Highlights in this issue

22 March: National Dementia Strategy approved in Greece
8 April: Ireland launches Charter of rights for people with dementia
11 April: MEPs launch Written Declaration on dementia
15 April: New Dementia in Europe magazine released
30 April: Alzheimer Europe closes call for abstracts

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Editorial

Welcome!

First of all, I would like to extend our most sincere condolences to Jean-Pierre Frognet’s wife Marie-Anne, family and friends. Jean-Pierre passed away on 7 April. He was a former member and Vice-Chair of our European Working Group of People with Dementia (EWGPWD) and was very active in the group. He was also a keen campaigner for younger people living with dementia in Belgium. Everyone here remembers him with great fondness.

On a brighter note, in mid-April we were pleased to learn of a new European Parliament cross-party Written Declaration on Alzheimer’s disease, launched by 11 MEPs. Similarly to our Glasgow Declaration campaign last year, it calls for a European Dementia Strategy. It also calls upon the Council and the Commission to make dementia a top EU health priority and to put further emphasis on cooperation among Member States. We gratefully acknowledge this initiative and are asking MEPs to sign it.

Also on the policy front this month:

The Alzheimer Society of Ireland and the Irish Dementia Working Group have published a Charter of Rights for People with Dementia, influenced by its Scottish equivalent from 2009. Good news from our friends in Switzerland also, where the 2014-2017 National Dementia Strategy is being rolled out. The Strategy calls upon each Canton to ensure the roll-out locally and this month, the Canton of Geneva announced its own plan, consistent with the national strategy. Also in Switzerland, the government has just approved a national non-communicable diseases (NCDs) strategy. Although dementia is only briefly mentioned in the strategy, the Association Alzheimer Suisse welcomes it. Last but not least, our friends in Greece informed us that the Greek National Dementia Strategy was approved by Parliament in late March and that the implementation of the strategy has already begun. If you want to delve further into policy matters from around Europe, you may like to read Issue 22 of our Dementia in Europe magazine, which came out this month.

At the end of the month ADI held its 31st international conference in Budapest. There was an impressive selection of presentations, including two from our very own Dianne Gove and Ana Diaz, who spoke about their recent work on ethical guidelines for professional carers and on dementia-friendly communities. Four members of our EWGPWD were also in attendance.

On the subject of conferences, we are pleased to have received over 350 abstracts for our upcoming annual conference in Copenhagen. The call is now closed and submitting authors will be contacted at the end of May, following the Programme Committee’s review.

Last, but by no means least, I’d like to thank the newest member of the EWGPWD, Karin Gustafsson from Sweden, for taking the time to write an article for this month’s “Living with dementia” section, in which she describes her experience of diagnosis and the effects this has had on her and her family.

Jean Georges
Executive Director
5 April: AE releases an updated dementia strategy map

Alzheimer Europe recently published an updated map of the status of national dementia strategies in Europe. AE is always pleased to include new countries that previously did not have dementia strategies. The current update reflects new strategies in Austria and the Czech Republic and the inclusion of Israel, which has had a strategy since 2013.

www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies

5 April: Carers’ survey kick off meeting held in Amsterdam

This piece of research will explore the experiences of diagnosis of family carers of people with dementia. The survey will be conducted in collaboration with five AE members (Czech Republic, Finland, Italy, Netherlands and Scotland). The University of Bangor is the academic leader for the survey.

The kick-off meeting was held in Amsterdam on 5 April and the group discussed the specific topics that will be addressed in the survey, as well as other relevant methodological aspects. The group decided to use some of the questions that were used in the “Who cares?” survey in 2006.

In addition, other questions that will provide information on the pathways that people with dementia need to follow to get a diagnosis, disclosure of diagnosis and post-diagnostic support, will be also incorporated in the questionnaire. The sample will be the same as in 2006 (i.e. 1000 carers in total, 200 per country).

The survey will be available online and paper copies will also be used when necessary. The survey will be conducted after the summer in the five countries and its findings will be published in 2017. Jean and Ana attended the meeting on behalf of AE.

8 April: Alzheimer Europe’s ethics working group meets to discuss changing definition of AD

This year, Alzheimer Europe will be exploring the ethical issues linked to the changing definitions of Alzheimer’s disease (e.g. pre-clinical AD, MCI/prodromal AD and AD dementia). The working group, which is chaired by Dianne Gove, is comprised of eminent ethicists, representatives from Alzheimer associations, healthcare professionals, a person with dementia and dementia researchers. The group had its first meeting in Amsterdam on 8 April, where the participants agreed on the focus, style and structure of the planned report and on various ethical issues to be covered. It will meet again in June and the report will be published in December.

In memoriam Jean-Pierre Frognet (1951-2016)

We were very sad to learn of the passing of our dear friend, Jean-Pierre Frognet, on 7 April. Jean-Pierre (pictured, with his wife Marie-Anne) was diagnosed with Alzheimer’s disease in 2007 and joined the Belgian Alzheimer association (Ligue Nationale Alzheimer Liga) to find out more about his condition. The Ligue nominated him as a member of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD), on which he served from 2012 to 2014 and was elected as Vice Chairperson in 2013. Jean-Pierre was very active in the group and also participated in Alzheimer Europe’s annual conferences in Malta in 2013 and in Glasgow in 2014. He was keen to see more services for younger people with dementia, so they can remain active for a longer time.

He had long dreamed of travelling to Senegal and we were delighted to hear that on 26 February this year, he and Marie-Anne travelled to the capital Dakar to begin a two week trip, together with other members of the Belgian dementia working group, and the Ligue’s President Sabine Henry.

Everyone in the EWGPWD and at Alzheimer Europe who knew him remembers his kindness and warm sense of humour. He will be sorely missed by all of us and our heartfelt condolences go out to his wife Marie-Anne, family and friends.

15 April: AE releases new issue of Dementia in Europe magazine

Alzheimer Europe has circulated issue 22 of the Dementia in Europe magazine. The new issue features an interview with Zsuzsanna Jakab, WHO Regional Director for Europe, reports on the Luxembourg and Dutch EU Presidencies and the launches of the 2nd European Joint Action on Dementia and the European Covenant on Demographic Change.

This issue also covers the implementation of Austria’s new national dementia strategy and the renewal of Norway’s existing programme. AE Chair Heike von Lützau-Hohlein looks back at a long career with the German Alzheimer Society while Collette Kelleher speaks about her first few months at the helm of the Alzheimer Society of Ireland. Issue 22 also showcases the activities of AE’s new member associations in Israel and Bosnia and Herzegovina, as well as a presentation about a new booklet written by and for people with dementia.

The Dementia in Europe magazine appears twice per year and reaches more than 3,000 readers. Issue 23 will appear in October at the 26th Alzheimer Europe Conference in Copenhagen. The current issue is available for purchase on the Alzheimer Europe website and previous issues can be freely downloaded.

www.alzheimer-europe.org/Publications/Dementia-in-Europe-magazines

21-24 April: ADI holds its 31st international annual conference in Budapest, AE and EWGPWD attend

Alzheimer’s Disease International (ADI) held its 31st international conference (Dementia: global perspective – local solutions) from 21 to 24 April in the beautiful city of Budapest. Hundreds of people from all over the world attended the conference and there was an impressive selection of presentations, plenary speeches and posters, as well as ample opportunity for networking.

Alzheimer Europe Director for Projects Dianne Gove and Project Officer Ana Diaz both presented their recent work on ethical guidelines for professional carers and on dementia-friendly communities.

People with dementia from around the world attended the ADI conference (pictured), including Helga Rohra (Germany), Agnes Houston (Scotland) and Hilary Duxford (England) from our European Working Group of People with Dementia (EWGPWD). Group member Nina Balackova (Czech Republic) was also present, though not pictured here.

30 April: Alzheimer Europe closes call for abstracts

The call for abstracts for the 26th Alzheimer Europe Conference (26AEC) is now closed. We are delighted to have received more than 350 abstracts. These will be reviewed by the Programme Committee in May. All submitting authors will be informed of the Committee’s decision by 31 May 2016.

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

EU projects

21 March: EPAD launches largest ever pre-dementia cohort

On 21 March, between 40 and 50 representatives of the European Prevention of Alzheimer’s Dementia (EPAD) project met in Edinburgh, to launch the largest ever specific pre-dementia cohort. Participants at the “1st wave Investigator meeting” included representatives from Clinical Research Organisations (CROs) and six dedicated teams from France, Italy, the Netherlands, Spain, Sweden, Switzerland and the UK. The objective of the meeting, which took place at St Leonard’s Hall, was to prepare attendees from trial delivery centres (TDCs) to put the EPAD Longitudinal Cohort Study (LCS) into action.

Day one of the two-day meeting mainly focused on explaining how the LCS works conceptually. Tony Brooks, Graciela Muniz Terrera and Craig Ritchie amongst others explained the purpose of the protocol and how the LCS is different from other cohort studies. Ray French also spoke about the role and responsibilities of ACCORD (The Academic and Clinical Central Office for Research and Development - a partnership between the University of Edinburgh and NHS Lothian Health Board) in the LCS, and Judi Syson closed the first day of the meeting with a few words on progress made with the Ethics Committee (EC) approvals for the different sites.

Day two focused on the truly operational aspects of the project, and included training for all site personnel on monitoring and data management (Quintiles) sample handling (The Roslin Institute), the procedure for taking and processing MRI images (IKICO) and how cognitive tests work, including a hands-on session using tablets (Medavante). To close the day, a few words were said by Mila Etopolski from WP4, on how the LCS will continue into the Proof-of-Concept (PoC) study.

Lisa Vermunt, based at the VU University Medical Center Amsterdam (VUMC), is involved in WP3, helping to set up the EPAD Register and the TDC in Amsterdam. “Since the beginning I am looking forward to the start of the cohort - actually seeing participants for our investigations - and now we are really almost there!” she enthused after attending the Edinburgh meeting.

