onset and/or halt the progression of these devastating diseases.”


11 May: US study further explores tau and amyloid AD pathologies using advanced PET imaging

Researchers at Washington University in the US have completed a study, exploring relationships among tau pathology and Aβ using advanced PET imaging, cerebrospinal fluid measures of disease, and cognition. Overall, they found that tau imaging provided a more robust predictor of disease status than Aβ imaging did. While Aβ imaging provides a good marker for early disease state, tau imaging is “a more robust predictor of disease progression” they concluded. Their results were published on 11 May in the journal Science Translational Medicine.

Alzheimer’s disease is pathologically defined by the accumulation of β-amyloid (Aβ) plaques and tau tangles. The cognitive and pathological correlates of Aβ deposition have been well studied owing to the availability of PET imaging ligands.

Using newly available tau imaging agents, Professor Matthew R. Brier and his team were able to better explore the relationships among tau pathology and Aβ in the brains of 46 study participants.

Participants with normal cognitive function showed minimal tau tangles throughout the brain, while those with cognitive impairment showed a substantial increase in the amount of the protein present in the temporal lobes and cerebral cortex.

http://stm.sciencemag.org/content/8/138/338ra66

12 May: US company completes enrolment in AD treatment Phase III trial

On 12 May, US company Accera announced it had completed enrolment for its Phase III NOURISH AD clinical trial of orally administered therapy AC-1204 for the treatment of mild to moderate Alzheimer’s disease (AD). Accera is a clinical stage biotechnology company developing therapies for central nervous system disorders.

AC-1204 works by inducing a mild state of ketosis, thereby providing an alternative energy source to the brain. The Phase III trial is a 26-week, double-blind, randomised, placebo-controlled, parallel-group trial. Top-line data should be reported later this year, which will inform the design of a second pivotal Phase III trial - compulsory for regulatory approval of the drug. This pivotal trial is planned for early 2017.


20 May: Forum pharma CEO leaves following failed encenicline trial

Deborah Dunsire, the former head of Millennium Pharmaceuticals and a well-known US biotech veteran, is no longer the CEO of Forum pharmaceuticals as of 20 May.

Forum’s lead drug, encenicline, has suffered a double whammy of bad news in recent months. The FDA placed a clinical hold on two late-stage studies of encenicline in Alzheimer’s disease last year, and then the drug failed two Phase III trials in schizophrenia in March 2016. This double blow has left Forum in a precarious position. When it announced the failed trial in March, Forum said it would restructure to “appropriately scale its spending and resources and evaluate a potential path forward, if any.”

If encenicline does move forward, Ms Dunsire says, it “would have to be done with a different company or investor.” She stressed that she can no longer speak for the company, but it is her understanding that Forum was “in the process of shutting down.” It’s unclear if that is still the case and she deferred all additional questions regarding Forum’s current status to the company.

Forum is an unusual biotech story. Instead of the typical syndicate of venture backers, it has been mainly been funded by Fidelity, thanks to former Fidelity CEO Ned Johnson’s passion and support for Alzheimer’s research. Forum had no need for deals or outside investors to survive. When Ms Dunsire took the helm in 2013, she planned to find outside investors, however, and shoot for an IPO. But without the success of encenicline, those plans have fallen by the wayside.

http://www.economy.com/boston/2016/05/25/after-failed-trial-forum-ceo-leaves-company-fate-unclear/

24 May: Study finds drug clopidogrel may slow progression of AD

A team of German, Swedish and Italian researchers from Örebro University have come up with a new therapeutic strategy to slow the progression of Alzheimer’s disease
(AD). They tested the drug clopidogrel - an oral, thienopyridine-class antiplatelet agent used to inhibit blood clots in coronary artery disease, peripheral vascular disease, cerebrovascular disease, and to prevent myocardial infarction (heart attack) and stroke – in mouse models. Their results, which they say show that the anticoagulant drug can reduce the speed at which AD destroys the brain. Their results were published in the journal Science Translational Medicine on 24 May. Professor Margitta Elvers led the study.

