Editorial

Welcome!

First of all, I would like to extend our deepest condolences to Peter Ashley’s family, friends and colleagues. Mr Ashley passed away on 10 November. He was a real pioneer for people with dementia and was the first person with dementia to speak at one of our annual conferences, back in 2002 in Maastricht. He will be sorely missed.

On a contrasting note, I am delighted to tell you that we achieved our target of 10,000 individual signatures on the Glasgow Declaration campaign this month! We hit the target on 23 November – one week ahead of schedule – and the signatures are still rolling in. As I write this, we have over 11,000 signatures, meaning we have had support from more than 3,600 people this month alone! Thank you to our members for all their hard work, with a particular mention for Slovenia, the UK, Finland and Italy, who were our top four in terms of numbers. I also extend my thanks to all of those who signed, whether as individuals, policymakers, or organisations. Now to make your voices heard and get the ball rolling on a European Dementia Strategy! We will present results in Brussels this week and keep you updated on any progress.

MEPs who sign our Glasgow Declaration automatically join the European Alzheimer’s Alliance (EAA) and we are delighted to welcome three new members this month. I extend a warm welcome to them.

I am also pleased to announce that we have just brought out five new publications: A 25th Anniversary Supplement - which traces our initiatives and activities since we came into being in 1990; our 2015 Yearbook on dementia-friendly initiatives in Europe; our 2015 Ethics report aimed at health and social care professionals in care homes and hospitals, faced with ethically sensitive situations and dilemmas; Issue 21 of Dementia in Europe magazine; and our 2014 Annual Report. More information is on our website.

On the policy front, good news from Slovenia, where a public consultation was launched this month on its National Dementia Strategy. We look forward to hearing about an official launch soon! We were also pleased to hear similar news from Gibraltar, and will keep an eye on happenings on “The Rock”.

Last but not least, I am pleased to inform you that you can already find information on our website about the 26th Alzheimer Europe conference (26AEC), which will take place next year in Copenhagen. Registrations are not open yet, though we will inform you as soon as we have a date for that, but I can already say that our call for abstracts will open on 1 February. Please keep an eye on our website, newsletter and look out for future conference announcement emails for further details.

I wish you all an excellent festive period and end of year. I am looking forward to telling you about our achievements during December, which promises to be another busy month, and to writing my first editorial of 2016!

Jean Georges
Executive Director
Alzheimer Europe

10 November: Helga Rohra is elected Vice-chair of Dementia Alliance International

On 10 November, the Dementia Alliance International Annual General Meeting (AGM) elected Helga Rohra - Chairperson of the European Working group of People with Dementia (EWGPWD) and member of Alzheimer Europe (AE)’s Board – as its Vice-chair.

The position of Chair remains with Kate Swaffer.

http://www.dementiaallianceinternational.org/

12 November: AE contributes to Joint Position Statement on continence care

Earlier this year, a collective of pan-European patient and civil society groups - of which Alzheimer Europe (AE) is a member - came together to discuss improving continence care in Europe (see our meeting report here).

The resulting Joint Position Statement has now been published, setting out the following key policy recommendations and principles, to help improve the management and care of people with continence problems at home and in the community:

- Increase awareness, recognition and understanding of incontinence.
- Recognise continence care as a human right to live independent and dignified lives.
- Improve information and communication about incontinence.
- Enable choice, involvement and empowerment of people affected by incontinence.
- Develop continence-friendly urban/community and home environments.
- Support and prioritise a research agenda on incontinence.

This was initiated and supported by Svenska Cellulosa Aktiebolaget (SCA).

Read the full Report here: https://goo.gl/6R1iIG

13 November: 25AEC videos now with English subtitles

Videos from the opening session of our recent annual conference #25AEC have been updated on our website and YouTube channel, to include subtitles in English for the Slovenian presentations.

https://www.youtube.com/watch?v=WYQGRHANixk&feature=share

19 November: 26th Alzheimer Europe Conference will be in Copenhagen

The 26th Alzheimer Europe Conference (26AEC), on the theme of “Excellence in dementia research and care” will take place in Copenhagen, Denmark from 31 October to 2 November 2016. For further information, check out our website:

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

19 November: Alzheimer Europe proudly represents 37 members from 32 countries

Check out our new members’ map. We are proud to represent 37 member associations in 32 countries across Europe.

http://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Our-members

In Memoriam Peter Ashley

On 10 November, we received the sad news that Peter Ashley, pioneer and champion of people with dementia, passed away. He lost his final battle with cancer.

Following a long and successful career in computing, Mr Ashley was diagnosed with dementia with Lewy bodies in 2000. He chose to speak openly and publicly about his dementia, challenging stigma and stereotypes, and coining the phrase “I’m not dying with dementia, I’m living with dementia”.

Mr Ashley was the first person with dementia to address an Alzheimer Europe (AE) Conference, in Maastricht in 2002 and was also a keynote speaker at our Brussels conference in 2009. He contributed to a range of AE reports and publications, such as our position and report on the use of advance directives by people with dementia and was also the first person with dementia to be an active member of our project working groups, participating in meetings alongside scientists, researchers, lawyers and ethicists.

We are very grateful to Mr Ashley for his important work in the dementia field and our thoughts are with his wife Ann - who was a stalwart companion at the many conferences and events he attended – and with the Ashley family, at this sad time.

http://www.dementiaallianceinternational.org/peter-ashley-life/
23 November: 10,000 target reached on the Glasgow Declaration!

We are delighted to announce that as of 23 November, we reached (and even surpassed) the target of 10,000 individual signatures we set for our Glasgow Declaration campaign!

The top four countries for individual signatures were Slovenia (1615), UK (1394), Italy (914) and Finland (910).

We have also received the support of 184 organisations and 103 policymakers at the time of writing.

We are continuing to collect signatures until midnight on 30 November and will report on the final numbers in next month’s newsletter.

Our lists will continue to be updated and signatures are still coming in, so please visit http://alzheimer-europe.org/Policy-in-Practice2/Glasgow-Declaration-2014 to see up to date results.

We would like to thank our member organisations for their efforts, without which we would have got nowhere near these numbers. We would also like to thank everyone who signed the Glasgow Declaration. We hope to make your voices heard next week in Brussels, and to move a step closer to a European Dementia Strategy. We will keep you posted on our progress!

30 November: AE releases five new publications


The 2014 Annual Report covers AE’s activities and finances and also has a new look, with many photos of AE meetings, lunch debates and the 24th Annual Conference in Glasgow. www.alzheimer-europe.org/Alzheimer-Europe/Our-work/Annual-Reports

The 2015 Dementia in Europe Yearbook contains an overview of dementia-friendly initiatives in European countries. Like every year, the report is a compilation of information gathered from its member associations; this year, 33 organisations from 31 countries participated in the work. They were joined by members of the European Working Group of People with Dementia, who gave valuable input on how communities, villages, cities and countries can become more dementia inclusive and dementia friendly, www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks

AE’s 2015 Ethics Report is aimed at health and social care professionals in care homes and hospitals who are faced with ethically sensitive situations and dilemmas. It provides them with training materials to tackle any issues they might encounter and enables them to reflect on the approach they adopt. The report was produced by a group of renowned experts and highly trained professionals in the field of ethics and dementia care. www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports

Issue 21 of Dementia in Europe carries coverage of AE’s June lunch debate in the European Parliament, the association’s new strategic plan and its new reports. The magazine also covers the launch of a new Written Declaration on Alzheimer’s disease in the European Parliament, a recent EU Presidency meeting and Spain’s progress toward a national dementia strategy. This issue concludes with a special section covering highlights from Alzheimer Europe’s 25th Conference in Slovenia. www.alzheimer-europe.org/Publications/Dementia-in-Europe-magazines

The 25th Anniversary supplement looks back at the association’s beginnings in 1990 and traces the initiatives and activities that allowed AE to grow, both in terms of membership and recognition as a key player in helping to improve the lives of people with dementia and their families and carers. Alzheimer Europe is very grateful to all the people and organisations who gave of their time and effort to make this possible!

www.alzheimer-europe.org/Publications/S-Shop

EU projects

3-4 November: AETIONOMY holds Steering Committee, General Assembly and LEAB meeting

The AETIONOMY project aims to generate disease-specific, mechanism based taxonomies for Parkinson’s (PD) and Alzheimer’s diseases (AD), which will hopefully lead to better treatments. The Steering Committee meeting took place in Barcelona (Spain) on 3 November. The meeting was followed by the annual General Assembly (GA) on 4 November.