Samuel Rabanaque, based at the Fundación Pasqual Maragall, is mainly working on WP4 and will be involved in running the trial at the Barcelona site. “The Investigator meeting allowed us to review in a concentrated way all
materials and procedures involving EPAD-LCS protocol. Besides, it gave us the opportunity to share our doubts and expectations with colleagues from other centres”, he said.

The goal of the EPAD initiative is the prevention of dementia in people with evidence of the disease (such as biomarker abnormalities) who still may have little or no complaints or clinical symptoms. EPAD’s European-wide cohort will consist of over 6,000 participants, of which 1,500 will be invited to participate in a trial to test new treatments for the prevention of Alzheimer’s dementia. The five year programme is part of the Innovative Medicines Initiative.

Follow EPAD on Twitter @IMI_EPAD and keep up to date with the cohort via the hashtag #EPADCohort.

6 April: POW Health joins SMART4MD project

On 6 April, Anglia Ruskin University, coordinator of the SMART4MD project, announced that the Commission has accepted an amendment request, allowing POW Health to be officially welcomed on board as a project partner.

Ify Ahmed, Founder & CEO of POW Health, was welcomed by the SMART4MD consortium at its meeting via teleconference on 14 April.

7 April: EPAD scientist is awarded Söderberg Prize for his work on AD

One of the scientists working on the European Prevention of Alzheimer’s Dementia (EPAD) project, Professor Kaj Blennow, has been awarded the Söderberg Prize for his work on Alzheimer’s disease. Prof. Blennow, of the University of Gothenburg, was awarded the prize of one million SEK (EUR 110,000) for his “uniquely innovative research” on 7 April during a ceremony at the Swedish Society of Medicine seminar.

“I am extremely happy! It is a great honour to receive the Söderberg Prize in Medicine,” said Prof. Blennow (pictured), who will be performing cerebrospinal fluid (CSF) analyses for the EPAD Longitudinal Cohort Study (LCS).

“It is also very gratifying that this type of clinically tied biochemical research receives attention. Currently there are a number of highly promising drugs that are in the final phase of their clinical trials, and on the day they hopefully become available for patients, there will be an enormous need to be able to diagnose Alzheimer’s early in the course of the disease.”

The Söderberg Prize in Medicine awards clinical medicine researchers whose results have been recognised for the past ten years. The prize, which has been awarded since 1986 by the Torsten Söderberg Foundation, is given to Laureates chosen in cooperation with the Swedish Society of Medicine.

Professor Miia Kivipelto, EPAD WP4-lead, also gave a lecture during the seminar, called “Is Alzheimer’s Preventable?”. http://sahlgrenska.gu.se/english/research/news-article/Aaj-blennow-receives-the-soderberg-prize-in-medicine.cid1346942

7 April: Researchers and companies discuss 2nd stage application for project on real world evidence in Alzheimer’s disease

After the successful first stage evaluation of their application by the Innovative Medicines Initiative, researchers, company representatives and Alzheimer Europe met in Zug, Switzerland to discuss the development of the 2nd stage application of the ROADMAP project.

The aim of ROADMAP is to deliver a series of data integration methods and tools for patient outcomes, developed and tested through pilot projects, which are scalable and transferable, and which will provide the foundation for a future Europe-wide Real World Evidence platform on AD. In parallel, the project will develop tools for stakeholder engagement, understanding the ELSI context and health economics impact of a RWE approach in AD.

If successful, the project will be coordinated by the University of Oxford with active contributions of Alzheimer Europe to dissemination activities and the discussion of ethical issues raised by the project.

18-19 April: The INDUCT project kicks off with a meeting in Nottingham

The INDUCT project held its kick-off meeting in Nottingham (UK) on 18 and 19 April. The participating universities presented the 15 future PhD positions, which will be available under the INDUCT project and discussed secondments. The role and contribution of the European Working Group of People with Dementia (EWGPWD) was also discussed. Director for Projects Dianne Gove attended the meeting on behalf of Alzheimer Europe.

INDUCT - Interdisciplinary Network for Dementia Utilising Current Technology - is a European Commission Horizon 2020-funded project. The project now has a website and logo. Please see www.dementiainduct.eu

21 April: INTERDEM meets in Budapest before the ADI meeting

On 21 April, the INTERDEM group had a meeting in Budapest. Several researchers presented their work in the morning and in the afternoon there were workshops and discussions about the ongoing work of the social health and assistive technology task forces, led by Rose-Marie Dries and Franka Meiland respectively, as well as on outcomes measures, led by Gail Mountain.

Alzheimer Europe Project Officer Ana Diaz and Director for Projects Dianne Gove were formally accepted as members of the INTERDEM group and attended the meeting together with Executive Director Jean Georges.
21 April: SyDAD project kicks off

On 21 and 22 April, the SyDAD – Synaptic Dysfunction in Alzheimer Disease – project held its kick-off meeting at Vår Gård, Saltsjöbaden, Sweden.

SyDAD is a European Training Network (ETN), sponsored by Marie Skłodowska Curie Actions. It will train 15 Early Stage Researchers (ESRs) and perform a collaborative research program to reveal the mechanisms behind synaptic dysfunction in Alzheimer’s disease (AD).

The project is led by Professor Bengt Winblad (Coordinator) and researcher Susanne Frykman (Project Manager), at the Department of Neurobiology, Care Sciences and Society (NVS) of the Karolinska Institutet, Sweden.

The kick-off meeting gathered together all ESRs, their supervisors and partner organisations, to discuss research projects and the project’s training programme.

http://www.sydad.eu/

28 April: EMIF has revamped its website

The European Medical Information Framework (EMIF) project is proud to announce the revamped version of its website www.emif.eu

A full update has been done on the overall structure and design, as well as the content management system. More content and features will be added in the coming weeks and months.

EMIF is connecting data on 52 million individuals to decipher links between genetic background, biological abnormalities, brain imaging changes, mental symptoms and disease progression. The main objective is to create an environment that allows for efficient re-use of existing health data.

Alzheimer Europe networking 2016

On 1 April (Luxembourg, Luxembourg) Dianne and Ana had a meeting with a representative of the INSIDE programme of the University of Luxembourg, in relation to the MIND project.

On 5 April (Amsterdam, Netherlands) Jean and Ana attended the kick-off meeting of AE’s carers’ survey project.

On 7 April (Zug, Switzerland) Jean participated in a meeting to discuss the second stage application for the Innovative Medicines Initiative project ROADMAP.

On 8 April (Amsterdam, Netherlands) Dianne and Jean attended the first meeting of the Alzheimer Europe working group on the ethical implications of the new definition of Alzheimer’s disease.

On 13 April (Brussels, Belgium) Vanessa attended an EFGCP Workshop on the new Clinical Trials Regulation.

On 13 April (Luxembourg, Luxembourg) two representatives from Black Swan visited the AE offices to discuss about a project proposal.

On 16-19 April (Frankfurt, Germany) Gwladys participated in the ICCA Association Expert Seminar and to IMEX.

On 18-19 April (Nottingham, United Kingdom) Dianne took part in the INDUCT kick-off meeting.

On 20 April (Brussels, Belgium) Vanessa attended the Science-Business event “How to get market-creating innovations: Research Infrastructure and the EIC.”

On 20-21 April (Budapest, Hungary) Heike and Jean attended the Elected Board meeting of Alzheimer’s Disease International (ADI) and the ADI Council Meeting.

On 21 April (Brussels, Belgium) Vanessa attended the European Commission meeting “Towards better prevention and management of chronic diseases.”

On 21 April (Budapest, Hungary), Dianne and Ana attended the INTERDEM meeting.

On 22 April (Brussels, Belgium) Jean attended by phone in the European Brain Council working group on its Value of Treatment project.

On 22-24 April (Budapest, Hungary) Ana and Dianne attended the ADI annual conference.

On 25 April (Brussels, Belgium) Vanessa attended an EESC public hearing on “The rights of live-in carers.”

On 26 April (London, United Kingdom) Jean attended the Annual Conference of Dementias Platform UK.

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 of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance:

Austria: Heinz K. Becker (EPP); Kappel Barbara (NI); Rübig Paul (EPP); Belgium: Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE). Bulgaria: Andrey Kovatchev (EPP). Croatia: Biljana Borzan (S&D); Tonino Picula (S&D); Ruda Tomašić (ECR). Cyprus: Costas Mavrides (S&D); Eleoni Theocharous (EPP). Czech Republic: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). Denmark: Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). Estonia: Urmas Paet (ALDE); Finland: Liisa Jakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Mieperta Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP). France: Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chantier (EPP); Gilles Pargneaux (S&D). Germany: Angelika Niebler (EPP); Udo Voigt (NI). Greece: Kostas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyraki (EPP); Eleftherios Synadinos (NI); Elisavet Vozemberg (EPP). Hungary: Ádám Kósa (EPP). Ireland: Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Liadh Ni Riada (GUE/NGL). Italy: Brando Benifei (S&D); Elena Centile (S&D); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D); Damiano Zoffoli (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 (EPP); Bogdan Wenta (EPP). Portugal: Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (S&D). Romania: Cristian-Silviu Busoi, MEP (EPP); Daciana Octavie Sarbu (S&D); Claudiu Ciprian Tanasecu (S&D); Renate Weber (EPP). Slovakia: Miroslav Mikolásik (EPP); Ivan Stefanec (EPP); Anna Záborská (EPP). Slovenia: Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Sulin (EPP); Romana Tomc (EPP); Ivan Vajgl (ALDE); Milan Zver (EPP). Spain: Iázkun Bilbao Barandica (ALDE); Soledad Cabezón Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estarás Ferragut (EPP); Juan Carlos Girauta Vidal (ALDE); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Ernest Maragall (Greens/EFA); Pablo Zabalideegain (EPP). Sweden: Jytte Guteland (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE). United Kingdom: Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Anneliese Dodds (S&D); Renata Mir Esko (EPP); Samira Nati (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP); Anneliese Dodds (S&D); Jan Olbrycht (EPP); Marek Laimbeer (ALDE).

