Highlights in this issue
20 January: Glasgow Declaration continues to influence EU policy
1 February: EC dementia experts group holds meeting
3 February: Czech Republic has a National Dementia Plan
5 February: Ireland gets EUR 4.5M in research funding
29 February: AE newsletter looks “behind the headlines”

Table of contents
Editorial.................................................1
Alzheimer Europe.................................2
EU projects..........................................3
Alzheimer Europe networking.............3
European Alzheimer’s Alliance............4
EU developments...............................5
Members’ news....................................8
Policy watch......................................11
Science watch....................................13
Science – behind the headlines..........19
Living with dementia.........................21
New publications and resources........21
AE Calendar 2016...............................23
Conferences 2016...............................23

Editorial
Welcome!
I am very pleased to open February’s newsletter with excellent news from our friends in the Czech Republic, where the government has accepted the “National Action Plan for Alzheimer’s disease and similar diseases”. It will run from 2016 to 2019.

Across the Irish Sea, Wales’ close neighbours Ireland had a policy-heavy month as well, with general elections taking place at the end of February. In amongst all the electioneering, the research arm of the country’s first National Dementia Strategy was launched, with some EUR 4.5 million in funding for seven new projects. In 2016 to 2019.

The AE team has been hard at work too, with the call for abstracts for our 26th annual conference opening at the start of the month and registrations opening today, 1 March. The conference will take place in Copenhagen later this year, under the theme “Excellence in dementia research and care”.

Last but not least, I am delighted to announce that our newsletter has a new section: “Science – behind the headlines”, aiming to provide a scientific commentary on previously reported science stories. I would like to thank the first two contributors to this section, Professor Magda Tsolaki and Dr José-Luis Molinuevo. Both are members of our Expert Advisory Panel.

Jean Georges
Executive Director

Welcome!
I am very pleased to open February’s newsletter with excellent news from our friends in the Czech Republic, where the government has accepted the “National Action Plan for Alzheimer’s disease and similar diseases”. It will run from 2016 to 2019.

Also on the policy front, we were proud to see our Glasgow Declaration at the forefront of European dementia policy again. Welsh Health and Social Services Minister Mark Drakeford, who signed the Declaration last year, wants Wales’ forthcoming National Dementia Strategy to be rooted in the Glasgow Declaration. It’s great to see all our hard work paying off!

Across the Irish Sea, Wales’ close neighbours Ireland had a policy-heavy month as well, with general elections taking place at the end of February. In amongst all the electioneering, the research arm of the country’s first National Dementia Strategy was launched, with some EUR 4.5 million in funding for seven new projects. In 2016 to 2019.

On the European front, I joined a meeting of the European Commission’s group of governmental experts on dementia at the start of February, which provided an excellent forum for an exchange on national policy initiatives and developments.

The AE team has been hard at work too, with the call for abstracts for our 26th annual conference opening at the start of the month and registrations opening today, 1 March. The conference will take place in Copenhagen later this year, under the theme “Excellence in dementia research and care”.

Last but not least, I am delighted to announce that our newsletter has a new section: “Science – behind the headlines”, aiming to provide a scientific commentary on previously reported science stories. I would like to thank the first two contributors to this section, Professor Magda Tsolaki and Dr José-Luis Molinuevo. Both are members of our Expert Advisory Panel.

Jean Georges
Executive Director
Alzheimer Europe

4 February: Alzheimer Europe opens call for 2016 conference abstracts

Alzheimer Europe and Alzheimerforeningen (the Danish Alzheimer association) are pleased to announce that the call for abstracts for the 26th Alzheimer Europe Conference in Copenhagen, Denmark from 31 October to 2 November is now open. Abstracts for oral and poster presentations are welcome in the following categories:

- Dementia-friendly society: Involving people with dementia; Perceptions and image of dementia; Art and dementia; Dementia-Friendly communities.
- Policies and Strategies - Dementia strategies; Legal issues; Care financing; Minority groups.
- Innovative care: Hospital care; Post-Diagnostic support; Residential care; End-of-life care.
- Medical aspects: Timely diagnosis; Risk factors and prevention of dementia; Behavioural and psychological aspects of dementia; Treatment of dementia.

Please read the abstract submission guidelines carefully before submitting an abstract. The submissions deadline is 30 April 2016.

More information is available on our website: http://alzheimer-europe.org/Conferences/2016-Copenhagen/Abstract-submission

Conference registrations will open from 1 March, via our website.

4 February: EWGPWD Vice-Chair Helen Rochford Brennan talks to The Journal.ie about her dementia

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, has spoken to The Journal.ie – an online Irish newspaper - about her experiences of being diagnosed with, and living with dementia. Ms Rochford Brennan (pictured with her husband, Sean) was interviewed and quoted by The Journal as part of an article on dementia research and investment in Ireland, in the run-up to the Irish general election on 26 February.

She is quoted as saying the last four years - since her diagnosis - has been "an uphill battle", but is very positive about her experiences as a dementia advocate in Ireland:

“To be involved in that and to participate in that has been wonderful," she said. “I realised that life goes on and we can live well in our communities.”

http://www.thejournal.ie/dementia-research-2583156-Feb2016/?utm_source=shortlink

16 February: The EPF and AE consult on position paper on EU Clinical Trials Regulation

The European Patients’ Forum (EPF) is consulting on a position paper that will provide recommendations for patient-centred implementation of the provisions of the new EU Clinical Trials Regulation (Regulation 536/2014).

The survey focuses on informed consent and information to patients. Alzheimer Europe (AE) has been invited to contribute and looks forward to being involved in this consultation.

For information about the EPF consultation:

To see the EU regulation:

23 February: Alzheimer Europe sets up 2016 Ethics Working Group

Alzheimer Europe has set up this year’s Ethics Working Group, which will develop a report and position paper on the ethical issues linked to the changing definitions of Alzheimer’s disease.

The report and position paper will explore the changing definitions of Alzheimer’s disease in the context of research, diagnosis and people’s everyday lives and wellbeing. This will include touching on the implications of representations of health and disease, acquiring patient status, understanding risk, asymmetrical power relations, conflicting biomedical and everyday discourses.

The precise topics and ethical issues to be addressed eventually will be determined and developed by the group.

24 February: EWGPWD Chairperson Helga Rohra gives keynote speech at Romanian Conference

From 24 to 27 February, the Romanian Alzheimer Conference was held in Bucharest. Helga Rohra, Chairperson of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) was invited to speak. She made a big contribution to the conference, speaking at the opening as well as giving a keynote lecture. She was also interviewed on local and national television channels and spoke at the press conference prior to the conference.

Ms Rohra (pictured, left, alongside Maria Moglan from the Romanian Alzheimer Society, right) said she was pleased and honoured to have been invited as such a high profile guest at this conference. As a person living with dementia, she feels her contribution was an important one. She took numerous opportunities to speak about the work being done both by Alzheimer Europe (AE) and by the EWGPWD.
She also spoke about the importance of national dementia working groups.

Despite there being no translators at the conference, which made things quite difficult, Ms Rohra was able to adapt to the situation: she asked for her speeches and comments to be written down in Romanian and read this out, to ensure local politicians and other local participants were able to understand her, as many of them did not speak English. She was keen to emphasise that people with dementia can adapt, when faced with new and difficult situations such as this and that her efforts were appreciated by the organisers and local participants.

The conference attracted over 350 delegates.

http://www.alzcongres.ro/

29 February: AE newsletter has a new “behind the headlines” section

The Alzheimer Europe (AE) newsletter has a new section, “Science - behind the headlines”, which consists of commentaries on previously reported stories from our “Science Watch” section that received a lot of media attention. Commentaries are provided by members of our Expert Advisory Panel (EAP), scientific experts in the field of dementia with proven track records.

While AE always tries to focus on the original journal study in its newsletter articles rather than on the media’s take on things, which can be quite misleading, we have decided to include these commentaries to ensure we have a scientific perspective on how important these “breakthrough” stories are, whether they have been “blown out of proportion” and on what might happen next.

http://alzheimer-europe.org/News/Science-behind-the-headlines

EU projects

15 February: EPAD researchers obtain funding for new ethics project

European Prevention of Alzheimer’s Dementia (EPAD) project researchers Edo Richard and Maartje Schermer have obtained a new grant from the Dutch Organisation for Health Research and Development, to delve deeper into some of the ethical and conceptual issues around early diagnosis in dementia.

Their project is entitled “Early diagnosis of Alzheimer’s disease: conceptual considerations and ethical guidance” and will be executed in close collaboration with other EPAD members including AE Executive Director Jean Georges.

15 February: PredictND making steady progress

The consortium meeting of the PredictND project was held in Kuopio in Finland on 15 February.

Project partners discussed progress to date and the next steps, and AE’s Director for Projects, Dianne Gove presented the findings of the consultation with the European Working Group of People with Dementia about the citizen portal.

19 February: AFE-INNOVNET brochure on Covenant on Demographic Change available in five languages

The brochure about the Covenant on Demographic Change is available in five European languages:


French: http://agefriendlyeurope.org/sites/default/files/Covenant_brochure_FR.pdf

Italian: http://agefriendlyeurope.org/sites/default/files/Covenant_brochure_IT.pdf

Polish: http://agefriendlyeurope.org/sites/default/files/Covenant_brochure_PL.pdf

Spanish: http://agefriendlyeurope.org/sites/default/files/Covenant_brochure_ES.pdf

The Covenant, which was launched on 7 December 2015, brings together 112 organisations to build on the outcomes of the AFE-INNOVNET project’s Thematic Network on innovation for age-friendly environments. All the deliverables of the AFE-INNOVNET project are available here:

http://agefriendlyeurope.org/library/deliverables/

Alzheimer Europe networking

On 1 February Ana participated in a User Test of a prototype of the EMA’s clinical data publication website (London, UK).

On 1 and 2 February Jean participated in the government expert meeting on dementia convened by the European Commission (Luxembourg, Luxembourg).

On 5 February, Jean attended the Roche Dementia Forum (Frankfurt, Germany).

On 15 February, Dianne attended the Management Board meeting and the Consortium meeting of the PredictND project (Kuopio, Finland).


On 18-21 February, Gwladys attended the ICCA workshop (Uppsala, Finland).
On 19 February, Dianne and Ana had a meeting with the Luxembourg Institute of Science and Technology LIST (Esch-sur-Alzette, Luxembourg).

On 24 February, Vanessa attended the European Parliament Interest Group on Brain, Mind and Pain (Brussels, Belgium).

On 24 February, Vanessa attended the IMI Lunch debate on “How IMI is accelerating access to affordable innovative medicines?” (Brussels, Belgium).