To start the meeting, Prof McHale welcomed the delegates and gave a general report of the progress of the project to date and of the results of the Interim Review that was held in September in Brussels. Dr Elisabetta Vaudano, IMI Scientific Officer for the project, also provided feedback from the Interim Review.

Prof Jirsa and Prof Pasquier delivered two keynote speeches on the virtual brain and on an examples of regional research organisation for AD in France.

During the morning, work package leaders gave detailed updates of their ongoing tasks. Delegates had the opportunity to see a live demo of the AETIONOMY Knowledge Base (AKB) and of the transSMART platform. Delegates were informed that in France, the recruitment of participants for the PD study has already started.

During the afternoon, different breakout sessions were held. In parallel to the breakout sessions, the Second
External Legal and Ethical Advisory Board (LEAB) meeting took place.

In the LEAB meeting, the Advisory Board was informed of the progress of the AETIONOMY Legal and Ethical Framework, and the challenges for the following 12 months, including the analysis of patient stratification implications of the AETIONOMY observational study, were discussed with its members. Dianne and Ana attended the various meetings on behalf of AE.

3-6 November: EPAD begins consultation on “Approaches to the communication of Alzheimer’s disease risk”

On 3, 5 and 6 November four focus groups were conducted in Barcelona. These groups are part of a larger research project lead by the University of Cambridge in the context of the EPAD project (European Prevention of Alzheimer’s Dementia).

The focus groups research aims at providing insights into how understandings of Alzheimer’s disease risk and its implications are shaped by cultural, social and economic conditions, including health and social care systems, attitudes to dementia and dementia care, and understandings of the role and responsibilities of researchers and research participants.

The groups in Barcelona were organised by Fundacion Pascual Maragall and facilitated by Ana Diaz, Alzheimer Europe (AE) Project Officer.

Participants of three of the groups were drawn from the ALPHA cohort study (Fundacion Pasqual Maragall). The other group consisted of people who had expressed their interest to collaborate with the Fundacion.

The groups included people who do and do not have a family history of Alzheimer’s disease. Similar groups will be conducted in the UK and Sweden, and in December in Brussels with the European Working Group of People With Dementia (EWGPWD).

10-11 November: SyDAD start-up meeting takes place in Stockholm

The start-up meeting of the SyDAD (Synaptic Dysfunction in Alzheimer Disease) project was hosted by the Karolinska Institutet (KI) on 10-11 November, in Stockholm, Sweden.

SyDAD is a European Training Network, sponsored by Horizon 2020 Marie Sklodowska Curie Actions. The research programme will focus on synaptic dysfunction, the main connection point between pathology and cognitive decline in Alzheimer’s disease. It will support and train 15 Early Stage Researchers (ESRs, PhD students) with an interest in the area of Alzheimer’s disease and synaptic dysfunction, focusing on new drugs and biomarkers.

The project is led by the Department of Neurobiology, Care Sciences and Society at KI. AE is a Partner Organisation in this project. Ana Diaz, AE Project Officer attended the meeting.

Alzheimer Europe networking

On 3-4 November (Barcelona, Spain) Dianne + Ana attended AETIONOMY Steering Committee, General Assembly, Ethics meeting.

On 3-4 November (Birmingham, UK) Jean attended the Dementia Service Development Centre International Advisory Board.

On 3-6 November (Barcelona, Spain) 4 EPAD focus groups were conducted on “Approaches to the communication of AD risk”.

On 6 November (Barcelona, Spain) Jean attended a meeting of the WP6-Dissemination working group of the EPAD project.

On 5-7 November (Barcelona, Spain) Jean attended the CTAD (Clinical Trials in Alzheimer’s disease) Conference

On 10 November (Brussels, Belgium) Vanessa attended Politico’s Annual Health Care Summit.

On 10-11 November (Stockholm, Sweden) Ana attended the start-up meeting of the SyDAD project.

On 16 November (Brussels, Belgium) Gwladys attended meetings with various hotels, about future AE meetings.

On 17 November (Brussels, Belgium) Vanessa attended the European Parliament MEPs Interest group on Access to Healthcare.

On 18 November (Brussels, Belgium) Jean met with representatives from Roche.


On 23 November (Luxembourg, Luxembourg) Jean and Ana met with representatives from Quintiles.

On 24-24 November (Vilnius, Lithuania) Vanessa attended the JA CHRODIS (Joint Action on Chronic Diseases) Conference.

On 25 November (London, UK) Ana attended a training session for patients and consumers involved in EMA activities.

On 26 November (London, UK) Jean attended European Medicines Agency (EMA) Patients’ and Consumers’ Working Party (PCWP)

On 26 November (Luxembourg, Luxembourg) Gwladys attended a meeting by HRG to meet various travel suppliers

On 27 November (London, UK) Jean attended the Health Advisory Board of GSK.
Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 126, representing 27 Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support 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); Ruđa Tomašić (ECR). Cyprus: Costas Avgvridis (S&D); Eleni Theocharous (EPP). Czech Republic: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). Denmark: Ole Christensen (ALDE); Jens Rohde (ALDE); Christel Schaldemose (S&D). Estonia: Urmas Paet (ALDE); Liisa Jaakonsaar (S&D); Anneli Jätteenmäki (ALDE); Miapetra Kumpula-Natri (S&D); Merja Yliköttönen (GUE/NGL); Sirpa Pietikäinen (EPP). France: Nathalie Griesbeck (ALDE); François 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 Mititsidis (S&D); Dimitrios Papadimonoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyridi (EPP); Elefherios Synadinos (GUE/NGL); Eleftherios Synadinos (NI). Hungary: Ádám Kós (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). Italy: Brando Benifei (S&D); Elena Gentile (S&D); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D); Damiano Zoffoli (S&D). Latvia: Oļena Mašļa (ALDE); Ints Piņķe (EPP). Lithuania: Vilija Blinkyte (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 (S&D); Lambert van Nistelrooij (EPP); Kirsten De Vries (EPP); Miroslav Mitro (EPP); Jo Drye (ALDE); Reiner Reinhard (EPP); Casper Van den Bremt (N-VA); Maja Gojkovita (Greens/EFA). Poland: Elżbieta Łukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Strus (EPP); Bogdan Wenta (EPP). Portugal: Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (S&D). Romania: Cristian Silviu Busoi, MEP (EPP); Daciana Octavia Sârbu (S&D); Claudiu Ciprian Tanasescu (EPP); Renate Weber (EPP). Slovakia: Miroslav Mikolásik (EPP); Ivan Stefanec (EPP); Anna Záborská (EPP); Jana Žitňanská (ECR). Slovenia: Franc Bogovic (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Suman (S&D); Romana Tomc (EPP); Ivo Vajgl (ALDE); Milan Zver (EPP). Spain: 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 Zabal Bizdegain (EPP). Sweden: Ylva Johanson (EPP); Peter Lundgren (EFD); Cecilia Wikström (ALDE). United Kingdom: Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Anneliese Dodds (S&D); Ian Duncan (ECR); Theresa Griffin (EPP); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D); Glenis Willmott (S&D).

European Alzheimer’s Alliance

18 November: Three MEPs sign Glasgow declaration, join European Alzheimer’s Alliance

Alzheimer Europe (AE) is very pleased to welcome three more MEPs (pictured) to the European Alzheimer’s Alliance (EAA) this month. Each became an EAA member upon signing AE’s Glasgow Declaration, which calls for the creation of a European Dementia Strategy and national strategies in every country in Europe:

- MEP Jana Zitnánska (Slovakia)
- MEP Ivan Stefanec (Slovakia)
- MEP Jeroen Lenaers (Netherlands)

EU developments

29 October: EUR 100 million EU loan granted to fund AD research

A Spanish company has become one of the first companies to receive an EU loan under Jean-Claude Juncker’s EUR 315 billion European Fund for Strategic Investments (see our report on the launch of the fund here).

The loan, given out by the European Investment Bank (EIB) to be invested into Research and Development (R&D) into plasma proteins to treat Alzheimer’s disease (AD) and other diseases, at the Barcelona-based blood specialist Grifols.