European Alzheimer’s Alliance

20 April: MEP Jana Žitňanská discusses health priorities of Slovakian EU Presidency with AE

On 20 April, MEP Jana Žitňanská (ECR, Slovakia) met with Alzheimer Europe (AE) Policy Officer Vanessa Challinor at the European Parliament in Brussels to talk about the health priorities of the upcoming Slovakian Presidency, which will run from 1 July 2016 until the end of the year. The Presidency will then pass to Malta.

The website of the upcoming Slovakian Presidency is http://www.eu2016.sk/. It will be fully up and running in May.

Ms Žitňanská has been a member of the European Alzheimer’s Alliance (EAA) since 2015 and was one of the 84 MEPs who signed the Glasgow Declaration last year, in support of creating a European Dementia Strategy, national dementia strategies in every country in Europe and recognising dementia as a public health priority. She is Vice-chair of the Committee on Women’s Rights and Gender Equality and is a member of the Committee on Employment and Social Affairs.

http://alzheimer-europe.org/Policy-in-Practice/2-European-Alzheimer’s-Alliance/Members/Zitnanska-Jana

EU developments

21 March: The UN Convention on the Rights of Persons with Disabilities is being implemented

On 21 March, MEP Nessa Childers (Ireland) presented a European Parliament draft opinion to the Environment, Public health and Food Safety (ENVI) Committee. This opinion will feed into the Employment and Social Affairs (EMPL) Committee’s own-initiative report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD), with special regard to the Concluding Observations of the UN Committee on the Rights of Persons with Disabilities (CRPD Committee).

In 2011, the European Union (EU) ratified the UN CRPD. With the ratification, the EU is now subject to scrutiny by the CRPD Committee. This was the first international human rights treaty the EU ratified as a whole.
While the EMPL Rapporteur, MEP Helga Stevens (Belgium) focuses in particular on accessibility issues, ENVI Rapporteur Ms Childers (pictured) puts more emphasis on the right to health and access to healthcare for persons with disabilities in the EU (Article 25 CRPD).

The ENVI Committee calls on the EMPL Committee, as the committee responsible, to incorporate the following suggestions into its motion for a resolution:

1. Highlights the strong correlation between disability, which touches about 13 % of the EU’s population, and ill-health, with difficulties and barriers in access leading to the inadequate or unmet provision of healthcare services to people with disabilities;

2. Stresses the need to consider and address intersectional discrimination issues, in light of the especially high incidence of reported serious health problems among women with disabilities, the overall higher percentages of mental difficulties among the female population, particularly migrants, and other instances of preventable discrimination arising from gender, sexual orientation and identity;

3. Emphasises informed consent as a condition to the right of people with disabilities to freely exercise decisions concerning their medical treatment to the fullest possible extent;

4. Calls on the Commission to integrate disability-oriented approaches in its health instruments and policies so as to contribute to improved health outcomes for people with disabilities in the Member States, through better physical and sensory accessibility, quality and affordability;

5. Urges the Commission and the Member States to evaluate the Cross-Border Healthcare Directive and its implementation from the perspective of the needs of people with disabilities and their right to know, and effectively avail of, the provisions and instruments contained therein, awareness of which is low even among the general population;

6. Expects the Commission to ensure that electronic and mobile health services, applications and devices are fully accessible to patients with disabilities and their respective carers, and to further exploit the potential of telemedicine to improve access and care in this context.

In the ENVI committee, 56 amendments were tabled. A set of 8 compromise amendments are currently being elaborated upon.


1 April: STOA publishes “What if others could read your mind?”

“What if…?” is a publication of the Scientific Foresight Unit (STOA) of the EPRS | European Parliamentary Research Service Brain-computer interface technology, about Brain-computer interface (BCI) technology.

A Brain-computer interface is a direct communication pathway between the brain and an external device. This technology can be used to restore motor and sensory capacities which may have been lost through trauma, disease or congenital conditions. For example, combined with limb-replacement technology, BCI may allow patients not only to move prosthetic limbs, but also to feel the sensation of touch.

Over 100,000 patients already use “brain pacemakers” to treat Parkinson’s disease and other movement disorders, and these devices may be used in the future to treat a wider range of disorders, including Alzheimer’s disease, STOA says.

The technology can either be implanted (invasive) or used externally (non-invasive). Invasive BCIs, including neuro-prosthetics and brain implants, are devices which connect directly to the brain and are placed on its surface, or attached to the cortex. Non-invasive BCIs consist of a range of technological devices which provide a similar interface between the brain and other machines without the need for surgery.

Debate about BCIs can lead to speculation about a “sinister future”, with the concept of surveillance exaggerated to include “thought police” and even mind control, says STOA. It insists, however, that “while functional implants are increasingly common, mind reading (and, indeed, mind control) remains firmly in the realm of science fiction”.

“However, if we allow fears about potential problems in the future to overly restrict the development of BCI technology, we might also hinder the development of medical treatments for diseases such as Parkinson’s and Alzheimer’s”.


1 April: AAL launches 2016 call on “Living well with dementia”

The Active and Assisted Living Programme (AAL) has launched its 2016 call for proposals, on “Living well with dementia”, looking into the contribution of ICT to integrated solutions for enabling the wellbeing of people living with dementia and their communities.

The aim of this call is to support innovative, transnational and multi-disciplinary collaborative projects with a clear route to market and added-value. The deadline is 26 May 2016, 5PM CET.

See more at: http://www.aal-europe.eu/get-involved/call-2016/

8 April: Amsterdam is the European Capital of Innovation 2016

The European Commission has awarded the European Capital of Innovation ("Capitalk") award 2016 to the city of Amsterdam. Carlos Moedas, European Commissioner for Research, Science and Innovation (pictured), announced the results at an award ceremony in the European Committee of the Regions on 8 April.
Amsterdam was chosen by a panel of independent experts, in recognition of its approach to innovation related to four basic areas of urban life: governance, economics, social inclusion, and quality of life. The city will use its first prize of EUR 950,000 to scale up and expand its innovation efforts. Turin and Paris were runners up, and will receive prizes of EUR 100,000 and EUR 50,000 respectively. 

http://ec.europa.eu/research/innovation-union/index_en.cfm?action=capital

11 April: European Institute for Innovation through Health Data (i~HD) is formed

The European Institute for Innovation through Health Data (i~HD) is being formed as one of the key sustainable entities arising from the Electronic Health Records for Clinical Research (EHR4CR) and SemanticHealthNet projects, in collaboration with several other European projects and initiatives supported by the European Commission. Its vision is to become the European organisation of reference for guiding and catalysing the best, most efficient and trustworthy uses of health data and interoperability, for optimising health and knowledge discovery.

The i~HD mission will be to enable, coordinate, and accelerate the efficient development and deployment of interoperable and seamless eHealth solutions and research strategies, towards achieving best practices and sustainable integrated person-centred health care, to optimise health and wellness in Europe, and beyond. i~HD recently welcome 210 participants at its Inaugural Conference on 10 March, in Paris, which also marked the parallel launch of a novel European platform to support multi-centre clinical research. This operational platform, the result of the European project EHR4CR, connects securely to the data within multiple hospital EHR systems and clinical data warehouses across Europe, to enable a trial sponsor to predict the number of eligible patients for a candidate clinical trial protocol, to assess its feasibility and to locate the most relevant hospital sites.

Dipak Kalra, President, explained that the role of i~HD, as a not-for-profit Institute, is to provide independent governance oversight of clinical research platforms and services, as these expand to connect with multiple hospitals across Europe.

http://www.i-hd.eu/

11 April: Written Declaration launched on the prioritisation of a European Dementia Strategy

Eleven Members of the European Parliament (MEPs) have submitted a Written Declaration on the prioritisation of a European Dementia Strategy. The MEPs call upon the Council and the Commission to make combating Alzheimer’s and other types of dementia a top priority of the European Union, and to put further emphasis on cooperation among Member States in the areas of research, care and prevention.

Alzheimer Europe gratefully acknowledges this initiative launched by the following MEPs: Deirdre Clune (Ireland), Roberta Metsola (Malta), Alberto Cirio (Italy), José Inácio Faria (Portugal), Neena Gill (UK), Ivan Štefanec (Slovakia), Tomáš Zdechovský (Czech Republic), Brian Hayes (Ireland), Simona Bonafé (Italy), Mairead McGuinness (Ireland), Giovanni La Via (Italy).

A Written Declaration is a text of a maximum of 200 words relating exclusively to a matter falling within the competence of the European Union (EU).

A Written Declaration can be submitted with a minimum of 10 MEPs’ signatures, from at least three political groups. They then have three months to present it to their colleagues for signature. For the declaration to get to the next stage and be forwarded to the EU institutions named in the text, it must attract more than half of all MEPs’ signatures (376/751). If it has not been signed by at least half of the MEPs it will lapse.

Written Declaration 0027/2016 is open for signatures until 11 July 2016.

http://goo.gl/mpPrft

13 April: European Forum for Good Clinical Practise hosts a workshop on implementing new clinical trials regulations

On 13 April, the European Forum for Good Clinical Practise (EFGCP) held a multi-stakeholder workshop and discussion called “How to Ensure Optimal Ethical Review within the New Clinical Trials Regulation? Where do we currently stand with the implementing in different Member States?”

A revision of the European Clinical Trials Regulation was adopted by legislation makers in 2014. This revised legal framework will bring significant advances compared to today’s situation and is expected to be fully implemented as soon as the supporting Clinical Trials Portal and Database are fully functional.

The EMA presented an update on the development of the new EU Clinical Trials Database and Portal which is the key working tool to facilitate a streamlined and swift coordination process between the various parties involved. In addition, Member States presented the results of some early pilots to test the new assessment scenario.

This workshop showcased the tremendous progress that has been made with the implementation over the past 18 months. The European Commission, for example, is facilitating discussions to resolve some key harmonisation questions across Europe and finally Ethics Committees are intensifying or starting up new collaborations across countries to discuss important aspects of harmonisation of assessment criteria, methodologies and training of reviewers.