**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). **Croa**

**Germany:** Angelika Niebler (EPP); Udo Voigt (NI). **Greece:** Kostas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyriakos Mitadiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyridaki (EPP); Elefterios Synadinos (NI); Elissavet Vozemberg (EPP). **Ireland:** Lynn Boylan (GUE/NGL); Matt Courtney (EPP); Nessa Childers (S&D); Deirdre Clune (EPP); Ádám Kósa (EPP). **Italy:** Brando Benfiè (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). **Lithuania:** Vilija Bliknevičiute (S&D). **Luxembourg:** Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP). **Malta:** Therese Comodini Cachia (EPP); Roberta Metsola (EPP). **Netherlands:** Esther de Lange (EPP); Jeroen Lenaers (EPP); Lambert van Nistelrooij (EPP). **Poland:** Elżbieta Łukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Plura (EPP); Bogdan Wenta (EPP). **Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP). **Romania:** Cristian Silviu Busoi, MEP; Daciana Octavia Sarbu (S&D); Claudia Ciprian Tanasescu (S&D); Renate Weber (EPP). **Slovakia:** Miroslav Mikolásik (EPP); Ivan Stefanec (EPP); Anna Záborská (ECR). **Slovenia:** Franc Bogović (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Šulin (EPP); Romana Tomc (EPP). **Spain:** Izauskun Bilbao Barandica (ALDE); Soledad Cabezón Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estarás Ferragut (EPP); Juan Carlos Giraulta Vital (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 Hudgton (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

1 February: What is the European Alzheimer’s Alliance and what has it done so far?

The European Alzheimer’s Alliance (EAA) has been active in the European Parliament since 2007. It is a non-exclusive, multinational cross-party group that brings together Members of the European Parliament (MEPs) to support Alzheimer Europe and its members in making dementia a public health priority in Europe. Since 2007 membership has grown from 30 to 126 MEPs from all 27 Member States of the European Union and all seven political groups in the European Parliament.

The EAA is led by a Board including MEPs Françoise Grossetête (EPP, France), Chairperson and Vice-Chairs: Nessa Childers (S&D, Ireland), Marisa Matias (GUE-NGL, Portugal), Sirpa Pietikäinen (EPP, Finland), Frédérique Ries (ALDE, Belgium) and Keith Taylor (Greens/EFA, UK).

The EAA’s mission is to send out the political message that concerted action is needed in the field of prevention, diagnosis and treatment of dementia, as well as research and social policies, and promoting actions to make dementia a priority at European and national level.

The membership of the alliance was recently boosted by Alzheimer Europe (AE)’s 2015 Glasgow Declaration, calling for a European Dementia Strategy, which was supported by 84 Members of the European Parliament, 150 policy makers from 25 European countries and over 11,600 individual citizens. Thirty seven MEPs, who were not already members, joined the EAA.

AE and the EAA have continuously campaigned for a European Dementia Strategy, many countries now have National Dementia Plans and others have identified the need for one to be developed.

Over the past ten years there have been many positive political actions towards building the momentum for a European Dementia Strategy. Most recently, following Luxembourg’s EU Presidency term in 2015, the Council of European Health Ministers (EPSCO) adopted Conclusions on supporting people living with dementia, including calling on all member states to have National Dementia Strategies. In early 2016, a second Joint Action on dementia was launched covering diagnosis and post-diagnostic support, crisis and care coordination, residential care, and dementia-friendly communities.
Another achievement at European level is the Innovative Medicines Initiative (IMI), which is a successful joint effort between the EU and the pharmaceutical industry association EFPIA. The IMI funds research projects into neurodegenerative diseases, including Alzheimer’s disease and other forms of dementia.

The EAA is also active within the European Parliament, hosting various activities to support dementia including: two annual AE Lunch Debates. In 2016 these will be held on 28 June and 6 December. More details of the agendas will be available closer to the time.

More on information on the EAA activities can be read here:
http://alzheimer-europe.org/Policy-in-Practice2/European-Alzheimer-s-Alliance/Alliance-activities

12 February: Marian Harkin, MEP hosts health information seminar in Galway, Ireland

Marian Harkin, MEP (Ireland), a member of the European Alzheimer Alliance (EAA) recently hosted an information seminar in Galway on issues relating to the delivery and accessibility of health services in the region - “Promoting good health in older age: engaging with Europe”. Ms Harkin spoke on health and safety at work and recent EU legislative measures including the UN convention on rights of persons with disabilities, which is not yet ratified in Ireland. She also spoke on universal accessibility, cross-border health care and funds available under the Horizon 2020 healthy ageing programmes.

Maureen Mannion, Dementia Adviser, Alzheimer Society of Ireland gave a talk on dementia including:

- Dementia in Ireland today and the significant impact of dementia.
- Information and support needs following a diagnosis.
- Outline of the ASI’s Dementia Adviser Service.
- How people can access the service.
- Additional supports and new services in Galway.

After the speakers, the topics of discussion centred on funding, prevalence of dementia, the impact of dementia and early intervention. The event was well attended with around 120 people present.

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

EU developments

22 January: ERC awards EUR 20 million in top-up grants for most promising European innovation projects

On 22 January, the European Research Council (ERC) awarded 135 grants in the third round of its EUR 20 million Proof of Concept competition, which awards the most promising innovation projects by existing ERC grantees with up to EUR 150,000 in funding.

Carlos Moedas, EU Commissioner for Research, Innovation and Science said:
"There can be no sustainable environment for European innovation without scientific excellence. Proof of Concept grants help researchers bridge the divide between academia and the market. They support the frontier science that leads to innovation with real-life applications, creating new opportunities for European jobs and products."


1 February: EMA releases new draft guidance on development of AD treatments

The European Medicines Agency (EMA) has released a revised guideline on medicines for the treatment of Alzheimer’s disease (AD) and other types of dementia, for a six-month public consultation.

The EMA considers dementia as a key public health priority and follows a multi-stakeholder approach to facilitate research and development of more effective medicines. The revised guideline takes into account comments received at the EMA’s workshop on the clinical investigation of medicines for the treatment of Alzheimer’s disease in November 2014.

The revised guideline specifically addresses the:

- Impact of new diagnostic criteria for AD, including early and even asymptomatic disease stages, on clinical trial design;
- Choice of parameters to measure trial outcomes and the need for Distinct assessment tools for the different disease stages in AD (different signs and symptoms, differences in changes over time, severity);
- Potential use of biomarkers and their temporal relationship with the different phases of AD at different stages of medicine development (mechanism of action, use as diagnostic test, enrichment of study populations, stratification of subgroups, safety and efficacy markers etc.);
- Design of long-term efficacy and safety studies.

Comments received during the consultation will be taken into account in the finalisation of the guideline. Stakeholders are invited to send their comments by 31 July.


1-2 February: EU governmental experts discuss national dementia initiatives

On 1 and 2 February, the European Commission convened its group of governmental experts on dementia in Luxembourg. The meeting was attended by government representatives from Bulgaria, Cyprus, Denmark, France, Germany, Greece, Hungary, Ireland, Italy, Luxembourg, Malta, Netherlands, Norway, Portugal, Romania, Slovakia, Slovenia and the United Kingdom (Department of Health and Scottish Government) who had an exchange on
national policy initiatives and developments in the dementia field.

The representatives of the Netherlands and Luxembourg provided an update on the past activities and future plans of their respective priorities with both Slovakia and Malta indicating that their Presidencies would continue to keep dementia on the European agenda.

Tarun Dua from the WHO and Tim Muir from OECD presented their organisations’ plans in developing indicators to better allow benchmarking and comparison of national policies. Geoff Huggins from the Scottish Government presented the plans for the 2nd Joint Action on Dementia which will be officially launched at a kick-off meeting in Luxembourg on 3 and 4 March 2016 and which will bring together national health ministries and academics to identify best practices and run pilot schemes in the following four key areas:

- Timely diagnosis and post-diagnostic support
- Care coordination and crisis management
- Quality of residential care
- Dementia-friendly communities.

The second day was dedicated to an exchange on prevention initiatives in the dementia field with Tila Ngandu presenting the results of the FINGER study, Paul Lincoln the Blackfriars Consensus on dementia prevention and Lara Passante the research projects on prevention supported through FP7, Horizon2020 and the Innovative Medicines Initiative. Jean Georges represented Alzheimer Europe at this meeting.

2 February: "Understanding Welfare Models" call open for research proposals

The JPI Joint Transnational Call 2016 is now open. The aim of the call is to support research, which will improve the understanding of how different approaches to welfare secure the quality of life, especially of older people. The objective is to develop comparative perspectives on welfare models, and the ways in which they are changing, drawing on the great diversity of approaches to welfare across Europe and Canada. A better understanding of these differences can help policymakers to identify potential ways of meeting needs, as their own models evolve in response to changing demographic pressures and circumstances.

The Joint Programming Initiative (JPI) “More Years, Better Lives – The Potential and Challenges of Demographic Changes” seeks to enhance coordination and collaboration between European and national research programmes related to demographic change.

http://www.jpi-demographic.eu/activities/calls/

5 February: EC releases report on health-related constraints to raising retirement ages in the EU

The European Commission (EC) has released the final report of the project on health-related constraints to raising retirement ages in the EU from the Health Systems Performance Assessment Expert Group. The project investigated the impact of preventing chronic diseases on disability, unemployment and death by developing a simulation model that describes the path running from chronic diseases to disability, unemployment and death for several European Union countries.

Results from the model show that decreasing incidences of disease and disability increases the total number of years lived and of years lived free from disabilities. This allows more active years in the labour force and decreases public payer expenditures. Moreover, results also depict the limitations of public policies aimed at increasing the pension age for the investigated countries, and the impact variation of different public policies and epidemiological scenarios on various population groups within the EU.


5 February: New ERC Scientific Council members appointed

On 5 February, the European Commission appointed two new members to the Scientific Council of the European Research Council (ERC):

Professor Sir Christopher Clark (pictured, left) and Professor Barbara Romanowicz (pictured, right).

Sir Christopher Clark is Regius Professor of History at the University of Cambridge and Barbara Romanowicz is professor and chair in Physics of the Earth’s interior at the Collège de France, and is also professor of Geophysics at UC Berkeley, USA. Their mandate is for four years.

The ERC Scientific Council, composed of 22 distinguished scientists and scholars representing the European scientific community, is the governing body of the European Research Council. Its main role is setting the ERC strategy and selecting the peer review evaluators.

The ERC - set up by the European Union in 2007 - is the first European funding organisation for excellent frontier research and is part of the EU research and innovation programme, Horizon 2020. Each year, it selects and funds creative researchers of any nationality and age, to run projects based in Europe, attracting high level researchers from around the world to Europe.

16 February: JPND rapid-action call on brain imaging methods closes soon

Last month, the EU Joint Programme – Neurodegenerative Disease Research (JPND) launched a rapid-action call for working groups on brain imaging methods. The call aims to support leading scientists in this field in exploring new approaches to enhance the use of imaging for neurodegenerative disease research. The deadline for submission of proposals is 10 March.
16 February: European Commission launches Call for Ideas for a European Innovation Council

The European Commission has launched a Call for Ideas for a European Innovation Council to support Europe's most promising innovators. Commissioner Moedas (DG Research and Innovation) launched the Call for Ideas at the Science/Business Annual Conference in Brussels. He said that "Europe has excellent science, but we lack disruptive market-creating innovation. This is what is needed to turn our best ideas into new jobs, businesses and opportunities."

The Commission would like to base the European Innovation Council on the best possible ideas and welcomes input from all important stakeholders, business, entrepreneurs, academia, national and regional authorities and representative bodies.

The call for ideas is a series of questions but position papers are also welcomed. The deadline for responses is 29 April and an analysis of the responses will be published by June this year.

http://ec.europa.eu/research/sic/index.cfm

17 February: EC closes public consultation on challenges of work-life balance faced by caregivers

On 17 February, the European Commission (EC) closed its public consultation on the development and implementation of a range of possible tools at EU-level, to support work-life balance for working parents and caregivers.

