Highlights in this issue
1 June: EMA selects AD med for PRIME programme
7 June: France may no longer reimburse AD meds
23 June: EPAD and EMIF voice concerns over Brexit
30 June: French translation of 2015 ethics report published
30 June: 26AEC Early Bird rates close

Editorial
Welcome!
Where to begin? June has certainly been a busy and interesting month!
The topic on everyone’s lips, it seems, is “Brexit”, so I’ll begin there. In the run up to the UK’s EU Referendum - in which voters elected not to continue as a Member State of the EU - partners from two of the most important research programmes in the dementia field, EPAD and EMIF published an article in The Lancet Psychiatry, titled “Better together for better dementia research and care”, voicing serious concerns over what the future might hold for dementia research in the case of the UK leaving the EU. We are a partner in both projects, and I was pleased to contribute to the article alongside other project leaders. In the aftermath of the vote, we were reassured to hear that IMI has said it will not affect the IMI-2 programme, nor the funding of the projects, including UK partners.
Brexit is not the only thing on our minds this month, however, on the policy front. France’s health authority, the Haute Autorité de Santé, is currently considering removing the four existing anti-Alzheimer’s drugs on the market from the list of reimbursed medications - a possible move that our national member association Alzheimer’s France is understandably extremely concerned about. The decision will be reached in the coming days. In more positive medicines-related news, the first statistics on the European Medicines Agency’s PRIME programme were released at the start of the month, and we were pleased to see that one of the first four investigational treatments accepted into the programme is an experimental Alzheimer’s treatment.

Also on the policy front, we were delighted to be involved in a focus group advising on the development of a new Swedish dementia strategy this month and to have been involved in the European Commission’s “Guidelines on Summaries of Clinical Trial Results for Laypersons”, on which a public consultation was launched at the start of the month. The publication should be finalised by the end of the year. I am also pleased to announce that a French translation of our 2015 Ethics report is now available, in the “Publications” section of our website. Finally, on the publication front, our Director for Projects Dianne Gove has had another article published in the journal Dementia, on the ethical implications of perception and portrayal of dementia. Congratulations, Dianne!
On a less happy note, we were sad to hear that Raoul has decided to leave our European Working Group of People with Dementia (EWGPWD) as he no longer feels able to participate.

Last but not least, I’d like to remind everyone that today, 30 June, is the final day for Early Bird rates on our 26th annual conference (26AEC) registrations. The rate will no longer be available as at midnight tonight, CET.

Our next newsletter will be a double-month summer edition for July and August and will be published on 31 August. Until then, I wish you all an excellent summer!

Jean Georges
Executive Director
On 30 May, Helen Rochford-Brennan, Vice-Chair of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) and chair of the Alzheimer Society of Ireland’s Irish Dementia Working Group (IDWG), gave an inspiring speech at a conference on “Living with Dementia in Rural Ireland”, hosted by NUI Galway (National University of Ireland).

During her address Helen (pictured, 3rd from right in green jacket) spoke about the stigma that comes with a diagnosis of dementia and about the challenges facing those in rural areas, including access to transport.

“We can’t deny this condition but we can continue to defy it with support” Helen said.


31 May: Second meeting for the Carers’ Survey held in Amsterdam

The second meeting for Alzheimer Europe (AE)’s carers’ survey was held in Amsterdam on 31 May. AE members from the five countries where the survey will take place and Bob Woods from the University of Bangor attended the meeting.

A first draft for the questionnaire that will be used for the survey was circulated prior to the meeting and all participating countries had the opportunity to send comments.

In the meeting, the group discussed the comments and necessary changes for the questionnaire. Also additional methodological issues such as sampling were discussed.

Bob Woods will apply for ethics approval at Bangor University. He will also finalise the questionnaire, pilot it in the UK and will send the final version to all participating countries for translation. Data collection will start after the summer.

The next meeting is scheduled for 24 January 2017 in Amsterdam. At this meeting members of the group will have the opportunity to contribute towards the interpretation of the results.

AE’s Executive Director Jean Georges and Project Officer Ana Diaz attended the meeting.

1 June: AE involved in Commission Guidelines on Summaries of Clinical Trial Results for Laypersons

On 1 June, a public consultation was launched by the European Commission on its “Guidelines on Summaries of Clinical Trial Results for Laypersons”. The consultation will run for three months, until 31 August.

The aim is to finalise the publication by the end of 2016.

Alzheimer Europe (AE) was involved in the task force set up by the Commission to develop these guidelines.


3 June: AE Chairperson Heike von Lützau-Hohibein reports on Alzheimer Scotland Conference

On 3 June, AE Chairperson Heike von Lützau-Hohibein (pictured, middle) attended the Alzheimer Scotland National Conference 2016 in Edinburgh. The conference was held under the theme “Global to Local: research, practice, innovation” and well attended by nearly 600 participants.

In the session “global update” she presented the work of AE the achievements in the field of making dementia a Scottish government priority, explaining the instruments for lobbying for dementia at EU-level, referring to the Glasgow Declaration and its great support in 2015. AE’s contributions in the various European research projects were described - AE’s role in these projects is always to act as advocate for people with dementia and their carers. Also developments like the second Joint Action on Dementia under the lead of the Scottish government and the legacy events under the actual and coming EU Presidencies were mentioned.

10 June: Dianne Gove’s article on ethical implications of perception and portrayal of dementia is published

On 10 June, an article on “Ethical implications of the perception and portrayal of dementia” was published online in the journal, Dementia, co-authored by Dr Dianne Gove, Director for Projects, Alzheimer Europe, Dr Debby L Gerritsen, Department of Primary and Community Care, Radboud University Medical Centre Nijmegen, Netherlands and Prof. Jan Oyebode, School of Dementia Studies, University of Bradford, Bradford, UK.

The article explores the way we perceive and portray dementia and the implications this has on how we act towards people with dementia and how we address the issue of dementia within society. Perceptions of dementia as reflected in explanatory models of its cause and nature, descriptions of characteristics of people with dementia, the use of language, media portrayals and the views of people living with dementia are examined.
20 June: Raoul Grönqvist leaves the EWGPWD

On 20 June, we received news that Raoul Grönqvist has decided to leave our European Working Group of People with Dementia (EWGPWD). His wife, Milja Ahola contacted us to let us know that Raoul no longer feels able to participate in the group and will step down from his position as a member.

Raoul was born in 1951 in Helsinki, Finland. He is a tribologist and a Doctor of Technology and speaks four languages. He has always enjoyed playing classical guitar and also enjoys walking his poodle. After his diagnosis of Alzheimer’s disease and dementia with Lewy bodies at the age of 60, he joined the EWGPWD in the hope that his work experience would help him contribute to the work of the group and consequently help other people with dementia. He has also belonged to a self-support group in Finland during this time.

We would like to thank Raoul for his important contributions and Milja for supporting her husband at meetings.

30 June: French translation of Alzheimer Europe ethics report is published

A French translation of the 2015 Alzheimer Europe Report: “Ethical dilemmas faced by health and social care professionals providing dementia care in care homes and hospital settings: a guide for use in the context of ongoing professional care training” has been published and is available on our website:

http://alzheimer-europe.org/Publications/Alzheimer-Europe-Reports

Many thanks to the Fondation Médéric Alzheimer and our national member association, France Alzheimer for the support they provided on this translation.

30 June: Early Bird rates for our Copenhagen conference will end today

Early Bird rates for our 26th annual conference end at midnight tonight, 30 June.

The conference programme overview for 26AEC, which will take place in Copenhagen from 31 October to 2 November, is available on our website:

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

REGISTER NOW!

26th Alzheimer Europe Conference
EU projects

13 June: Alzheimer Europe and University of Luxembourg host MinD exchange visit

From 13 June to 2 July, the second exchange visit of the MinD project took place. This project aims to help people with dementia engage in social contexts to improve psychosocial wellbeing. Using the concept of mindful design, the project aims to find new innovative design solutions to enable self-empowerment and confidence building of people living with dementia.

During this second exchange, designers, clinicians and dementia experts came together to plan the data collection material for the interviews and focus groups that will take place in Germany, Spain, the Netherlands and the UK. The interviews and focus groups will help to gather information from people with dementia and their carers about their daily lives, wellbeing, decision making and social engagement.

The visitors were hosted by the University of Luxembourg (academic host) and Alzheimer Europe (non-academic partner).

During the second week of the exchange, the visitors attended an Alzheimer Europe Lunch Debate and Public Affairs meeting in Brussels. Dianne Gove, Vanessa Challinor and Ana Diaz participated in the meetings.

14 June: NILVAD releases latest issue of participant and carer newsletter

The NILVAD partners have released a new issue of the project’s biannual Participant and Caregiver Newsletter. As its title implies, the publication is intended for all the people who have taken part in NILVAD’s clinical trial of nilvadipine for mild to moderate Alzheimer’s disease and also for their carers.

