WELCOME!

I hope that 2017 has begun as successfully for you all as it has for us at Alzheimer Europe. I am delighted to announce that the year began with confirmation that we are now an official member of the European Disability Forum (EDF)! We look forward to working together with the EDF and also to examining, together with our Ethics working group and members of our European Working Group of People with Dementia (EWGPWD), the ethical implications of recognising dementia as a disability.

I am also pleased to announce some team changes to start the New Year. We have welcomed three new colleagues: Policy Officers Christophe Bintener and Cindy Birck, and Administrative Assistant Ute Corail. I also regret to announce the departure of Alex Teligadas. Alex joined the team in 2011 and served as Communications Officer and then as Director for Communication and Editor of the Dementia in Europe magazine. I would like to thank him for his outstanding contributions and wish him every success in the future.

On the subject of changes this month, you may have noticed that our newsletter has had a makeover. We hope you like the fresher, more modern look and will find both the email template and the PDF document even more user-friendly than the previous version.

It has been a good month in the field of dementia policy, with an exciting development at the end of January concerning the WHO Global Action Plan on dementia, which has moved a step closer to approval during the 140th session of the WHO Executive Board in Geneva. We were also interested to read that another European Parliament Motion for Resolution has been launched on the subject of advancing research into an effective treatment for Alzheimer’s disease. We will keep a close eye on any progress. Also on the European front this month there has been more change afoot, with Malta assuming the rotating EU Presidency as of 1 January and later in the month, the European Parliament electing Antonio Tajani as its new President.

Last but not least, work has already begun towards our 27th Annual Conference (27AEC), taking place this year in Berlin from 2 to 4 October. Last year’s conference in Copenhagen was attended by over 700 delegates and if you were among them, you may be interested to know that photos, videos and presentations are now available on our website, in the “Conferences” section. I hope you will enjoy a look back at some of the great memories from 26AEC and I wish you all an excellent February!

Jean Georges
Executive Director
1 January: Alzheimer Europe is a member of the European Disability Forum

Alzheimer Europe (AE) is delighted to announce it has joined the European Disability Forum (EDF) as an ordinary member, as of 1 January.

The EDF is an independent NGO that represents the interests of 80 million people with disabilities in Europe and brings together representative organisations of persons with disabilities from across Europe.

AE will contribute to working groups at EDF and participate in meetings and the general assembly

This year as part of its work plan AE will be looking at the ethical implications of recognising dementia as a disability.

http://www.edf-eph.org/

12 January: AE and the EWGPWD participate in the 1st INDUCT school

INDUCT is a European project (Marie Skłodowska Curie Action) aimed at developing a multi-disciplinary, inter-sectorial educational research framework for Europe to improve technology and care for people with dementia. The project provides a training programme for 15 Early Stage Researchers (ESRs) to acquire a deep understanding of the nature of dementia and needs in relation to the use of technology and to equip them with the right skills needed for work in academia, industry or the health and social sector.

The 1st INDUCT School took place during the week of 9-13 January in Maastricht, The Netherlands. Chris Roberts and Alv Orheim, Vice-Chairs of the European Working Group of People with Dementia (EWGPWD), together with Alzheimer Europe (AE) Officer Ana Diaz, participated in the school on 12 January.

Chris and Ana gave a speech on the topic of “Involving people with dementia as advisors in Alzheimer Europe’s research and activities”. In their speech, Ana and Chris emphasised the challenges but also important benefits of involving people with dementia in research. Chris also referred to his personal experience of living with dementia and to how research can give hope to people with dementia.

Chris and Alv participated in the meetings of Work Packages 4 and 5, where they provided feedback to the ESRs on their planned studies.

https://www.dementiainduct.eu/

15 January: Photos and videos from 26th AE conference are online

The 26th Alzheimer Europe Conference (26AEC) on “Excellence in dementia research and care” was held on 31 October - 2 November 2016 in Copenhagen under the Honorary Patronage of Her Royal Highness Princess Benedikte of Denmark, who was also the first speaker at the Opening Ceremony.