The objective of the initiative, which is included in the 2016 Commission Work Programme, is to increase the participation of women in the labour market by improving the current EU legal and policy framework and adapting it to today's labour market. The hope is to allow for working parents and people with dependent relatives to better balance family and work life, and to allow for a greater sharing of care responsibilities between women and men, thereby strengthening gender equality.


18 February: Successor to Horizon 2020 - European Commission launches consultation

Discussion is already underway as to what the successor to Horizon 2020 will look like. In autumn 2016 the European Commission will launch a consultation. This will be the EU’s ninth R&D programme.

Officials in the European Commission are preparing the ninth research and innovation programme and a preliminary proposal, "will be on the table by the end of 2017, beginning of 2018" as part of the Commission's long-term budget planning, said Robert-Jan Smits, Director-General for Research and Innovation, speaking at the Science|Business Horizon 2020 conference this month.

http://www.sciencebusiness.net/news/77437/Work-begins-on-the-next-EU-research-programme

24 February: How is IMI accelerating access to affordable innovative medicines?

On 24 February, the Innovative Medicines Initiative (IMI) held a lunch debate in the European Parliament, Brussels on how IMI contributes to efforts to accelerate access to affordable, innovative medicines. More broadly, it provided an opportunity to discuss how a public-private partnership such as IMI offers value for money for European citizens by paving the way for faster, more affordable access to health and innovation.

The event was hosted by Françoise Grossetête, MEP (France). The debate focused on:

- The socio-economic impact of IMI’s projects for European citizens.
- IMI’s ability to boost competitiveness in health and innovation sectors across the EU.
- IMI’s role in gathering together all the stakeholders in the health sector for a common goal – improving and accelerating patient access to affordable and advanced medicines.
- IMI’s contribution in tackling cutting-edge diseases through a cross-sector approach, fuelling innovation into research on health.

All the presentations can be viewed here:

http://www.imi.europa.eu/events/2016/01/18/how-imi-accelerating-access-affordable-innovative-medicines

The event was attended by Alzheimer Europe’s Policy Officer, Vanessa Challinor (pictured, with Rami Nissilä, Permanent Representation of Finland to the EU).

24 February: MEP Interest Group on Brain, Mind and Pain hosts event on Neurological and Chronic Pain Disorders at Work

Dutch MEP Jeroen Lenaers, hosted an MEP Interest Group on Brain, Mind and Pain working breakfast at the European Parliament in Brussels on 24 February.

Chronic pain is invisible and in Europe urgent action is required to address the problem of integrating people with chronic pain into the workplace. Work impacts on the social cohesion and on the quality of people’s lives.

Dr Chiara Scaratti, Besta Neurological Institute, Italy presented the findings of “Further results of the EFNA Patient Experience Survey: Focus on Stigma at Work”. The survey highlighted the need for urgent action for women, the under 50s and those with a middle to low level of
education, who are at most risk of difficulties and stigma at work. Identifying and then looking out for the needs of workers with neurological conditions could be beneficial to employers, and a healthier work force can be a facilitator.

Professor M.F. Michiel Reneman, talked about the programme "Fit for Work, Netherlands. What are the solutions? A Medical Professional’s Perspective: Focus on Rehabilitation". The EU should be focusing on keeping people at work, as work is good for health and wellbeing and can even be considered therapeutic. There is strong scientific evidence to support this, he said. The question, however, is: How can it be done?

There are many groups who need to be rehabilitated and return to work, with a focus on healthy ageing at work. Vocational rehabilitation (VR), which is already used in Canada, is a model that could be applied in Europe. Currently, this is not an option as too many silos exist between health and work policies.

Karin Hellviek of Biogen gave an employer’s perspective of pain at work and spoke about the “Believe and Achieve” programme, supporting young people in employment with Multiple Sclerosis (MS), and the "Challenges and Benefits of adapting a workplace for a person affected by Multiple Sclerosis and what are the solutions?"

An employee’s perspective was given by Jane Whelan, European Headache Alliance on “Impact and burden of living with migraine and developing a career”, she describe her personal story of trying to build a career whilst living with severe migraine.

Matthijs Gruneveld of the Dutch Presidency of the EU, Attacé Social Affairs at the Permanent Representation of the Netherlands talked about the European Semester and country-specific recommendations towards a more social, coherent policy of inclusiveness and long-term employment. He emphasised that member states should foster social inclusion.

The meeting included a Call to Action with the presentation of a Written Declaration on Access to Employment and Education for those affected by Brain and Chronic Pain Disorders, currently supported by MEPS Jeroen Lenaers (Netherlands), Marian Harkin (Ireland) and Daciana Sarbu (Romania). It will be finalised and published with the co-authorship of at least ten other MEPs.

In summing up, Marian Harkin said she believes that it is within the competence of the EU and is achievable. With enough leverage, it is possible to achieve the goal of access to employment for those affected by brain disorders and chronic pain conditions, Ms Harkin concluded.

http://efna.net/

Follow us on Twitter

Members’ news

18 January: Norwegian Health Association awards research prize to Dag Aarsland

On 18 January, the Norwegian Health Association’s newly established dementia research award was given to Professor Dag Aarsland. Prof. Aarsland received the prize for his significant scientific contributions and his important role in the process of building an environment for dementia research at SESAM - Centre for Age-related Medicine at Stavanger University (SUS). He has also been professor of clinical dementia research at Karolinska Institutet in Stockholm, Sweden.

Prof. Aarsland (pictured, left) is renowned worldwide in the field of Lewy body dementia and Parkinson’s disease, and has made contributions across the spectrum of old age psychiatry. He recently took on a new position as Chair of old age psychiatry at the Institute of Psychiatry, Psychology and Neuroscience at King’s College London. As well as heading the department, he will contribute to new initiatives including dementia research in the institute’s forthcoming bid to renew its Biomedical Research Centre. He will also carry out some clinical work within South London & Maudsley NHS Trust and will help in training the next cohort of old age psychiatrists.

The SESAM Centre for Age-related Medicine was established by the Western Norway Regional Health Authority in 2010 to improve coordination, research and professional development, networking and education within Geriatrics. Under Prof. Aarsland’s leadership, the centre has moved from practicing pure clinical research to translational research - a more complex approach that combines basic research with research on how best to treat patients.

A second prize, for cardiovascular research, went to Professor Kenneth Dickstein, who is heading the department, for his significant scientific contributions and his important role in the process of building an environment for dementia research at SESAM - Centre for Age-related Medicine at Stavanger University (SUS). He has also been professor of clinical dementia research at Karolinska Institutet in Stockholm, Sweden.


20 January: France Alzheimer launches carer campaign

France Alzheimer has launched a large-scale awareness campaign called “Aidons les Aidants” (Care for Carers), to help raise awareness of the impact dementia has on the lives of caregivers, as well as those living with dementia themselves.

The campaign consists largely of testimonials given by carers, speaking out about their experiences of and difficulties in caring for people with dementia. It also highlights the work being carried out by France Alzheimer throughout the country’s 92 counties, to support them.

The difficulties most often encountered by the carers were: lack of time, stress, fatigue, guilt, social and professional isolation and loss of income.

The campaign hashtag to follow is #AidonsLesAidants

And you can also follow @FranceAlzheimer
2 February: Spominčica’s President discusses dementia on national television

On 2 February, Mrs L. Zlobec appeared, together with Dr Milica Kramberger of the Neurology Clinic Ljubljana, on national television programme HALO TV. The hour-long show included discussion around viewers’ questions on dementia, first signs, diagnosis, treatment and the Spominčica programme for persons with dementia and their carers. Mrs L. Zlobec also took this opportunity to highlight the role of Alzheimer Europe in the preparation of guidelines to support people with dementia and their families, and to promote dementia as a public health priority.

The second TV show took place on 22 February on NET TV, a local channel in Maribor (the second largest city in Slovenia). On this occasion, Mrs L. Zlobec presented the work and activities of Spominčica in providing help and support for persons with dementia and their carers.

Both TV shows elicited a huge response among the viewers, and Spominčica is pleased to have made these appearances, which it says will significantly contribute to raising awareness around dementia in Slovenia.

You can see the HALO TV appearance here (one hour long, in Slovenian): http://4d.rtvslo.si/arhiv/halo-e/174386201

4 February: UK Alzheimer’s Society launches study to find ways to support dementia carers

On 4 February, the Alzheimer’s Society (UK) launched “Caring for Me and You”, an online therapy package designed specifically to support people caring for someone with dementia. It was developed by the Society, in partnership with psychologists working at Oxford Health NHS Foundation Trust.

90% of carers for people with dementia experience feelings of stress or anxiety several times a week, an Alzheimer’s Society survey has found. Moreover, 80% find it difficult to talk about the emotional impact of caring. The “Caring For Me and You” trial will test tailored online cognitive behavioural therapy (CBT) and other support, specifically designed to help carers find ways of coping with the pressures of their role.

“Many carers have told us that they often struggle to find the time to attend therapy sessions. Our study is investigating whether accessing tailored therapy and support online can help carers to overcome some of these difficulties” writes the Society.

Please note that to participate in the study and access the online programme you will need to use a PC or a laptop.

https://www.caringformeandyou.org.uk/

12 February: Jersey strengthens ties with Guernsey

On 12 February, the Jersey Alzheimer’s Association met with the Guernsey Alzheimer’s Association, with the aim of increasing communication and cooperation between the two charities, and to learn from one another.

The website for the Guernsey Alzheimer’s Association is: www.alzheimer.gg

15 February: Former France Alzheimer President comments on dementia village project

The former president of France Alzheimer, Marie-Odile Desana recently spoke to Parisian newspaper La Croix about her visit to the “dementia village” of De Hogeweyk in the Netherlands. Ms Desana, now President of France Alzheimer’s Bouches-du-Rhône regional faction, was part of a delegation of five people from France Alzheimer. Their visit served as part of a project to build a similar village in the Landes region of France, in 2018.

Ms Desana said she found the village itself to be homely and welcoming despite being set in the heart of a “not great” neighbourhood. She was also impressed by the attention paid to respecting the cycle of the seasons, and the fact the residents had been involved in choosing the plants in their own gardens.

The France Alzheimer delegation visited one of the homes in the village, which, again, Ms Desana was impressed with in terms of its comfort, homeliness and how “real” it felt. She found the fact that a cake was being baked by one of the carers - a “real” cake made with real eggs – pleasantly surprising, as compared with the strict sanitary regulations in French care homes, which do not allow elderly residents to eat cakes baked using eggs. She also found the kindness and supportive nature of the people working in the village to be very encouraging.

Ms Desana was impressed with how much attention to detail was paid in creating an environment as close to the residents’ lives prior to moving into the village as possible, down to the types of homes they live in being “bourgeois” apartments, with crystal chandeliers for those who had come from such a background and rather more “rustic” efforts for those who had a more rural background. She remained sceptical, however, about the benefits of putting so fine a point on the differing social statuses of the residents.

Overall, Ms Desana told Parisian newspaper “La Croix” she was struck by the serene atmosphere, with “no clashes, no sudden movements” and a general feeling of acceptance. She was impressed, also, with the number of volunteers working in the village.