The newsletter highlights the latest project news in lay language and provides links to national Alzheimer associations. The current issue also features a link to a series of short animations about dementia that were produced by Trinity College Dublin. These can be seen at http://freedemliving.com/

The NILVAD Participant and Caregiver Newsletter is available in all eight languages of the countries where the study is taking place: Dutch, English, French, German, Greek, Hungarian, Italian and Swedish. It can be downloaded from the project website: http://www.nilvad.eu/dissemination/newsletter-for-patients-and-carers/

15 June: Intermediate PACE Policy Conference held

On 15 June, AGE platform organised the first PACE policy conference, on “Mainstreaming Palliative Care for an Age-friendly Society”, in Brussels. The conference highlighted the need to consider palliative care as an intervention contributing to the quality of life of older people with a life-threatening health condition.

During the conference, discussions emerged around the need to go beyond the traditional silos and consider palliative care as an integrated practice that should be part of the relevant public policies, and allow the person receiving palliative care to live well and actively for as long as possible.

The programme of the conference addressed the state of play and the benefits of palliative care, the perspectives of end-users and practitioners and policy issues.

Iva Holmerová (pictured) gave a presentation on behalf of AE discussing the benefits of palliative care for older people with dementia. AE’s Policy Officer Vanessa Challinor and Project Ana Diaz attended the meeting.

Alzheimer Europe networking 2016

On 2 June (Groningen, Netherlands), Dianne attended the board meeting of the Covenant on Demographic Change.

On 3 June (Edinburgh, UK), Heike attended the Alzheimer Scotland annual conference during Scotland’s Dementia Awareness Week.

On 6-7 June (Lindau, Germany), Helen Rochford-Brennan from the European Working Group of People with Dementia and Jean attended a Roche seminar on the importance of a timely diagnosis.

On 10 June (Lyon, France), Jean attended the Francophone Conference on Alzheimer’s disease and related disorders where he presented Alzheimer Europe’s campaign to have dementia recognised as a European priority.


On 14 June (Vienna, Austria), Dianne took part in a focus group organised by the European Centre for Social Welfare Policy & Research.

On 14-15 June (Benediktbeuern, Germany), Heike attended the 8. “Benediktbeurer Zukunftsgespräche” on the care sector, benchmarking people’s needs and how and where to live in old age.

On 15 June (Brussels, Belgium), Jean met with Biogen for an exchange of views.

On 15 June (Brussels, Belgium) Vanessa attended the Interest Group on Carers meeting on the challenges of work-life balance faced by working families.
On 16 June (Brussels, Belgium) Iva and Vanessa attended the conference “Fighting elder abuse in health and long-term care”.

On 17 June (Amsterdam, Netherlands), Dianne and Hilary took part in the second ethics meeting of Alzheimer Europe’s working group addressing the changing definitions of Alzheimer’s disease.

On 17-23 June (Luxembourg) Dianne and Ana participated in various meetings of the second exchange visit of the MinD project.

On 21-22 June (Lille, France) Jean attended the meeting of the Scientific Advisory Board of DISTAL2.

On 22 June (Brussels, Belgium) Vanessa attended the Brain, Mind and Pain EFNA MEP Interest Group meeting on Patient Involvement in Research.

On 27 June (Brussels, Belgium) Jean met with BMS for an exchange of views.

On 27-28 June (Brussels, Belgium), the Alzheimer Europe Board met.

On 28 June (Brussels, Belgium), Alzheimer Europe organised a lunch debate on “Using the UN CRPD to support the rights of people living with dementia” in the European Parliament.

On 28 June (Brussels, Belgium) Alzheimer Europe organised a company round table meeting with its sponsors and member organisations.

On 28 June (Brussels, Belgium), the Board and members of Alzheimer Europe met with Axovant for an exchange on the company’s clinical trial programme.

On 29 June (Brussels, Belgium), Alzheimer Europe organised a public affairs meeting with its national member organisations.

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Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 127, 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); Rübg плот 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); Rđa Tomasić (ECR).

**Cyprus:** Costas Mavrides (S&D); Eleni 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:** Urmass Paet (ALDE); Liia Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE);

**Germany:** Angelika Niebler (EPP); Udo Voigt (NI).

**Greece:** Kostas Chrysogonos (S&D); Manolis Kefalogiannis (EPP);

**Hungary:** Ádám Kósa (EPP); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (S&D); Marian Harkin (ALDE); Brian Hayes (EPP); Séan Kelly (S&D); Mairéad McGuinness (S&D); Lidia NDi Ria (S&D).

**Italy:** Brando Benifei (S&D); Elena Gentile (S&D); Pier Antonio Panzeri (S&D); Patrizia Toia (S&D); Damiano Zoffoli (S&D).

**Lithuania:** Vilija Blinkyteviciute (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 Lukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Plura (EPP); Bogdan Went (EPP).

**Portugal:** Carlos Coelho (EPP); Marisa Matias (S&D); Sofia Ribeiro (EPP).

**Romania:** Cristian-Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (S&D); Daciana Octavia Sârbu (S&D); Claudiu Ciprian Tănase (S&D); Renate Weber (EPP).

**Slovakia:** Miroslav Mikolásik (EPP); Ivan Stefanec (S&D); Anna Žaborská (EPP); Jana Žitňanská (ECR).

**Slovenia:** Franc Bogovič (EPP); Tanja Fajon (S&D); Aljoz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Šulin (EPP); Romana Tomc (EPP); Ivo Vajgl (ALDE); Milan Zver (EPP).

**Spain:** Iázekun Bilbao Barandica (ALDE); Soledad Cabezón Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estaräs Ferragut (EPP); Juan Carlos Girauta (ALDE); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Ernest Maragall (Greens/EFA); Pablo Zalba Bidegain (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); Ian Duncan (ECR); Theresa Griffin (S&D); 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).
Ms Pietikäinen has over the years been very active in her contributions to AE’s campaign to make dementia a European priority.

- Gave the closing summary at an AE lunch debate on 1 December 2015 in Brussels entitled “Dementia, a priority of two EU Presidencies”.
- Gave the closing summary at an AE lunch debate at the European Parliament on 30 June 2015, on the Global Action Against Dementia.
- Signed the Glasgow Declaration on 29 January 2015.
- Participated in an AE lunch debate in Brussels on 2 December 2014, on the topic of dementia prevention.
- Agreed to be a Vice-Chairperson of the EAA in October 2014.
- Attended a European Parliament lunch debate in February 2014 that focused on IMI.
- Attended a European Parliament lunch debate in December 2013 that focused on the European Dementia Monitor.
- Attended a European Parliament lunch debate in June 2013 that focused on the results of the ALCOVE project.
- Hosted a European Parliament lunch debate in February 2013 that was dedicated to clinical trials.
- Attended a European Parliament lunch debate in December 2012 entitled “Living with dementia: learning from the experiences of people with dementia”.
- Attended a European Parliament lunch debate in June 2012 which explored “Alzheimer’s disease in the new European public health and research programmes”.
- Hosted a European Parliament lunch debate in June 2011 entitled “the Alzheimer Cooperative Valuation in Europe” or ALCOVE project.
- Attended a European Parliament lunch debate in June 2010 called “Alzheimer’s disease and dementia as a national priority: contrasting approaches by France and the UK”.
- Participated in the interview with MEPs in the run up of the elections for Alzheimer Europe’s “Electio
24 June: Five more EAA members sign Written Declaration on prioritisation of a European Dementia Strategy

Alzheimer Europe would like to thank the five members of the European Alzheimer’s Alliance (EAA) who signed Written Declaration 0027/2016 on the prioritisation of a European Dementia Strategy, during the month of June:
- Liisa, Jaakonsaari (Finland, S&D)
- Kostadinka Kuneva (Greece, GUE/NGL)
- Catherine Stihler (UK, S&D)
- Eleftherios Synadinos (Greece, NI)
- Keith Taylor (UK, Greens/EFA)

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

EU developments

1 June: First statistics on EMA’s PRIME are released

On 1 June, the European Medicines Agency (EMA) released the outcome of the assessment of the first batch of applications received from medicine developers for its PRIME (PRIoritised MEdicines) scheme, an initiative launched in March this year that aims to foster research on and development of medicines that have the potential to address an unmet medical need.

18 applications for PRIME were received as of 6 April 2016 and subsequently assessed by EMA’s Scientific Advice Working Party, Committee for Advanced Therapies and Committee for Medicinal Products for Human Use. Four medicines have been accepted for PRIME:
- CCX168 for the treatment of patients with active ANCA-associated vasculitis.
- KTE-C19 for the treatment of adult patients with diffuse large B-cell lymphoma (DLBCL).
- NI-0501 for the treatment of primary haemophagocytic lymphohistiocytosis (HLH).

Since 6 April 2016, another 14 applications have been received and are being processed by EMA. Going forward, the Agency will release information on PRIME on a monthly basis.