According to the research team, a medication that’s able to reduce platelets’ aggregation may also slow down the build-up speed of Amyloid plaques in the brain. Clopidogrel was chosen as it can inhibit the activation of thrombocytes – platelets crucial to normal blood clotting. Evidence provided by the study revealed that beta-amyloid plaques grew more slowly in mouse models receiving this treatment.

Much further study is needed to see if the drug has the same results in humans.

http://stm.sciencemag.org/content/8/340/340ra72

25 May: US researchers have a radical new theory about the cause of Alzheimer’s disease

Researchers at the University of Harvard in the US believe they may have found the root of Alzheimer’s disease. They think the immune system plays a key role in the development of AD and that beta amyloid, long held as the villain in AD, actually has a positive role to play. Their work, published in the journal Science Translational Medicine on 25 May, suggests that getting rid of amyloid – as many drug trials have tried to do - could actually be dangerous.

Beta amyloid helps fight off bacteria and fungus in mice, worms and cells, the researchers showed, and assuming that also held true in people, targeting amyloid could be stripping the brain of an important defence mechanism. Instead, they conclude, approaches that stimulate the immune system could be safer and more effective.

The researchers, Professors Rudy Tanzi and Robert Moir, both of Harvard Medical School and Massachusetts General Hospital, say that AD could be triggered by a normal immune response gone astray or into over-drive in response to bacteria or other pathogens.

Amyloid plaques were traditionally thought to be “garbage” that accumulates in the brain with age. But Prof. Moir noticed that they looked a lot like proteins of the innate immune system, a primitive system that is the body’s first line of defence against infections. Elsewhere in the body, such proteins trap microbes — viruses, fungi, yeast and bacteria. Then white blood cells “clear up”. Prof. Moir thought perhaps amyloid was part of this system too and it according to the results of this new study, he was right.

For the study, cultured human and hamster cells that were infected with the fungus Candida albicans and had a high expression of amyloid beta doubled the number of cells that were not infected. They found that beta amyloid had a similar protective effect in roundworms, or nematodes, which usually die within two to three days after fungal infection. Those worms with overexpression of amyloid beta continued to live five to six days after infection. It was also reported that mice genetically engineered to overproduce human amyloid beta lived about twice as long as mice without the protein.

In one study, the group injected Salmonella bacteria (pictured) into the brains of young mice that did not have plaques.

“Overnight, the bacteria seeded plaques,” Prof. Tanzi said. “The hippocampus was full of plaques, and each plaque had a single bacterium at its centre.”

In contrast, mice that did not make beta amyloid succumbed more quickly to the bacterial infection, and did not make plaques.

This would not mean that AD is contagious, but rather that some brains may over-react to, or get overwhelmed by a variety of pathogens, including chlamydia, herpes and the bacteria that causes Lyme disease, stressed Prof. Tanzi. It is possible that younger people’s brains are better able to handle these issues than some older ones. This view also adds weight to the idea that adequate exercise, high quality sleep, healthy diet and other lifestyle factors like treating gum disease can help prevent AD, he said.

Vaccines or drugs that reduce inflammation might also be helpful, though the timing of such approaches will be key, said Professor Gary Small, of UCLA’s Semel Institute. His own research has shown that healthy people who took anti-inflammatory drugs for 18 months had better brain function than those who took a placebo. But if they started the drugs after AD began developing, it could accelerate the disease. “There’s a tipping point,” he said, but no one yet knows where that is.

At this point, the Harvard researchers have an intriguing hypothesis, but they acknowledge much work lies ahead.

The Cure Alzheimer’s Fund is starting a collaborative project that will use gene-sequencing technology to look for microbes in brains from people who had Alzheimer’s and those who did not. Researchers will also look for microbes in plaques from human brains.

That, though, “is a big, big second step,” Prof. Tanzi said. “First we need to ask whether there are microbes that may sneak into the brain as we age and trigger amyloid deposition.”

http://stm.sciencemag.org/content/8/340/340ra72

26 May: Brain “cleaning” discovery could help combat Alzheimer’s disease

Research led by the Achucarro Basque Center for Neuroscience, the University of the Basque Country (UPV/EHU), and the Ikerbasque Foundation has revealed mechanisms that keep the brain clean during neurodegenerative diseases. The study, led by Dr Amanda Sierra, director of the Laboratory of Glial Cell Biology at the Achucarro Basque Center for Neuroscience, was published in the journal PLOS Biology on 26 May.
When neurons die, their debris need to be quickly removed in order for the surrounding brain tissue to continue to function properly. Elimination of the neuron corpses, in a process called phagocytosis, is carried out by highly specialised cells in the brain called microglia. These small cells have many ramifications that are in constant motion and are specially equipped to detect and destroy any foreign element, including dead neurons. Or so it was thought until now.