Alzheimer Europe Policy Officer Vanessa Challinor attended the event.

For more information on the Clinical trials regulation:
To find out more about the EFGCP: www.efgcp.eu
15 April: Commission launches major campaign to promote sustainable work and healthy ageing

The European Commission and the European Agency for Safety and Health at Work (EU-OSHA), in cooperation with the Dutch EU Presidency has launched a two-year Europe-wide campaign on “Healthy Workplaces for All Ages”.

The campaign will focus on sustainable work, workplace safety and health in the context of the ageing workforce.

https://www.healthy-workplaces.eu/

22 April: European Brain Council discusses value of treatment of brain disorders

The European Brain Council initiated the Value of Treatment (VoT) project bearing in mind that brain disorders, including both mental and neurological disorders, represent an enormous burden on both individuals and societies. The broad impact of brain disorders is threatening the quality of life of millions of European citizens with important implications for the potential achievement of the Europe 2020 strategy on economic growth.

The EBC considers that the current healthcare systems do not adequately respond to the need of patients with brain disorders, as these are fragmented and essentially reactive – responding mainly when a person is sick – and have many deficiencies in the management of patients with brain disorders who need long-term care and treatment.

At its meeting of 22 April 2016, representatives from academia, companies and patient organisations discussed the EBC priorities in the field of dementia and schizophrenia. Alzheimer Europe was represented at this meeting by its Executive Director, Jean Georges.

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Members’ news

18 March: Alzheimer Hellas holds conference for caregivers

On 18-20 March, Alzheimer Hellas held a Scientific Conference for Caregivers in Thessaloniki titled “Caring for the Carers”. The conference gave the opportunity for interaction and discussion between the 200 caregivers that participated and the specialised health professionals, about dementia and difficult aspects of caregiving. The main aim was to offer support to caregivers on their role, as well as information about the social, economic and emotional aspects of caregiving.

Caregivers mentioned that the conference met their expectations and needs, as it helped them to learn useful information for daily life with their relatives and gave new meaning to their role.

On the second day of the conference, the Board of the Federation had a productive meeting with representatives of associations from across the country (Athens, Thessaloniki, Volos, Crete, Kozani, Larisa).

31 March: Inventions to Remember - German Alzheimer’s association awards prizes to Young Inventors

Susanna Saxl from the German alzheimer’s association Deutsche Alzheimer Gesellschaft (DAaG) reports on a recent initiative, pitting young inventors’ ideas against each other, to find the best new inventions to help people living with dementia:

Prove your inventive mind and help people with dementia in their day-to-day-lives! More than 140 young people between the ages of 12 and 21 answered this call and participated in a contest organised by the German Alzheimer’s Association in September 2015. The contest is part of the association’s youth program intended to raise awareness among teenagers. The best inventions were awarded in March 2016.

The winners are Ann-Kathrin B. and Hanna P., who developed an App for smartphones and tablets, designed to remind the user of certain tasks and to suggest recreational activities. It provides individualised messages concerning their plans for the day, their appointments, or their meals.

Second place went to a talking digital picture frame, developed by Naomi B. It shows a person’s picture and plays a pre-recorded message by or about that person. People with dementia can thus see a familiar face and hear the voice associated with it.

The jury also rewarded ideas that were not based on technology, like a note book invented by Vincent M.: It consists of small strips of paper, which can be ripped out and used as a wristband to remind a person of a task ahead.

The jury was impressed by the dedication of the young inventors and their thoughtfulness throughout. Most students drew from their own experiences spending time with relatives with dementia.

All winners and their projects can be found at www.alzheimerandyou.de

1 April: Alzheimer Nederland – “Together with one voice”

“Together with one voice!” As of 1 April, the two largest fundraising organisations in the field of dementia in the Netherlands - Alzheimer Nederland and Internationale Stichting Alzheimer Onderzoek (ISAO), have joined together as one organisation called Alzheimer Nederland and ISAO will move its offices from Elsloo to Amersfoort, where Alzheimer Nederland’s headquarters are located.
Alzheimer Nederland says this merger will bring together a wealth of knowledge across the spectrum and will allow even better information provision for people with dementia, as well as scientific contributions. Another advantage of this merger is that funds will be freed up to use on disseminating informing about dementia and scientific research.

For more information see: www.alzheimer-nederland.nl/samenwerken

19 April: Alzheimer Nederland launches online platform for carers

On 19 April, Alzheimer Nederland officially launched its new online platform for informal carers: www.dementie.nl.

The platform is intended for informal carers of people with dementia, to help them find and share concrete tips, answers and experiences. It is a source of information for practical and healthcare questions, all about the informal care of people with dementia. The ultimate goal is to give support in the different phases of the disease.

You can watch a video about the launch of the platform, with comments from Dutch Health Secretary Martin van Rijn, informal carers Gijs Wanders and Marijke van Oploo-Visser, and Gea-Broekema-Procházka, CEO of Alzheimer Nederland:

https://www.youtube.com/watch?v=W8-Du0qzw5g

Gea Broekema-Procházka, CEO of Alzheimer Nederland said “There is a growing group of informal carers in the Netherlands, which – together with the changing healthcare system – makes dementie.nl one of the main activities of Alzheimer Nederland. Together, we have to do everything in our power to support the carers.”

A previous “soft launch”, announcing the platform only to the visitors of the organisation’s regular website and followers on social media, took place in November 2015. The platform received over 50,000 visitors in its first months.

23 April: Alzheimer Bulgaria completes youth project

On 23 April, Alzheimer Bulgaria and the "Youth Initiative for Civil Society" association completed their joint project, "Dialogue of Generations. For a new understanding of dementia". The project was funded as part of the Support Programme for NGOs in Bulgaria, by the EFTA Financial Mechanism 2009-2014.

The project was implemented in response to the need to improve communication between young people and their relatives living with dementia. Because of the disease specifics, people with dementia gradually lose their ability to make rational decisions, writes Irina Ilieva, of Alzheimer Bulgaria. One of the project’s objectives, therefore, was to provide to young people in Bulgaria with the necessary knowledge, skills and confidence to allow them to represent their relatives at various institutions.

Within the scope of the project, six training meetings were organised, for 140 young people to get a real idea of what it is to experience dementia. They were trained on how to communicate and to relate to grandparents with dementia, were encouraged to become their “voice”, and to help protect their rights and interests. For the purposes of the training, a book was published - "Dialogue of Generations" - intended for and addressed to teenagers. It can be found on www.alzheimer-bg.org. Copies were also distributed to all trainees, as well as to school libraries and teachers involved in the project.

The project also led to the creation of a youth Facebook group bearing the same name as the project. 100 young people are already members of the group and have two specialists-consultants at their disposal.

A short documentary is also in the process of completion. In it, adolescents speak about the situation with their relatives who have dementia and about their feelings and thoughts about the disease.

The project partners hope to continue with this work, supporting children and young people to cope with dementia in their families.

25 April: Swiss association announces new blog

The Association Alzheimer Suisse has announced its new blog “Alois & Auguste”, offering future perspectives on living with Alzheimer’s and other forms of dementia.

The first contribution came from the association’s Director Stefanie Becker, who wrote about the recent ADI conference in Budapest.

https://alzheimerblogdotch.wordpress.com/blog-en-francais/

25 April: Czech Alzheimer Society wins award for most beautiful book of 2015

A book published by the Czech Alzheimer Society has won an award in the “Most Beautiful Czech Books” competition 2015. The publication - Procvičování krátkodobé paměti 2 (The training of short-term memory – a workbook for training of memory and other cognitive functions, part 2) was written by Jiřka Suchá, Eva Jarolimová and Martina Mátlová, with graphic design by Zuzana Lednická and Anna Dvilišová (Studio Najbrt). It won the first place in the category of printed textbooks and teaching aids and earned a prize from the Czech Ministry of Culture. It will be exhibited at the Book World fair, Designblok or the National Technical Museum.

The Czech Alzheimer Society has published 10 Workbooks for memory training and other cognitive functions last year (among these were “The training of short-term memory”,
“The training of executive functions” and “The training of concentration”).

The "Most Beautiful Czech Books" competition, which dates back to 1928, appraises the graphics, illustrations and printing of books brought out by Czech publishing houses and printed by Czech printers during the preceding calendar year.


25 April: Greece has a choir for the elderly, in northern town of Kozani

The Kozani Association of Alzheimer’s Disease and Related Disorders, “Agios Nikolaos”, covers the Kozani Prefecture, in Macedonia, northern Greece.

Dr Peter Natsis, a member of the Board, is a Physical Education teacher and musician. Voluntarily, he organised and now directs a choir for the elderly. People with dementia can watch, attend, participate and even star in the choir.

“It is striking and touching to see a person who does not remember even close relatives, recalling rhythms and lyrics, singing old favourites and enjoying themselves every Tuesday afternoon” writes the PanHellenic Federation of Alzheimer’s Disease and Related Disorders.

The choir has appeared several times on local TV and has sung at a variety of social events.

26 April: UK Alzheimer’s Society continues partnership with the Scouts Association

Scouts across the UK are mobilising as part of a partnership aimed at creating a dementia-friendly generation. The “A Million Hands” partnership sees the Alzheimer’s Society join forces with the Scouts to encourage the younger generation to understand the condition better and take action to help people affected by dementia. A third of young people know someone with dementia and learning about it can make it easier for young people to cope and understand, while improving the life of the person living with dementia. Throughout the Easter holidays, Scout groups across the UK were invited to volunteer at Alzheimer’s Society services. Young people helped out at memory cafes, participated in and led music workshops for people affected by dementia and created a sensory garden at their local centre, as well as becoming Dementia Friends.

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

“We’re excited to be partnered with the Scouts and are delighted a million young hands will be tackling important issues, including dementia, in their community. Almost two thirds of young people know someone with dementia, through this partnership young people will be able to remove social barriers, connect communities and improve lives by better understanding dementia and taking action. Young people are key in shaping what society looks like in the future – they are the prospective customer service managers, health care professionals, police officers, MPs and HR Directors who will have more patience with someone who seems confused, or can influence policies to better support people with dementia and carers.”