Despite the risk, she said of “ghettoisation” when grouping people with the same disease in the same area, she felt the concept to be interesting and was optimistic about the French project and its potential benefits for future residents.
De Hogeweyk is a gated community is Weesp, near Amsterdam. It is built like a small town, with its own town square, houses, pub, theatre and shops, and accommodates 150 people living with dementia. Guided tours are paid and are highly regulated.


16 February: Danish Alzheimer Society celebrates 25 years, aims for 100,000 Dementia Friends

In 2016 the Danish Alzheimer Society celebrates its 25th anniversary by launching a new campaign, aiming for 100,000 Dementia Friends in Denmark by 2018.

The aim is to increase knowledge about dementia and the ability and inclination of the Danish people to lend a helping hand to people with dementia in everyday situations. The ultimate goal of this and other efforts is to achieve a dementia-friendly society.

When someone signs up as a Dementia Friend, they receive a free lapel pin to show their engagement, as well as an easy-to-read, attractive booklet, giving background knowledge and practical information about how to be supportive to people with dementia. Dementia Friends will also be regularly updated with information and ideas. Particularly interested persons can be trained as Dementia Friend Instructors, able to give information to groups of families, companies and associations in the local community.

Good Friends are important to everybody – especially for people living with dementia, says the Danish Alzheimer Society.

18 February: The first “Rocking Alzheimer” concert in Europe took place in Greece!

On 18 February, the first “Rocking Alzheimer” concert took place in a concert hall in Thessaloniki, Greece. Following recent news about several famous musicians being diagnosed with Alzheimer’s disease, Alzheimer Hellas had the idea to organise a rock concert with various artists, to advocate for people living with Alzheimer’s disease and dementia.

Alzheimer Hellas reports that the concert was a success, as well as proving to be a great opportunity to campaign and raise awareness among younger audiences, and to highlight the importance of prevention and of caring for those affected by the disease.

Of course, the people living with dementia and their carers also enjoyed the music and danced to it! “Why not make it a trend?” said Alzheimer Hellas.

18 February: Memory Association of Oulu receives award from Finland’s Slot Machine Association

“Vaikuttavaa!” (“Impressive!”). This year an award was given to the Memory Association of Oulu (Oulun Muistihdyntys).

The Alzheimer Society of Finland and its member associations are mainly funded by RAY, whose grant funding is collected from slot machines and casino gaming operations. These funds are then channelled into organisations seeking to tackle health and welfare challenges caused by, among others, the ageing of the population and memory disorders. The final decision on funding allocations rests with the Finnish Ministry of Social Affairs and Health.

For more information about the award and the winners (in Finnish):
http://www2.ray.fi/fi/avustukset/ray-tukee/vaikuttavaa-tunnustuspalkinto

22 February: Alzheimer Nederland shares news about new online platform for carers

Last year, Alzheimer Nederland launched a new online platform for informal carers: www.dementie.nl. The launch, which took place on 10 November 2015 - Dutch “Caregiver Day” - was a special moment for the organisation. Employees and the social and commercial partners of this platform gathered at head office in Amersfoort for the “soft launch” - only announced to the visitors of the organisation’s regular website and followers on social media.

The first results have proved very promising, reported Alzheimer Nederland on 22 February, with the site receiving over 50,000 visitors in its first months. Almost a quarter of these visited the platform more than once.

In 2016, Alzheimer Nederland will continue optimising the platform and adding content and new functionalities to it. First up: a test for caregivers about stress and coping, and the integration of the organisation’s current forum.

23 February: Norway’s “Activity Friends” programme is well established

Using funds from its 2013 telethon, the Norwegian Health Association created a programme for volunteers called “Activity Friends for people with dementia”. The aim is to give people with dementia the opportunity to have more varied experiences, by participating in more activities.

An Activity Friend is a volunteer, who - after training and guidance - is paired with someone living with dementia. The Activity Friend and the person with dementia participate in activities together. For instance, going for a walk, attending the theatre, seeing a movie, playing games, fishing, painting, gardening, or just meeting for a cup of coffee and a chat.

These activities are organised by municipal employees, in cooperation with volunteer centres and local branches of the Norwegian Health Association. Municipalities receive materials for recruitment, training, and monitoring from the Association. They also receive financial grants for training courses for volunteers.
Two years into the scheme, the Association reports that it now has Activity Friends established in over 70 municipalities and in all counties in Norway. 1,500 volunteers have attended courses to become Activity Friends for people living with dementia.

23 February: Jersey’s Long-Term Care scheme is launched, in partnership with States of Jersey

A new Long-Term Care (LTC) scheme has been launched by the Jersey Alzheimer’s Association (JAA), in partnership with the States of Jersey. The scheme supports people with high-level, long-term care needs. Having such needs means requiring substantial help with daily activities such as getting out of bed and dressing.

The LTC scheme provides financial support to Jersey residents who are likely to need long-term care for the rest of their lives, either in their own homes or in care homes. The aim is to remove much of the financial worry that people would otherwise have around the cost of long-term care.

The JAA has experience of seeing many people work through this process, who are now in receipt of care financed by this scheme. The JAA’s Counsellor and Family Support Co-ordinator Sian Wareing-Jones is available to help people understand the process and to talk through any issues or worries about the scheme. Ms Wareing-Jones is available on 07797 907753 or via e-mail: jaa.ch@hotmail.co.uk

See the States of Jersey website for more about the scheme and how to apply: http://www.gov.je/benefits/longtermcare/Pages/index.aspx

26 February: The Alzheimer Society of Ireland runs “Vote to Remember” campaign in run up to General Election

A general election was held in Ireland on 26 February. There are 48,000 people living with dementia in Ireland. By the end of the next Government, in 2021, that number will have increased by 40%. The Alzheimer Society of Ireland (ASI) launched its election campaign “Vote to Remember” at the end of January, asking candidates to pledge to:

- Renew Ireland’s National Dementia Strategy;
- Reform Ireland’s National Dementia Strategy;
- Resource Ireland’s National Dementia Strategy;
- Ensure that dementia-specific home and community care, timely diagnosis and post diagnostic support is provided to people living with dementia.

Launching the campaign, Colette Kelleher, ASI CEO, said, “This year alone every day in Ireland 11 people will develop dementia. That’s eleven mothers, fathers, grandparents, sisters or brothers. The ASI’s Vote to Remember campaign is asking candidates to Renew, Reform and Resource the National Dementia Strategy to address this growing demand for dementia care”.

Supporter packs containing the ASI election manifesto, voter prompt card, candidate pledge cards and campaign stickers were distributed through ASI services and to the Irish Dementia Working Group and Dementia Carers Campaign Network. A campaign website www.votetoremember.ie shared stories from people living with dementia and family carers. It also allowed voters to contact their candidates directly and gave candidates the opportunity to pledge their support for people with dementia.

In the lead up to the election, a number of lobbying events were held around Ireland, including a briefing for candidates in Dublin on 9 February. Thanks to ASI supporters, and the work of the ASI grassroots network, approximately 4,600 letters were sent to candidates asking them to pledge their support for people living with dementia, and over 140 cross-party candidates signed the campaign pledge.

In addition to this, five political parties - Fine Gael, The Labour Party, Fianna Fáil, Sinn Féin, and The Green Party - included references to dementia in their election manifestos, and the three largest political parties committed to the full implementation of Ireland’s National Dementia Strategy. ASI will continue to work hard to ensure dementia is a political priority in the next Irish Government.

Pictured: Minister Heather Humphreys with ASI Staff and Branch Members.

26 February: Association Alzheimer Suisse reports on the unresolved issue of care financing in Switzerland

Unfortunately, in the five years since its implementation, the new financing of care regulation has proved to be substantially problematic. Issues within the system are becoming more and more apparent as time goes by, in particular concerning people living with dementia.

The Swiss system covers all costs for physical and medical care, but other support needs, which people with dementia may have, are not covered. These costs fall to the people with dementia themselves, even though they are as a direct consequence of the disease.

The lack of political will to solve this problem is evident and extremely regrettable, and the issue remains high on the agenda of the Swiss Alzheimer’s Association.

Policy watch

12 January: Spain is first country to apply new EU regulations on clinical trials

The Spanish Council of Ministers recently passed a Royal Decree regulating clinical drug trials, drug-research ethics committees (RECs) and the Spanish Clinical Studies Registry, in order to put in place criteria to increase
transparency and simplify procedures for clinical trials. The decree came into force on 12 January and on 27 January, the Spanish Agency of Medicines and Medical Devices (AEMPS) organised a workshop to inform stakeholders about its implications.

By passing this decree, Spain is adapting to the new EU regulations on clinical trials, which will be in force as of May 2016. Spain was the first to apply the European regulations.

The regulations establish that clinical trials may be approved with an evaluation and report from just one accredited ethics committee and the Spanish Agency of Medicines and Medical Devices (AEMPS). Previously they required authorisation from ethics committees at each participating hospital.

They also affect the make-up of research ethics committees, which from now on must have “at least one patient or person representing the best interests of the people taking part in the trial, protecting their rights and wellbeing”.

Additionally, the decree aims to promote public, non-commercial research by creating a “promoter of non-commercial clinical trials” to incentivise research in areas the pharmaceutical industry ignores, at universities (where there are powerful teams in areas that aren’t priorities for the market) and within the National Health System.

The project’s aim to make the process more transparent can be seen in the regulation of the Spanish Clinical Studies Registry (REec), which is already available online and allows anyone to see which clinical trials have gained authorisation in Spain and which centres are participating. All drug trials must appear on this registry, which is also open to any other sort of clinical trial.


20 January: The Glasgow Declaration continues to influence European dementia policy

On 20 January, Alzheimer Europe (AE)’s Glasgow Declaration was once again at the forefront of European dementia policy, during a debate at the Welsh Senedd (Welsh National Assembly) on Wales’ forthcoming National Dementia Strategy.

Welsh Labour politician Lynn Neagle commended Health and Social Services Minister Mark Drakeford (pictured) for signing the Declaration last year, which she said “commits to developing national strategies and firmly lays the next steps for tackling the dementia challenge.” The Minister himself said, of the new strategy itself, “We want to root it in the Glasgow Declaration and the lessons we can gain worldwide, and, by drawing on that widest possible range of expertise, to create a plan for dementia here in Wales that will be at the forefront of what is possible in a modern health and social care service such as ours, and rooted in that wider ambition to create a more compassionate and dementia-friendly society.”

The hope is to have the plan in place by end of 2016.


25 January: WHO launches Global Dementia Observatory, AE is involved

The World Health Organization (WHO) holds two Executive Board meetings and one Assembly every year. The 138th session of the WHO Executive Board took place in Geneva from 25 to 30 January. The agenda included the WHO strategy and plan of action on ageing and health which is relevant for dementia.

Dementia will be firmly on the agenda at the next WHO Board meeting in May where a resolution - led by Switzerland with support from around 12 to 15 other countries, including European, global and some developing countries - will set out political commitments for a future programme. This should lead to a strategy and action plan for dementia which will probably be completed by 2017 and will be presented in May 2017 at the World Health Assembly.

Another development from the WHO, resulting from the Ministerial Conference in March 2015 and the G7 meetings, is the Global Dementia Observatory (GDO). The GDO will be a knowledge hub for dementia, providing data analysis, epidemiological trends, policy formulation and adoption, country implementation through health and social care systems, partnerships and research.