This new study investigated, for the first time, the process of neuronal death and microglial phagocytosis in the diseased brain. To this end, scientists collected brain samples from epilepsy patients at University Hospital of Cruces and from epileptic mice.

It is known that during epilepsy-associated seizures, neurons die. However, contrary to what happens in the healthy brain, during epilepsy, microglia seem to be “blind” and unable to find the dead neurons and to destroy them. Their behaviour is abnormal. Therefore, dead neurons cannot be eliminated and accumulate, spreading the damage to neighbouring neurons and triggering an inflammatory response that worsens the brain injury.

This discovery opens a new avenue to explore therapies that could alleviate the effects of brain diseases including Alzheimer’s and Parkinson’s. In fact, the research group that undertook these studies is currently developing drugs to try and boost phagocytosis for the treatment of epilepsy.

http://dx.doi.org/10.1371/journal.pbio.1002466

Science – behind the headlines

30 May: Is there a link between Herpes and Alzheimer’s disease? - Professor Giovanni B Frisoni comments

Neurologist, Professor Giovanni B Frisoni - Professor of Clinical Neuroscience and Head of the Memory Clinic, University Hospital of Geneva and University of Geneva, Geneva, Switzerland; Scientific Director, IRCCS Fatebenefratelli, The National Centre for Alzheimer’s Disease, Brescia, Italy - graduated in 1986 in Medicine from the University of Brescia, and in 1990 specialised in Neurology at the University of Parma. His thesis was published in the journal Stroke.

Since 2013, he has led the Memory Clinic at the University Hospital of Geneva and has a Chair in Clinical Neuroscience at the University of Geneva. In 2013, he was appointed as Scientific Director of the Scientific Institute for Research and Care, IRCCS-FBF. Since 1999, he has also been the head of the LENITEM — Laboratory of Epidemiology Neuroimaging & Telemedicine at the IRCCSFBF, a research facility with a staff of 20 to 25.

Find out more about Prof. Frisoni here: http://alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Expert-Advisory-Panel/Members/Giovanni-B-Frisoni

Following recent media headlines claiming there is a link between Herpes and Alzheimer’s disease, we asked Professor Giovanni B Frisoni - a member of our Expert Advisory Panel – to comment:

Were the headlines right or were they misleading in some way?

The headline is consistent with the content of the original editorial. Indeed, authors suggest a causative role of microbes, including the herpes simplex virus and several bacteria, in the development of Alzheimer’s disease (AD). In summary, the team of scientists states that some biomarkers used for AD diagnosis, such as the deposition of amyloid-β peptide and the presence of abnormal forms of tau protein, may be indicators of an infectious etiology. In detail, the authors hypothesise that some specific microbes reach the brain overcoming the blood-brain barrier, and there remain dormant for years. As the immune system declines, during aging or under stress conditions, viruses and bacteria can undergo reactivation. When it happens, the direct microbes’ action on the cerebral tissue induces inflammation, against which amyloid-β is acted, as authors speculate. For unclear reasons, over time, this defense mechanism becomes dysfunctional and leads to the progressive neuronal loss, typical of AD.
How important is this story/study for furthering dementia research? Should we be excited?

Surely, alterations in the inflammatory and immune system responses are widely observed in AD patients and, nowadays, a growing amount of evidence proposes that inflammation may promote amyloid-β accumulation. For example, recent data suggest that gut microbiota could play a key role in modulating peripheral and central inflammation, contributing to the neuropathological alterations observed in several brain disorders with an inflammatory component. Dysbalance in the gut microbiota, together with a specific and correlated pro-inflammatory pattern, may increase intestinal permeability, thus allowing bacteria to reach blood stream. In this way, this peripheral inflammation could reach the brain.