For more information, please visit:
www.alzheimers.org.uk/youngpeople

26 April: Alzheimer Croatia presents its new infographic

2015 was a big year for Alzheimer Croatia, not least because it saw the association’s first ever Educational Conference on Alzheimer’s Disease - EdukAl 2015 - held at the end of December in Zagreb. EdukAl 2015 gathered more than 250 participants from various medical and social professions, as well as family caregivers. A short video about the event can be found on the conference website:
www.edukal.alzheimer.hr

During the conference, Alzheimer Croatia announced its new “infographic”, which gives the following facts about dementia in Croatia:

- Each year in Croatia, about 3000 people get dementia - one every 3 hours.
- 90% of people with dementia in Croatia live at home.
- Family caregivers cover 61% of treatment costs.
- Almost 3 times more women than men are family caregivers.
- Alzheimer’s disease affects 2 times more women than men.
- Caregivers are often affected by stress and depression.
- Women are more prone to “caregiver stress and depression” than men.
- According to estimates in Croatia at the end of 2015, there were 86,000 people with dementia. By the end of 2030 this number will rise to 112,000.

According to estimates, the total annual cost of dementia in Croatia in 2015 was EUR 0.5 billion. By the end of 2030 this amount will rise to EUR 0.8 billion, and by the end of 2050 to EUR 1.3.

27 April: Italy pilots dementia-friendly community project near Milan

Federazione Alzheimer Italia, the biggest Italian non-profit organisation for people with dementia and their families in Italy, has chosen the town of Abbiategrasso, near Milan, as a pilot city for its first “Dementia-Friendly Community in Italy” project.
The choice was dictated both by the number of inhabitants (31,000) and by the fact that Abbiati Grasso is already a friendly city with a great culture of solidarity, as demonstrated by the large number of voluntary associations.

Federazione Alzheimer Italia involved, as active members of the DFC project, the Golgi Concelli Research Foundation, the “Golgi Public Company for Service to the People” of Abbiati Grasso, the Federation of Palliative Care and the Municipality. Indeed, the City Council passed a resolution for the Deputy Mayor, the Councilor for Social Services Graziella Camerani and various other officials to be actively involved in the dementia-friendly project.

Some of the initiatives planned in the short term are: analysis and better understanding of the needs of the community, and informative trainings for merchants and law enforcement, regarding cultural and social aspects related to the stigma of the disease.

The phase of drafting the questionnaires for the various stakeholders is already complete, and focus groups have been created to assess the needs and expectations of people with dementia and their families. The organisation is now preparing for widespread distribution of these questionnaires.

They are also building city-involvement activities through the voluntary associations in the area, the Public Library and some recreational centers to help restore a more sociable community in order to increase the participation of people with dementia and their families in city life.

The work continues, under the slogan "The strength of not being alone", dictated by the sharing of a common effort to ensure that no one is left alone to deal with dementia. Federazione Alzheimer Italia is guided by the belief that life for people with dementia can and should continue to be full and meaningful.

27 April: Ireland has new video resources for carers

Two new animated short films, aimed at providing support for dementia carers, have been developed by the Alzheimer Society of Ireland and Trinity College Dublin.

The videos, “Caring for Carers” and “Managing Challenging Behaviours”, remind dementia carers that looking after themselves is vitally important.

These videos are additions to a collection of 10 videos released by Trinity Brain Health in 2014, which set out to allay fears about memory loss, promote brain health and tackle the stigma associated with dementia.

They were developed in partnership with Trinity Brain Health, with funding from the Health Research Board.

You can view the new videos here: 
http://www.hellobrain.eu/en/carers?utm_i=2KSOQLFR8929WE1TE5P1

28 April: UK Alzheimer’s Society reports on its transport project

Public transport remains of huge importance to people affected by dementia and their carers and can be an essential factor to maintaining independence and quality of life for people affected by the condition. Working with leading transport providers in the North East on a project led by Alzheimer’s Society, the British Transport Police and the Dementia Action Alliance, we have produced a pilot pledge for testing with service providers for a 3 month period (May-July) which outlines the 5 key components that should be provided in order to support customers affected by dementia and ensure they can continue to feel confident in using public transport services.

These components include: Identifying a champion, knowing your customer and involving people affected by dementia, sharing best practice, raising awareness and measuring impact. We are looking to make the final document available from August/September 2016 with a view to this work setting the foundations for further development in this space, under the remit of the Prime Minister’s Champion Group on Dementia-Friendly Communities.

28 April: The German Alzheimer association has a new logo

As of 28 April, The German Alzheimer association, Deutsche Alzheimer Gesellschaft (DAzG) has adopted a new logo.

http://www.deutsche-alzheimer.de/

Policy watch

22 March: National Dementia Strategy approved by the Greek Parliament

The Greek National Dementia Strategy was discussed during two subsequent sessions and approved by the Standing Committee of Social Affairs of the Greek Parliament on 22 March.

All political parties agreed that “the basic principles, directives and priorities of the Strategy constitute the basis for developing specific regulations on dementia at a national level”. They also acknowledged the key role of the National Observatory for Dementia.

Professor Magda Tsohaki, President of the Panhellenic Federation of Alzheimer’s Disease and Dr Paraskevi Sakka, Head of the National Observatory for Dementia participated and gave speeches emphasising the need for a permanent dialogue between the patient organisations, the clinical and research community and the public authorities.
Dr Sakka said: “The major challenge to implementing the National Dementia Strategy is unquestionably financial. It is crucial that we balance needs, set priorities and focus on targets that can be met currently”.

The implementation of the Strategy has already begun with three basic actions: Firstly, a national dementia registry is underway at the Greek National Health Service Organisation, aiming at systematic recording of dementia cases and the standardisation of information collected. Secondly, a rating system to measure the impact of dementia on families is being developed by the National School of Public Health. This will be used by the State to accordingly establish financial benefits for persons with dementia and their carers. Thirdly, day care centres for people with dementia are scheduled to operate in collaboration with Municipalities throughout the country, by the end of 2016.

All three projects are funded by the National Strategic Reference Framework 2014-2020.

8 April: Ireland launches Charter of Human rights for people with dementia

The Alzheimer Society of Ireland (ASI) and the Irish Dementia Working Group have published a charter highlighting the rights of people with dementia, influenced by the Scottish Charter of Human Rights developed by the Cross-Party Group in the Scottish Parliament on Alzheimer’s. The Charter of Rights for People with Dementia stresses the need for a parity of rights for the 48,000 people estimated to have the condition in Ireland.

(Pictured, left to right: Helen Rochford-Brennan (Chair IDWG and Vice-Chair EWGPWD), Colette Kelleher (CEO of The Alzheimer Society of Ireland), Mary Robinson (former Human Rights Commissioner and former President of Ireland), and John Clifford (Chair of the Alzheimer’s Society of Ireland Board).

The Charter of Rights for People with Dementia calls for greater participation, accountability, equality, empowerment, and legal recognition for the rights of people with dementia. Specifically, it highlights policy gaps in the areas of stigma and the “inadequate and inappropriate” nature of services.

A charter is a document setting out a body of rights. While those with dementia have the same rights as others in society, they often face obstacles accessing them, the authors have said.

“The objective is to inform a human rights-based approach to the development of services and supports for people with dementia and carers living in Ireland,” said ASI chief executive Colette Kelleher.

Launching the charter, former President of Ireland Mary Robinson said: “I hope that the launch of this charter will enable us all to see people with dementia in a new light, with the same human rights as all of us and with a voice that needs to be heard. It was a significant step to see the importance of using a human rights lens because that would empower those with dementia to be as involved as possible in addressing the challenges. That is what has happened and that is what this charter is all about.”

http://www.alzheimer.ie/About-Us/Policy/Human-Rights/A-Charter-of-Rights-for-People-with-Dementia.aspx

19 April: UN holds Day of General Discussion on the rights of persons with disabilities to live independently

On 19 April, the United Nations (UN) will hold a Day of General Discussion (DGD) on the rights of persons with disabilities to live independently and be included in the community.

The Committee on the Rights of Persons with Disabilities was established in 2009 to monitor the implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) by States parties.

In 2014, the Committee decided to prepare a draft General Comment on article 19 of the Convention. It identified implementation gaps and, to a certain extent, misconceptions about the rights of persons with disabilities to choose their place of residence and where and with whom to live.

At its fourteenth session in August-September 2015, the Committee decided to devote one day of its fifteenth session to a general discussion on the right of persons with disabilities to live independently and be included in the community (article 19 of the Convention). The inputs and outcomes of the DGD will feed into the drafting process of the Committee’s General Comment on article 19.

On behalf of Dementia Alliance International (DAI), Professor Peter Mittler (pictured), DAI Member and Human Rights Adviser has written a submission, which is posted on the UN website and which reflects DAI’s current position on the rights of persons living with dementia to be supported to live independently in the community.

You can read Prof. Mittler’s full submission here:

http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CallDGDtoliveindependent.aspx

21 April: Geneva launches its regional dementia plan

On 21 April, the Department of Employment, Social Affairs and Health of the Canton of Geneva presented its Alzheimer Plan 2016-2019 to the State Council. The plan is divided into five overarching objectives, considered a priority, and 15 action points. A group, consisting of the main partners of the Geneva care network will be created to oversee and support the progressive implementation of the action plan, which will begin in the 2nd quarter of 2016.

The five overarching objectives of the plan are:

- Improve, at the cantonal level, the efficiency of diagnosis and monitoring of people with cognitive disorders.
25 April: Swiss National Strategy for the Prevention of Non-communicable Diseases includes dementia

The Swiss government and cantons have approved a national strategy for preventing and combating non-communicable diseases (NCDs). Some 2.2 million people in Switzerland are currently living with one or more chronic diseases, generating around 80 percent of the country’s entire health-related costs. The objective of the strategy is to prevent or delay the development of conditions such as cancer, cardiovascular diseases and diabetes and to mitigate their consequences. It builds on existing prevention activities and combines the resources of all the players involved. Appropriate measures will be drawn up by the end of the year.