2 June: Covenant on Demographic Change holds its first Board Meeting

Groningen, Netherlands on 2 June.

The meeting was opened by the President, Furio Honsell, Mayor of Udine, Italy and was followed by a reception at Groningen City Hall. Discussions focused on the necessity to obtain stable funding and on the development of a work programme for the first year.

Dianne Gove, AE’s Director for Projects and a member of the Covenant Board, attended the meeting.

For more information about the Covenant, please see: www.agefriendlyeurope.org

3 June: Progress of Accessibility Act presented at EPSCO council meeting

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) contains the obligation to increase the accessibility of goods and services. As most EU Member States have already ratified the Convention, they need to undertake action to implement it.

It was against this background that, in December 2015, the Commission submitted its proposal for a European Accessibility Act (EAA), which includes uniform accessibility criteria for selected goods and services for which the Commission deems the risk of divergence to be highest. The criteria are also meant to provide guidance for the implementation of other Union acts that include the obligation or possibility to improve accessibility.

During the Dutch EU Presidency, the Working Party on Social Questions met eight times to discuss the proposal and the Commission’s Impact Assessment.

The proposal has been welcomed by many delegations but they have also raised a number of questions concerning the scope, definitions and implementation.

Included amongst the questions that need to be further discussed is: Definitions of persons covered: Should it include people with functional limitations and elderly persons as separate categories? This could also include people with dementia.

At the EPSCO council meeting on 16 and 17 June President Jan Van der Velden of the Dutch Presidency of the European Council presented the progress made so far, taking note of a progress report on the proposal for a European accessibility Act, submitted by the Commission at the end of 2015.

The report reflects the discussions in the relevant working party of the Council which clarified a large number of issues and undertook a thorough examination of the
Commission’s impact assessment. Particular attention was paid to the legal basis, to the scope of the proposal and to which products, services and sectors should be covered.

On 28 June, the Accessibility Act will be discussed at the Alzheimer Europe Lunch Debate in the European Parliament.

Progress report:
?&typ=ENTRY&i=ADV&DOC_ID=ST-9627-2016-INIT

PDF of council conclusions (page 7):

6 June: Motion for a European Parliament resolution on the importance of a proper diet for the prevention of Alzheimer’s

| The European Parliament, |
| --having regard to Rule 133 of its Rules of Procedure, |
| A. whereas, despite the prevention campaigns that have already been launched, Alzheimer’s remains a disease that affects many European citizens in the Member States; |
| B. whereas some studies on this topic have shown that eating a fish-based meal that contains omega-3 at least twice a week prevents loss of memory and other related ailments; |
| C. whereas a healthy lifestyle and a healthy diet, accompanied by the consumption of fish and shellfish, would dramatically reduce the percentage of cases of Alzheimer’s disease; |
| 1. Calls on the Commission to consider that Alzheimer’s is still a problem to be eradicated in the Member States; |
| 2. Calls on the Commission to raise awareness among European citizens of the importance of eating meals based on fish and shellfish in order to prevent memory loss and Alzheimer’s. |


15 June: Ten international JPND working groups recommended for funding

The EU Joint Programme – Neurodegenerative Disease Research (JPND) has released the results of a "rapid-action" call to support working groups of leading scientists in bringing forward novel approaches to enhance the use of brain imaging for neurodegenerative disease research.

Ten working groups have been recommended for funding to address the methodological challenges facing different imaging modalities, among them MRI, PET, ultrasound, MEG and EEG, as well as multimodal approaches. The working groups cover a range of neurodegenerative diseases, including Alzheimer’s disease, Parkinson’s disease, Frontotemporal dementia and Huntington’s disease.

Each working group is expected to run for a maximum of 9 months. The outputs of the working groups are to be produced by the end of the funding period, and will be published on the JPND website and used for further JPND actions. In addition, a joint workshop will be organised to bring together and present the recommendations of each working group, encouraging the further exchange of ideas and wider dissemination to different stakeholder groups.


16 June: Commission hosts event on Fighting Elder Abuse in Health and Long Term Care

For the occasion of World Elder Abuse Day the European Commission with the support of the Council of Europe, Age
Platform Europe and ENNHRI co-hosted an event - Fighting elder abuse in health and long term care. The conference raised awareness of how inequalities, stereotypes and the lack of a rights-based approach can increase maltreatment in these sectors.

Speakers included representatives from the Commission, the Council of Europe, UNECE and Peter Mittler of Dementia Alliance International, who presented the experience of abuse by people living with dementia - A human rights perspective.

AE Vice Chair Iva Holmerová presented - Providing the right skills for health care professionals in her capacity as a geriatrician on behalf of European Union Geriatric Medicine society (EUGMS).

AE was also represented by Policy Officer Vanessa Challinor at this meeting.

17 June: Vytenis Andriukaitis, announces the State of Health in the EU initiative for 2016-17

At the EPSCO Council meeting on 17 June, Health Commissioner Vytenis Andriukaitis announced the State of Health in the EU initiative for 2016-17.

With the State of Health in the EU, the Commission will bring together internationally recognised expertise and will make every effort to provide Member States with the evidence relevant to their specific context, without judging on their comparative performance.

Announcing the State of Health in the EU at the Health Council, Commissioner Andriukaitis said: "I am pleased to announce a new effort the Commission is undertaking to bring together a wide array of country-specific and EU-wide knowledge on health in a concise, digestible and coherent package. This effort, called the "State of Health in the EU", is a two-year exercise in cooperation with the OECD, the European Observatory on Health Systems and Policies, and Member States. The aim is to boost analytical capacity and support Member States with their evidence-based policy making."

http://ec.europa.eu/dgs/health_food/health_safety/lyna/enews/enews.cfm?id=1696

22 June: EPF presents two new policy instruments emerging from its Patient Empowerment campaign

The European Patients’ Forum (EPF) organised a policy roundtable to close the Patient Empowerment campaign launched in May 2015. After a year promoting the concept among policy-makers and health stakeholders, EPF gathered around 70 participants to share the results of the campaign and discuss further steps on how to take patient empowerment to the next level.

The event took place on 22 June, at the European Parliament in Brussels, and was co-hosted by MEPs: Karin Kadenbach (S&D, Austria), Andrey Kovatchev (EPP, Bulgaria) and Roberta Metsola (EPP, Malta). Under the title “Making Empowerment a Reality: Patients as Partners”, the policy roundtable resulted in a very productive discussion where health professionals, policy makers and patients agreed on the need to empower patients to build a better and more sustainable healthcare system.

The event was the perfect opportunity to officially present the two campaign policy instruments created by EPF: the Charter on Patient Empowerment and the Roadmap for Actions. The Charter defines the fundamental principles of patient empowerment from the patients’ perspective, and the Roadmap turns these principles into 8 priority action areas that need to be taken at different levels in order to apply the principles in policy and practice. In this regard, EPF will use both tools to continue advocating for patient empowerment and to ensure the right follow-up of the topic after the summer.

The roundtable was therefore a great point of discussion where panelists and participants debated different approaches of empowerment - such as access to quality healthcare for all, health literacy and patient education – and shared their perspectives from their different backgrounds.

Finally, Nicola Bedlington, EPF Secretary General, closed the session by concluding that “we need a joint strategy on Patient Empowerment, led by the EU Commission, which involves stakeholders and Members States."

A full report and pictures of the event will soon be made available on EPF’s website.

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Members’ news

24 May: Alzheimer Uniti receives prize in recognition of its work as a voluntary association in Rome

At a prize giving ceremony called “Eccellenze in Sanita’” (Excellence in Healthcare) at the MAXXI Museum in Rome, Alzheimer Uniti received a prize for its work as a voluntary organisation in the field of social and health care in Rome. The prize was awarded by Fondazione San Camillo-Forlanini and was received by Luisa Bartorelli, President of Alzheimer Uniti on behalf of the association.

Besides its regular office in Rome, Alzheimer Uniti has also recently opened a new office in a setting within the San Camillo Hospital in Rome, which is to be a place where people can drop by to get information about the disease. The new office wants to collaborate with the hospital staff in welcoming people with Alzheimer’s dementia, including those who come to Accident and Emergency and those who might be admitted to the hospital itself.
24 May: 160 plus – an innovative programme for integrated dementia care at home is introduced in Athens

A member of the Panhellenic Federation in Greece, Nestor Psychogeriatric Association, has launched a new programme called “160 Plus”, to provide integrated and specialised care at home for 160 people with Alzheimer’s dementia and their caregivers. The programme is supported through an exclusive grant from the Stavros Niarchos Foundation (SNF) as part of its “2nd initiative against the Greek crisis”.

It is a pioneering programme, introducing the role of the Case Manager (CM) for each benefitting family. The CM is responsible for organising integrated care at home for the person with dementia and his/her caregiver and throughout the two-year programme will be a point of reference for each family, according to the needs of the family.