Photos, videos and presentations (where approval has been received from the speakers) from the conference are now available on our website:

http://www.alzheimer-europe.org/Conferences/Previous-conferences/2016-Copenhagen

15 January: Alzheimer Europe welcomes another new colleague

As of 15 January, Alzheimer Europe (AE) is pleased to welcome another new colleague to its Luxembourg office; Administrative Assistant Ute Corail. Ute will offer administrative support to the Executive Director and Board of Alzheimer Europe.

Ute completed her master’s degree in International Management in France 15 years ago and has worked in Luxembourg since, for various international companies.

She can be reached at ute.corail@alzheimer-europe.org

On 1 January, AE welcomed two other new colleagues, Project Officers Christophe Bintener and Cindy Birck.

Finally, AE regrets to announce the departure of Alex Teligadas. Alex joined Alzheimer Europe in September 2011 and served as Communications Officer until January 2014, when he took on the role of Director for Communication and became the Editor of the Dementia in Europe magazine. We would like to thank him for his outstanding contributions and wish him every success in the future.
15 January: AE contributes to EPF roadmap towards inclusion of vulnerable groups in patient organisations

Alzheimer Europe (AE) is delighted to have been involved in a new publication from the European Patients’ Forum (EPF) – a “roadmap towards inclusion of vulnerable groups’ perspective within patients’ organisations”.

Seven volunteers from EPF membership, including AE Director for Projects Dianne Gove and Policy Officer Vanessa Challinor, participated in the task force, which worked on the publication during 2016.

The aim of the roadmap, published on 15 January 2017, is to raise awareness and foster reflection and action on inclusiveness in the patient movement, and to support patient organisations’ advocacy for the rights and specific needs of all groups of patients in an inclusive way within the EU.


EU PROJECTS

9-10 January: Members of the ethics work packages for EPAD and AMYPAD meet in Cambridge

On 9 and 10 January, members of the work packages for the EPAD (European Prevention of Alzheimer’s Dementia) and AMYPAD (AMYloid imaging to Prevent Alzheimer’s Disease) projects met in Cambridge, UK to discuss ongoing work to provide ethics guidance for the two projects.

Richard Milne presented the preliminary findings from a related study, which explored attitudes towards the communication of various kinds of risk status linked to Alzheimer’s dementia.

Members of the group discussed plans for work related to the two projects and emphasised the need to progress with the setting up of the participant panel to ensure that research participants have the opportunity to contribute towards improving the experience of research participants involved in these studies.

Director for Projects Dianne Gove represented AE at this meeting.

The EPAD project has received support from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 115952. The Joint Undertaking receives support from the European Union’s Horizon2020 research and innovation programme and EFPIA.

9-13 January: INDUCT project hosts first ever Winter School in Maastricht

From 9 to 13 January, fifteen Early Stage Researchers from the INDUCT project (Interdisciplinary Network for Dementia using Current Technology), along with their respective supervisors and second-level partners, met in Maastricht for the first of five training schools. Funded through the H2020 Marie Skłodowska Curie Actions-Innovative Training Networks, INDUCT is aimed at developing a multi-disciplinary, inter-sectoral educational research framework for Europe to improve technology and care for people with dementia, and to provide the evidence to show how technology can improve the lives of people with dementia.

Various interactive workshops on topics such as media training and the MRC Framework were held throughout the week, as well as lectures from Alzheimer’s Disease International and the World Health Organisation (WHO) on developments in global dementia policy. Participants were also able to learn from the Dutch companies Silverfit and Betawerk about the types of technology they have developed as solutions for healthcare.

Finally, Chris Roberts and Alv Orheim from Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) provided participants with an insight into their experiences of taking part in dementia research, as well as a number of helpful strategies for involving people with dementia in research.

http://www.dementiainduct.eu/

9-23 January: MinD project members meet in Berlin for data analysis

The latest MinD project visit took place in Berlin and was hosted by St Hedwig Kliniken, Alexaner Krankenhaus Hedwigshöhe (Prof. Dr. med. Vjera Holthoff-Detto). This time, the visit really centred on interview analysis and paper writing.