12 November: European Accessibility Act planned to coincide with European Day of Persons with Disabilities

In August, the UN Committee reviewed the EU for the first time on the work it has done to implement the UN Convention on the Rights of Persons with Disabilities. Following the “Concluding Observations” that the UN has addressed to the EU we can now look forward to the next stage.

The European Accessibility Act is ready for discussion and could possibly be approved by the College of Commissioners on 2 December. If approved, it could be published on 3 December, coinciding with the European Day of Persons with Disabilities.

The Commissioner for Employment, Social Affairs, Skills and Labour Mobility, Marianne Thyssen stressed the importance of the Accessibility Act in ensuring that innovative, affordable and accessible goods and services will be available for persons with disabilities in the EU.

Alzheimer Europe welcomes this news and will be interested to see how areas of particular importance to people with dementia such as employment rights and

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voting rights will be covered. How broad the scope of the Act will be and the areas that it will cover are still unknown.


13 November: The European Union Road Federation addresses older drivers’ needs

The European Union Road Federation (ERF) has published a position paper on improving traffic signs on European roads. The paper takes into account the ageing of the EU population, and highlights the importance of the efficient placement, proper maintenance, visibility and clarity of road signage.

Some specific needs of older drivers are pointed out in chapter 4.3, pages 17-19 of the document.

Read more and download ERF position paper here

17 November: EP Interest Group discusses “Preliminary opinion of Expert Panel on Access to Health Services in the EU”

The meeting was chaired jointly by Andrey Kovatchev MEP and European Patients’ Forum (EPF) Secretary General Nicola Bedlington, with the question at the heart of the debate: “Where are we and where do we need to go?”

Maria Iglesia Gomez from the European Commission’s DG Santé underlined the importance of the preliminary opinion and the potential it has to support the Commission’s reflections and future policy agenda relating to patient access. Health care needs are changing and health expectations are increasing, plus there is more demand and less resources due to changing demographics, such as the ageing population. The ongoing challenge is that health care systems still have to deliver, but with less resources.

Anne Calteux, Senior Advisor, Ministry of Health, Luxembourg, spoke about how during its presidency, Luxembourg had addressed access to healthcare, the need for better healthcare access and the need to have a patient-centred approach to make personalised medicine a reality, which would eventually assure better outcomes for patients.

Opinion platform Chair Jan de Maeseneer (Ghent University) and Rapporteur Sarah Thomson (WHO-Europe), presented the preliminary opinion, which addresses the main barriers to access: affordability, availability, timeliness and acceptability of services. The report highlights key access responses and includes a focus on minority groups with unmet needs; Roma, undocumented migrants and people with mental health issues.

The report calls for better monitoring to identify access problems and to measure change over time more effectively, with calls for better date monitoring and comparable indicators. This is in line with the principal objectives of the Interest Group as well as with the Patient Access Partnership (PACT).

The cross-party Interest Group on Patient Access to Healthcare was launched on 27 January in the European Parliament (EP) and has already gathered the support of almost 30 MEPs from 15 Member States.

Alzheimer Europe Policy Officer, Vanessa Challinor attended the meeting.

http://www.europatientaccess.eu/page.php?id=63

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Members’ news

21 September: EMDA-The Alzheimer’s Association of Israel holds conference for WAD

EMDA, the Alzheimer’s Association of Israel, sees great importance in raising awareness of dementia among family members and professionals. As part of EMDA’s activities for World Alzheimer’s Day (WAD), the association held a conference on the subject of the relationship between people living with dementia, their spouses and foreign care workers.

In Israel, many families hire a foreign care worker, who lives with the person with dementia and his/her spouse, and helps the spouse support the person with dementia. There are currently 40,000 legal foreign care workers in Israel. The conference was held in the centre of Israel, allowing many social workers, from a variety of nursing companies, welfare offices of municipalities and nursing homes, to attend.

The conference began with a lecture by psychologist Michal Herz: “How can I know if he is satisfied? Findings on the connection between the concept of mentalisation and the relationship between foreign care workers and couples, where one spouse is living with dementia”. Dr Herz interviewed each person forming part of this “triangle”. He initially tried to examine the relationship by using the method of mentalisation, which is the process by which people consciously interpret their own actions and those of others as having meaning, in the context of desires, needs, beliefs and opinions.

He found that it was difficult to apply this concept to the interviews, due to the complexity of definition surrounding the term. Instead, he developed a new term, “the carer’s curiosity”, the five components of which are: mutual respect, challenges, ambiguity, who the couple is, and the way the spouse perceives his/her relationship with the person with dementia. He re-examined how the ideas of “the carer’s curiosity” are expressed in interviews conducted with the couples and foreign care workers and presented examples of different relationships between them.

A second lecture was given by Daphna Golam Shemesh and Debbie Lahav: “How to make the foreign care worker familiar and helpful. Teamwork with foreign care workers and family members”. The lecture discussed a support group pilot for families and care workers at a day-care centre.

The group had four meetings. The first meeting was for the family members, two meetings were for the foreign care workers, and the last meeting was a joint meeting. During the pilot the needs and expectations of family members and care workers were identified. The purpose of the pilot was to allow people in the relationship triangle to become helpful and familiar to one another.

There were a number of conclusions from the pilot: There is a significant need for knowledge and skills among foreign care workers, it is very important to hold both separate and joint meetings for family members and foreign workers. It is important to have a workshop at the beginning of the foreign care worker’s employment and it is important to advise family members on how to bring a foreign care worker into the family.

The third and final lecture was given by Prof. Liat Ayalon: “The foreign care worker, the patient and their family”. Prof. Ayalon presented findings from a study she had conducted, based on interviews among older people, their families and foreign care workers. The study dealt with treatment preferences among older people: Do they prefer foreign workers or Israeli workers? The study found that older people, who employed foreign care workers preferred to employ foreign workers, whereas elderly people, who employed Israeli workers preferred to employ Israeli workers.

2 November: The Alzheimer Society of Finland celebrates 10 years with a conference

This month, The Alzheimer Society of Finland (Muistiliitto)’s annual conference celebrated 10 years since it was formed. The conference, held in the Finnish capital of Helsinki, attracted 350 participants.

2 November: Association Alzheimer Suisse launches second wave of its awareness campaign

On 2 November, the Association Alzheimer Suisse, alongside Pro Senectute Suisse – a private organisation dedicated to supporting the over 60s, with branches in each of Switzerland’s 26 cantons - published a press release to launch the second wave of their information and awareness campaign on dementia. They stress that, where Alzheimer’s and other dementias are concerned, information is king.

Currently, they say, only 35% of the population aged below 40 in Switzerland feels well informed, while a third believes prevention to be impossible. These are statistics they hope to change through their MEMO-INFO campaign.

https://www.memo-info.ch/fr/

4 November: The Alzheimer’s Society (UK) is “Singing for the Brain”

“Singing for the Brain” is a service provided by the Alzheimer’s Society (UK), which bring people with dementia and their carers together in a friendly and stimulating social environment.

Singing is not only an enjoyable activity, it can also provide a way for people with dementia and their carers to express themselves, as well as allowing them to socialise with others in a fun and supportive environment.

To learn more about this service, watch the Alzheimer’s Society (UK)’s YouTube video: https://www.youtube.com/watch?v=ko_9B7W4hMs&campaign=General-131115&utm_content=12351042902&utm_medium=Email&utm_source=SmartFocus

Or visit their website: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentid=760

6 November: Czech monograph on long-term care is published

On 6 November, a monograph called “Long-term care. Geriatric aspects and quality of care” was published in the Czech Republic. The publication, written by Iva Holmerová, CEO of the Czech Alzheimer’s Society and her colleagues, focuses on the issues of long-term care for older adults in the Czech Republic and presents one of the outcomes of the research project “Long-term care for seniors: quality of care in institutions, organization’s culture and support of frail older persons” - analysing systems of long-term care in the Czech Republic and the EU based on available literature and on data from the Department of Health, Department of Labour and Social Affairs or health insurance companies. The project was funded by the Internal Grant Agency of the Ministry of Health.

The aim of the monograph is to provide basic information and viewpoints of long-term care in the light of the Czech Alzheimer’s Society’s research and their own findings. Its 176 pages contain chapters on global issues such as the direction of long-term care in Europe, “functional status” issues in late life, the evaluation of both somatic and psychological functions with respect to planning and providing long-term care for older adults, inter-professional collaboration in healthcare and quality of long-term care.