The following will be offered:

- Psycho-education on Alzheimer’s and other dementias.
- Consultation on managing behavioural and psychiatric symptoms of dementia.
- Home ergonomic assessment and possible interventions.
- Information on and settlement of insurance and legal issues.
- Medical follow up by a specialised psychiatrist.
- Programme of psychotherapeutical treatment to confront the psychological impact of caring.
- Food aid.
- Cleaning assistance, including the home, laundry and bathing.

The programme has a multidisciplinary team consisting of psychologists, a social worker, an occupational therapist, a psychiatrist and domestic helpers. Volunteers will also assist with services rendered.

The SNF grant will support 160 families of older people who take care of people with dementia and live in the city of Athens. It is estimated that the number of older people benefitting will reach 480.

25 May: Mediterranean Alzheimer Alliance holds successful 7th workshop

During its 10th Pittsburgh-Barcelona Conference, held from 25 to 28 May, Fundació ACE gave the Mediterranean Alzheimer Alliance (MAA) the opportunity to meet for a 7th workshop, this year in Barcelona. The MAA is growing and now consists of 40 members representing 17 countries in the Mediterranean region: Alzheimer’s associations, scientific experts and healthcare professionals combined.

This workshop was an opportunity for members to present an overview of the current situations and political breakthroughs in their countries, regarding the care and support of people with dementia and their carers. To help inspire other Mediterranean countries, Fundació ACE presented its ongoing projects on robotics and social media.

For the first time, Delphine Borione, Deputy Secretary General for Social and Civil Affairs at the Union for the Mediterranean (UfM) attended the workshop and officially confirmed that UfM would support MAA initiatives.

Prof. Bruno Vellas presented the results of the Multidomain Alzheimer Preventive Trial (MAPT) study, regarding prevention. One of the concrete actions regarding prevention that will be completed in the region is the distribution of a short video to raise public awareness on dementia and its prevention.

MAA members also approved the final version of the “Alzheimer and the Mediterranean report”, to be published in September for World Alzheimer’s Day. The report aims to assess needs related to dementia and to analyse the emerging medical and social challenges in the region. It also makes recommendations on regional and international levels, to anticipate solutions and provide better support and care for people with dementia.

The workshop was also an opportunity for the scientific committee to work on the implementation of relevant research programmes and for a second working group to decide on projects regarding professional training and public awareness.

27 May: Alzheimer Society of Ireland CEO nominated to Irish Senate

The Alzheimer Society of Ireland (ASI) is delighted to announce the nomination of its CEO, Colette Kelleher by An Taoiseach (Prime Minister Enda Kenny), to Seanad Éireann (the Irish Senate).

“Colette has tirelessly worked in the NGO sector and championed the rights of the disenfranchised, the disadvantaged and those without a voice for the majority of her working life” writes ASI.

Ms Kelleher was previously CEO of Cope Foundation (supporting people with intellectual disabilities) in Cork, Ireland and was also Director of the Cork Simon Community (helping fight homelessness) for eight years.

Originally from Macroom - a market town and civil parish in the barony of Muskerry West, County Cork - Ms Kelleher trained in social science at University College Cork, before becoming a social worker in Dublin. She also holds an MBA, and worked in the UK Department of Education for a number of years.

She will use this role to give a voice to people who are not always directly heard in the political process, and use the position to advance their rights, wellbeing and the supports they need to participate as full citizens of Ireland.
3 June: Romanian Alzheimer Society hosts event “Alzheimer – before and after diagnosis”

On 3 June, the Romanian Alzheimer Society hosted an event: “Alzheimer – before and after diagnosis” - a full day of activities, held during the “Senior Expo Fair” - the first Romanian fair for seniors.

Workshops such as: Thinking Home Dementia Friendly, Contemporary Design, Cognitive Screening and Cognitive Stimulation, Patient Pathway - from the first signs of illness to diagnosis, How to Prevent Falls and The Importance of Physical Exercise attracted more than 100 participants (carers, families, persons with dementia).

The event aimed to raise awareness about dementia, to help create a dementia-friendly community and to empower people with dementia and their carers.

Partners involved in the event were:
- Mihai Zamfir - “Carol Davila” University of Medicine and Pharmacy.
- Roxeta Draghi - National Institute of Gerontology and Geriatrics “Ana Aslan”.
- Paula Onu, Ioana Vartan, Alexandra Avadanei, Andreea Marin - RoPsiho Clinic.
- Manuela Balan - ICEMED.
- Maria Moglan - Bucharest University, Faculty of Psychology and Educational Sciences.

5 June: Alzheimer Scotland hosts global dementia conference in Edinburgh

Alzheimer Scotland staged its 2016 flagship annual conference during Scotland’s Dementia Awareness Week, which ran from 30 May to 5 June. The event took place on the final day, Friday 5 June, at the award-winning Edinburgh International Conference Centre (EICC) and the ambitious line-up brought together dementia experts from Scotland, the rest of the UK and across the world to explore the theme: “Global to local: research, practice, innovation.”

Attracting almost 600 delegates, the annual conference attracted leading dementia speakers from The US, China, Australia, and from across Europe to gather, discuss and debate the latest dementia advances and findings. Highly anticipated guest speakers included: Kate Swaffer from Alzheimer Australia, Professor Huai Wang from Peking University and Dr G. Allen Power from the University of Rochester, US. Highly respected speakers and professionals from Scotland were also given the stage to present their latest findings including Professor Craig Ritchie and Dr Louise Ritchie.

Playing a major focal point during the annual awareness week calendar, the conference offers the opportunity to put the spotlight firmly on challenging dementia to support ongoing campaigning and fundraising and supporting the mission to ensure that nobody lives with dementia alone.

Alzheimer Scotland Chief Executive Henry Simmons (pictured, front row, holding left of sign) commented: “Our Dementia Awareness Week conference is a true showcase of collaboration amongst organisations and colleagues with an interest in dementia. From global developments to local projects, it is wonderful to see so many people engaging in meaningful conversations to raise awareness, better practice and to help us make sure that nobody faces dementia alone.”

Designed for people living with a dementia diagnosis, their carers and families, through to health and care professionals, researchers, care home staff and students, the conference is open to everyone interested in or affected by dementia. By bringing speakers together from across the globe in one venue, this brings the opportunity for all to hear from key global experts and is also an opportunity to network, to discuss challenges and to share best practice with international colleagues and investigate what these progresses mean for those living with dementia in Scotland.

The programme included a series of plenary presentations, a panel debate, along with a selection of dynamic parallel sessions and a wide range of exhibitors and interactive ‘soap-box' presentations from innovation groups developing non pharmacological therapeutic interventions.

http://daw.dementiascotland.org/

14 June: Birgitta Martensson becomes Honorary Member of Alzheimer Suisse

On the proposal of the Central Committee, the Assembly of Delegates awarded Birgitta Martensson the title of Honorary Member of Alzheimer Suisse.

The title was granted with the intention of honouring Ms Martensson’s dedicated, dynamic and fruitful efforts and her unwavering support for people with dementia and their relatives, during her time as Director of the association, from 1 December 2001 to 31 December 2015.

The association attributes much of the credit for the fact that Switzerland has a national dementia strategy in place since 2014 to Ms Martensson.

15 June: First Alzheimer workshop takes place in eastern Croatia

Funded by the project of the Croatian Ministry of Health "Education of families and caregivers through counselling, workshops and self-help groups" the first workshop in the series "Alzheimer’s Disease - how to live with it" was organised by Alzheimer Croatia and held in the city of Vukovar, eastern Croatia, on 15 June.

The workshop, prepared in collaboration with the Centre for Social Welfare and Health Centre Vukovar, gathered numerous medical practitioners, social workers, caregivers, family members and citizens. They stressed that dementia in the Vukovar region is expressed in a special
way because the older population is still traumatised by the consequences of large-scale destruction of this old Baroque city during the Croatian War of Independence.

The second workshop is planned in September, when the first Alzheimer Café in Vukovar will also take place.

15 June: Nordic Conference held in Finland

The Alzheimer Society of Finland gathered Swedish-speaking sister organisations, memory associations and professionals from Finland and the Nordic countries at a Nordic Conference in Vaasa in early June.

The inspiring and heart-warming two-day conference included networking and lectures about memory diseases and brain health, as well as an excellent 15-course dinner.

16 June: First book written in Croatian about Alzheimer’s dementia from the carers’ perspective

The first book to be written in Croatian about Alzheimer’s dementia from the perspective of carers was launched on 16 June, in the Croatian Medical Chamber in Zagreb and it was a great success. More than 120 people from a variety of professions were present.

Ljiljana Kerepčić Ratkaj, who was her late husband Ivan Kerepčić’s carer, wrote her life story. Dr Kerepčić was a neuropsychiatrist and the Director of a large Psychiatric Hospital in Popovača, near Zagreb.

While writing about their life, Mrs Kerepčić Ratkaj also explains the first symptoms of Alzheimer’s dementia, of which she was not previously aware. When she wrote her story, she was an active member of Alzheimer Croatia and so decided to expand the scope of her writing and started to collect stories from other families. In the end she was in possession of 20 stories, among them two from friends in Slovenia.