The interviews coded and analysed during this visit were conducted in the autumn of 2016 in the Netherlands, and involved people with dementia and their carers. Analysing the data was a very insightful journey, as it allowed team members to actually ‘step into the shoes’ of people with dementia and their carers, and thus to get an insider perspective.
Apart from getting to know about the struggles and joys they encounter during daily activities (such as shopping or riding a bike) and social interactions (such as visiting neighbours and meeting others at the supermarket), what emerged as really important for people with dementia and their carers in experiencing and coping with dementia was the social-psychological factors such as personality, social support, empathy, and openness towards others.

For instance, a strong need for control makes it difficult to hand over control as a person progresses through the stages of dementia, and might bring about additional marital problems between partners. Openness and willingness to talk about dementia also surfaced as crucial - that is, to experience social support in one’s environment (rather than just within the walls of one’s own house). Additionally, the interviews showed examples of cases in which an unwillingness to let other people know were very energy-consuming, aggravating fatigue and weariness.

“These are just a few examples of what the interviews brought to the fore, but it does show why it is so important to conduct them and give a voice to people with dementia”, commented project leader Kristina Niedderer.

Interview analysis will continue, and results from the Dutch as well as the German and Spanish data collection will be compared to see how the German, Dutch, and Spanish interviews differ and/or overlap. Are there cultural differences in terms of, for instance, social and professional support? Do the same problems and issues in activities and social interactions arise? And what about support tools people use? Things mentioned during the interviews varied from large scale calendars, print-outs of pictures of products to be bought at the supermarket, to a newspaper on the table throughout the day to tell date and time.

MinD continues in Brisbane, Australia, where the diaries that complemented the interviews will be analysed. What will they reveal about people with dementia and their ways of coping? Together with the interviews and focus groups (one of them conducted in Berlin during the visit by the project’s Berlin hosts), they will provide the much-needed basis to enter the design phase of MinD.

13 January: AMYPAD project presented at two international conferences

The Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) project, which began its activities on 1 October 2016, is delighted to have been invited to two recent international conferences. Members of the project consortium gave two poster presentations, at the following events:


The focus of the Lancet Neurology Conference in London was prevention and early diagnosis of neurodegenerative diseases. The objectives and design of both AMYPAD and its sister project EPAD were introduced to the scientific community, who welcomed with great interest and enthusiasm the efforts of identifying a trial-readiness cohort for secondary prevention of Alzheimer’s disease (AD). The need to find new and more effective ways to identify subjects at high risk of developing Alzheimer’s dementia before they actually experience the clinical symptoms was underlined throughout the talks, and the level of commitment from both EPAD and AMYPAD to those objectives was demonstrated to participants at the congress.

The “Amyloid imaging to prevent Alzheimer’s disease” project aims to improve the diagnostic workup of patients suspected to have AD and their management. The partners aim to improve knowledge of the natural history of AD in a pre-symptomatic stage, in order to better select patients for trials. In addition, they will monitor changes in beta amyloid deposition in the brain, in order to quantify the impact of novel therapies.

For more information about the project visit: www.amypad.eu

Pictured: Silvia Ingala from VUmc with the poster presentation at The Lancet Neurology Conference.

The AMYPAD project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 115952. The Joint Undertaking receives support from the European Union’s Horizon2020 research and innovation programme and EFPIA.

16 January: EMIF Data Catalogue extends access to European Medical Research Community

On 16 January, the European Medical Information Framework (EMIF) announced it has extended access to its EMIF Data Catalogue, making it available to others within the research community. This development is linked to its mission to improve identification, access and assessment, and the (re)use of health data within the European Union.
The Catalogue will allow users to explore the population-based and cohort-derived data sources, who are partners within EMIF and have consented to provide such information for the purposes of researchers wanting to explore potential data partners for studies. Currently 14 population-based and 46 cohort-based data partners are contained within the Catalogue, from across 14 countries.

The Catalogue in its current form provides initial information, but EMIF expects to see further development and expansion of capabilities to assist users to investigate data sources.

This is the first EMIF platform tool with wider access, but in the coming, final year of the programme there are plans to deploy platforms for researchers to be able to go beyond the Catalogue phase, right through suitability evaluation and ultimately conducting studies with data source collaborators.

EMIF hopes that extending access the first tool of the EMIF platform in this way will be a significant asset to the EU research community, and very much looks forward to its continued development and use, eventually within a broader research platform and communities.