The purpose is to increase countries’ capacity to systematically generate information and to use it for policy and practice, as well as to monitor progress within countries and globally.

The UK, Switzerland and Japan have provided funding for this and it is expected to be formally launched by the end of 2016.

Alzheimer Europe (AE) has been invited to work with the WHO on this initiative.


3 February: The Czech Republic has a National Dementia Plan

At a meeting on 3 February, the Czech government accepted the “National Action Plan for Alzheimer’s disease and similar diseases”, which will run from 2016 to 2019. The plan has 14 aims and 28 objectives. The Ministry of Health will play a key role in its implementation, in cooperation with the Ministry of Labour and Social Affairs and the Ministry of Education, Youth and Sports.

The Czech Alzheimer Society commented that, “although the plan is not very specific - more than half of the goals have no explicit dead-line, targets are not always measurable, and there is no budget agreed for the implementation” it welcomes the new plan and its symbolic meaning: “the government has declared that the situation of the people with dementia and those who care for them is worthy of government attention for the first time”.

4 February: Research arm of Ireland’s National Dementia Strategy launched, with EUR 4.5 million in funding

On 4 February the research arm of Ireland’s first National Dementia Strategy was launched, with some EUR 4.5 million in funding for seven new projects. This research will explore topics such as the use of home computer tablets for care management, dementia-friendly hospital design and the links between stroke and dementia.

Strong investment from the Health Research Board and The Atlantic Philanthropies has made it possible to fund these projects which aim to improve the quality of life for people living with dementia and those caring for them.

Welcoming the launch, Tina Leonard, head of advocacy at the Alzheimer Society of Ireland, said “ongoing investment is needed to ensure this future research talent is supported and to address the long-term sustainability of the partnerships and centres announced today as we are starting from a low base in terms of investment into dementia research,”

There are currently 48,000 people living with dementia in Ireland. This number is set to reach 68,000 by the end of the next government’s lifetime (2016-2021).

http://www.thefjournal.ie/dementia-research-2583156-Feb2016/?utm_source=shortlink

24 February: UK initiative urges people with dementia to consider joining research studies

People affected by dementia, particularly those in the early stages, are being urged to consider volunteering for research, to help vital new studies get off the ground. The call was launched on 24 February, the first anniversary of UK initiative Join Dementia Research, which allows people with and without dementia to find research studies in their area.

While Join Dementia Research has seen a great public response – with almost 16,000 people signing up in its first year – only around one in 10 of those currently registered with the service have a diagnosis of dementia and more people with diseases like Alzheimer’s disease are being asked to come forward.

Only one in three dementia research studies recruit enough volunteers within the first year, which can significantly slow down the progress being made towards better care, new treatments and ultimately a cure. Join Dementia Research was launched on 24 February 2015 as part of the Prime Minister’s Challenge on Dementia

Hilary Doxford, Vice-Chair of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) and World Dementia Council member, is involved in a study looking at brain inflammation as dementia develops. Ms Doxford said:

“I have enjoyed taking part in the study and love being involved in research. I am well looked after, I have interesting discussions, I gain an insight into the latest theories, I am aware of the latest results and it keeps my brain active. I also have a better understanding of my disease progression than I would otherwise have”.

Life Sciences Minister George Freeman MP said “I would encourage more people, especially those with dementia, to join this vital service so they too can help in our fight against this condition”.

Join Dementia Research is open to anyone over the age of 18 and people can act as a representative to register a loved one, including someone who has dementia finding it difficult to register themselves or manage their own account. Approved researchers looking for study volunteers can then use the service to look for people who match their study criteria and contact them to see whether they are interested in taking part. So far over 4,600 people have already taken part in research studies across the UK.

www.joindementiaresearch.nihr.ac.uk

25 February: World Dementia Council has a new Chair and a second member living with dementia

On 25 February, the World Dementia Council (WDC) re-formed at a meeting in London, becoming “truly globally representative and fully independent”.

The Council has expanded to “bring together the broadest range of influential global leaders with expertise and experience in dementia from all sectors”. Its aim, now, is “to challenge and support Governments, industry, NGOs, public sector, academia, the research community and people with dementia worldwide in a concerted effort” to address dementia.

World Dementia Envoy Dr Dennis Gillings handed over his post as Chair of the Council to Dr Yves Joannette, Scientific Director at the Canadian Institutes of Health Research (CIHR) Institute of Aging, and Vice-Chair, Raj Long, Senior Advisor at the Bill & Melinda Gates Foundation.

The WDC also welcomed a second member living with dementia, Kate Swaffer (pictured, front row, second from left). Ms Swaffer is Australian and Chair of Dementia Alliance International.

The first member of the WDC living with dementia is Hilary Doxford (pictured, front row, far left), Ms Doxford, who joined the WDC in January 2015, is also Vice-Chair of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD).

https://worlddementiacouncil.files.wordpress.com/2016/02/160224-wdc7-final.pdf

Science watch

25 January: Phase 1 trial announced for AD drug candidate for agitation

On 25 January, Alkermes plc announced the initiation of a phase 1 clinical study of ALKS 7119, an oral, investigational drug candidate being developed for the treatment of
agitation in patients with Alzheimer’s disease (AD) and other central nervous system (CNS) indications. The double-blind, placebo-controlled study will evaluate the safety and tolerability of single ascending doses of ALKS 7119 in approximately 60 healthy participants. ALKS 7119 is a new small molecule that acts on multiple key receptor systems in the brain.

http://www.reuters.com/article/alkermes-plc-idUSnBw255347a+100+BSW20160125

25 January: Study looks into eating abnormalities in frontotemporal dementia subtypes

A team of researchers at the Universities of Sydney and New South Wales in Australia has tried to determine the occurrence of eating abnormalities in subtypes of frontotemporal dementia (FTD) besides the already established behavioural variant of frontotemporal dementia (bvFTD). Their study, “Quantifying the Eating Abnormalities in Frontotemporal Dementia”, was published on 25 January in the journal JAMA Neurology.

“Abnormal eating behaviours” are present in up to 60% of patients with frontotemporal dementia (FTD), according to previous research and eating abnormalities are one of the main criteria to diagnose behavioural variant FTD (bvFTD). These include appetite changes, increased carbohydrate intake, changes in food preference, including increased sweets intake. These eating alterations have been also observed in patients with semantic dementia (SD).

Study lead Olivier Piguet and his colleagues compared patients with bvFTD and semantic dementia (SD) with patients with Alzheimer’s disease (AD) and a group of healthy control participants. Measured eating behaviour included energy, intake of sugar, carbohydrates, proteins and fat, as well as indices of metabolic health.

All 73 participants were assessed via clinical interviews, neurological examinations, cognitive assessments, and structural brain magnetic resonance imaging (MRI). Results revealed that the bvFTD group had higher abnormalities in appetite, eating habits, food preferences and swallowing, when compared with the AD group. The bvFTD and SD group revealed increased energy consumption. The bvFTD also had higher levels of carbohydrate intake compared to controls, and the SD group had significantly increased sugar intake. The SD group was found to have lower hunger and satiety scores compared with the bvFTD group.

Based on these results, Dr Piguet and colleagues indicate that abnormal eating behaviours are more obvious in patients with bvFTD and those with SD. However, eating abnormalities are not limited to increased appetite, but also involve higher intake of sugar and carbohydrates.

The researchers suggest that future studies should include actinography to understand caloric intake vs expenditure.


26 January: NHS Choices looks into second study finding AD “may have been spread during surgery”

The study in question was carried out by researchers from University Hospital Zurich and Medical University Vienna and was published in the online peer-reviewed journal Swiss Medical Weekly on 26 January.

The research was carried out after a previous study in 2015 unexpectedly found amyloid protein in brains of some people in the UK who had died of Creutzfeld Jakob Disease (CJD) after being infected by injections of contaminated human growth hormone.

It was a case-controlled study, involving post-mortem pathological investigations of the brains of patients who had died from CJD caused by brain surgery. CJD related to surgery is known as iatrogenic CJD, which is extremely rare, thanks to precautionary measures taken as a result of current medical knowledge.

The researchers carried out autopsies of seven people who died from CJD after a dural graft (procedure often used to repair severe head injuries and treat brain tumours). Unfortunately, in these seven cases, the dura was contaminated with the CJD prion. In five out of the seven cases, researchers also found amyloid beta proteins associated with Alzheimer’s disease. None of the brains studied showed signs of tau, the other protein linked to Alzheimer’s disease.

But could the grafting procedure have introduced amyloid beta protein, as well as prions? And could this have theoretically caused Alzheimer’s disease if they had not died of CJD? These were the two questions asked by NHS Choices, who looked into the headlines around - and the actual results of - this new study.

The researchers said: “The presence of amyloid beta pathology in young individuals who present with neither a family history of early-onset dementia or prominent AD-related tau pathology is highly unusual and suggests a causal relationship to the dural grafts.”

In other words, says NHS Choices, the researchers think it is “plausible” that the amyloid proteins in the brains had not arisen naturally as part of ageing, or because people had genes predisposing them to Alzheimer’s disease, but that they had been deposited in the brains during the dural graft surgery.

The study calls for a “critical re-evaluation” of decontamination procedures for surgical instruments and drugs derived from human tissue, to prevent possible contamination being passed on during medical treatment.

There are other possible explanations, however, points out NHS Choices: For example, “the head injury or brain tumour which led to the dural graft surgery could also have led to the presence of amyloid beta in the brain.”

NHS Choices concludes that while this latest research “adds some evidence to the possibility that amyloid beta proteins could have been passed on during certain types of treatment, which introduced substances derived from donor brains or pituitary glands into the body...these types of treatment are no longer used.” Dural grafting is now done using artificial material, not material derived from human brains, it points out to concerned readers.

NHS Choices stresses that “there is absolutely no need to worry about “catching” Alzheimer’s disease through day-to-day contact with people who have the disease, whether you are a carer or a family member.”

27 January: 1950s room created for personalised dementia care

A 1950s-themed “memory room” has been created to help nurses forge better relationships with patients living with dementia, and to offer more personalised care, reported UK magazine Nursing in Practice on 27 January.

Staff and volunteers at one of Lincolnshire Partnership NHS Foundation Trust’s (LPFT) dementia inpatient units, the Manthorpe Centre, transformed the interactive space, to be enjoyed by “dementia patients whose needs are too complex to be safely managed within the community”.

Liz Lester, occupational therapist at Manthorpe, who originally came up with the idea, said the room will help encourage patients to reminisce about their past lives so staff can get to know them better and deliver more personalised care.

“Dementia care is changing. In the past, the focus was very much on the disease and impairment, however, the aim now is to identify each patient’s strengths and remaining abilities and to adapt the environment to maximise these - the 1950s lounge is a way of doing this” Ms Lester commented.


27 January: Diabetes increases the risk of cerebrovascular but not Alzheimer’s pathology, study says

Diabetes has previously been linked to cognitive impairment and dementia, including Alzheimer’s dementia, in multiple studies of aging and cognition and is considered by many to be a risk factor for Alzheimer’s disease (AD). A new US-based study, published in Alzheimer’s & Dementia: The Journal of the Alzheimer’s Association, however, says that the relationship between diabetes and specific neuropathologic causes of dementia is incompletely understood. The study authors, led by Dr Erin L. Abner at the Sanders-Brown Center on Aging and Alzheimer’s Disease Center, University of Kentucky, set out to better understand this relationship.