However, available evidence is still limited and more studies are required.

What might be the impact of this story/study in the scientific community?

This editorial focuses the attention on the role of microbes, probably underestimated. So, it encourages dementia experts to consider the current AD etiopathological theories from a new and different point of view.

Moreover, these new theoretical adaptations could have a strong impact on pharmacological research. To date, we are seeing failure of hundreds of disease-modifying drugs, conceiving to remove deposition of amyloid. If the hypothesis, according to which neuronal inflammation is linked to microbes’ reactivation, is confirmed, new treatments might be quickly available to be tested in randomised clinical trials.

Although exciting, further research is still required to prove the anti-inflammatory role of amyloid-β.

What are the next steps?

Hitherto, only a few studies have demonstrated the antimicrobial activity of amyloid-β against bacteria, viruses and yeasts, and all of them applied in-vitro models. So, first of all, we need to translate the in-vitro results to in-vivo models, such as animal models as well as in human patients, with specific risk factors.

In addition, there are many uncertainties surrounding the findings that should be clarified before advancing with this hypothesis. For example, it will be necessary to investigate how microbes reach the brain and the causes leading to their reactivation. Lastly, it will be important to understand the possible mechanisms that link peripheral and central inflammation, as we know it happens in several brain disorders with an inflammatory component, such as Parkinson’s disease and Multiple Sclerosis.

There is still a long way to go.

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Living with dementia

18 May: EWGPWD member Nina Baláčková reports on her experience of ADI’s 31st conference

I was at the 31st Conference of Alzheimer’s Disease International (ADI) last month from 21 to 24 April 2016 in Budapest.

I was happy to meet my colleagues there from the European Working Group of People with Dementia (EWGPWD) - Helga Rohra, Agnes Houston and Hilary Doxford. I also met colleagues from the Dementia Alliance International (DAI) - Kate Swaffer, Prof. Peter Mittler, John Sandblom, Mary Radnofsky and many others in Budapest too.

At the conference, there was very interesting information, and projects from all around the world, including many speeches by people with dementia.

For me, one surprise was Haylo Theatre’s “Over the Garden Fence”. The play encourages people to join the discussion, not only about dementia, but about family life as well.

At the conference, there were more than 800 people from all around the world. They spoke very often about human rights and improving the quality of life people with dementia.

I was grateful to be there, to make new friends, and hear new ideas. I came home completely exhausted, but satisfied.

Nina Baláčková, member of the EWGPWD, Czech Republic.

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Dementia in society

18 May: Scottish voluntary organisation is creating a dementia-friendly guide for places of worship

Edinburgh-based voluntary organisation Faith in Older People is working on creating a dementia-friendly guide for places of worship, drawing on a framework created by the Joseph Rowntree Foundation, to try to create a more dementia-friendly environment:

- **Place**: How does the physical environment support people with dementia? Signage, lighting, flooring.
- **People**: How does the congregation respond to the needs of people with dementia and what support is available.
- **Networks**: How do you plan and collaborate?
Resources: Are there sufficient services, facilities and resources available?

Faith in Older People wants to draw on the work that has been done to date by a number of organisations and to bring it together to form a guide, using an audit tool of gold, silver and bronze levels. This approach takes into account the capacity of the individuals within the community and the members of the congregation to respond to the identified needs. The guide is intended to be practical and sympathetic.

The intention is to pilot the approach to make sure that it fits what different congregations need. The work being done is aimed to be appropriate across Europe and to embrace all faiths, although it has commenced with the Christian congregations as they currently offer a number of support activities irrespective of belief.

A conference will be held in November 2016 to discuss these elements.

The website is: http://faithinolderpeople.org.uk/Home/home.php

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Education

17 May: Karolinska Institutet offers online MSc in Dementia Care for Occupational Therapists and Physiotherapists

The Karolinska Institutet in Sweden is offering web-based Master’s Courses (MSc) in Dementia Care for Occupational Therapists and Physiotherapists, in cooperation with Stiftelsen Silviahemmet, a Swedish non-profit foundation devoted to improving the quality of life for persons affected by dementia and their carers. Participants who complete the courses will earn the title of Silviasjöterapeut (Silvia Occupational therapist) or Silviasjöterapeut (Silvia Physiotherapist). The diploma and the official pin of completion will be presented by H. M. Queen Silvia of Sweden at a ceremony.