The publication is intended, primarily, for physicians, but also nurses in both domestic and institutional environments. In addition, it may serve as a resource of valuable information to managers of long-term care institutions, social workers and other interested parties.

10 November: The Mediterranean Alzheimer’s Alliance has a new logo

The Mediterranean Alzheimer’s Alliance (MAA) has a new logo, as of 10 November.

For more information about the MAA, visit http://ampa-monaco.com/fr/maa2
12-14 November: Queen Sofia of Spain inaugurates CEFAA’s 6th National Congress

The 6th National Congress of the Spanish Confederation of Associations of Families of People with Alzheimer’s and other Dementias (CEFAA) was held in Valladolid, Spain from 12 to 14 November.

During the welcome and introduction press conference, the President of CEFAA, Koldo Aulestia noted that this framework should serve to “build the Confederation we want”. The President of the Alzheimer Federation of Castile and Leon, Milagros Carvajal, for his part, stressed that the Congress should be a “meeting place”, while the President of the Alzheimer Association of Valladolid, Nieves Ramos was proud that the congress was hosted in his city.

On Friday 13 November, Her Majesty Queen Sofia of Spain, Honorary President of CEFAA since 2002, inaugurated the Congress, emphasising the pride she feels, observing the work being carried out by the Associations and the Confederation over time, and the effort and care given for “our dear Alzheimer patients and their families”, which she said was “worthy of admiration”. She also assured delegates that “together we will continue fighting to alleviate possible effects of this terrible disease and support research, in which we place our hopes”.

Throughout the three days of the Congress, held at Feria de Valladolid, about 450 delegates - representatives from all the confederal structure, volunteers and professionals from 307 Associations of Families of People with Alzheimer’s disease and other dementias - were welcomed at the event.

Coinciding with CEFAA’s 25th anniversary, under the theme “25 years ahead together”, the 6th Congress “has encompassed the spirit of the Confederation of the future, open, transparent and participatory for its members, and - if it were possible - even more committed to defending the rights of all those living with the disease; patients and family caregivers.”

15 November: The Alzheimer Society of Finland publishes “Memory Barometer 2015” this month

The Alzheimer Society of Finland (Muistiliitto), together with The National Institute for Health and Welfare (THL) has completed research into how services for people living with dementia are organized in Finland, an into the standard of these services around the country.

This “Memory Barometer” has been done every five years since the 1990s, by the Society. This year’s Memory Barometer is included in the implementation plan of The National Memory Programme 2012–2020.

Ten major improvement objects will be gleaned from the findings, with special attention being paid to services that support independent living at home.

The Barometer will be published in late November.

16 November: Alzheimer Scotland’s latest policy report is launched

Alzheimer Scotland’s latest policy report, “Advanced Dementia Practice Model: understanding and transforming advanced dementia and end of life care” was launched at its Staff, Volunteers’ and Members’ Conference and AGM this month.

Alzheimer Scotland’s Advanced Dementia Practice Model sets out an integrated and comprehensive approach to providing care and support for people with advanced dementia and at end of life with dementia.

As the life expectancy of people in Scotland increases, more people will experience dementia and the proportion of people dying with dementia will also grow. Advanced dementia presents the most complex phase of the illness and needs a coordinated and planned approach to care.

The Advanced Dementia Practice Model promotes the wellbeing and quality of life of both the person with advanced dementia and those closest to them. It also provides the essential support to care homes and those providing day-to-day care.

From the point of diagnosis to the end of life, every person with dementia and their family deserves nothing but the best care we have at our disposal. To achieve this we must change our current practice and transform our system. The Advanced Dementia Practice Model provides the key to the best possible care in advanced dementia and at end of life. We look forward to working alongside our many partners to test and refine the Model.

You can download a full copy of the report here: http://www.alzscot.org/assets/0001/9474/AlzScot_ACReport_FINAL.pdf alternatively, you can download the Executive Summary: http://www.alzscot.org/assets/0001/9484/AOJM_Summary.pdf

17 November: ASI’s Dementia Carers Campaign Network launches campaign

The Alzheimer Society of Ireland (ASI)’s Dementia Carers Campaign Network (DCCN) has launched an online campaign to raise awareness of the significant impact of caring for a loved one with dementia.

“Caring for a loved one with dementia takes time, energy and, above all, love. It can be a long and emotional journey but with the proper support, it can be a rewarding one too”, writes ASI.

As part of this campaign, six DCCN members have shared their experience of caring. A booklet containing extracts from these powerful stories is available to download here: http://alzheimer.ie/getattachment/Get-Involved/Campaigning/Current- Advocacy-Campaigns/The-impact-of-Caring/The-impact-of-Caring-2015.pdf.aspx For further information on this campaign and to access full versions of these personal stories please visit www.alzheimer.ie

Photo: Judy and Norman Williams. Courtesy of Richard Kendrick.
18 November: Panhellenic Federation participates in "Patients in Power" conference in Athens

The Panhellenic Federation of Alzheimer Disease and Related Disorders participated in the 4th National Conference of Patients "Patients in Power", held on 18 November in Athens.

Dozens of patient organisation representatives from all over Greece discussed with all actors in the Health sector (State, doctors, nurses, pharmacists, health industry, academics, hospital administrators etc.), to highlight serious problems in the health sector, evaluate the health policies implemented, and to make recommendations on major issues that concern patients and their families.

This year’s conference focused on the participation of patients in Health Policy, patient access to medication and treatment, patient safety, and quality of services in hospitals.

The Federation’s President, Magda Tsolaki coordinated the conference section on "Patient safety and quality of hospital services".

Aristides Liapis, President of the Alzheimer Institute in Volos and Treasurer of the Federation, and Vasiliki Pattakou, Board member of the Federation, both attended the conference.

Representatives of The Panhellenic Federation’s member associations, Alzheimer Hellas (Eleni Antoniadou), GAADRD Allilengii in Herakleion (Simeon Panagiotaki, Garyfalla Perisynaki and Aspasia Bizaki) and GAADRD in Halkida (Evangelia Aggelidou, Chairman of the Board), also participated in the conference.

18 November: Alzheimer Bulgaria raises awareness of dementia among young people

This month, Alzheimer Bulgaria organised an initiative at a secondary school in the small, picturesque town of Teteven, to raise awareness about dementia among young people.

They asked students to take on the role of an adult with dementia themselves, to help them understand the difficulties they might encounter and to gain a better understanding of what it means to live with dementia.

They then talked with the students about cognitive problems that can develop as the disease progresses. During the training they supported the students in gaining knowledge, skills and confidence to defend the interests of their close relatives in front of various institutions.

For more information about, and pictures from the event, visit Alzheimer Bulgaria’s official website http://alzheimer.bg.org/

20 November: Jersey Alzheimer’s Association to embark on dementia-friendly housing project

In the most recent "Friendship Group" newsletter of the Jersey Alzheimer’s Association, Beverley Woolley writes about identifying a need for dementia-friendly housing on the island:

“I recently attended a meeting concerning the need to design dementia-friendly housing in Jersey. Specifically we explored how best to support the State’s Housing Department to deliver a housing plan for people living with dementia. The housing plan will reflect the recommendations of the Mental Health Service Review, which has just been completed.”

21 November: DA1zG elects Monika Kaus as new Chairperson

On 21 November, the Deutsche Alzheimer Gesellschaft (DA1zG) elected a new Chairperson, Monika Kaus. Ms Kaus was previously DA1zG Treasurer – a role she held since 2006.

The outgoing Chairperson, Heike von Lützau Hohlbein – who held the office for 14 years - congratulated her successor.

A new Vice-Chairperson, Bärbel Schönholz was also elected as well as a new Treasurer, Swen Staack. Other re-elected Board members are: Heidemarie Hawel, Prof. Dr Alexander Kurz and Dr Winfried Teschauer. New to the Board is Sylvia Kern.

Pictured: Heike von Lützau Hohlbein (left), outgoing Chairperson and Monika Kaus (right), new Chairperson of the DA1zG.