Although all the stories share similarities, as they all talk about life before and after Alzheimer’s, they are also very much different and unique, sharing with the reader all the joy, fear and frustration, the good and the bad days. After each story, the author sums up, comments and imparts advice to readers, who may wonder why people with dementia behave in a particular manner.

The book itself is interesting and is an easy read, and there are also many beautiful illustrations done by the author, who is also a successful artist. The publication also includes some poems dedicated to her beloved late husband.

At the end of this special book, there is an addendum with some professional articles about Alzheimer’s disease and dementia, giving the current state of affairs in the field, in terms of epidemiology, diagnosis and treatment. The preface and afterword were written by Prof. Ninoslav Mimica, President of Alzheimer Croatia and the book is recommended by the Croatian Alzheimer Alliance.

Details of the book:


16 June: Dutch documentary “Uitgetekend” now available with English subtitles

Alzheimer Nederland has informed us that the 2014 Dutch documentary “Uitgetekend” (Drawing is over) is now available with English subtitles.

The documentary follows artist Antoon Goes, over the course of four years. The viewer gets to know him as a person with early dementia in a home for the elderly, and follows him all the way to the nursing home. The film is an honest and movingly clear picture of what dementia can do to a man over the course of time, and shows the far-reaching and emotional consequences for the family.

You can view the film for free at www.antoongoes.nl

18 June: Portugal organises first national meeting of carers of people with dementia

On 18 June, in Lisbon, Portugal’s first national meeting of carers of people with dementia took place. The meeting was organised by the Parliamentary group GUE/NGL’s “Bloco de Esquerda”, represented by MEP Marisa Matias, Vice-Chair of the European Alzheimer’s Alliance.

Alzheimer Portugal was a partner in this initiative, and its Vice-Chairperson, Leonor Guimarães had the opportunity to share the association’s work, its strategy and priorities. Ms Guimarães highlighted the urgent need to put in place a National Dementia Strategy for Portugal, to the 200 or so participants - mainly family carers from throughout the country.

Feedback from participants showed that huge iniquities exist with regards to care and support for people with dementia and their family carers. These are due to: the economic capacity of each family; differences in awareness and knowledge of healthcare professionals within hospitals and other healthcare units; nursing homes and other facilities with varying levels of quality and prices.

Some of the most important conclusions of the meeting were: the severe lack of services for people with early onset dementia; families are the main support for people with dementia in Portugal, but their important role is completely ignored by political decision-makers; among the 183,000 people living with dementia, there are also many living alone without support; stigma remains a widespread reality, though according to testimonies from carers who regularly attend Memory Cafés, these events are important tools to help fight stigma and to promote social inclusion. Unfortunately, despite invitations from Ms Matias, no other policy makers attended the event.

“This is a significant signal that we still have a long way to go and plenty of hard work to do, before dementia will be recognised as a national challenge, regardless of the
political colour of the “decision maker” said Alzheimer Portugal.

The association remains nonetheless hopeful, that this meeting could be a significant milestone for the national dementia movement in Portugal.

Alzheimer Portugal is very grateful to Ms Matias and her party for having organised such an important meeting.

21 June: WHO Health publication uses Athens Alzheimer’s association as an example of good practices

In June, the World Health Organisation - European Region released a new publication, “Lessons from transforming health services delivery: compendium of initiatives in the WHO European Region”. The publication gives examples of health services delivery transformations from each Member State and the Athens Association of Alzheimer’s Disease and Related Disorders (AAADRD) is used as the example for people affected by dementia in Greece.

Key points analysed are the chronological milestones for the growth of AAADRD and the constructive collaboration between the association and the Government and municipalities. The important role played by AAADRD in the development of the recently approved National Action Plan for Dementia in Greece is also mentioned.

The publication can be downloaded here: http://www.euro.who.int/__data/assets/pdf_file/0004/303026/Compendium-of-initiatives-in-the-WHO-European-Region-rev1.pdf?ua=1

23 June: Norway forms new tripartisan parliamentarian group

The Norwegian Health Association, together with and on the initiative of some Members of Parliament (MPs), has formed a new tripartisan parliamentarian group at Stortinget (the Norwegian Parliament). The working group is headed by three MPs: one from the Conservative Party (Høyre) one from the Labour Party (Arbeiderpartiet) and one from the Christian Democrats (Kristelig Folkeparti). All three are also members of the standing committee for Health.

The group holds two meetings every session, open for all MPs, local and regional politicians and people from different organisations and NGOs working in the field of dementia research and care. The working group is especially involved in sharing best practices, and wants to inspire local politicians and planners regarding good care and innovation. They also want to focus on the importance of research, both nationally and internationally.

This parliamentarian group is special because it is tripartisan. In Norwegian politics is it rare that politicians from different parties work together to solve issues and create new policies. Cooperation with NGOs in an ongoing and structured manner is also rare.

The Norwegian Health Association is proud to facilitate the working group, and finds it both interesting and beneficial to cooperate on a long-term basis with MPs on matters around improving care, innovation and research in the field of dementia.

24 June: Cyprus Alzheimer Association organises seminar for professional nurses

The Cyprus Alzheimer Association (CAA), in co-operation with the Technological University of Cyprus (TUC) and the Cyprus Nurses and Midwives Association organised one day seminar, in the Paphos District, aiming to educate professional nurses about the care of people living with dementia. The seminar was held under the auspices of the Mayor of Paphos.

The presenters were mainly doctors and lecturers from TUC.

Given the success of the event, it has been decided to offer the same seminar to all Cyprus districts.

Special thanks go to Dr Evridiki Papastavrou, Assistant Professor, TUC for her valuable contribution, both in helping organise the seminar and in presenting her research.

24 June: Series of workshops on dementia care organised in Cyprus

The Cyprus Alzheimer Association (CAA), in co-operation with the Technological University of Cyprus (TUC) organised a series of lectures, titled “The care of people living with dementia”, with the aim of informing and educating their carers.

A total of 12 seminars took place between February and June 2016, in TUC’s Nursing Department, in the Limassol district, with great success.

The seminars were open to the public and were attended mostly by informal carers and care professionals. Presenters were mainly doctors and lecturers from TUC.

Special thanks goes to Dr Evridiki Papastavrou, Assistant Professor, TUC for her valuable contribution, both in organising the seminar and in presenting her researched.

Policy watch

26 May: WHO adopts global strategy and action plan on ageing and health 2016–2020

During the 69th World Health Assembly (WHA69) held from 23 to 26 May 2016, the World Health Organization (WHO) adopted its Global Strategy and Action Plan on Ageing and Health 2016–2020.

Overview of Adopted Strategy and Action Plan on Ageing and Health 2016-2020:
Vision
A world in which everyone can live a long and healthy life.

Strategic objectives
1. Commitment to action on Healthy Ageing in every country.
2. Developing age-friendly environments.
3. Aligning health systems to the needs of older populations.
4. Developing sustainable and equitable systems for providing long-term care (home, communities and institutions).
5. Improving measurement, monitoring and research on Healthy Ageing.

Goals
1. Five years of evidence-based action to maximise functional ability that reaches every person.
2. By 2020, establish evidence and partnerships necessary to support a Decade of Healthy Ageing from 2020 to 2030.

Read more on the Global Strategy here: http://www.who.int/ageing/global-strategy/en/

7 June: France Alzheimer campaigns to ensure Alzheimer medications continue to be reimbursed

France’s health authority, the Haute Autorité de Santé (HAS), is currently reviewing the effectiveness of four anti-Alzheimer’s disease (AD) drugs currently on the market, namely galantamine, memantine, rivastigmine and donepezil. The drugs are being considered for removal from the list of reimbursed medications.

France Alzheimer is totally opposed to this possible “delisting” of all existing AD drugs, as it believes such a decision would be both inappropriate and dangerous. Previously, reimbursement for the four drugs had been at 65% but this was reduced to a meagre 15%, following a decision by the HAS in 2011. On the effectiveness of current treatments, France Alzheimer believes that, even if their impact on cognitive impairment is somewhat limited, these drugs can improve behavioural disorders in some people with dementia.

France Alzheimer also emphasises that the total “delisting” of Alzheimer drugs would have a limited economic impact on the Social Security budget, given that all four molecules are all generic as of 2016.

The decision will be made by the HAS in the coming days.

http://www.actucaite.net/maladies/quatre-medicaments-anti-alzheimer-devraient-etre-dernemourress-5629 ...

9 June: US Alzheimer’s research funding increased by USD 400 million

On 9 June, the US Senate Appropriations Committee approved a USD 400 million (EUR 360 million) increase in Alzheimer’s disease (AD) research funding at the National Institutes of Health (NIH) and included the Health Outcomes, Planning, and Education (HOPE) for Alzheimer’s Act (S. 857) in its funding bill. The US Alzheimer’s Association is delighted with this decision.