Although dementia is briefly mentioned, the Association Alzheimer Suisse welcomes this strategy:

“We know that the reduction of the risk factors (smoking, excessive alcohol consumption, low levels of physical activity etc.) plays an important role for prevention of dementia too. An interface to the National Dementia Strategy is explicitly mentioned. It is now important to develop efficient and viable measures to reach the objectives fixed in the strategy”, writes the association.


11 March: Meta-analysis finds high reversion rate from MCI to normal cognition

A meta-analysis, published in the journal Alzheimer Disease & Associated Disorders on 11 March, has found that around a quarter of individuals who are diagnosed with amnestic mild cognitive impairment (aMCI) subsequently revert to normal cognition, rather than progressing to Alzheimer’s disease (AD) or other dementias.

The analysis appeared as a “Research Highlight” in the journal Nature, in its Nature Reviews – Neurology section, concluding that:

“MCI has attracted considerable attention in recent times, owing to the prevailing view that disease-modifying treatments for AD are likely to be most effective if administered early in the disease course. However, whether MCI can be considered as an early manifestation of AD remains controversial.”

15 March: Lilly announces change to outcome goals in Phase III solanezumab study

On 15 March, Eli Lilly and Company announced a change to the primary endpoint for its EXPEDITION3 clinical trial – a Phase III study of solanezumab in people with mild Alzheimer’s dementia.

The original study design included co-primary endpoints of cognition and function - measured by ADAS-Cog14 (Alzheimer’s Disease Assessment Scale-Cognitive subscale) and ADCS-IADL (Alzheimer’s Disease Cooperative Study-Instrumental Activities of Daily Living), respectively.

Emerging scientific evidence supports the idea that cognitive decline precedes and predicts functional decline in Alzheimer’s disease, particularly in earlier stages of the disease. Lilly has therefore decided to amend its trial to include a single primary endpoint of cognition (ADAS-Cog14). Functional outcomes will be measured during the trial in the same manner as previously designed, using both the ADCS-IADL and the FAQ (Functional Assessment Questionnaire). These two functional outcomes will now be considered key secondary endpoints for the EXPEDITION3 study.
15 March: Mixture of brain ailments could be behind dementia, study says

New research that analysed two long-term ageing studies has concluded that dementia is most likely caused by a combination of different brain ailments, as opposed to just one condition. The research was published on 15 March in the journal Neurology.

A team led by Dr Lon White, of the University of Hawaii and the Pacific Health Research and Education Institute, analysed data on more than 1,100 people who had taken part in the Nun Study or the Honolulu-Asia Aging Study. The two studies included 334 Roman Catholic nuns and 774 Japanese American men. The average age of death was about 90 in the Nun Study and 88 in the Honolulu-Asia Aging Study. Both studies followed hundreds of older adults and included cognitive tests and post mortem brain autopsies.

After examining the participants’ brain autopsies, the researchers found that about 50% of the brains had signs of Alzheimer’s disease (AD). The researchers noted that not all of the brains with AD had the same lesion type. The researchers could only categorise AD as the main lesion type in half of this group. When they looked at the 279 participants with severe AD pathology, however, at least 75% of them had one or more other types of lesions. In other participants who experienced cognitive decline, their brains did not have any signs that would point to AD.

Based on the differences between the participants, the researchers concluded that dementia is most likely caused by multiple conditions. They added that a greater combination of ailments was associated with a more dramatic effect on a participant’s risk of dementia.

They were able to identify five varying brain pathologies that could all cause dementia. These pathologies were: AD, hippocampal sclerosis, micro infarcts, low brain weight and Lewy bodies. Researchers could potentially develop better treatments for dementia by targeting the different brain pathologies, they concluded.

http://www.neurology.org/content/86/11/1000

28 March: Study says benzothiazole amphiphiles could help combat neurodegenerative diseases

A team of scientists at the University of California, San Diego (UCSD) in the US has completed a study treating neurons from a brain region critical for forming and recalling memories using compounds called benzothiazole amphiphiles. They used the compounds to increase the density of the dendritic spines on those neurons. Dendritic spines are small membranous protrusions from a neuron’s dendrite that typically receives input from a single axon at the synapse. They serve as a storage site for synaptic strength and help transmit electrical signals to the neuron’s cell body.

Previous research has shown that dendritic spine density changes with time, and that increased density is associated with improved memory and learning.

As well as increasing the density of the spines, the study also found that the compounds prevented the loss of spines, which happens when the protein amyloid-beta is present. The protein accumulates in the brains of people with Alzheimer’s disease (AD) and is a main target for drug development.

Benzothiazole amphiphiles, the researchers concluded, show potential not only in heading off spine loss in people with neurodegenerative disease, but also in improving cognition in those with neurodevelopment disorders.

Their results were published in the Journal of Biological Chemistry (JBC) on 28 March.

http://www.jbc.org/content/early/2016/03/28/jbc.M115.701482.abstract

1 April: Tetra completes Phase I safety study for AD drug

On 1 April, Tetra Discovery Partners ("Tetra") announced that it had successfully completed its initial Phase I single ascending dose study of BPN14770 safety in 32 healthy volunteers. BPN14770 is the company’s experimental treatment aimed at improving memory and slowing the progression of Alzheimer’s disease (AD). Tetra plans to begin its second Phase I trial of BPN14770 in June, which will study multiple ascending doses.


4 April: Oryzon Genomics begins Phase I study for AD drug candidate

On 4 April, Oryzon Genomics - a clinical-stage biopharmaceutical company leveraging epigenetics to develop therapies in oncology and neurodegenerative diseases - announced that the first participant has been dosed in its Phase I, randomised, double-blind, placebo-controlled single and multiple ascending dose programme study to investigate the safety, pharmacokinetics and pharmacodynamics of its oral LSD1-MAOB dual selective inhibitor ORY-2001 in healthy subjects. The Phase I study is being conducted in Spain, pursuant to a Clinical Trial Application (CTA). If it has a successful study outcome, ORY-2001 is expected to proceed to a Phase II study in patients with Alzheimer’s disease (AD) in the first half of next year.

http://goo.gl/yJ6F

8 April: Allergan and Heptares announce AD treatment R&D and commercialisation partnership

On 8 April, Ireland-based global pharmaceutical company Allergan and Heptares Therapeutics, a clinical-stage pharmaceutical company have entered into a global research and development (R&D) and commercialisation partnership for the treatment of Alzheimer’s disease (AD) and other neurological disorders.

With the partnership, Allergan will license exclusive global rights to the pipeline of novel subtype-selective muscarinic receptor agonists that Heptares has under development for AD and other major disorders.

https://goo.gl/42VWmu
8 April: Lilly and AstraZeneca announce continuation of pivotal clinical trial for people with early AD

On 8 April, Eli Lilly and Company (Lilly) and AstraZeneca announced that AMARANTH, a Phase II/III study of AZD3293 - an oral beta secretase cleaving enzyme (BACE) inhibitor currently in development as a potential treatment for early Alzheimer’s disease (AD) - will continue to Phase III of the Phase II/III seamless trial.

The AMARANTH independent data monitoring committee recommended the study continue without modification after a scheduled interim safety analysis was conducted. The analysis was not designed to review efficacy.


8 April: US FDA grants Orphan Drug Designation to Anavex for frontotemporal dementia treatment

On 8 April, Anavex Life Sciences Corp. - a clinical-stage biopharmaceutical company developing differentiated therapeutics for the treatment of neurodegenerative diseases including Alzheimer’s disease (AD), other central nervous system (CNS) diseases, pain and various types of cancer - announced that the US Food and Drug Administration (FDA) has granted Orphan Drug Designation (ODD) for its drug ANAVEX 3-71, for the treatment of Frontotemporal dementia (FTD).


10 April: New proteins discovered to fight Alzheimer’s disease and cancer

A team of scientists at the University of Southern California in the US has discovered six new proteins that may help reveal secrets of how humans age - potentially unlocking new insights into diabetes, Alzheimer’s disease (AD), cancer and other commonly age-related problems. The study, led by Dr Pinchas Cohen, was published in the journal Aging on 10 April.

The researchers found that these tiny proteins are produced naturally in the energy-generating mitochondria - the powerhouse in human cells - and play key roles in metabolism and cell survival. The amount of each protein decreases with age, leading to the onset of diseases linked to older age.

To learn more, the researchers used computer analysis and uncovered the genes for six new proteins which were dubbed small humanin-like peptides (SHLP).

“The newly recognised SHLP family expands the understanding of the mitochondria as an intracellular signalling organelle that communicates with the rest of the body to regulate metabolism and cell fate,” Dr Cohen explained.

After identifying the six new proteins and successfully developing antibodies to test for several of them, the researchers examined mouse tissues and human cells to determine their abundance in different organs, as well as their functions.

The proteins were distributed quite differently among organs, suggesting that the proteins have varying functions based on where they are in the body.

The results revealed that these tiny proteins plays several big roles in the human body’s cells - from decreasing the amount of damaging free radicals and controlling the rate at which cells die, to boosting metabolism and helping tissues throughout the body respond better to insulin.


12 April: Study suggests strong link between diabetes and Alzheimer’s disease

A review analysis by Professor Melissa Schilling, a strategy and innovation expert at the New York University’s Stern School of Business, suggests a strong link between diabetes and Alzheimer’s disease (AD). The study, “Unraveling Alzheimer’s: Making Sense of the Relationship between Diabetes and Alzheimer’s Disease,” was published in The Journal of Alzheimer’s Disease on 12 April.

Alzheimer’s is a complex neurodegenerative disease whose origin is often unknown, except for a small number of cases linked to genetics. Its suspected causes include the aggregation of tau proteins, membrane damage, mitochondrial dysfunction, a buildup of intracellular toxic proteins, and axonal transport. The effects of pre-existent medical conditions, like diabetes, on neurodegeneration are also still unclear.