23 November: Spominčica publishes manual as part of "Living with dementia at home" project

Alzheimer Slovenia (Spominčica) recently published a manual on "Living with dementia at home" as part of its ongoing project of the same name. It reported on the launch of the manual and on the wider project, on 23 November:

The purpose of the project is to improve the quality of life and reduce the social exclusion of people with dementia and their families. In this way we contribute to the establishment of a dementia-friendly environment that will provide adequate treatment for people with dementia at home and an inclusive social environment. The project started successfully and we hope to expand our network of volunteers - companions for people with dementia living at home.

We formed a group of volunteers for the project "Living with dementia at home", who have been trained to assist the families of persons with dementia in their own homes,
for a few hours, to help with patient care. Our volunteers have already visited families and their feedback has been very positive. Before making the first visit, they met with the relatives of people with dementia in person, to discuss all the details of the cooperation.

Within the framework of the mentioned project, a manual called “Living with dementia at home” has been published by Spominćica. It is designed for anyone who is experiencing dementia, as well as those who are not, but may be in this position in the future (do not forget! Dementia does not chose - anyone who has a brain is a potential candidate for dementia!

The guide provides a rich variety of content, such as ethical issues, features of dementia, how the person with dementia feels, communicates, maintains social relationships, activities, and how to manage personal care for persons with dementia. The reader will also be happy to find many practical tips.

The project ‘Living with dementia at home’ was co-financed with the funds of the EEA Financial Mechanism and Norway Grants. Activities are designed in accordance with the Guidelines of Alzheimer Europe and Alzheimer’s Disease International (ADI), as well as the Norwegian partner, Norwegian National Advisory Unit on Ageing and Health.

23 November: DAItG launches competition for young inventors

The German Alzheimer Association (DAItG) has launched a competition for young people. “Alzheimer and you – show your inventive genius” – it hopes this slogan will encourage young people aged between 12 and 21 to get involved in the field of dementia.

The competition calls for them to develop small inventions to improve the lives of people with dementia and their caregivers.

Ideas can be sent to wettbewerb@alzheimerandyou.de until 31 January 2016.

More information can be found here (in German): www.alzheimerandyou.de

25 November: Panhellenic Federation reports on its members activities

Members of the Panhellenic Federation of Alzheimer Disease and Related Disorders were busy this month, all around Greece:

Alzheimer Hellas launched its new Twitter account (@AlzheimerHellas), as well as a new radio show entitled “All about Dementia”, and a successful concert called “We sing with love” was hosted on 11 November, dedicated to people with dementia and their caregivers.

GAADRD Allilengii in Heraklion organised lectures for the people of the islands' villages on "symptoms, early diagnosis, treatment and prevention of dementia and Alzheimer’s disease". Free screening for cognitive decline was offered to the audience after these lectures.

The Larissa Association of Alzheimer’s disease and related disorders implemented dance programs, as an alternative means of cognitive rehabilitation, as well as narrative programmes for people with Alzheimer’s dementia.

Living with dementia

26 November: Hilary Doxford writes “A month in the life of a volunteer”

I am fortunate to still be working full time despite my diagnosis of early onset Alzheimer’s disease. I also find great enjoyment in my volunteering role to do whatever I can, wherever I can, whilst I still can to make a difference for those of us with dementia and those who help us.

So what does a typical month look like for me? As Christmas approaches things quieten down on the volunteering front. But to give you some idea of what you can become involved with, here are some excerpts from my November diary.

Three filming sessions: to help with fundraising; working with researchers; and the importance of involving people with dementia in all aspects of project work.

Four conferences, speaking about: building a dementia friendly community; giving a patient perspective at the opening of a new brain research centre; “Together for Dementia” how to better work together to improve lives; and driving innovation.

Four clinical trial and research appointments: mapping disease progression and cognitive decline; seeing if a blood pressure drug can slow decline; understanding change in the hippocampus; changes in amyloid and tau.

Attending two steering group meetings: improving our local hospital for patients with dementia; evaluating services for younger people with dementia.

Document reviews: commenting on the Alzheimer’s Society five year strategy; providing feedback to four researchers on their projects; reviewing eight grant applications.

Completed a four week on-line course on “Improving Healthcare through Clinical Research”.

In addition I have written three articles, attended the AGM (online) of Dementia Alliance International, taken part in calls relating to the World Dementia Council’s plans for 2016, written a framework for the initial steps to set up a
Policy watch

20 October: New study explores reasons behind Europe’s rising healthcare costs

A new study, carried out by Janssen pharmaceutical, explores the reasons behind Europe’s rising healthcare costs and the corresponding stagnation in research and development (R&D) investment, despite decades of strong growth.

A large number of factors point to an unavoidable rise in healthcare, and trends that have pushed up healthcare expenditure in the past will become even more intense in the coming decades, including the rapid expansion of demand for services due to the ageing population.

The main points of the report are:

- Healthcare expenditure is estimated to rise from 13% to 18% of Europe’s GDP by 2030.
- The private sector in Europe accounts for two-thirds of R&D investment, with one-third coming from national or EU public funds.
- While national public health R&D in the EU has risen significantly in the last decade, the pace of growth has slowed since 2009 and stagnated in 2012. Between 2010 and 2012, of all major European economies only Denmark presented growth (17%).

Point of the report specific to dementia are:

- The report covers the ageing population and the need for renewed focus on specific disease areas. In this context it is important to recognise the impact of the cost of dementia.
- In order to avoid a deterioration of care for these patients, healthcare budgets will have to increase by 1% per year simply to cover the growth in patient numbers. By 2030 it is estimated budgets will have to rise by 23%.
- In 2009, 6% of healthcare spending was on dementia, however the prevalence of dementia is estimated to rise to 47.6% by 2030, thereby increasing this percentage.

The report argues that increased investment in R&D has a fundamental role to play in improved patient care and economic growth in Europe. Such investments also play a fundamental role in responding to the rise in healthcare spending by potentially reducing the burden on already-strained infrastructure. The current level of R&D investment in Europe leaves a lot to be desired. Although announcements made by policy makers regularly underline the importance of innovation in healthcare, the various components necessary to achieve that outcome are currently not in place.


24 October: Danish Ministry of Health national action plan for dementia receives 470 million Krone

The Danish Ministry of Health has announced it will earmark 874.3 million Krone (EUR 117.2 million) to help various groups, including older people with dementia and people with mental health problems.

Denmark’s national action plan for dementia will receive 470 million Krone (EUR 63 million), to help provide people with dementia and their families with better care and a higher standard of living.

A collective fund of 20 million Krone (EUR 2.68 million) is available for municipalities, voluntary associations, etc. who can apply for funding for activities to increase the quality of life of the more than 40,000 older people living in full-time residential care.


26 October: Global Alliance on Women’s Brain Health will fund gender-based brain health research

On 26 October, the Women’s Brain Health Initiative Canada, Alzheimer’s Research UK, WomenAgainstAlzheimer’s USA and 21st Century BrainTrust (US) announced the formation of a Global Alliance on Women’s Brain Health. The Alliance hopes to raise awareness of women’s brain health challenges and to significantly expand funding for gender-based brain health research that benefits both men and women.

The Global Alliance on Women’s Brain Health will define a scientific agenda, drive new funding for research, and convene scientific leaders to assure the most rapid and effective scientific strategies in women’s brain health. It will also raise awareness at public and private levels.

The Alliance has plans to expand to regions outside of North America and the UK, including Africa and Asia in the future.


9 November: Slovenia launches consultation on National Dementia Strategy

On 9 November, Slovenia’s Ministry of Health launched a public consultation on the country’s draft National Dementia Plan, via its website.

The impetus to develop the strategy, which will run until 2020 once finalised, came from the late Dr Ales Kogoj, founder of Alzheimer Slovenia (Spomincica), along with
two of his colleagues. Their initiative was supported by the Ministry of Health, and in 2010 a working group was set up. The document, prepared by the working group, represents a major step forward in supporting people living with dementia in Slovenia.

Public consultation on the draft plan will close on 9 December.

Link to document (in Slovenian): http://geo.gl/jC8DLk

10 November: Patient organisations express discontent at lack of action on neurodegenerative diseases strategy in France

On 10 November, six French patient organisations - including France Alzheimer – wrote an “open letter” to President François Hollande, expressing their discontent with the lack of action taken so far on the “plan maladies neurodégénératives” (national neurodegenerative diseases strategy).