For further information about accessing the Catalogue, and for any queries/feedback, please visit: http://www.emif.eu/about/emif-platform/emif-catalogue

EMIF is an Innovative Medicines Initiative (IMI) programme, operating under agreement number 115372.

18 January: INDUCT project is investigating facilitators and barriers to engaging with e-Health interventions in dementia

Maastricht University PhD student Hannah Christie (pictured), who is involved in the INDUCT project, has written the following report on recent developments:

In September 2016, 15 Early Stage Researchers (ESRs) commenced their PhDs as a part of the Interdisciplinary Network Using Current Technology in Dementia (INDUCT) project. In December 2016, the 15 ESRs completed the POSADEM online module “Living with dementia: personal perspectives”. The module ran for six weeks and was part of the INDUCT network-wide doctoral training, requiring roughly 120 hours per ESR to complete. The goal was to encourage ESRs to reflect on how dementia is experienced and how individuals live with dementia, as well as the effects of the condition on their personal relationships and loved ones. The module stimulated many interactive and thought-provoking discussions between ESRs and session leaders, both on the virtual platform as well as on the message boards. Indeed, by the end of the module there were over 600 posts on message boards! The ESRs rated the module very highly and formulated action points so as to use the lessons learned through POSADEM to improve their research.

In related news, an INDUCT ESRs at the University of Maastricht is investigating engagement with e-Health interventions for people with signs of dementia and their family caregivers. The first output is a systematic review that will determine what the current literature has identified as factors influencing engagement with these interventions. In this review, a theoretical model for tracing facilitators and barriers will be adapted specifically for e-Health interventions in dementia. The subsequent studies will apply the resulting framework to evaluate various digital social support interventions in dementia (e.g. Inlife and Partner in Balance), providing more information on the interactions of persons with dementia and their carers with e-Health technologies. The project will examine how persons with dementia and caregiver preferences, technology company needs, and implementation issues can be addressed in order to develop e-Health interventions that stimulate social inclusion and reduce stigma.

Persons with queries about INDUCT, POSADEM and the described project are encouraged to direct them to hannah.christie@maastrichtuniversity.nl

20 January: EPAD project welcomes new partner Roche

The European Prevention of Alzheimer’s Dementia (EPAD) consortium is pleased to welcome new project partner, Roche.

EPAD is a collaborative research effort to improve the chance of successfully preventing Alzheimer’s dementia and to better understand early aspects of Alzheimer’s disease before dementia develops. The goal of the initiative is the prevention of dementia in people with evidence of the disease (such as biomarker abnormalities), who still may have little or no complaints or clinical symptoms. EPAD is establishing a European-wide cohort of over 6,000 participants, of which 1,500 will be invited to participate in a trial to test new treatments for the prevention of Alzheimer’s dementia. The EPAD project has received support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115736, resources of which are composed of financial contribution from the European Union’s Seventh Framework Programme (FP7/2007-2013) and EFPIA companies’ in kind contribution.

http://ep-adi.org/
Alzheimer Europe networking 2017

On 6 January (Luxembourg, Luxembourg) Jean met with André Trottier from Roche for a discussion of Alzheimer Europe’s 2017 Work Plan.

On 9 to 10 January 2017 (Cambridge, United Kingdom) Dianne attended the EPAD/AMYPAD work package meetings on ethics.

On 10 January (Brussels, Belgium) Jean, Kate, Chris and Cindy attended a ROADMAP project communications meeting.

On 12 January (Maastricht, Netherlands) Alv, Chris and Ana participated in the 1st INDUCT school.

On 17 January (Edinburgh, UK) Dianne and Christophe attended a meeting of WP2 (Outcome measures) of the ROADMAP project.

On 18 January (Brussels, Belgium) Ana participated in the Value of Treatment Plenary Meeting organised by the European Brain Council.

On 20 January 2017, Dianne took part in a telephone conference for the GA of the PACE project.

On 24 January (Amsterdam, Netherlands), Jean attended the Steering Committee Meeting of the ROADMAP project.

On 24 January (via teleconference) Ana, Dianne and Kate attended a SMART4MD project meeting.

On 26 January (Brussels, Belgium), Jean met with Boris Azais from MSD for an exchange on 2017 activities and sponsorship opportunities.