Professor Schilling reviewed hundreds of publications related to the pathway between insulin and AD. She found that hyperinsulinemia - a condition marked by excess levels of insulin due to untreated or early diabetes, pre-diabetes, and obesity - is associated with nearly half of all AD cases.

“What I’ve learned from my innovation research is that specialists can become trapped in the logic of their field, so new perspectives often come from outsiders,” Professor Schilling said in a press release. “If we can raise awareness and get more people tested for hyperinsulinemia, especially those who have been diagnosed with or who are at risk for dementia, it could significantly lessen the incidence of Alzheimer’s disease and vascular dementia, as well as other diabetes-related health problems.”

Professor Schilling believes her findings are of significance to both policy-makers and clinicians, and suggests the following improvements: 1) individuals be tested for pre-diabetes, as one-third of the U.S. population is suspected of having the condition and ignoring it; 2) dementia patients be tested for glucose intolerance to slow or possibly reverse the disease; 3) adults be regularly tested for glucose tolerance, preferably using the hemoglobin A1c test; and, 4) glycemic indexing be included on the labels of all food products.

http://content.iosexpress.com/articles/journal-of-alzheimer’s-disease/jad150980

14 April: Study identifies memory suppressor gene

Scientists from the Florida (US) campus of The Scripps Research Institute (TSRI) have identified a unique memory suppressor gene in the brain cells of Drosophila, the
common fruit fly. The study, led by Professor Ron Davis, chair of the Department of Neuroscience at TSRI, was published on 14 April in the journal Neuron.

Prof. Davis and his colleagues screened approximately 3,500 Drosophila genes and identified several dozen new memory suppressor genes that the brain has to help filter information and store only important parts. One of these suppressor genes in particular caught their attention.

When the scientists disabled this gene, known as DmSLC22A, the Drosophila’s memory of smells (the most widely studied form of memory in this model) was enhanced, while overexpression of the gene inhibited that same memory function.

The gene in question belongs to a family of “plasma membrane transporters,” which produce proteins that move molecules, large and small, across cell walls. In the case of DmSLC22A, the new study indicates that the gene makes a protein involved in moving neurotransmitter molecules from the synaptic space between neurons back into the neurons. When DmSLC22A functions normally, the protein removes the neurotransmitter acetylcholine from the synapse, helping to terminate the synaptic signal. When the protein is missing, more acetylcholine persists in the synapse, making the synaptic signal stronger and more persistent, leading to enhanced memory.

The next step, concluded Prof. Davis, is to develop a screen for inhibitors of this pathway that, independently or in concert with other treatments, may offer a more effective way to deal with the problems of memory loss due to Alzheimer’s and other neurodegenerative diseases.


18 April: Immune protein could offer potential new therapeutic target for Alzheimer’s disease

Research published on 19 April in the journal Proceedings of the National Academy of Sciences (PNAS) suggests that an immune system protein could help to reverse some of the physical and cognitive changes seen in Alzheimer’s disease (AD). The study was conducted by researchers from the University of Glasgow and the Hong Kong University of Science and Technology.

For the study, transgenic AD mouse models (APP/PS1 mice) were given daily injections of the protein IL-33, and it appeared to not only clear out the toxic amyloid plaques that are thought to trigger Alzheimer’s in humans, it also prevented more from forming.

"IL-33 is a protein produced by various cell types in the body and is particularly abundant in the central nervous system (brain and spinal cord),” says lead researcher Eddy Liew, Distinguished Professor in Immunology at the University of Glasgow in the UK. "We found that injection of IL-33 into aged APP/PS1 mice rapidly improved their memory and cognitive function to that of the age-matched normal mice within a week."

They believe that collectively, their results demonstrate a potential therapeutic role for IL-33 in the treatment of AD.

It should be noted that these results are restricted to mice only at this stage, and the translation rate of positive results in mice to humans is very low (one study estimates 8%).

http://www.pnas.org/content/early/2016/04/13/1604032113.full

19 April: Drop in dementia rates suggests disease can be prevented, researchers say

Writing in the journal Nature Communications on 19 April, a team of UK researchers from the Universities of Cambridge, East Anglia and Newcastle describe how they ran two studies – the first between 1990 and 1995 and the second between 2008 and 2013.

Dubbed the Cognitive Function and Ageing Study (CFAS) and largely funded by the Medical Research Council, the research compared dementia rates then and now in three locations: Cambridgeshire, Nottingham and Newcastle.

The study reports that the number of new cases of dementia is lower than had been predicted in the 1990s, estimated at around 210,000 a year in the UK as opposed to 250,000.

The findings are potentially significant because they suggest that it is possible to take preventative action, such as stopping smoking and reducing cholesterol, that could help avoid the condition. “Physical health and brain health are clearly highly linked,” said Professor Carol Brayne of Cambridge University, who co-authored the study.

The scientists found that new cases of dementia had dropped from 20.1 in every 1,000 people per year in the first study conducted in the early 1990s to 17.7 in the second, which looked at new cases between 2008 and 2013. When sex and age differences were taken into account, the dementia rates were found to have dropped by 20%.

The trend emerges from a dramatic drop in new cases for men across all age groups. In the 1990s study, for every 1,000 men aged 70-74, 12.9 went on to develop dementia within a year. In the second study, 20 years later, that figure had dropped to only 8.7 men. For men aged 65-69 the rate of new cases had more than halved between the two studies.

The situation for women was more complex: while those aged 80-84 showed a small increase in rates between the two studies, there was a slight drop for other age groups.

The researchers did not look into the reasons behind the overall fall in dementia rates, or the differences between men and women.

http://www.nature.com/ncomms/2016/160419/ncomms11398/pdf/ncomms11398.pdf
Science – behind the headlines

The "Alzheimer’s drinks that stops brains from shrinking" - Professor Murat Emre comments

After studying medicine at the Istanbul Faculty of Medicine Professor Murat Emre trained in neuroscience and clinical neurology at the University of Zürich. He then worked in the fields of neurorehabilitation and clinical research in Switzerland for several years. He also trained in movement disorders with Prof. David Marsden at the Queen Square National Hospital for Nervous Diseases, London and in behavioural neurology with Prof. Marcel Mesulam at the Beth Israel Hospital and Harvard Medical School.

In 1996 he was assigned as Professor of Neurology at the Istanbul Faculty of Medicine, Department of Neurology, where he started the Behavioral Neurology and Movement Disorders Unit.

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

Following recent media headlines claiming the drink Souvenaid could “stop brains shrinking” and “protect memory” in people with early stage Alzheimer’s disease (AD), we asked Professor Murat Emre - a member of our Expert Advisory Panel – to comment:

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

The topline results of the LipiDiDiet study conducted with the medicinal drink Souvenaid were made public at the Geneva-Springfield Conference in Athens on 10 March. The media coverage of the results was rather enthusiastic, prone to induce high expectations, whereas the results indeed justify more a "cautious optimism" than too early conclusions. After all, the primary end-point of the study which was the progression of cognitive impairment failed to show any statistically significant difference between those who had the drink for two years as compared to those who did not. There was some evidence of benefits on a memory test and those who had the drink had less atrophy of the hippocampus, an area important for new memory formation. This is a positive sign, but not sufficient in the absence of clear, significant clinical benefits. In addition, the study was not conducted in patients with Alzheimer’s disease, as was erroneously reported, but rather it included patients with Mild Cognitive Impairment (MCI), which often represents prodromal Alzheimer’s disease, but not always.

How important is this story/study for furthering dementia research? Should we be excited?

Any study which suggests beneficial effects in patients with memory impairment is welcome. A reduction in hippocampal atrophy is obviously a positive signal, but we need to see if this is translated into clinical benefits in the long term. We should be cautiously excited, but should not be carried away; after all this is not the first time that we are seeing a reduction in brain atrophy under an intervention, this has been described in an earlier study of vitamins and also with some Alzheimer medications currently in use.

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

The scientific community will take the results as they are: a study which failed to meet the primary outcome but provided signals of beneficial effects. We will follow this up, we will wait to see the full results to be published so that we have a better understanding of which patients benefitted most, in which parameters etc. In the meanwhile the search for treatments to prevent or treat Alzheimer disease will continue uninterrupted.

What are the next steps?

We understand that the study is extended for another two years. We will wait to see if the initial positive signals will be maintained, and better if they will be enhanced which is what you will expect to see from an intervention if it is protecting brain cells or its connections from dying. Most important will be the clinical results, that is if the progression of the cognitive impairment can be stopped or slowed down, rather than proxy measures such as brain atrophy.
Living with dementia

25 April: Karin Gustafsson writes about her Alzheimer’s diagnosis

When I received comments from my husband and my children that I needed to seek medical advice at the health centre, to check why I occasionally repeat what I already said and be examined, I had to go through several tests of character, as well as a lumbar puncture. And also, I got to undergo a scan of the brain. I had the results of the investigations carried out and the diagnosis was “mild Alzheimer’s disease”. I was prescribed Donepezil.

After the diagnosis, my husband Lars and I invited our three adult children to lunch and then we told them about the disease. We cried together and talked about the disease. It was a very emotional time, and in the end, we began to laugh and talk about our reactions.

I also want to tell you about the situation with my employers at the University and my employer in the municipality. At both sites, I was gradually able to do easier tasks to tutor students and summarise research texts in the field of language and communication. I also participated in some workshops and lectures, etc. But I feel that they don’t rely on me as they did before, anymore, when it comes to both of my managers.

We have also been told about essential oils that can be used to relieve symptoms of Alzheimer’s disease. I use them twice a day on my scalp, the soles of my feet, my neck and along my spine. They smell good, and can also be used for their aroma.

In my spare time, I now devote myself to going to the gym, to work out different parts of the body, about three times a week. Recently, it has been reported that new findings show physical activity has an impact on the brain. My husband and I are trying to do 10,000 steps per day, which gives us both agility, strength and conditioning. Other than that, I usually go to yoga, but I have not done so this semester.