The letter refers to Mr Hollande’s commitment, on 21 September 2012, to implement the previous “Plan Alzheimer” (2008-2012) and indeed to expand on it, creating a strategy covering all neurodegenerative diseases. This commitment resulted in the launch of the “plan maladies neurodégénératives” (2014-2018) on 18 November 2014. The authors of the open letter point out, however, that little action has been taken beyond the launch of the strategy.

The letter bemoans a lack of clear leadership - which they concede is difficult with a strategy involving so many people from so many disease areas – and highlights the fact that the funding allocated to this plan is insufficient to respond to the needs of all the people it is trying to cover.

Patients represented by the six signatories, including people living with Alzheimer’s and other dementias, do not have time to wait for the political machine to get into gear, says the letter, drawing attention to the timeline for implementation of the 2014-2018 plan, which will only come into effect in 2016, and even then only in “small measures”. It closes with an appeal to Mr Hollande, to ensure action is taken by the relevant political actors as swiftly as possible.

You can read the full letter (in French) here:

16 November: Atlantic Philanthropies gives USD 177 million for Global Brain Health Institute

The Atlantic Philanthropies (AP) is awarding Trinity College Dublin (TCD), Ireland and University College San Francisco (UCSF), US a grant of USD 177 million – the highest program grant the AP has ever awarded - to create a Global Brain Health Institute (GBHI).

Co-led by UCSF and TCD, the GBHI initiative will train 600 global leaders over 15 years, to carry out dementia research, deliver better health care, and change policies and practices in their regions. In doing so, GBHI will be engaging with other institutions and partners around the world.


16 November: Gibraltar government issues draft dementia strategy

On 16 November, the Government of Gibraltar published its draft Dementia Strategy online for public consultation.

The strategy has been drafted by a multi-agency working group comprised of professionals across relevant public services such as the Gibraltar Health Authority, the Social Services Department at Care Agency and Elderly Residential Services, and has included consultation with the Gibraltar Alzheimer’s and Dementia Society.

It sets out the Government’s aims for improving the appreciation, diagnosis and care for dementia, and emphasizes the need to increased awareness and support both for those with dementia and their carers. It also sets out a number of targets with timelines and refers to the new Dementia centres, both day care and residential, set to open within months.

The draft strategy can be downloaded via www.gibraltar.gov.gi


24 November: UK’s first Dementia Research Institute will receive investment up to GBP 150M

The UK’s first Dementia Research Institute will receive up to GBP 150 million (EUR 213 million) to drive forward research and innovation in fighting dementia, Prime Minister David Cameron announced on 24 November.

Led by the Medical Research Council, the institute will bring together world-leading experts, universities and organisations to “drive forward research and innovation in fighting dementia”.

The institute will have a central UK hub, with links to universities across the country and will build on the centres of excellence in dementia already operating across the UK. The Medical Research Council will open a competitive process in early 2016, asking universities to come forward to host the institute itself and will lead the search for a director to head it.

The commitment to form a UK-based institute, was announced by Mr Cameron in his Challenge on Dementia 2020 in February – a long-term strategy focused on boosting research, improving care and further raising public awareness.

The institute is expected to be up and running before 2020.

https://www.gov.uk/government/news/pm-announces-funding-for-uk-s-first-dementia-research-institute
**Science watch**

**15 October: Seems size may matter, where the Hippocampus is concerned**

Performance in non-verbal memory tests - such as remembering geometric shapes and patterns - has been shown to be linked to the size of the hippocampus.

This could potentially provide a way to improve the diagnosis of Alzheimer’s disease (AD), according to research published in the journal Alzheimer's Research and Therapy on 15 October.

The preliminary study of 226 people, who had been referred to a memory clinic, indicates an association between brain volume, and particularly the size of the hippocampus, and memory.

As the hippocampus shrinks in AD, this could help to diagnose the condition at an earlier stage and potentially identify those people with mild cognitive impairment (MCI) at higher risk of developing AD.

http://www.alzres.com/content/7/1/61

**4 November: Three-minute test helps diagnose Lewy Body Dementia**

Researchers at Florida Atlantic University have developed a new test that they say works to diagnose both Lewy Body dementia (LBD) and Parkinson’s disease dementia (PDD) in about three minutes. The test is known as the “Lewy Body Composite Risk Score” (LBCRS) and uses a brief rating scale completed by a clinician to assess clinical warning symptoms associated with the disease.

Researchers recently examined the test in a study, called “Improving the Clinical Detection of Lewy Body Dementia with the Lewy Body Composite Risk Score”. For the study, 256 patients were compared with the clinical dementia rating and gold standard measures of cognition, motor symptoms, function and behaviour. The researchers administered the test in a “real-world” clinic setting with a clinic sample of varying genders, educational backgrounds and cognition, motor symptoms, function and behaviour.

During the study, caregivers were asked to complete evaluations that determine the presence of severity of cognitive symptoms observed in the patient and how this impacted the caregiver. Patients were administered a 30-minute test to assess their cognitive status. The LBCRS was completed after all other rating scales were scored and the diagnosis was presented to the patient and family, according to the study authors.

The study claims that the LBCRS was able to differentiate between Alzheimer’s dementia and LBD with 96.8% accuracy and with a 90% sensitivity and an 87% specificity.

Lewy Body dementia (LBD) is the second-most-common type of dementia, after Alzheimer’s dementia.


**10 November: Alzheon announces pre-phase III trial clinical studies for AD drug candidate**

Alzheon Inc. – a Biopharmaceutical company focused on developing new medicines for patients with Alzheimer’s disease (AD) and other neurological and psychiatric disorders - announced the initiation of two clinical studies with its AD drug candidate ALZ-801.

These studies will provide final clinical data necessary to progress ALZ-801 into the Phase 3 program. Completion is expected by Q1 of 2016.


**10 November: Changes in humour may be an early sign of dementia**

Researchers at University College London (UCL), UK have revealed that a change in sense of humour could be an early sign of dementia. The findings could help improve dementia diagnosis, by highlighting changes not commonly thought to be linked to the condition. The research was published in the Journal of Alzheimer’s Disease on 10 November.

The research team was particularly interested in how sense of humour can change in frontotemporal dementia (FTD) and Alzheimer’s disease (AD). While AD is the leading cause of dementia, FTD is the most common cause of dementia in the under-55s. Unlike in AD, memory difficulties are not an early indicator of FTD. Rather, people tend to experience behaviour and personality changes before they develop problems with memory. The research team wanted to explore these behavioural symptoms, to reveal early clues of underlying brain changes and aid diagnosis.

Because sense of humour is such an important part of our personalities and our dealings with other people, the research team focused on shifting preferences in comedy genre in people with dementia. Using a series of questionnaires, they asked friends or relatives of 48 people with different forms of FTD and AD to rate their loved one’s liking for different kinds of comedy. This included slapstick comedy such as “Mr Bean”, satirical comedy such as “Yes, Minister” or absurdist comedy such as “Monty Python”. The researchers also asked those completing the questionnaire to say whether they had noticed instances of inappropriate humour. As well as collecting data about current humour preferences, the team asked the friends and relatives to reflect on the past 15 years – well before any of the study volunteers received a diagnosis – to identify any shifts in preference.

The team found that people with behavioural variant FTD – a particular form of FTD associated with behavioural changes – had an altered sense of humour compared to those with AD and healthy individuals. This included laughing at events others would not find funny such as a badly parked car or barking dog. The questionnaires and anecdotes revealed that people with bvFTD frequently laughed inappropriately at tragic events on the news or in their personal life. This did not happen in people with AD.

The researchers also found that people with both bvFTD and AD tended to prefer slapstick humour to satirical and absurdist...
Fitter legs may be linked to better brain ageing

Researchers at King’s College London, UK say that muscle fitness as measured by power in the legs is strongly associated with an improved rate of ageing in the brain. Their findings, published in the journal “Gerontology” on 10 November, suggest that simple interventions, such as increased levels of walking, targeted to improve leg power in the long term, could impact positively on cognitive ageing.

Scientists studied a sample of 324 healthy female over a ten-year period, measuring various health and lifestyle predictors. They were thus able to control for genetic factors affecting changes in cognitive function.

Thinking, learning and memory were measured at the beginning and end of the study and it was found that leg power was a better predictor of cognitive change than any other lifestyle factors tested. Generally, the twin who had more leg power at the start of the study sustained their cognition better and had fewer brain changes associated with ageing, measured after ten years.