The researchers evaluated the association between diabetes and infarcts, Braak stage, neuritic plaque score, and level of Alzheimer’s neuropathologic changes in 2,365 autopsied research volunteers. They found that when they looked at this large sample, they found that “brain infarcts were more common among people with diabetes compared to people without, but Alzheimer’s pathology was about the same in both groups”.

Others have made this observation before, but in much smaller samples. “Replicating this finding in a large sample is strong evidence that it is in fact cerebrovascular disease and not Alzheimer’s pathology that should be the primary concern among people with diabetes”, said Dr Abner.

“Diabetes is very likely an important preventable cause of cognitive decline and dementia, and we think most of this is due to its negative effects on the vasculature structures of the brain. It is unknown at this time what the effects of different management strategies might be on improving cognitive outcomes, but we think that patients who have well-controlled diabetes are likely better off than those who do not. If patients do not have diabetes currently, they should take steps to avoid it”.

Dr Abner stressed, however, that the study deals in population averages, which is to say, on average, a person with diabetes will develop cerebrovascular disease more often than Alzheimer’s disease. This doesn’t, mean that people with diabetes do not have to worry about Alzheimer’s disease, she concluded.

http://www.alzheimersanddementia.com/article/S1552-5269(16)30030-7/abstract

28 January: Study says sexual activity improves cognitive function in over 50s

Researchers at Coventry University in the UK have found that people over the age of 50, who engage in regular sex, appear to have sharper cognitive function.

Tests on older men and women revealed that those who enjoy intimacy are better able to recall lists and recognise patterns, both signs of healthy cognitive function. The study was published in the journal Age And Ageing on 28 January.

The research team asked more than 6,800 people from across England aged between 50 and 89 about their sex lives and set mental tests. Results showed that sexually active men scored higher by 23% on word tests and 3% higher on number puzzles than those who were not sexually active, while sexually active women did better than their counterparts who were not having sex, by margins of 14% and 2% respectively. Stronger performance persisted even when factors such as age, wealth and physical activity were taken into consideration.

The researchers suggest the results could be due to the release, during sex, of hormones such as dopamine and oxytocin, linked to feelings of reward, and so promoting memory and learning.

“Maintaining a healthy sex life in older age could be instrumental in improving cognitive function and well-being”, they commented.

https://ageing.oxfordjournals.org/content/early/2016/01/28/ageing.afv197.abstract?sid=5fbbc076-c5eb-485b-a7ed-a039395099

28 January: Blood pressure drugs may be a therapeutic target for AD

A team of researchers at Georgetown University Medical Center in the US has completed a study, showing the potential usefulness of a blood pressure drug candesartan - as well as other Angiotensin receptor blockers (ARBs) - for the early treatment of AD. The study, led by senior author Dr Juan Saavedra, was published online on 28 January in the journal Alzheimer’s Research and Therapy.

High blood pressure can destroy small blood vessels in the brain, including those that help with thinking and memory. Scientists have therefore speculated that controlling blood pressure through medication may help lower AD risk. Previous studies have tied delayed AD progression in
people with hypertension (high blood pressure) to treatment with ARB drugs.

One such study, carried out by Johns Hopkins Medical Institutions (JHMI) in 2013 and published in the journal Neurology, found that people over the age of 75 with normal cognition who used diuretics, ARBs and angiotensin-converting enzyme (ACE) inhibitors showed a reduced risk of Alzheimer’s dementia by over 50%.

In this latest study, researchers investigated whether candesartan - already approved by the U.S. Food and Drug Administration (FDA) - might have an effect on AD neuron cultures. When the drug was exposed to neurons with excessive glutamate - a trait that can speed up cell death in the early stages of AD - the scientists found that candesartan prevented glutamate-induced neuronal death.

They then conducted in-depth gene analyses of these results and found that the drug also prevented inflammation in neurons as well as other pathological processes, including the build-up of amyloid.

Lastly, the researchers compared gene expression in the neuron cultures with published gene databases of post-mortem brain tissue samples from patients with AD. They showed that the expression of 471 genes that were altered by excess glutamate in the lab culture were also altered in brain samples from those with AD.

“We hypothesise that candesartan, or other members of the ARB group, may not only slow progression of Alzheimer’s but also prevent or delay its development,” Dr Saavedra said. This is a very early-stage study, and much further study is needed before any solid conclusions can be drawn.


1 February: Researchers find connection between MCI risk and weight loss after midlife

Increasing weight loss per decade as people age from midlife to later life is associated with an increased risk of mild cognitive impairment (MCI), according to a study published online in the journal JAMA Neurology on 1 February.

Participants who developed MCI had a greater average weight change per decade from midlife than those who remained cognitively normal.

“These findings suggest that increasing weight loss per decade from midlife to late life is a marker for MCI and may help identify persons at increased risk for MCI”, the study concludes.

It suggests that dysfunctional production of hormones associated with dietary intake and energy metabolism or the effect of neuropsychiatric symptoms accompanying MCI and dementia, such as apathy and depression, on an individual’s appetite are possible causal explanations for the association.

Alternatively, it could be the result of shared aetiologies, they say, such as olfactory dysfunction associated with cognitive impairment affecting an individual’s smell and taste and decreasing appetite.

9 February: US pharmaceutical company announces three clinical trials for dementia with Lewy bodies

On 9 February Axovant Sciences, a US-based biopharmaceutical company focused on the treatment of dementia, announced details of three new clinical trials it is conducting to address cognitive, behavioural and functional aspects of dementia with Lewy bodies (DLB). Two out of the three studies were recently initiated and the third is expected to start later this quarter.

Axovant has initiated a 24-week double-blind, randomised, placebo-controlled Phase 2b study of RVT-101 as a potential DLB treatment. Daily doses of 35 mg and 70 mg of RVT-101 will be evaluated. The enrolment target is 240 patients and results are expected in 2017.

The Company has also initiated a double-blind, randomised, placebo-controlled, cross-over Phase 2 study in patients with DLB or Parkinson’s disease dementia, with visual hallucinations. The study is a pilot program with primary outcome measures focused on safety and secondary measures evaluating changes in the frequency and severity of visual hallucinations after 28 days of treatment. The enrolment target is 20 patients and results are expected in the second half of 2016.

Later this quarter a 4-week double-blind, randomised, placebo-controlled Phase 2 study will also begin, for patients with DLB with REM behaviour disorder. The enrolment target this third study is approximately 50 patients and results are expected in the first-half of 2017.

10 February: US study finds significant disparities in dementia risk between racial and ethnic groups

In the largest and longest study thus far of ethnic disparities in dementia risk, US researchers compared six ethnic and racial groups within the same geographic population and found significant variation in dementia incidence among them. The study results were published online in Alzheimer’s & Dementia: The Journal of the Alzheimer’s Association on 10 February.

The researchers, based at the University of California, San Francisco (UCSF), found dementia incidence to be highest in African Americans and American Indian/Alaska Natives, lowest among Asian Americans, and intermediate among the Latino, Pacific Island and Caucasian populations.

They found that dementia incidence over the study period ranged from an average annual rate of 26.6% for African Americans, and 22.2% for American Indians/Alaskan Natives, to 15.2% for Asian Americans. In between were Latinos and Pacific Islanders with an average annual rate of 19.6 %, and Caucasians with 19.3%.

Using cumulative risk estimates, researchers projected that among those who reach age 65 without signs of dementia, 38% of African Americans, 35% of American Indians/Alaskan Natives, 32% of Latinos, 30% of...
Caucasians, 28% of Asian Americans and 25% of Pacific Islanders would develop dementia in the next 25 years.

The study population included more than 274,000 inhabitants of northern California. The researchers used electronic health records covering patient visits over 14 years — from January 2000 through December 2013 — to identify participants diagnosed with dementia, as well as their race and ethnicity. The dementia diagnoses were Alzheimer’s, vascular dementia or non-specific dementia.

The researchers emphasise that while this study documents racial and ethnic disparities in dementia, the next step is to understand the mechanisms driving these inequalities.

http://www.alzheimersanddementia.com/jb/assets/law/Health%20Advance/journal/jul1/A2%20-2117.pdf

10 February: UK pharmaceutical company announces positive results from Phase 1b clinical trial for dementia and schizophrenia drug

On 10 February, UK-based pharmaceutical company Heptares Therapeutics – a wholly-owned subsidiary of the Sosei Group Corporation – announced positive findings from its Phase 1b clinical study with HTL9936. HTL9936 is the first selective muscarinic M1 receptor agonist to enter clinical development as a new treatment for cognitive impairment in patients with dementia and schizophrenia.

The Phase 1b precision medicine study involved 28 healthy older subjects on different doses of HTL9936, and was designed to test the effect of the drug on measures of brain activity, while simultaneously monitoring side effects.

The drug exhibited “robust and statistically significant changes in brain electrical activity” measured using multiple electroencephalography (EEG) biomarkers relevant to cognition, including effects on the P300 evoked response potential (p=0.0052). These pro-cognitive effects were seen “at low doses and low blood concentrations that were safe and well tolerated”.

http://jcmp.lifekk.eu

11 February: Dementia rate has fallen 44% since the late 70s, study finds

A new analysis of health records from thousands of people in the city of Framingham, Massachusetts in the US, has concluded that the incidence of dementia has fallen 44% since the late 1970s and early 1980s, with nearly all of that drop being among high school graduates. The study, led by Dr Sudha Seshadri, Professor of Neurology at the Boston University School of Medicine, was published in the New England Journal of Medicine on 11 February.

So many people are now approaching the age when dementia becomes a threat, and life-expectancy is increasing so rapidly that the decline in rates of dementia will not translate to an overall drop in the number of dementia cases, cautioned Dr Seshadri.

The Framingham Heart Study is based in a predominately-white Massachusetts town west of Boston, where thousands of residents have been closely followed by doctors since 1948. The new analysis looked at dementia rates in four 5-year blocks and used data from 5,205 individuals.

Dementia rates were 3.6% among people over 60 beginning in 1977, falling to 2.8% for the block of people who were over 60 beginning in 1986, then 2.2 % for the block starting in 1992 and 2.0% for the most recent block, from 2004 to 2008. This translates to reductions of 22%, 38% and 44% in the second, third and fourth period, respectively, compared to the rate in the early years.

Given that dementia caused by vascular diseases such as stroke accounted for much of the drop, the researchers thought this could be due to declines in rates of stroke, heart failure and atrial fibrillation, as well as better treatments for those conditions, “but none of these trends completely explain the decrease in the incidence of dementia.”

Alzheimer’s disease (AD) also showed a reduction, but it was not a dramatic one, and could have been a “statistical fluke”, they said.

Residents without a high school (secondary school) diploma showed no decline in dementia, perhaps because improvements in heart health were only seen among people who had graduated from high school, the team noted.

Dementia also tended to show up later in life as time went on, with the average age of diagnosis being 80 during the late 1970s and 85 in the most recent group.

"Rising educational levels might have contributed to the 5-year delay we observed in the mean age at onset of clinical dementia”.