On 27 January (Brussels, Belgium) Jean met with representatives of the European Patient’s Forum to discuss Alzheimer Europe’s potential involvement in an EU project application.

On 27 January (by teleconference), Jean participated in the meeting of the Programme Board of the 2nd Joint Action on Dementia.

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 127, representing 27 Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer’s Alliance:

**Austria:** Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübig (EPP). **Belgium:** Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE).

**Bulgaria:** Andrey Kovatchev (EPP). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D); Eleni Theocarous (EPP). **Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). **Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (ALDE); **Finland:** Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Miapetra Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP). **France:** Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Christofer F歳dehagg (S&D); Eleni Theocarous (EPP); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargnaux (S&D). **Germany:** Angelika Niebler (EPP); Udo Voigt (NI). **Greece:** Costas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyra (EPP); Eleftherios Synadinos (NI); Elissavet Vozemb erg-Vronidi (EPP). **Hungary:** Ádám Kósá (EPP). **Ireland:** Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Liadh Ni Riada (GUE/NGL). **Italy:** Brando Benifei (S&D); Elena Gentile (S&D); Stefano Maullu (EPP); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D); Damiano Zoffoli (S&D).

**Lithuania:** Vilija Blinkėvičiute (EPP). **Luxembourg:** Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP). **Malta:** Therese Comodini Cachia (EPP); Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Esther de Lange (EPP); Jeroen Lenaers (EPP); Lambert van Nistelrooij (EPP). **Poland:** Elżbieta Łukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Plura (EPP); Bogdan Wenta (EPP). **Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP). **Romania:** Cristian-Cătălin Anghel (EPP); Mihaela Pascu (S&D); Marian-Jean Marinescu (EPP); Daciana Octavia Sarbu (S&D); Claudiu Ciprian Tanasescu (S&D); Renate Weber (EPP). **Slovakia:** Miroslav Mikolášik (EPP); Ivan Stefanec (EPP); Anna Záborská (EPP); Jana Žitnanská (ECR). **Spain:** Iñaki Ezpeleta (EPP); Jon Aitor Oña (S&D); Luis de Grandes Pascual (EPP); Rosa Estarás Ferragut (EPP); Juan Carlos Girauta Vidal (ALDE); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Pablo Zalba Bidegain (EPP). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE). **United Kingdom:** Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Anneliese Dodds (S&D); Ian Duncan (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D); Glenis Willmott (S&D).
EU DEVELOPMENTS

1 January: Malta assumes Presidency of the European Union

On 1 January, Malta assumed the six-month rotating Presidency of the Council of the European Union for the first time since its accession in 2004. Malta’s Presidency concludes the current Trio of Presidencies, with The Netherlands and Slovakia having preceded it.

The Maltese Presidency will focus on six main issues: migration, the single market, security, social inclusion; Europe’s neighbourhood and the maritime sector.

The health priorities of the Maltese Presidency include three main areas of action: tackling childhood obesity, fighting HIV and enhancing cross-border cooperation. Activities in the area of eHealth are also foreseen.

The Maltese Presidency will also continue the work on accessibility and affordability of medicines started by the Dutch Presidency, with the adoption in June 2016 of European Council conclusions on strengthening the balance in the pharmaceutical systems in the EU and its Member States. The focus will be on encouraging greater transparency of price-setting negotiations through the set-up of regional and joint procurement mechanisms according to countries’ GDP (gross domestic product).

There is no specific action on dementia to follow on from the work and activities in the preceding Slovak, Dutch and Luxembourgish Presidencies. The Luxembourg Presidency’s efforts on dementia notably resulted in the adoption, in December 2015, of European Council conclusions on “Supporting people living with dementia”, which called on all Member States to address dementia as a priority, to develop national strategies or actions plans, and to strengthen the collaboration between European countries. However, Malta’s Presidency will once again bring together the EU group of Governmental Experts on Dementia, which met most recently in November 2016 during the Slovak Presidency conference on Alzheimer’s disease (AD).