If signed into law, the HOPE for Alzheimer’s Act will ensure newly diagnosed Medicare beneficiaries receive comprehensive care planning services. The US Alzheimer’s Association grassroots advocates and staff have held thousands of congressional meetings to secure support for the HOPE for Alzheimer’s Act since the bill’s introduction, and have worked tirelessly to secure support for increased funding for NIH research.

http://www.alz.org/news_and_events/alzheimers_association_celebrates_ex traneous_week.asp

14 June: Focus group held in Vienna to advise development of new Swedish Dementia Strategy

The European Centre for Social Welfare Policy & Research held a focus group on 14 June in Austria with the aim of bringing together experts in the field of dementia care. The meeting, which was commissioned by the Swedish Ministry of Health and Social Affairs and chaired by Kai Leichsenring, was part of a measure to inform the development of a new Swedish Dementia Strategy.

Alzheimer Europe Director for Projects Dianne gove attended the meeting. The other participants were from Germany, Austria, Switzerland and the UK. The group addressed a range of issues related to the provision of community care such as whether there is a point at which community care becomes untenable, at what point advanced care planning should be initiated and how to benchmark progress, to name but a few.

23 June: EPAD and EMIF partners voice concern for future of dementia research, UK votes to leave the EU

In the run up to the UK’s historic “EU Referendum" of 23 June, in which voters have decided not to continue as a Member State of the European Union (EU), partners from two of the most important research programmes in the dementia field - the European Prevention of Alzheimer’s Dementia (EPAD) initiative and the European Medical Information Framework (EMIF) - published an article in the journal Lancet Psychiatry, titled “Better together for better dementia research and care”.

They argued that the EU has made dementia research a priority and has made substantial funds available for research that is driving faster, more effective clinical trials, which they said is the best hope of finding a disease-modifying therapy.

Both EMIF and EPAD are funded through the Innovative Medicines Initiative (IMI), a funding stream including both EU funding and matching funds from pharmaceutical
industries. Both projects are led by UK partners and bring over EUR 17 million in direct funding to the UK.

Through the four IMI programmes that are focused on dementia, 24 UK institutions receive funding. In addition to IMI, dementia funding across Europe receives strong support from schemes such as the Centres of Excellence Network and the Joint Programme – Neurodegenerative Disease Research (JPND). These collaborative programmes, which bring UK researchers together with some of the best scientists from across Europe, bring substantial funding to the UK and leverage funds from industry.

This research is also dependent on the free movement of scientists across Europe point out the authors. Collaboration between UK and EU scientists “brings knowledge, skills, and a vibrancy and energy to our work that would be missing were we not to be part of the EU”.

“Through our collaboration in Europe we have learnt from clinical service developments, refined tests and diagnostics, and through working closely with pan-European patient organisations...we are able to speak with a clearer, louder, and more consistent voice” they concluded.

Authors include Alzheimer Europe’s Executive Director Jean Georges.

http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(16)30090-6/abstract

Science – behind the headlines

27 June: “Protein injection hope for Alzheimer’s” - NHS Choices comments

Following recent media headlines claiming “Alzheimer’s symptoms could be reversed by restoring protein in brain” we looked to the NHS Choices website for a grounded “behind the headlines” commentary:

Where did the story come from?

The study was carried out by researchers from a number of institutions, including the Hong Kong University of Science and Technology and the University of Glasgow.

Funding was provided by the Research Grants Council of Hong Kong SAR, the National Key Basic Research Program of China, a Hong Kong Research Grants Council Theme-based Research Scheme, and the SH Ho Foundation.

The study was published in the peer-reviewed journal, Proceedings of the National Academy of Sciences of the United States of America (PNAS) on an open access basis, so you can read it for free online.

This has been reported widely and accurately by the UK media, with a clear message that this is early research in mice and therefore caution should be taken – though many of the headline writers failed to pick up on this message.

Many of the reports include the somewhat world-weary, yet realistic, quote from lead author Professor Eddy Liew, who said: “Exciting as it is, there is some distance between laboratory findings and clinical applications. "There have been enough false ‘breakthroughs’ in the medical field to caution us not to hold our breath until rigorous clinical trials have been done."

What kind of research was this?

This is an experimental study in an animal model of Alzheimer’s disease that aimed to investigate whether injecting the interleukin 33 (IL-33) protein into mice leads to improved dementia symptoms.

IL-33 is a cell signalling protein, and previous studies have shown that levels of a receptor to "catch" IL-33 are increased in people with mild cognitive impairment (pre-dementia).

As the name suggests, cell signalling proteins play an important role in transmitting "messages", or instructions, between cells.
This suggests that impaired IL-33 signalling could contribute to the development of the disease changes seen in Alzheimer’s, such as the build-up of beta-amyloid protein plaques.

The researchers therefore speculated there may be a role for IL-33 treatment to stop the changes of Alzheimer’s.

Animal studies like this are required to provide a path for further research in humans, but the findings are not directly applicable to people.

What were the basic results?

IL-33 was found to reach the brain within 30 minutes of injection and did not affect the general health of the mice.

The IL-33 group were found to have improved memory and cognitive function compared with the control group for learning, memory, response to stimulus and retrieval abilities. There was also a reduction in protein levels and the accumulation of amyloid plaques.


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**Science watch**

**23 May: Loss of Y chromosome is a risk factor for AD, study finds**

Researchers reporting on 23 May in the American Journal of Human Genetics found that men with blood samples showing loss of chromosome Y developed Alzheimer’s disease (AD) as often as people born with genes that put them at the most risk for the disease. Their work was presented at the annual conference of the European Society of Human Genetics, held this year in Barcelona from 21 to 24 May.

"Most genetic research today is focused on inherited gene variants -- mutations that are inherited by the offspring, but what we're looking at are postzygotic mutations that are acquired during life," says senior author Lars Forsberg, a researcher in the Department of Immunology, Genetics, and Pathology at Uppsala University in Sweden.

One such postzygotic mutation found in the cells of biological males is the loss of the Y chromosome in a degree of blood cells. Loss of Y (LOY) occurs in up to 17% of men and is more likely to be found in older men and men who smoke. This study expands on the idea that LOY, already known risk factor for cancer, could be a predictive biomarker for a wider range of poor health outcomes, specifically AD.

Why LOY can be linked to an increased risk for disease remains unclear, but the authors speculate it has to do with reduced immune system performance.

The researchers looked at over 3,000 men to ascertain whether there was any predictive association between LOY in blood cells and AD. Participants came from three long-term studies that could provide regular blood samples. Across the datasets, those with the highest fraction of blood cells without a Y chromosome were consistently more likely to be diagnosed with AD.

Dr Forsberg and colleagues will next investigate the effect of LOY in larger cohorts and explore in greater detail how it confers risk for specific types of cancers and disease. They also plan to look at the cellular changes caused by LOY and how it affects different types of blood cells.


**30 May: Experts call for patient care guidelines and effective therapies to combat AD**

On 30 May, during the Congress of the European Academy of Neurology (EAN Congress) held in Copenhagen, Professor Gunhild Waldemar, Director of the Danish Dementia Research Centre, issued an appeal for researchers to work together and draw up standardised guidelines for early identification, and treatment of Alzheimer’s disease (AD). She also rated the care currently provided for dementia as unsatisfactory and called for patient care guidelines.

"European science could play a leading role, providing that it adopts a concerted approach and sufficient funds are made available. While research is expensive, standing by helplessly is even more so," she commented.

To date, there is still no treatment that can halt or reverse the progress of the disease. "For this to happen we would need a better understanding of the neurodegenerative mechanisms," Prof. Waldemar explained.

A raft of studies presented at the EAN Congress show that people living with dementia are often treated with unsuitable or controversial medication, and that there is a tendency to overlook and undertreat comorbidities.


**31 May: Leaky blood-brain barrier linked to Alzheimer’s disease**

Researchers using contrast-enhanced MRI have identified leakages in the blood-brain barrier (BBB) of people with early Alzheimer’s disease (AD), according to a new study published online in the journal Radiology on 31 May, under the title “Blood-Brain Barrier Leakage in Patients with Early Alzheimer Disease”. The results suggest that increased BBB permeability may represent a key mechanism in the early stages of the disease.

The BBB, a collection of cells and subcellular structures in the cerebrovascular wall that separates the circulating blood from the brain, is essential to keep brain tissue in healthy condition. It regulates the delivery of important...
nutrients and blocks neurotoxins, while removing surplus substances from the brain.

For the study, researchers used contrast-enhanced MRI to compare 16 early AD patients with 17 healthy age-matched controls. They measured BBB leakage rates and generated a histogram to help determine the amount of the leaking brain tissue.