We also participate in a network once per month called “Alzheimer’s café”, with other people who have Alzheimer’s disease, and their families. At these meetings, there are various scientists, who talk about the latest research.

Finally, we are very grateful that we may be included in the European Working Group of People with Dementia (EWGPWD), which both gives us power and strength. At present, we have chosen not to talk about the disease with other relatives and good friends, because there are a lot of prejudices in society and fear of this disease.

Karin Gustafsson
Member of the EWGPWD

Dementia in society

9 April: England World Cup winners diagnosed with dementia, FA calls for research into possible link with heading the ball

It was reported widely in the UK on 9 and 10 April that three members of English football’s winning 1966 World Cup squad Martin Peters, Ray Wilson and Nobby Stiles are all living with dementia and a fourth, Jack Charlton is experiencing severe memory problems.

England’s Football Association (FA) is calling upon world football governing body Fifa to investigate whether former players have dementia as a consequence of playing football.

Dr Ian Beasley, Head of Medical Services for the FA and Doctor to the England Senior Mens’ Team, is keen to discover if dementia is more common in ex-professional footballers. He wants researchers to assess whether the severity of any brain damage depends on which position the person played, how many games they played, and at which level - and also if there is any danger to modern footballers.

"The hope is [Fifa] will tell us one way or another," he said. "You may still want to be a professional footballer but at least we can advise you what the chances are of something irreversible happening to you."

Fifa’s Chief Medical Officer Jiri Dvorak, speaking at the Football Medicine Strategies conference in London, said there was no confirmed link between brain trauma in footballers and dementia.

"We have very little evidence that would substantiate that assumption for football players," he said. "But that’s the reason why we are also studying the long-term changes of former professional male and female footballers. Not only for brain dysfunction but also early onset of osteoarthritis...We are looking at the long-term changes without having any suspicions yet."

New publications and resources

31 March: Journal of Prevention of Alzheimer’s Disease (JPAD) published

In March, the Journal of Prevention of Alzheimer’s Disease (JPAD) Volume 3, Number 1, 2016 was published.

JPAD publishes reviews, original research articles and short reports to help improve knowledge in the field of AD prevention including neurosciences, biomarkers, imaging, epidemiology, public health, physical cognitive exercise, nutrition, risk and protective factors, drug development, trials design and health economic outcomes.

18 April: Joseph Rowntree Foundation publishes report on women’s experiences of dementia

The Joseph Rowntree Foundation (JRF) - an independent organisation working to inspire social change through research, policy and practice in the UK – has published a report on “Women’s Experiences of Dementia”.

“Dementia is an issue that disproportionally affects women”, says the JRF, and its “personal is political” project, from which the publication emerges, addresses the hidden stories behind the statistics - the experiences of women affected by dementia.

They found that women’s experiences of dementia reflect their experiences in society: they are affected by stereotypes, by the lack of a voice in decision-making, and by the low value placed on ‘feminine’ attributes such as kindness and empathy.

“Service provision needs to reflect the needs, skills and attributes of women with dementia, female carers and the female care workforce. Being person-centred means taking gender into account: gender-blind policy and services are unhelpful for both women and men” writes the JRF.

“Organisations and individuals can think differently about dementia if they consider women as a marginalised majority” it concludes.


21 April: ADI releases two reports on dementia-friendly communities

During the opening ceremony of the 31st Alzheimer Disease International (ADI) conference in Budapest on 21 April, the association launched two new publications, “Dementia Friendly Communities: Key principles” and “Dementia Friendly Communities: Global Developments”.

http://www.alz.co.uk/dementia-friendly-communities/resources

Education

4 April: Worcester University will run dementia course at its 2016 Summer School

The Association for Dementia Studies (ADS) at the University of Worcester is running a three-day intensive programme Introduction to Person Centred Dementia Care as part of a multi-disciplinary six-day residential summer school running from 26 June to 3 July.

The aim of the course is to allow international practitioners and students to explore how to meet the needs of people with dementia, empowering them to work with colleagues to undertake a person-centred approach, putting the person, not the task at the centre of the service. It will be taught by the ADS multidisciplinary team, led by Professor Dawn Brooker. The deadline for applications is 30 May 2016.

Find out more and apply via:
http://www.worcester.ac.uk/discover/dementia-summer-school

Job opportunities

23 April: Marie Curie Research Fellowships in Stirling, Scotland

The University of Stirling in Scotland (UK) is looking for researchers to apply for a Marie Sklodowska Curie Actions (MSCA) individual fellowship in the fields of Aging and Dementia.

The University is organising a fully funded workshop for potential applicants in Stirling on 7-8 June. Applications for a place at this workshop close on Friday 6 May and places will be confirmed by 13 May.

The Ageing and Dementia Research Group at the University of Stirling has active research programmes covering the fields of Dementia Friendly communities, Technology, Outcomes in the General Hospital, Frailty, Community Support and Care, Quality of life, and Population Research and the group’s researchers work in collaboration with the Dementia Services Development Centre (DSDC). Researchers with an interest in applying for a 1 or 2 year MSCA fellowship in order to undertake a research project within these fields may apply.

Applicants should either have a doctorate or at least 4 years fulltime research experience. The MSCA grant provides the fellow with an allowance to cover living, travel and family costs. Potential applicants should contact Emma Reynish emma.reynish@stir.ac.uk in the first instance.
Contact Alzheimer Europe
Alzheimer Europe, 14 rue Dicks, L-1417, Luxembourg; info@alzheimer-europe.org, www.alzheimer-europe.org

Alzheimer Europe Board
Chairperson: Heike von Lützau-Hohlebin (Germany); Vice-Chairperson: Iva Holmerová (Czech Republic); Honorary Secretary: Charles Scerri (Malta); Honorary Treasurer: Maria do Rosario Zincke dos Reis (Portugal); Members: Marie-Odile Desana (France), Sabine Henry (Belgium), James Pearson (UK - Scotland), Sirpa Pietikäinen (Finland), Jesús Rodrigo (Spain), Helga Rohra (Germany), Štefanija Lukić Zlobec (Slovenia).

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AE Calendar

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<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>2 May</td>
<td>Discussion meeting on Swiss dementia strategy (Bern, Switzerland)</td>
<td>Jean</td>
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<tr>
<td>9-10 May</td>
<td>EU Presidency Conference “Living well with(d) dementia“ (Amsterdam, Netherlands)</td>
<td>Heike and Jean</td>
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<tr>
<td>17-20 May</td>
<td>EPAD Consortium Meeting (Barcelona, Spain)</td>
<td>Dianne and Jean</td>
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<tr>
<td>22-24 May</td>
<td>PACE consortium meeting (Helsinki, Finland)</td>
<td>Kate and Dianne</td>
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<tr>
<td>23-25 May</td>
<td>16th International Conference for Integrated Care (Barcelona, Spain)</td>
<td>Ana</td>
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<tr>
<td>24-25 May</td>
<td>AETIONOMY Steering committee meeting (Paris, France)</td>
<td>Jean</td>
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<tr>
<td>25 May</td>
<td>5th NILVAD General Assembly (Dublin, Ireland)</td>
<td>Alex</td>
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<tr>
<td>25 May</td>
<td>European Brain Council Value of Treatment meeting (Brussels, Belgium)</td>
<td>Jean</td>
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Conferences 2016

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tr>
<td>9-10 May</td>
<td>Living well with(d) dementia, <a href="http://english.eu2016.nl/latest/events/2016/05/09/living-well-with(d)-dementia">http://english.eu2016.nl/latest/events/2016/05/09/living-well-with(d)-dementia</a></td>
<td>Amsterdam, Netherlands</td>
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<tr>
<td>28-31 May</td>
<td>2nd Congress of the European Academy of neurology, <a href="http://www.eaneurology.org">www.eaneurology.org</a></td>
<td>Copenhagen, Denmark</td>
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<td>8-10 June</td>
<td>l3me IF MASA, <a href="http://imasia2016.univ-lyon1.fr/en">http://imasia2016.univ-lyon1.fr/en</a></td>
<td>Lyon, France</td>
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<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.dementiasconference.com/">http://www.dementiasconference.com/</a></td>
<td>Sydney, Australia</td>
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<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>4-8 July</td>
<td>INTERDEM Academy Summerschool, “Multidisciplinary Perspectives on Dementia”</td>
<td>Nottingham, UK</td>
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<tr>
<td>24-28 July</td>
<td>AAC Annual Conference, <a href="https://www.alz.org/aac/">https://www.alz.org/aac/</a></td>
<td>Toronto, Canada</td>
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<tr>
<td>31 August-2 September</td>
<td>10th International Conference on Frontal-temporal Dementias, <a href="http://tchd2016.de/">http://tchd2016.de/</a></td>
<td>Munich, Germany</td>
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<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>
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<tr>
<td>29 September-1 October</td>
<td>9th “Conference of the German Alzheimer’s Association (DAZG) on “Dementia. Looking at diversity”, <a href="http://www.demenz-kongress.de">www.demenz-kongress.de</a></td>
<td>Saarbrücken, Germany</td>
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<tr>
<td>5-9 October</td>
<td>Croatian Congress on Alzheimer disease with International participation (CROCAO 16), <a href="http://www.alzheimer2016.com/">http://www.alzheimer2016.com/</a></td>
<td>Tuzla, Croatia</td>
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<tr>
<td>31 October-2 November</td>
<td>29th Alzheimer Europe Conference (BAAEC) on &quot;Excellence in dementia research and care&quot;</td>
<td>Copenhagen, Denmark</td>
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<tr>
<td>10-11 November</td>
<td>EUDUAL 2016 - Second educational conference on Alzheimer’s disease, <a href="http://www.edualalzheimer.hr">www.edualalzheimer.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>
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26\textsuperscript{th} Alzheimer Europe Conference
Excellence in dementia research and care
Copenhagen, Denmark
31 October – 2 November 2016
www.alzheimer-europe.org/conferences  
#26AEC