3 January: European Parliament Motion for Resolution launched on an effective treatment for Alzheimer’s disease

On 3 January 2017, a Motion for Resolution was launched in the European Parliament (EP), by MEP Mireille D’Ornano (France), calling for an effective treatment for Alzheimer’s disease (AD). Pointing to recent research into AD treatments targeting beta-amyloid, which “have either proved ineffective or caused serious side effects”, the “Motion for a resolution on an effective treatment for Alzheimer’s disease” urges the European Commission to support European research into AD treatments, putting particular emphasis on research into a vaccine for AD and other innovative therapeutic treatments. The motion refers the Commission to a study conducted by Sweden’s Karolinska Institute in December 2016 - a phase I clinical trial investigating a vaccine that targeting tau - which “concluded that the vaccine is likely to prove effective”.

The motion will be put to the Environment, Public Health and Food Safety Navigation (ENVI) Committee, who will decide whether any follow-up action will be taken.


9 January: JPND launches call for research proposals for pathway analysis across neurodegenerative diseases

The EU Joint Programme – Neurodegenerative Disease Research (JPND) has launched a joint transnational call for research proposals to perform network analyses in different neurodegenerative and other chronic diseases such as Alzheimer’s disease (AD) and Parkinson’s disease in order to elucidate the common underlying mechanisms involved.

This call, which follows a similar call successfully launched by JPND in 2013, will see EUR 23 million made available to applicants from 20 countries.

The deadline for pre-proposals is 6 March, 2017.


17 January: European Parliament elects Antonio Tajani as its new President

On 17 January in Strasbourg, the European Parliament elected its new President, MEP Antonio Tajani (Italy). The veteran centre-right deputy emerged as the clear winner after the election went to the maximum four rounds. He succeeds Socialist member Martin Schulz, who stood down to return to German politics. In the final ballot, Mr Tajani secured 351 votes, an absolute majority, while his main rival, the Socialist candidate Gianni Pittella, received 282.

His election means the centre-right European Peoples’ Party (EPP) political grouping now holds the presidencies of each of the three main EU institutions: the European Commission, Council and Parliament.

18 January: Value of Treatment plenary meeting takes place in Brussels

On 18 January, the European Brain Council (EBC) held a plenary meeting in Brussels for the Value of Treatment for brain disorders project.
During the meeting, Working Group leaders of each condition (stroke, schizophrenia, normal pressure hydrocephalus, epilepsy, Alzheimer’s disease, Parkinson’s disease, multiple sclerosis, headache and restless legs syndrome) presented the preliminary results of the cases studies.

In the afternoon, an expert round table took place. The discussions and suggestions made during this round table will help to inform the development of the policy recommendations and Policy White Paper that the EBC is planning to develop in the next months.

Project Officer Ana Diaz attended on behalf of AE.

23 January: Commission opens consultation on 3rd EU Health Programme

The European Commission’s Directorate General for Health and Food Safety (DG Santé) recently launched an online, open, public consultation of the mid-term evaluation of the 3rd Health Programme 2014-2020. It will be open until the 23 February 2017.

All citizens and organisations with an interest in health policy, public health, and/or healthcare in Europe are welcome to contribute to this consultation. The objective is to ensure that stakeholder groups as well as the general public have a say in its performance and future priorities. Its results will be used to inform the mid-term evaluation of the Third Health Programme.

Concretely, respondents are invited to take part in the consultation by completing an online questionnaire. The questionnaire is available in English, but contributions may be submitted in any official EU language:


MEMBERS’ NEWS

27 December 2016: UK Global Dementia Friends Ambassador was guest editor of UK radio programme

Oscar-nominated actress and Alzheimer’s Society Global Dementia Friends Ambassador Carey Mulligan (pictured, centre) was invited to be guest editor on one of the UK’s top radio shows on 27 December 2016.

Ms Mulligan spoke passionately on Radio 4’s Today programme, which has approx. 7.4 million listeners per week. During the programme she spoke about her personal connection to dementia (Ms Mulligan’s grandmother ‘Nans’ was diagnosed with dementia in 2004) and the key role the Dementia Friends programme plays in reducing stigma.

Joining her on the show was interviewer Michael Parkinson (pictured, left) - whose mother was also diagnosed with a form of dementia two years before she passed away aged 96 - and Monty Python star Michael Palin (pictured, right), who discussed publicly what it was like to see his Python co-star Terry Jones live with the disease.