The BBB leakage rate was significantly higher in participants with AD compared with controls and the leakage was distributed throughout the cerebrum - the largest part of the brain. Those with AD had a significantly higher percentage of leaking brain tissue in the gray matter, including the cortex - the brain’s outer layer. The researchers also found that measurements derived from the histogram showed very subtle BBB impairment in white matter.

“Blood-brain barrier leakage means that the brain has lost its protective means, the stability of brain cells is disrupted and the environment in which nerve cells interact becomes ill-conditioned,” said study author Walter H. Backes, Ph.D., from the Maastricht University Medical Center in Maastricht, the Netherlands. "These mechanisms could eventually lead to dysfunction in the brain."

Indeed, the researchers found a relationship between the extent of BBB impairment and decline in cognitive performance, suggesting that a compromised BBB is part of the early pathology of AD and might be part of a cascade of events eventually leading to cognitive decline and dementia.

The connection between BBB impairment and AD pathology was strengthened by the fact that the addition of diabetes and other non-cerebral vascular diseases to the analysis model did not change the results.

https://www2.rsna.org/timssnet/media/pressreleases/14_pr_target.cfm?ID=1885

1 June: Investigational AD drug candidate BIIB037 accepted into EMA’s PRIME programme

**PRIME - PRIority MEDicines**

On 1 June, it was announced that an experimental Alzheimer’s disease (AD) treatment - BIIB037 or aducanumab - being developed by biotechnology firm Biogen was accepted into the European Medicines Agency’s (EMA) PRIority MEDicines (PRIME) programme. PRIME aims to bring treatments to patients faster by enhancing the EMA’s support for the development of investigational medicines for diseases without available treatment or in need of better treatment options.

Investigational treatments accepted into PRIME must demonstrate potential for a major therapeutic advantage in areas of unmet medical need. Aducanumab was accepted into PRIME based on results from its Phase 3b placebo-controlled study in patients with prodromal or mild AD.

Through the PRIME program Biogen will have access to enhanced support from EMA, including its advice at key development milestones and the potential for accelerated assessment of a marketing authorisation application (MAA).

Aducanumab is currently being evaluated in two global Phase 3 studies designed to evaluate its safety and efficacy in slowing cognitive impairment and the progression of disability in people with early AD.

http://goo.gl/uO4M3N

1 June: Toxic substance acrolein may play role in preventing fibrillation linked to AD

Scientists from RIKEN - Japan’s largest comprehensive research institution - have discovered that acrolein, a toxic substance produced in cells during times of oxidative stress, in fact may play a role in preventing the process of fibrillation - an abnormal clumping of peptides that has been associated with Alzheimer’s disease (AD). Their study was published on 1 June in the journal Advanced Science.

The key to this new role is a chemical process known as 4+4 cycloaddition, where two molecules with “backbones” made up of four-atom chains come together to form a ring-like structure with eight atoms. The group found that in some circumstances, acrolein can combine with a class of molecules called polyanymes, which themselves are important biological players, to make substances that can prevent the fibrillation of Aβ40 peptides.

As the team began the experiments, they were surprised to find that polyanymes such as spermine and spermidine seemed to prevent the peptides known as amyloid-beta from aggregating together - a process linked to the progression of AD.

The group tested the hypothesis by incubating Aβ40 peptides in mixtures of acrolein, spermine, and a cyclic compound formed by acrolein and polyanymes. Neither of the first two molecules alone had any effect on fibrillation, but the cyclic compounds turned out to be powerful inhibitors. The researchers also found that when acrolein and polyanymes were added together into a living cell, they combined naturally through 4+4 cycloaddition to create the diazacylooctane molecule. According to Katsunori Tanaka, who led the team, this is important for two main reasons. Firstly, it gives us insights into the mechanism through which polyanymes exert their action and secondly, given that acrolein and polyanymes combine naturally in cells to form these powerful anti-fibrillation substances, this study may open the way for the researchers to influence the progression of AD and other neurological disorders.

The research group used Aβ40, an amyloid peptide with 40 amino acids in the chain, but they also hope in the future to conduct experiments with Aβ42, which is more prone to fibrillation and is also believed to play a key role in AD.


8 June: Actinogen phase II AD drug trial is one step closer to FDA approval

Following feedback from the U S Food and Drug Administration (FDA), Actinogen Medical - a publicly listed clinical-stage biotechnology company aiming to treat
cognitive impairment in chronic neurodegenerative diseases by inhibiting cortisol production – told its investors in a note on 8 June that good progress had been made in securing final FDA regulatory approval under an Investigational New Drug (IND) for its Phase II trial.

Actingen will develop a revised protocol around the Phase II trial which will be harmonised across the US, UK and Australian research sites.

Participants are expected to be enrolled in the Phase II trial in the second half of this year.


9 June: Blood progranulin may not be suitable AD marker after all, researchers say

Recent hopeful statements that blood levels of progranulin could be a biomarker for Alzheimer’s disease (AD) and other causes of dementia seem to have been halted with the results of a recent study demonstrating there is no link between the blood and cerebrospinal fluid levels of the substance. This disrupts the idea of a progranulin blood test for dementia. The results are published in the journal Current Alzheimer Research under the title “Serum Levels of Progranulin Do Not Reflect Cerebrospinal Fluid Levels in Neurodegenerative Disease”.

While mutations in the progranulin gene, GRN, have been linked to hereditary forms of dementia, researchers agree that the factor also plays an important part in sporadic dementia cases where no mutations are present. Based on these findings, scientists had proposed that low levels of progranulin could serve as a biomarker for AD and other neurodegenerative conditions.

The substance, which is a growth factor with anti-inflammatory and neurotrophic properties, has also been suggested as a potential treatment for dementia. The new study, led by Carlo Wilke and Matthis Synofzik of the Hertie-Institute for Clinical Brain Research, the German Center for Neurodegenerative Diseases (DZNE) and the University of Tübingen in Germany, shows a more complicated picture of progranulin regulation than scientists had anticipated.

The team measured the molecule in blood and cerebrospinal fluid in patients with AD, frontotemporal dementia and amyotrophic lateral sclerosis (ALS), and found that the blood levels did not mirror the brain concentration of progranulin. Their results suggest that different mechanisms control levels of the factor in the brain and blood.


9 June: Avanir publishes full results from its PRISM II study

On 9 June, results from the Avanir Pharmaceuticals PRISM II study were published online in BMC Neurology. The study demonstrated significant improvement of pseudobulbar affect (PBA) following treatment with dextromethorphan hydrobromide/quinidine sulfate capsules in patients with Alzheimer’s disease (AD) and other causes of dementia, as well as stroke and traumatic brain injury (TBI).


9 June: Researchers develop early-stage AD blood test with “100% accuracy”

Researchers say they’ve developed a blood test that detects an early stage of Alzheimer’s disease (AD) with “unparalleled accuracy.” The test, developed by researchers at the Rowan University School of Osteopathic Medicine and Durin Technologies, Inc. - both based in New Jersey, US - was recently demonstrated in a proof of concept study involving more than 200 subjects and returned a 100 % rate of overall accuracy, sensitivity and specificity.

“The remaining 40 percent of cases are caused by other factors, including vascular issues, drug side-effects and depression. To provide proper care, physicians need to know which cases of AD are due to early Alzheimer’s and which are not.”

For the study, researchers analysed blood samples from 236 subjects, including 50 MCI patients with low levels of amyloid beta 42 peptide in their cerebrospinal fluid, which is an indicator of ongoing AD pathology in the brain. They then identified the top 50 autoantibody biomarkers capable of detecting early-stage AD pathology in MCI patients by using human protein microarrays, which contain human proteins that are used as bait to attract blood-borne autoantibodies.

According to the Rowan University news release, the 50 biomarkers were 100% accurate in distinguishing patients with MCI due to AD, in multiple tests. Results were published in Alzheimer’s & Dementia: Diagnosis Assessment & Disease Monitoring, where researchers also reported the test’s ability to distinguish early-stage AD from more advanced stages. They also noted the test’s capability to distinguish AD at the MCI stage from other diseases such as Parkinson’s disease, multiple sclerosis and early stage breast cancer.

The researchers noted the MCI biomarker test will have to be replicated in a larger study to determine whether it can be used in a patient setting. If successful, researchers predict the test could possibly help people delay disease progression through lifestyle changes and earlier treatment.


Dementia in society

11 May: Flemish project takes people with young onset dementia to Nepal

On 11 May, the Flemish Expertise Center on Dementia (expertisecentrum dementie Vlaanderen) reported on the project “New Energy for Young Dementia”, which organised a recent expedition to Nepal, with and for people with young-onset dementia. The project, which aimed to
raise awareness of young-onset dementia, received a lot of media attention in Belgium and an account of it has been published in the journal The Lancet Neurology. For a free version of the article in PDF format please contact olivier.constant@dementie.be

The project has also resulted in a documentary film, to be released in September, for World Alzheimer’s Day. It will later be made available for international screenings, with an English translation.