It should be noted that one of the limitations of the Framingham Heart Study is that the participants are overwhelmingly of European ancestry, so these findings would need to be replicated in groups that include a larger number of participants of other races and ethnic backgrounds.


12 February: Immune system may play larger role in AD than thought

Another study into the role of immune cells in Alzheimer’s disease (AD) has concluded they may play a larger role than originally thought. The study, conducted by neurologists at the University of California, Irvine, the Sue & Bill Gross Stem Cell Research Center and the Institute for Memory Impairments and Neurological Disorders, was published online in the journal Proceedings of the National Academy of Sciences of the United States of America (PNAS) on 12 February.

The team of researchers, including Mathew Blurton-Jones, Assistant Professor of Neurobiology and Behaviour, worked with AD mouse models, genetically modified to lack these key immune cells in their blood. The mouse models developed amyloid brain plaques associated with AD much more quickly than other mice.

Microglia - immune cells that reside in the brain - attempt to clear amyloid build-up in the brain, but in AD they appear not to be able to do this effectively. While many studies have explored the role of microglia in AD, very few
researchers have asked whether a different set of immune cells, called T-cells and B-cells, might also impact on AD. T-cells and B-cells reside outside the brain and play a big role in autoimmune diseases.

To test this idea, Dr Blurton-Jones and his colleague, doctoral student Samuel Marsh bred genetically modified AD mouse models mice to lack three key immune cell types: T-cells, B-cells and NK-cells. Six months later, when the brains of these mouse models were compared to those of AD mouse models with intact immune systems, the scientists found a more than twofold increase in beta-amyloid plaque accumulation.

"We were very surprised by the magnitude of this effect," said Dr Blurton-Jones. "We expected the influence of the deficient immune system on Alzheimer’s pathology to be much more subtle." To understand how the loss of these immune cells was increasing beta-amyloid, the researchers examined the interactions between these peripheral cells and microglia within the brain.

"We found that in Alzheimer's mice with intact immune systems, antibodies - which are made by B-cells - accumulated in the brain and associated with microglia. This, in turn, helped increase the clearance of beta-amyloid."

To further confirm the importance of this interplay between immune cells in the blood and those in the brain, the researchers transplanted healthy bone marrow stem cells into the immune-deficient AD mouse models. Since T- and B- and NK-cells develop from bone marrow stem cells, this transplantation led to a reconstitution of the missing immune cells. This allowed the B-cells to produce antibodies that once again reached the brain and aided microglia in eradicating the beta-amyloid.

"We know that the immune system changes with age and becomes less capable of making T- and B-cells," Dr Blurton-Jones said. "So whether aging of the immune system in humans might contribute to the development of Alzheimer's is the next big question we want to ask."

http://www.pnas.org/content/early/2016/02/12/1525466113.abstract?sid=32f0662-49a-4d65-9b32-261b7ad7779d

12 February: Bexarotene may help protect against AD, worm study finds

Research carried out by an international team of researchers from the University of Cambridge, UK Lund University, Sweden and the University of Groningen, Netherlands has concluded that cancer drug bexarotene could potentially be used to help protect against Alzheimer’s disease (AD). The study, which was done using nematode worms, was published on 12 February in the journal Science Advances.

The researchers used bexarotene to target the first step in the chain reaction that leads to brain cell damage in AD, administering it to nematode worms that had been genetically programmed to develop AD symptoms.

The drug was shown to interfere with the first steps in the process of amyloid plaque formation and when given early enough, bexarotene was able to completely suppress the formation of amyloid plaques in the worms.

NHS Choices commented that this study has limitations, in that it only provides very early-stage findings, which are so far in nerve cells and a short-lived worm model. As worms are much simpler organisms than humans, the next step would be to test this in more complex animal models such as mice, before considering testing in humans.

"Bexarotene has been investigated before in animals, with mixed results. The drug only appears to slow the formation of beta-amyloid aggregates, so even if it does show an effect in further studies, it may not be able to prevent AD completely...It’s also likely bexarotene would need to be refined in some way to reduce its side effects, before it could ever be used", concludes NHS Choices’ analysis of the study.

http://advances.sciencemag.org/content/2/2/e1501244

15 February: Study shows possible link between proton pump inhibitors and dementia – NHS Choices is sceptical

A study carried out by researchers at the German Centre for Neurodegenerative Diseases in Bonn has shown a statistical association between the use of drugs called proton pump inhibitors (PPIs) and dementia risk. Using insurance data from 74,000 people over the age of 75, gathered between 2004 and 2011, the researchers found that those taking PPIs – normally used for gastroesophageal reflux and peptic ulcers - were 44% more likely to have dementia than those who did not take the drugs. The study was published online in the journal JAMA Neurology on 15 February.

PPIs work by restricting the amount of acid produced in the stomach. The study only looked at PPIs, and did not extend to antacids and other indigestion treatments.

The authors admitted their study had limitations, because they were not able to separate out different risk factors for dementia from their data. “The possible underlying causal biological mechanism has to be explored in future studies”, they conceded.

NHS Choices commented that it would be inaccurate to draw the conclusion that this “44% higher risk of developing dementia” was down to the PPIs:

“There are many possible explanations. For a start, the groups weren’t very similar. Those taking PPIs had poorer health, and were more likely to be taking a number of medicines and have conditions linked to a higher risk of dementia, such as diabetes and heart disease.”

NHS Choices advised people taking prescribed PPIs not to stop taking them on the basis of this inconclusive study.


24 February: Keeping brain active may delay physical symptoms of AD in those with ApoE4 gene

Research published on 24 February in the journal Neurology suggests that staying in school for longer and keeping the brain active may help to delay some of the physical changes
that occur in Alzheimer’s disease (AD), for people carrying the gene ApoE4.

393 people aged over 70 without dementia were divided into groups based on their education, the extent to which they kept mentally active in middle age, and whether they had the ApoE4 gene, which is associated with higher risk of AD. The team of researchers, from the Mayo Clinic, Minnesota, US looked for signs of neurodegeneration often associated with AD, including build-up of amyloid protein clumps.

Those who had the ApoE4 gene, along with at least 14 years of education, and who kept mentally active in mid-life had less amyloid build-up in their brains. For people without the ApoE4 gene, education and mental activity appeared to have little effect on levels of neurodegeneration.

This research supports previous findings that indicate more education and keeping the mind active in mid-life may help to reduce the risk of dementia for some people. The underlying reasons for this are still unclear, but this study suggests genetics may have a part to play.

It is important to note, however, that the study were only looked at physical changes in the brain and did not include other important aspects of dementia such as difficulties with memory and thinking. It also did not take into account those who went on to develop AD.

http://www.neurology.org/content/early/2016/02/24/WNL.0000000000002490.full?rss=1

25 February: Study pinpoints locus coeruleus as starting point of AD

A recent study pinpoints the locus coeruleus – a region in the brain, which produces the hormone and neurotransmitter norepinephrine - as the starting point of Alzheimer’s disease (AD). The study, conducted by researchers at the University of Southern California and published in the March 2016 edition of the journal Trends in Cognitive Sciences, also found evidence that tau protein may be visible in this region as early as young adulthood.

The locus coeruleus is small, but interconnects with a lot of the body’s processes - including the circulatory and cardiovascular systems, attention, memory, cognitive function, and identifying new information. It is also involved in the physiological responses to stress and anxiety, and its main function is producing norepinephrine, which plays a role as both a neurotransmitter and hormone during “fight-or-flight” response to stressful situations. Norepinephrine can impact heart rate, glucose release, and blood flow as it is pushed from the locus coeruleus to the spinal cord, cerebral cortex, and limbic system.

According to Mara Mather, lead author of the study, production of norepinephrine is triggered when someone is mentally engaged or challenged by an intellectual activity - anything from reading a book, doing a word puzzle, or tackling a difficult problem-solving or musical task. Activation of the locus coeruleus-norepinephrine system by doing new things and through mental challenges throughout life may contribute to cognitive reserve, she said.

http://www.cell.com/trends/cognitive-sciences/fulltext/S1364-6613%2816%2900018-8

Science – behind the headlines

“Algae linked to rare neurodegenerative condition similar to AD” - Professor Magda Tsolaki comments

Professor Magda Tsolaki, MD, PhD, was born in Thessaloniki, Greece in 1954. She has been a Professor of Neurology since 2010, a Neuropsychiatrist since 1983, and has worked at the Aristotle University of Thessaloniki since 1982, as well as at the 3rd Department of Neurology of Aristotle University, Thessaloniki since 1988.

Find out more about Prof. Tsolaki here:

http://alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Expert-Advisory-Panel/Members/Magda-Tsolaki

Just how important do you think this story is?

I think that this information can add something new to our knowledge about the pathogenesis of Alzheimer’s disease (AD). The media got it right in thinking these results are important.

What happens next?

The next steps are:

To examine other areas of our planet where dementia is a common disease to see if this or other similar toxins are present.
To measure this toxin - or other toxins which could produce amyloid plaques and neurofibrillary tangles - in blood samples of patients with neurodegenerative diseases.

To investigate whether this toxin is present in other food types.

What might be the impact of the study in question?

Diet is a big issue for humans. It may prevent AD or Parkinson’s disease (PD), or it may be the cause. We need to do more research about the correlation between diet and neurodegeneration.

The study is important because it also suggests a protective strategy: adding L-serine to the diet can reduce the risk of disease, but the media did not report on this idea.

Link to original AE article on 20 January 2016:
http://alzheimer-europe.org/News/Science-watch/Wednesday-20-January-2016-Algae-linked-to-rare-neurodegenerative-condition-similar-to-AD/

“Traces of fungus found in AD brains raises questions” - Dr José L. Molinuevo comments

The work and research activities of Dr José L. Molinuevo (MD, PhD), neurologist, are related to neurodegenerative diseases, mostly Alzheimer’s disease (AD) and related disorders. His MD career was performed at the University of Valencia, his neurology training at the Hospital Clinic de Barcelona, and his PhD, on Parkinson’s disease (PD) was completed at the University of Barcelona. Nowadays, he directs the Alzheimer’s disease and other cognitive disorders unit at the Hospital Clinic de Barcelona, which includes a genetic counselling program for monogenic dementias (PICOGEN). He is also the Scientific Director of the BarcelonaBeta Brain Research Centre of the Fundación Pasqual Maragall.

Find out more about Dr Molinuevo here:
http://alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Expert-Advisory-Panel/Members/Jose-Luis-Molinuevo

Just how important do you think this story is?

The hypothesis of an infectious origin of Alzheimer’s disease (AD) is not new. There is extensive literature linking various infectious agents such as herpes and some spirochetes with AD. For example, in 2014, there were 80 scientific publications on this topic. However, in this recent publication in Scientific Reports, different brain areas in AD brains were shown to have fungus, which is responsible for the revival of this discussion, generating new questions and hypotheses.

What happens next?

This finding should be confirmed in independent populations with a methodology that allows the identification of a potential infectious agent with greater specificity, as well as in groups of patients with specific risk factors. In addition, there are many uncertainties surrounding the finding that should be clarified before advancing with this hypothesis.