Ms Mulligan said:

“Too many common myths and misconceptions around dementia still exist. Time and again I hear reference to dementia just being a natural part of ageing and, unfortunately, it is often the butt of distasteful jokes. But dementia is a disease of the brain and it requires understanding, care and support.

“The first step in changing the landscape of dementia and improving the lives of people who have the condition involves educating people not just on our doorstep, but across the world.”

As the UK’s Global Dementia Friends Ambassador, Ms Mulligan aims to bring both international attention to the benefits of making communities dementia friendly and a renewed focus on the Dementia Friends programme in England. The Alzheimer’s Society’s Dementia Friends initiative now has over 1.8 million people taking action to change the way people think, act and talk about dementia.

By making her voice heard on the radio, Ms Mulligan helped to raise awareness of dementia during the Christmas period, a time which can often be difficult for people affected by the disease.

“It’s so important that everyone living with the condition is treated with the respect and dignity that they deserve. At the moment, there’s not nearly enough awareness about what dementia is and as a society we all have a duty to change that”, she urged.

Find out more about the Dementia Friends programme at www.dementiafriends.org.

Listen to Carey on BBC Radio 4’s Today programme on BBC iPlayer.

31 December 2016: Bosnia looks to further collaborate with Slovenia

During December 2016, representatives of Association A&R and the Center for dementia, Bosnia and Herzegovina (B&H) visited Alzheimer Slovenia (Spominčica) in Ljubljana (pictured, top) as well as the Clinic of Neurology at UKC Ljubljana (pictured, bottom). The representatives from B&H met with Spominčica President
In the spring of 2016 the State Secretary of the Ministry of Health, Welfare and Sports kick-started a five-year campaign aiming to make The Netherlands dementia friendly. Now, eight months later the campaign is really ‘on a roll’. Together Dementia Friendly aims to increase society’s knowledge about how to properly interact with people with dementia. An additional goal is that some of the people not only know how to recognise dementia, but as a next step also help people with dementia or their loved ones. A nationwide campaign, website www.samenedementievriendelijk.nl and online and offline training programmes are all part of the growing movement.

Since the start of the campaign in May 2016, Together Dementia Friendly has achieved several results:

- A basic online training has been developed for the general public and four specific trainings for staff working in a store, at town hall, as a taxi driver, and people that work as a volunteer.
- Apart from the online training one can also request an offline training on location by one of the 115 voluntary trainers.
- Four television commercials have been developed and aired on national television and via the internet.
- Over 10,500 people who support the movement have registered on the website.
- 5,100 people have completed online training sessions.
- Several companies have shown interest in Together Dementia Friendly trainings for their staff, some of which have already been trained or have scheduled a training for early 2017.

The strategy particularly emphasises the fact that the Society is the only Finnish one specifically for people with memory-related diseases and their loved-ones. Thus, the Society will be strengthening its involvement and participation in work and activities in this area of society.

The strategy underlines the need for health and social services that genuinely meet the needs of people with these diseases and their caregivers and also involves the Society as a close-knit part of the service system. Brain health and prevention of memory-related diseases are also essential parts of the Society’s work.

Finland has for years been a bold reformist with regard to terms, wanting to decrease stigmatising and medical terms used to describe these diseases and the people who have them. The goal is to use vernacular terms that people themselves feel OK with. The strategy is aligned with this goal.

15 January: Alzheimer Bulgaria publishes report on using existing structures more effectively to benefit people with dementia

Alzheimer Bulgaria recently published a report (in Bulgarian) on “Using the Existing Institutional and Human Capacity More Effectively to the Benefit of People with Dementia in Bulgaria”.

The full text (in Bulgarian) can be found on the Alzheimer Bulgaria website:

http://alzheimer-bg.org/печатни-издание/доклади/

A summary of the report is also available in English.

17 January: The Alzheimer’s Society launches UK Dementia Friendly Communities ‘accelerator sites’ project

The Alzheimer’s Society UK has chosen 10 areas in England to receive additional support to enhance the inclusion and empowerment of people living with dementia in their communities. This Department of Health funded ‘accelerator sites’ project is a 12-month project where different Alzheimer’s Society UK towns/sites have applied to have additional support to make their community as dementia friendly as possible over the course of the year.