Previous studies have shown that physical activity can have a beneficial effect on the ageing of the brain with animal studies showing that exercising muscles releases hormones that can encourage nerve cells to grow.

This new study is thought to be the first that shows a specific link between power (i.e. force and speed) in the lower limbs and cognitive change in a normal, healthy population. As the legs contain the largest muscles they are of particular relevance for muscular fitness and can be exercised easily through various habitual activities such as simply standing or walking.

More studies are needed to better understand the relationships between measures of fitness such as leg power or aerobic capacity and brain changes, and the specific cause-and-effect of physical activity on brain structure and cognition. Also, the study only assessed female participants with an average age at baseline of 55 [range 43–73], so further studies would be needed to establish whether these findings can be generalised to older or male populations.

The research was funded jointly by the National Institute for Health Research (NIHR) and the Wellcome Trust.

http://www.karger.com/Article/FullText/441029

13 November: Researchers in Korea test blue LED lights as possible AD treatment

Korean scientists have conducted research into the suppression of an abnormal assembly of beta-amyloid proteins, using photo-excited porphyrins. It was published online as the lead article in a recent issue of “Angewandte Chemie” (pictured).

The research team effectively prevented the buildup of beta-amyloids by using blue LED lights and a porphyrin inducer - a biocompatible organic compound. By absorbing light energy, a photosensitiser such as porphyrin reaches the excitation state. Active oxygen is created as the porphyrin returns to its ground state. The active oxygen oxidises a beta-amyloid monomer, and by combining with it, disturbs its assembly.

The technique was tested on drosophila or fruit flies, which were produced to model Alzheimer on invertebrates. The research showed that symptoms of Alzheimer’s disease in the fruit flies such as damage on synapse and muscle, neuronal apoptosis, degradation in motility, and decreased longevity were alleviated. Treatments with light provide additional benefits: less medication is needed than other drug treatments, and there are fewer side effects. When developed, photodynamic therapy will be used widely for this reason.

The team, jointly led by Prof. Chan Beum Park of the Materials Science and Engineering Department at the Korea Advanced Institute of Science and Technology (KAIST) and Dr Kwon Yu from the Bionano Center at the Korea Research Institute of Bioscience and Biotechnology (KRIIB), say their findings suggests new ways to treat neurodegenerative illnesses including Alzheimer’s disease (AD).

“We plan to carry the research further by testing compatibility with other organic and inorganic photosensitizers and by changing the subject of photodynamic therapy to vertebrate such as mice” said Prof. Park.


16 November: Avanir Pharmaceuticals announces phase III trial of Alzheimer’s disease drug

On 16 November, Avanir Pharmaceuticals announced the start of enrolment for a phase III clinical trial evaluating its drug AVP-786 for the treatment of agitation in patients with Alzheimer’s disease. Avanir recently received Fast Track designation from the U.S. Food and Drug Administration (FDA) for this development.

This trial is the first of two placebo-controlled phase III trials in the company’s “TRIAD” program, both of which are multicentre, randomised, double-blind, and placebo-controlled, to evaluate two doses of AVP-786 versus placebo over a period of 12-weeks.

TRIAD-1 is expected to enrol approximately 380 patients in 60 centres in the United States. TRIAD-2 is expected to enrol approximately 325 patients in 50 centres in the U.S. and will begin later in 2015. In addition to these two U.S.
based trials, there will be additional global trials that will be conducted as part of the same program.


17 November: UK drug trial opens to test hypertension drug in AD

People with Alzheimer’s disease (AD) who live in Scotland, UK are being asked to consider taking part in a government-funded trial investigating if the drug losartan could help slow the progression of AD.

Losartan is an angiotensin II receptor antagonist drug, used mainly to treat high blood pressure (hypertension).

The trial is being led by academics from the Universities of Bristol, Cambridge, Queen’s University Belfast, and University College London and hosted by North Bristol NHS Trust. The researchers believe losartan can slow down the progression of AD by improving brain blood flow and altering chemical pathways that cause brain cell damage, brain shrinkage and memory problems in AD.

The trial, known as RADAR (Reducing pathology in Alzheimer’s Disease through Angiotensin targeting), is hoping to recruit approximately 230 participants, together with a similar number of carers, from across the UK including sites covering the Tayside, Lothian, Grampian, Glasgow, Border and Lanarkshire areas, all of which are partners in the Scottish Dementia Clinical Research Network (SDCRN).

http://www.bristol.ac.uk/news/2015/november/radar-trial.html

25 November: New centre for dementia research opens in Edinburgh

On 25 November, the new Centre for Dementia Prevention (CDP) at the University of Edinburgh, Scotland opened its doors. The CDP calls itself an institute “without walls”, aiming to bring together social sciences, basic sciences, drug discovery and clinical expertise to help understand and tackle the key risk factors that underlie dementia.

The CDP is led by Professor Jean Manson of the Roslin Institute (a National Institute of Bioscience at the University of Edinburgh), Professor Charlotte Clarke of the University’s School of Health in Social Science, and Professor Craig Ritchie of the Department of Psychiatry.

The launch was marked with an academic day of talks at the Edinburgh College of Art, outlining the centre’s mission and the science behind secondary prevention of dementia. Speakers at the opening included Chief Scientist, Prof. Andrew Morris, Prof. Miia Kivipelto from the Karolinska Institutet in Sweden and Henry Simmons, Chief Executive of Alzheimer Scotland.

www.centrefordementiaprevention.com

Newsletter: November 2015

Dementia in society

27 October: US study finds financial toll of dementia is much higher than other disease areas

The National Institutes of Health (NIH) in the US have conducted a report into the toll dementia can take on finances.

In the last five years of life, total health care spending for people with dementia was more than USD 250,000 per person, some 57 percent greater than costs associated with death from other diseases, including cancer and heart disease.

The new analysis appeared on 27 October in the online issue of the Annals of Internal Medicine.


19 November: University of Bradford awarded Queen’s Anniversary Prize for dementia work

The University of Bradford in the UK has been awarded the Queen’s Anniversary Prize for Higher and Further Education, for its work to improve the lives of people living with dementia.

The announcement was made by the Royal Anniversary Trust by permission of Her Majesty The Queen at a reception at St James’s Palace on 19 November, attended by Bradford Vice-Chancellor Professor Brian Cantor and Prof. Munra Downs, Chair in Dementia Studies at the University (pictured, right alongside Prof. Jan Oyebode, Professor of Dementia Care).

Read more about the work done by the University of Bradford in the field of dementia, and about the award itself here:


New publications & resources

4 November: OECD report “Health at a Glance 2015” is available

The 2015 edition of the Organisation for Economic Co-operation and Development (OECD)’s report, “Health at a Glance” was published on 4 November and is now available to purchase or to read online.

This new edition of “Health at a Glance” presents the most recent comparable data on the performance of health systems in OECD countries. Where possible, it also reports data for partner countries (Brazil, China, Colombia, Costa Rica, India, Indonesia, Latvia, Lithuania, Russian Federation and South Africa).

Compared with the previous edition, this new edition includes a new set of dashboards of health indicators to summarise in a clear and user-friendly way the relative strengths and weaknesses of OECD countries on different key indicators of health and health system performance, and also a special focus on the pharmaceutical sector. It
also contains new indicators on health workforce migration and on the quality of health care.

http://www.oecd.org/els/health-systems/health-at-a-glance-19991312.htm

11 November: Peer Support Resource Pack available for download

On 15 September, Alzheimer Europe informed newsletter readers about a report conducted by the UK Health Innovation Network (HIN) on “Peer Support for People with Dementia – A Social Return on Investment (SROI) Study”, emphasising the positive social value of peer support groups for people with dementia, their carers and volunteers.

As a follow-up to this, we would also like to draw our readers’ attention to the Peer Support Resource Pack available for download on the HIN website:

http://www.hin-southlondon.org/system/resources/resources/000/000/095/original/HIN_Interactive_Toolkit_September_15_V1.pdf

17 November: The Alzheimer Society of Finland’s brain health app now also in Swedish

The Alzheimer Society of Finland (Muistiliitto), The Memory Association in Espoo and Kauniainen and Perry Mitchell (volunteer worker), released a brain health application in Finnish, “Äivoterveydeksi!” earlier this year (March).