Courses begin on 11 November 2016 for a two-year period part-time and are entirely web-based. They are equivalent to a one-year MSc.

The language of instruction is English.

The Master’s courses are offered as contract education and can be commissioned only by a legal entity – an organisation, company or the equivalent.

The deadline for applications is 19 September 2016.

http://ki.se/en/education/masters-courses-in-dementia-care-

Job opportunities

25 May: Applications open for position of Professor in “Health care research with a focus on neurodegenerative diseases” in Germany

Applications are sought for the joint appointment of a Professor (W3) at the University Medicine Greifswald (UMG), appendant corporation of the Ernst Moritz Arndt University Greifswald, and the Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE) – the German centre for neurodegenerative diseases.

The DZNE and UMG are seeking an experienced researcher as soon as possible for the position of a Full Professor in “Health care research with a focus on neurodegenerative diseases”.

Please send your application CV, description of scientific career, publication record, impact factors of the last five years, list of teaching courses, list of acquired third-party funding, documentation of academic exams, appointments, teaching experience, five selected original publications and a candidate’s short profile (form downloadable from http://www.medizin.uni-greifswald.de/bewerbungshinweise/) before 22 June 2016 (postmark) to Dekanat der Universitätsmedizin Greifswald, Fleischmannstraße 8, D-17475 Greifswald, Germany. Please also send a copy of the application to the DZNE via e-mail: application@dzne.de.


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Alzheimer Europe Staff
Executive Director: Jean Georges; Communications Officer: Kate Boor Ellis; Policy Officer: Vanessa Challinor; Project Officer: Ana Diaz; Director for Projects: Dianne Gove; Conference and Event Coordinator: Gwladys Guillory; Finance Officer: Stefanie Peulen; Director for Communication: Alex Teligadas; Administrative Assistant: Grazia Tomasin.

AE Calendar

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 June</td>
<td>EFPIA Patient Think Tank Meeting (Brussels)</td>
<td>Vanessa</td>
</tr>
<tr>
<td>2 June</td>
<td>Board meeting for the European Covenant on Demographic Change (Groningen, Netherlands)</td>
<td>Dianne</td>
</tr>
<tr>
<td>3 June</td>
<td>DAW Conference of Alzheimer Scotland (Edinburgh, UK)</td>
<td>Heike</td>
</tr>
<tr>
<td>6-7 June</td>
<td>Roche meeting (Lindau, Germany)</td>
<td>Jean</td>
</tr>
<tr>
<td>10 June</td>
<td>Francophone conference on Alzheimer’s disease (Lyon, France)</td>
<td>Jean</td>
</tr>
<tr>
<td>14 June</td>
<td>EMA Patient and Consumer Working Party (London, UK)</td>
<td>Jean</td>
</tr>
<tr>
<td>14 June</td>
<td>Workshop on dementia care in the community organised by the European Centre (Vienna, Austria)</td>
<td>Dianne</td>
</tr>
<tr>
<td>15 June</td>
<td>Interest Group on Carers: Meeting on the challenges of work-life balance faced by working families (Brussels, Belgium)</td>
<td>Vanessa</td>
</tr>
<tr>
<td>15 June</td>
<td>Intermediate PACE Policy Conference on palliative care (Brussels, Belgium)</td>
<td>Iva Holmerová, Ana and Vanessa</td>
</tr>
<tr>
<td>16 June</td>
<td>European Commission-Fighting elder abuse in health and long-term care (Brussels, Belgium)</td>
<td>Vanessa</td>
</tr>
<tr>
<td>17 June</td>
<td>GunReal Stakeholder Conference (London, UK)</td>
<td>Jean</td>
</tr>
<tr>
<td>17 June</td>
<td>Second AE ethics meeting on changing definitions related to Alzheimer’s disease (Amsterdam, Netherlands)</td>
<td>Dianne</td>
</tr>
<tr>
<td>20 June-1 July</td>
<td>MiniD workshop organised by AE and the University of Luxembourg</td>
<td>Dianne and Ana</td>
</tr>
<tr>
<td>21-22 June</td>
<td>DISTALZ Advisory Board meeting (Lille, France)</td>
<td>Jean</td>
</tr>
<tr>
<td>27-29 June</td>
<td>AE Board meeting, EP lunch debate “Using the UN Convention on the Rights of persons with disabilities to support the rights of people living with dementia”, Company round table meeting and AE Public Affairs Meeting (Brussels, Belgium)</td>
<td>AE Board, members, staff and sponsors</td>
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</tbody>
</table>