The expedition took place in the Himalayas from 23 October to 5 November 2015, mainly in a scenic area of Nepal where, together with caregivers and healthcare professionals, people with young-onset dementia pushed their limits for 10 days.

“We wanted to stress the global need for further policy work concerning young-onset dementia, hand in hand with the people and their families. Therefore we went ‘back to basics’. The ultimate goal: to get the challenges they face into the picture and to give the people a voice”, writes Olivier Constant, Communication Officer at the Center.

2 June: BBC broadcasts “Panorama - Living with Dementia: Chris’s Story”

BBC documentary, “Panorama - Living with Dementia: Chris’s Story”, which aired on 2 June, follows former businessman Chris Roberts, a fifty-five-year-old from Rhuddlan, Denbighshire, North Wales and his wife Jayne and daughter Kate during an 18 month period. The Roberts family recorded itself using video diaries and CCTV, to show how it has come to terms with Mr Roberts’ Alzheimer’s diagnosis.

Mr Roberts, who has been living with dementia for five years, since the age of 50, chronicles his changing life, from choosing his own care home to writing a living will.

He has had to give up some of the things he loved, due to developing motor and speech problems: biking, driving and reading have become impossible. He is shown getting lost in his own house (”Where’s upstairs?”), and is at times unable to recognise his own children.

“The person I miss most is me,” he confesses. At parties, he feels “on his own in a crowded room”.

In conclusion, however, he remains optimistic about his plight and that of others in a similar position:

“I hope this programme helps people and doesn’t scare them. You’ve seen that I still have a life, just a different quality one. Don’t be scared. Live life. Take it by the danglies and run with it.”


Like us on Facebook

Living with dementia

Nina Balackova writes about “The Potato Soup”

Nina Balackova, a member of our European Working Group of People with Dementia (EWGPWD), sent us a story this month called “The Potato Soup” for our “Living with Dementia” section - or should that be “cooking with dementia”?

The potato soup

Given my lack of taste, smell, poor estimate of time, distance and quantity, for me cooking is a matter of becoming more adventurous. And I did not mention even forgetfulness.

One autumn day a few years ago, I decided to cook potato soup. I prepared, scraped and cut up vegetables, I prepared a nice dark roux. I also had plenty of mushrooms, thanks to my daughter. I felt there might be something missing. But what? I added a hint of garlic, marjoram.

That day my friend Eva came to visit. The soup seemed to look pretty good and was nice and thick, so when Eva arrived I immediately gave her a taste to check whether it needed more garlic, salt, or marjoram. Eva, my husband and I then had dinner together and when my husband had almost finished, he innocently remarked that he couldn’t taste much of the potato in the soup. I thought long and hard, then burst out laughing: “Well, you couldn’t taste it, because I forgot to put potatoes in”. We laughed about it for a long time afterwards. Potato soup without potatoes...

Nina Balackova, EWGPWD member, Czech Republic

Education

8 June: Trinity College Dublin offers free online course on “Strategies for Successful Ageing”

Trinity College Dublin (TCD) is offering a free, five-week, online course on “Strategies for Successful Ageing”.

The main aims of the course are to:

• improve happiness and wellbeing, by defining what quality of life means to each individual;
• place a spotlight on health and presents tips for increasing physical fitness, improving nutrition, and maintaining brain health through the years;
• celebrate opportunities for staying connected by investigating the expectations set by each individual and by sharing personal strategies for staying involved;
• Look at ideas around creative ageing, exploring the talent, contributions and accomplishments of older adults.
This course is relevant for adults who wish to acquire strategies for successful ageing. No previous experience or qualifications are required.

The course is open for free registrations, and begins on 26 September 2016.

https://www.futurelearn.com/courses/successful-ageing

### Job opportunities

**9 June: Inclusion Europe is looking for a new Executive Director**

Inclusion Europe is an association fighting for equal rights and full inclusion of people with intellectual disabilities and their families in all aspects of life.

The association is currently seeking an Executive Director to help “make this the last generation of Europeans with intellectual disabilities to face exclusion and discrimination.”

More information about the position here: [http://inclusion-europe.eu/?p=1632](http://inclusion-europe.eu/?p=1632)

To apply, please download the Candidate Pack, including the Application Form, here. Applications close on 3 July.

### New publications and resources

**9 June: Global Forum on Incontinence publishes conference summary report**

Following the recent 6th edition of its annual conference, organised in partnership with AGE Platform and Eurocarers, the Global Forum on Incontinence (GFI) has published a conference summary report.

Key studies, themes and topics of the conference – held under the title “Sustainable health and social care: The role of Continence Care in enabling Independent and Dignified living” – included:

- The impact of incontinence compared to other chronic diseases.
- Incontinence 2030: future economic impact on health and social care.
- A shift from disease to functional capabilities.
- The “state of the nation” on continence care services and provisions in Europe.
- The importance of performance / outcome measurement.

During the 2nd day of the Conference, participants discussed and debated the outlines of a Quality and Outcome framework for the day-to-day management of Incontinence at Home and in the Community.

You can find the report here: [http://goo.gl/CxeFfb](http://goo.gl/CxeFfb)

**10 June: MHF published report on “The interface between dementia and mental health”**

The UK-based Mental Health Foundation (MHF), has published a report, exploring the complex relationship between dementia, mental health and mental health problems, which it believes to be “a neglected area in public discourse, policy and service provision”.

The main finding of this review is that co-morbidities are underdiagnosed in people living with dementia, not extensively researched and therefore not fully understood. Based on its review of the available information, the MHF has produced the following recommendations:

**Policy level**

- Co-produce a mental health and dementia research programme with people with lived experience of this co-morbidity, their families and carers.
- Develop data systems to ensure mental health and dementia data can be analysed in an integrated and strategic manner to inform provision, policy and research.
- Develop policy and practice guidance on the mental health needs of people living with dementia.

**Organisation level**

- Develop relationships between mental health and dementia representative organisations and the wider disability movement; and advocate for the inclusion of people living with mental health problems and dementia within the UN review of the UK’s compliance with the Convention on the Rights of Persons with Dementia.
- Develop a rights based approach to health and social care provision for people living with mental health problems and dementia, and their families and carers.

**Programme level**

- Develop a programme to pilot social inclusion and community based interventions, and to scale and test promising approaches.
- Develop programmes of provision, guidance, policy and research for people with early onset dementia; and scale and test promising approaches.

**Cross-cutting**

- Ensure that co-production principles and approaches are adopted across all provision, policy, research developments and resource the work of representative organisations such as the Dementia Engagement and Empowerment Project and the Dementia Alliance for Culture.
- Develop programmes of provision, guidance, policy and research for members of BAME communities; and scale and test promising approaches.

The full report can be downloaded for free on the MHF website:

[https://www.mentalhealth.org.uk/publications/dementia-mental-health](https://www.mentalhealth.org.uk/publications/dementia-mental-health)
AE Calendar

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tbody>
<tr>
<td>4 July</td>
<td>European Patients Foundation, Policy Advisory Group (EPI) (Brussels)</td>
<td>Vanessa</td>
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<tr>
<td>5-6 July</td>
<td>WHO Global Dementia Observatory (Geneva, Switzerland)</td>
<td>Jean</td>
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<tr>
<td>7 July</td>
<td>User test for clinical data publication website (EMA) (London, UK)</td>
<td>Ana</td>
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<tr>
<td>7-8 July</td>
<td>Programme Board of the Joint Action on Dementia (Edinburgh, United Kingdom)</td>
<td>Jean</td>
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<tr>
<td>15 July</td>
<td>GSK Health Advisory Board (London, United Kingdom)</td>
<td>Jean</td>
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<tr>
<td>21 July</td>
<td>Preparation of the 26 AEC (Copenhagen, Denmark)</td>
<td>Gwladys</td>
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<tr>
<td>23-29 July</td>
<td>Alzheimer’s Association International Conference (Toronto, Canada)</td>
<td>Jean</td>
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<tr>
<td>30 August/1 September</td>
<td>PRIVATE MICE Autumn 2016 (Amsterdam, Netherlands)</td>
<td>Gwladys</td>
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Conferences 2016

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>30 June-2 July</td>
<td>4th International conference on vascular dementia</td>
<td>Valencia, Spain</td>
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<tr>
<td>2-6 July</td>
<td>10th Federation of European Neurosciences Societies (FENS) Forum of Neuroscience</td>
<td>Copenhagen, Denmark</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>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 (DAuG) 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>31 October-2 November</td>
<td>26th Alzheimer Europe Conference (26AEC) on “Excellence in dementia research and care”</td>
<td>Copenhagen, Denmark</td>
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<tr>
<td>10-11 November</td>
<td>EDUKAL 2016 – Second educational conference on Alzheimer’s decease, <a href="http://www.edukal.alzheimer.hr">www.edukal.alzheimer.hr</a></td>
<td>Zagreb, Croatia</td>
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<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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26th Alzheimer Europe Conference
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www.alzheimer-europe.org/conferences
#26AEC