It is now also available in Swedish under the name “Hjärnhälsosam!”

www.muistiliitto.fi/su/muistiliitto/hjarnhalsa/hjarnhalsosam.

Education

29 October: INTERDEM Academy wants to fund more young researchers

The INTERDEM Academy gives fellowships to young researchers, allowing them to attain research experience in another PRIDE (PRomoting Independence in Dementia) / INTERDEM research centre. INTERDEM is keen to hear from PhD students and post-docs looking for funding.

Talented young researchers from PRIDE and INTERDEM sites, working on a PhD thesis, or who have a PhD degree for a maximum of three years, can apply. Fellows must be involved in research that is in line with INTERDEM’s mission. It is important that the fellowship has added value for the host institute, as well as the home institute.

The INTERDEM Academy fellowship covers expenses for travel and housing for a period of 3-6 months. Applicants need not stay in one place for the entire period, as the grant may also be used to visit more than one research institutes. The salary of the fellow is not covered by this fellowship, and must be provided by the fellow’s home institute.

Applications for 2016 are now open. There are two annual calls to submit applications for travel fellowships; the next deadline is 31 March 2016.

The experiences of Antonio Garcia, a PhD student from the University of Salamanca who has received an INTERDEM Academy fellowship to visit the research group of Prof. Martin Orrell at University College London in 2014, are detailed here:  http://interdem.org/wp-content/pdf/interdem-academy/IA_Fellowship_Report_Antonio_Garcia_2014.pdf

Hanneke Beerens went on an exchange between Maastricht University and the School of Dementia at Bradford University in 2015, to work with the group of Prof. Murna Downs. Read about her experiences here:  http://interdem.org/wp-content/pdf/interdem-academy/IA_Fellowship_Report_Hanneke_Beerens_2015.pdf

For more information about INTERDEM Academy, click here:  http://interdem.org/?page_id=4636

5 November: UCL announces new MSc in dementia and mental health

An MSc course in “Dementia: Causes, Treatments and Research Mental Health” is being offered jointly by the UCL Division of Psychiatry and Institute of Neurology, starting from September 2016.

The course provides research-led, postgraduate training about the scientific base of the prevention, detection and management of different dementias, with particular emphasis on the treatment and management of cognitive and neuropsychiatric symptoms, developing and evaluating psychosocial interventions for people with dementia and their family carers, and end of life care. Students are also taught the basic scientific principles of the clinical neuroscience of neurodegenerative diseases (taught by the Institute of Neurology).

For more information visit  https://www.ucl.ac.uk/psychiatry/study-here/msc-dementia-mental-health

Or contact Dr Vasiliki Orgeta:  v.orgeta@ucl.ac.uk
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-Hohlbien (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 Lulčič Zlobec (Slovenia).

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### AE Calendar 2015

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>30 Nov-2 December</td>
<td>AE Board meeting, lunch debate, Alzheimer’s Association Academy (Brussels, Belgium)</td>
<td>AE Board and staff</td>
</tr>
<tr>
<td>1-2 December</td>
<td>Meeting of the EWGIPWD</td>
<td>Dianne and Ana</td>
</tr>
<tr>
<td>7 December</td>
<td>Launch of the AFE-InnovNet Covenant on Demographics (Brussels, Belgium)</td>
<td>Ana, Dianne and Vanessa</td>
</tr>
<tr>
<td>8 December</td>
<td>EFPA Think Tank Meeting (Brussels, Belgium)</td>
<td>Vanessa</td>
</tr>
<tr>
<td>8-9 December</td>
<td>Joint AFE-INNOVNET and AFEE (WHO regional office for Europe) workshops on age-friendly environments (Brussels, Belgium)</td>
<td>Dianne and Ana</td>
</tr>
<tr>
<td>10 December</td>
<td>Mental Health Europe annual event in the European Parliament (Brussels, Belgium)</td>
<td>Vanessa</td>
</tr>
<tr>
<td>10 December</td>
<td>4th Conference of Partners of the European Innovation Partnership on Active and Healthy Ageing (EIP-AHA) in the European Parliament (Brussels, Belgium)</td>
<td>Dianne</td>
</tr>
<tr>
<td>10 December</td>
<td>Travel pro – meeting airlines and various travel supplier (Luxembourg, Luxembourg)</td>
<td>Gwladys</td>
</tr>
<tr>
<td>10-11 December</td>
<td>Lilly Working Group (St. Louis, United Kingdom)</td>
<td>Jean</td>
</tr>
<tr>
<td>15-16 December</td>
<td>OECD Workshop (Lausanne, Switzerland)</td>
<td>Jean</td>
</tr>
<tr>
<td>18 December</td>
<td>PharmaCog Steering Committee meeting (Lille, France)</td>
<td>Jean and Alex</td>
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### Conferences 2015-2016

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>7-9 December</td>
<td>Covenant on Demographic Change Towards an age-friendly Europe, <a href="http://afeinnovnet.eu/event/launch-covenant-demographic-change">http://afeinnovnet.eu/event/launch-covenant-demographic-change</a></td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>9-12 March 2016</td>
<td>14th International Athens/Springfield Symposium on Advances in Alzheimer Therapy, <a href="http://www.ad-springfield.com">www.ad-springfield.com</a></td>
<td>Athens, Greece</td>
</tr>
<tr>
<td>17-20 March 2016</td>
<td>The 15th World Congress on Controversies in Neurology (CONy), <a href="http://www.comtecmed.com/cony">http://www.comtecmed.com/cony</a></td>
<td>Lisbon, Portugal</td>
</tr>
<tr>
<td>16-17 June 2016</td>
<td>Grand Designs “Are we there yet?”, <a href="http://www.dementiaconference.com/">http://www.dementiaconference.com/</a></td>
<td>Sydney, Australia</td>
</tr>
<tr>
<td>24-28 July 2016</td>
<td>AAC Annual Conference, <a href="https://www.alz.org/aac/">https://www.alz.org/aac/</a></td>
<td>Toronto, Canada</td>
</tr>
<tr>
<td>31 Aug-2 Sept 2016</td>
<td>10th International Conference on Frontotemporal Dementias, <a href="http://www.icftd2016.de/">http://www.icftd2016.de/</a></td>
<td>Munich, Germany</td>
</tr>
<tr>
<td>6-9 September 2016</td>
<td>2016 IPA International congress, <a href="http://www.ipa-online.org">www.ipa-online.org</a></td>
<td>San Francisco, USA</td>
</tr>
<tr>
<td>5-9 October 2016</td>
<td>Croatian Congress on Alzheimer disease with International participation (CROCAD 16), <a href="http://www.alzheimer2016.com/">http://www.alzheimer2016.com/</a></td>
<td>Tuzla, Croatia</td>
</tr>
<tr>
<td>31 Oct-2 November 2016</td>
<td>26th Alzheimer Europe Conference (JAECC), on &quot;Excellence in dementia research and care&quot;</td>
<td>Copenhagen, Denmark</td>
</tr>
<tr>
<td>9-11 December 2016</td>
<td>2016 IPA Asian regional meeting, <a href="http://www.ipa-online.org">www.ipa-online.org</a></td>
<td>Taipei, Taiwan</td>
</tr>
</tbody>
</table>
1. Alzheimer’s disease is an incurable neurodegenerative disease of the brain tissue that causes progressive and irreversible loss of mental functions, including memory.
2. Six million people are affected by Alzheimer’s disease or related diseases in Europe, and the number of new cases diagnosed each year continues to increase.
3. There is currently no curative treatment for Alzheimer’s disease, but some drug treatments can help to slow the process and early detection can assist in better supporting patients and their carers.
4. The Commission and the Council are invited to recognise Alzheimer’s disease and related diseases as a public health priority in Europe.
5. The Commission and the Council are therefore called upon to adopt a comprehensive strategy for meeting the challenges presented by Alzheimer’s disease. Research aimed at developing sustainable treatment solutions and efforts to improve the efficient provision of information and support to carers should be promoted.
6. This declaration, together with the names of the signatories, is forwarded to the Council and the Commission.

Alzheimer Europe calls on all MEPs to sign the Written Declaration before 5 January 2016
Thank you

The Alzheimer Europe newsletter received funding under an operating grant from the European Union’s Health Programme (2014-2020). The content of this newsletter represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.