Conferences 2016

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>8-10 June</td>
<td>13eme RF MASA, <a href="http://ifmasa2016.univ-lyon1.fr/en">http://ifmasa2016.univ-lyon1.fr/en</a></td>
<td>Lyon, France</td>
</tr>
<tr>
<td>10-11 June</td>
<td>The Alzheimer’s show, <a href="http://alzheimershow.co.uk/">http://alzheimershow.co.uk/</a></td>
<td>London, UK</td>
</tr>
<tr>
<td>16-17 June</td>
<td>Grand Designs “Are we there yet?”, <a href="http://www.dementiaconference.com/">http://www.dementiaconference.com/</a></td>
<td>Sydney, Australia</td>
</tr>
<tr>
<td>30 June-2 July</td>
<td>4th International conference on vascular dementia</td>
<td>Valencia, Spain</td>
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<tr>
<td>2-4 July</td>
<td>12th Federation of European Neuroscience Societies (FENS) Forum of Neuroscience</td>
<td>Copenhagen, Denmark</td>
</tr>
<tr>
<td>4-8 July</td>
<td>INTERDEM Academy Summerschool, “Multidisciplinary Perspectives on Dementia”</td>
<td>Nottingham, UK</td>
</tr>
<tr>
<td>24-28 July</td>
<td>AAC Annual Conference, <a href="https://www.aac.org/aac/">https://www.aac.org/aac/</a></td>
<td>Toronto, Canada</td>
</tr>
<tr>
<td>31 August-2 September</td>
<td>10th International Conference on Fronto-temporal Dementias, <a href="http://www.icftd2016.de/">http://www.icftd2016.de/</a></td>
<td>Manchester, Germany</td>
</tr>
<tr>
<td>6-9 September</td>
<td>2016 IPA International congress, <a href="http://www.ipa-online.org">www.ipa-online.org</a></td>
<td>San Francisco, USA</td>
</tr>
<tr>
<td>29 September-1 October</td>
<td>9th Conference of the German Alzheimer’s Association (DAH) on “Dementia. Looking at diversity”, <a href="http://www.demenz-kongress.de">www.demenz-kongress.de</a></td>
<td>Saarbrücken, Germany</td>
</tr>
<tr>
<td>5-9 October</td>
<td>Croatian congress on Alzheimer disease with international participation (CROCAD 16), <a href="http://www.alzheimer2016.com/">http://www.alzheimer2016.com/</a></td>
<td>Tuzlje, Croatia</td>
</tr>
<tr>
<td>31 October-2 November</td>
<td>26th Alzheimer Europe Conference (26AEC) on “Excellence in dementia research and care”</td>
<td>Copenhagen, Denmark</td>
</tr>
<tr>
<td>10-11 November</td>
<td>EDUCAL 2016 – Second educational conference on Alzheimer’s disease, <a href="http://www.edukal.alzheimer.hr">www.edukal.alzheimer.hr</a></td>
<td>Zagreb, Croatia</td>
</tr>
<tr>
<td>9-11 December</td>
<td>2016 IPA Asian-regional meeting, <a href="http://www.ipa-online.org">www.ipa-online.org</a></td>
<td>Taipei, Taiwan</td>
</tr>
<tr>
<td>29 March-2 April 2017</td>
<td>13th International Conference on Alzheimer’s &amp; Parkinson’s (AD/PO 2017)</td>
<td>Vienna, Austria</td>
</tr>
</tbody>
</table>
26th Alzheimer Europe Conference
Excellence in dementia research and care
Copenhagen, Denmark
31 October – 2 November 2016
www.alzheimer-europe.org/conferences
#26AEC