The role of infections in the genesis of AD colludes with another recent hypothesis attributing anti-microbial properties to the beta amyloid peptide, intimately involved in the pathophysiology of AD. According to this hypothesis the physiological role of the beta amyloid peptide would be to protect against infections, and its appearance would be secondary to the entry of infectious agents into the central nervous system. This hypothesis has somehow been supported by the fact that patients with dementia associated to HIV infection have unusual accumulations of brain amyloid for their age.

Nevertheless, before concluding that AD is caused by an infection, we should be able to answer a series of questions that bring out both the limitations and the need for new data and evidences to complete existing work, such as: Is the material detected in the brain really from fungus? Is there any data suggesting that there is an active infection? Has this study been replicated in other laboratories? If there is really fungal material, is this the cause or the consequence of the disease?

The question of whether the material detected in the brains of patients is a fungus is not trivial. The reason being that the method used to detect fungal material is non-specific, which means it can also identify other molecules that do not come from a fungus, such as polysaccharides and fibrillar material associated with AD, which may be similar to the fungal hyphae.
To be really certain that the material can be linked to a fungus, more complex methods such as the use of electron microscopy, which allows us to see in more detail and with more clarity, and specific antibodies, which only bind to specific fungal proteins, should be used. It is also important to confirm that in the brain area around the potential infectious agent, there are signs of inflammation, meaning that the fungus is not just a bystander. With regards to the need for replication, this is an imperative in science and medicine. At present, some pathologists say they have never detected fungi in the brains they have analysed, while acknowledging that certain methods to detect them have not been used.

After confirming both the detection of the fungal material and the generation of inflammation around it, we will still have to elucidate whether the “fungal infection” is the cause of AD, or its consequence. These infective agents may appear in the brain due to immune decline caused by age or increased permeability of the blood-brain barrier, which protects the brain from outside - a characteristic of AD.

From another perspective, as I mentioned earlier, many infectious agents have been suggested to be associated with AD in the past. This fact, together with the one showing that in HIV-associated dementia amyloid plaques are also detected, raises the possibility - yet to be proven – of the existence of a link between infective agents and CNS (central nervous system) amyloid production.

We know that the amyloid protein has been associated with AD and may be present in the brain many years before symptoms appear, generating structural and functional changes in the brains of people who are in the preclinical phase of the disease, as we have shown in recent published work.

We therefore might ask: Could environmental and external agents, such as an infective agent, have a precipitating role and facilitate the deposition of a protein such as amyloid, which in turn would kick-start the degenerative process? Hence, both scenarios could be complementary; the infectious agent would be the factor initiating the accumulation of amyloid, which would be enhanced by other causes related to aging, such as decreased amyloid removal. The imbalance generated between amyloid production and removal would trigger the neurodegenerative cascade.

**What might be the impact of the study in question?**

The possibility of an infectious agent initiating the pathophysiology of AD remains to be proven, since there are a number of questions that remain to be answered. In this sense, the possibility that AD may be infective is far from real, even if an infectious agent had a role in the genesis of the disease. We have to remember that the disease has a window period of 15-20 years, during which the brain is showing clear signs of the disease pathology, such as the presence of amyloid, without manifesting any symptoms. In this context, the potential role of infection would be to facilitate the process of accumulation of amyloid, not to "transmit" or "cause" the disease, since the accumulation of amyloid will also depend on other factors, such as age, operation of removal systems (its clearance), presence of other risk factors, etc.

If it is eventually demonstrated that infections of the central nervous system have a pathophysiological role, this would generate new therapeutic approaches but will not invalidate current prevention therapeutic methodologies. Since the period between amyloid accumulation and the onset of symptoms is greater than a decade, acting on the amyloid protein may still be a valid preventive approach.

Link to original AE article on 15 October 2015:


---

**Living with dementia**

**23 February: Nina Baláčková, EWGPWD member, writes about Prague Memory Festival**

When I heard about increasing knowledge about dementia in other countries, I wished to have more activities here in the Czech Republic - especially around World Alzheimer’s Day in September.

For many years there were “Memory Weeks”: In various places around our country, people could take tests for their memory and materials about dementia were distributed. These events were organised by the Czech Alzheimer Society.

I was pleasantly surprised last September in Prague. There was a one week “memory festival”. In that time, people could come to the small theatre every evening to see films such as “Vergiss mein nicht”, “Terry Pratchett: Choosing to Die” and “Alda”, or theatre performance such as “Six Billion Suns”. I had the privilege, some years ago, to collaborate with young people from the theatre on that performance. I shared my opinions and experiences of my own dementia with them.

After this performance there were discussions between Dr Jarolimová, the actors, the producer and myself. After films there were discussions too.

During the festival, people were able to test their memory, like in previous years. They could also speak about their problems in this area with specialists. There was a lot of interest in this festival and I am really grateful for it!

Nina Baláčková, Member of EWGPWD

**New publications and resources**

**27 January: EUPATI launches educational toolbox on medicines R&D**

On 27 January, EUPATI launched a new toolbox to help patients make meaningful contributions to discussions on drug development and patient advocacy.
The toolbox is a comprehensive, self-explanatory, educational resource that has been built so that learning about medicines research and development (R&D) can be supported, developed and shared by patient advocates. It makes educational material available to a much wider audience of patient representatives, individual patients and anyone with an interest in medicines R&D.

The toolbox is available in six languages. It contains more than 3,000 items including fact sheets, graphics, slideshows, videos, recorded webinars and print-ready materials for public use.

EUPATI is a five-year multi-stakeholder project funded through the Innovative Medicines Initiative (IMI). It brings together European leaders in patient communities, universities, not-for-profit organisations and pharmaceutical companies.

https://www.eupati.eu/

3 February: WHO Kobe launches set of core indicators for age-friendly cities

A new publication from the World Health Organisation (WHO), “Measuring the age-friendliness of cities: a guide to using core indicators”, provides technical guidance on selecting and using core indicators for establishing baselines, setting targets, and monitoring and evaluating Age-friendly City initiatives. The guide is designed to enable comparisons, but also adaptations to various local contexts, depending on each one’s objectives.

This new WHO guide offers a framework and a set of core and supplementary indicators to inform the selection of a local indicator set to monitor and evaluate progress in improving the age-friendliness of urban environments.

The objectives of this Guide are:

- To provide structured guidance on selecting indicators of the age-friendliness of a city.
- To present a set of indicators which are suggested for use in measuring the age-friendliness of a city.
- To support local efforts to develop relevant and appropriate indicators of the age-friendliness of a city.

The guide also includes references and additional resources, such as examples of local initiatives to develop indicators for measuring the age-friendliness of communities.

The guide was developed by the WHO Centre for Health Development in Kobe, Japan, in collaboration with the WHO Department of Ageing and Life Course. It reflects inputs obtained through expert consultations, field surveys and pilot tests. The guide is intended for use not only by members of the WHO Global Network of Age-friendly Cities and Communities (GNAFCC), but also by other communities that are engaged in or interested in similar efforts.

The guide is available here in English, French, Spanish and Chinese.
### AE Calendar 2016

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE-representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>29 February - 2 March</td>
<td>AE Board meeting, Company round table and Public Affairs Meeting (Luxembourg, Luxembourg)</td>
<td>AE Board, members and staff</td>
</tr>
<tr>
<td>3-4 March</td>
<td>Joint Action on Dementia kick-off meeting (Luxembourg, Luxembourg)</td>
<td>Jean</td>
</tr>
<tr>
<td>8-9 March</td>
<td>Patients’ and Consumers’ Organisations Working Party of European Medicines Agency (London, United Kingdom)</td>
<td>Jean</td>
</tr>
<tr>
<td>10 March</td>
<td>Meeting of EPAD WP6 team (Luxembourg, Luxembourg)</td>
<td>Jean, Kate, Alex</td>
</tr>
<tr>
<td>10 March</td>
<td>Inaugural Conference of the European Institute for Innovation through Health Data (“HD”) (Paris, France)</td>
<td>Vanessa</td>
</tr>
<tr>
<td>14 March</td>
<td>AETIONOMY Steering Committee Meeting (Bonn, Germany)</td>
<td>Ana</td>
</tr>
<tr>
<td>14-16 March</td>
<td>EMIF General Assembly meeting (Budapest, Hungary)</td>
<td>Alex</td>
</tr>
<tr>
<td>16 March</td>
<td>EFPIA Think Tank (Brussels, Belgium)</td>
<td>Vanessa</td>
</tr>
<tr>
<td>21-23 March</td>
<td>EPF Annual General Meeting (Brussels, Belgium)</td>
<td>Vanessa</td>
</tr>
</tbody>
</table>

### Conferences 2016

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>9-12 March</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</td>
<td>The 10th World Congress on Controversies in Neurology (CONy), <a href="http://www.comtocmed.com/cony">http://www.comtocmed.com/cony</a></td>
<td>Lisbon, Portugal</td>
</tr>
<tr>
<td>9-10 May</td>
<td>Living well with (out) dementia, <a href="http://english.eu2016.nl/latest/events/2016/05/09/living-well-without-dementia">http://english.eu2016.nl/latest/events/2016/05/09/living-well-without-dementia</a></td>
<td>Amsterdam, Netherlands</td>
</tr>
<tr>
<td>28-31 May</td>
<td>2nd Congress of the European Academy of neurology, <a href="http://www.eaneurology.org">www.eaneurology.org</a></td>
<td>Copenhagen, Denmark</td>
</tr>
<tr>
<td>16-17 June</td>
<td>Grand Designs, “Are we there yet?”, <a href="http://www.dementiaconference.com/">http://www.dementiaconference.com/</a></td>
<td>Sydney, Australia</td>
</tr>
<tr>
<td>30 June-2 July</td>
<td>4th International conference on vascular dementia</td>
<td>Valencia, Spain</td>
</tr>
<tr>
<td>24-27 July</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 August-2 September</td>
<td>10th International Conference on Fronto-temporal Dementias, <a href="http://www.sctd2016.de/">http://www.sctd2016.de/</a></td>
<td>Munich, Germany</td>
</tr>
<tr>
<td>6-9 September</td>
<td>2016 IPA International congress, <a href="http://www.ipa-online.org">www.ipa-online.org</a></td>
<td>San Francisco, USA</td>
</tr>
<tr>
<td>29 September-1 October</td>
<td>9th Conference of the German Alzheimer’s Association (DAI(z)) on “Dementia. Looking at diversity”, <a href="http://www.demenz-kongress.de">www.demenz-kongress.de</a></td>
<td>Saarbrücken, Germany</td>
</tr>
<tr>
<td>5-9 October</td>
<td>Croatian Congress on Alzheimer disease with International participation (CROCAD 16), <a href="http://www.alzheimer2016.com/">http://www.alzheimer2016.com/</a></td>
<td>Tulepi, Croatia</td>
</tr>
<tr>
<td>31 October-2 November</td>
<td>26th Alzheimer Europe Conference (26AEC) on “Excellence in dementia research and care”</td>
<td>Copenhagen, Denmark</td>
</tr>
<tr>
<td>9-11 December</td>
<td>2016 IPA Asian regional meeting, <a href="http://www.ipa-online.org">www.ipa-online.org</a></td>
<td>Taipei, Taiwan</td>
</tr>
</tbody>
</table>
26th Alzheimer Europe Conference
Excellence in dementia research and care
Copenhagen, Denmark
31 October – 2 November 2016
www.alzheimer-europe.org/conferences

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.