They have chosen 10 sites to receive this support and have appointed a Project Support Officer, who will act as the central help and resource.

The successful sites are: Amber Valley (Derbyshire); Blackpool and Fylde; Bradford; Bournemouth; Cheshire East; Luton; Shropshire, Wrekin and Telford; Swindon; Waltham Forest (London) and York.
The Society will work with the 10 sites, the local communities and people affected by dementia in each of these areas to assess the work that they have already done, create objectives that are feasible for each of these localised communities, look at how they can maximise the impact of that work and help to prioritise and engage with new groups.

Some of the themes that they hope to influence will include:
- Increasing the number of Dementia Friends.
- Increasing membership to the local Dementia Action Alliances.
- Increasing engagement with specific areas of interest such as BAME communities, LGBT groups, public transport and schools.

During the 12 months, the accelerator sites will be evaluated and there will be several events to engage existing and new community members, allowing opportunity to spread and learn understanding of how a community can become more dementia-friendly.

At the end of the project, the aim is to develop guidance and best practice in the form of toolkits and other materials to support other communities to become dementia-friendly, in particular hard-to-reach communities.

18 January: Alzheimer Hellas named as best students’ internship foundation

On 18 January, Alzheimer Hellas received an award for being the “best students’ internship foundation”.

The Internship Office at Aristotle University, Thessaloniki (AUTH) organised the debriefing event “Internship Students AUTH program” for the year 2015-2016. The programme is co-financed by the ESF and National Resources (NSRF 2014-2020).

Alzheimer Hellas is delighted with the award, as said “it is important that we support the new generation of health professionals and promote the gaining of knowledge and experience in order to have quality health care for the people with dementia and their caregivers in Greece!”

19 January: Alzheimer Nederland announces more than EUR 900,000 for innovative dementia research

From its first annual call for basic research, Alzheimer Nederland has awarded EUR 949,981 to nine scientific studies. The studies are innovative in nature and are aimed at generating new knowledge about dementia. All the studies aim to contribute to a better understanding of the disease, which will hopefully lead to breakthroughs in its diagnosis, prevention or treatment. The call itself is a part of the Dutch Deltaplan for dementia. Alzheimer Nederland is also pleased to announce that there is a new call open for German and French researchers. The call for basic research 2017 is open for applications (letter of intent, via http://www.alzheimer-research.eu/, deadline 6 March). In cooperation with partners AFI in Germany and LECMA in France. Researchers from these countries can apply for a Dutch-French or Dutch-German crossing border grant.

23 January: Alzheimer Portugal has a new Chairperson

Alzheimer Portugal recently held elections for its new national bodies for the period of 2017 – 2020. José Carreira (pictured), 40, was elected as the new Chairperson of the Board.

As well as being a teacher (graduated in Portuguese and History from the Portuguese Catholic University), he has dedicated the last years to social issues, including minority groups and citizenship, being a specialist in the administration of social organisations.

Interested in dementia issues, he received a Master’s degree on “Intervención a Personas con Enfermedad de Alzheimer” (Intervention for persons with Alzheimer’s disease) from the Medical College of Salamanca University.

He is also specialised in Social Organisation Management at AESE Business School and has a Master’s degree on Social Work from Fernando Pessoa University in Oporto.

Currently, he is the Chairperson of a solidarity organisation and the pedagogic coordinator of various social facilities for child care, also working on human resources administration and coordination.

Mr Carreira is from Viseu (a city in the middle of Portugal), where he created a centre for helping people with dementia and their families, coordinates the local Memory Café and has organised the annual Memory Walk of Alzheimer Portugal.

He has been involved in the organisation of conferences, workshops and seminars – the most recent one in November 2016 in Viseu, with about 300 participants from 5 different countries - “II Seminário Internacional Alzheimer e outras demências: Conhecer, Compreender e Intervir” (2nd International Seminar on Alzheimer’s Disease and other Dementias: Knowing, Understanding and Intervention).

23 January: Demensforbundet reports on “making supermarkets in Sweden dementia friendly”

Many of us have heard of “fast tracks” in supermarkets – but how about introducing “slow tracks”? It would be very helpful to persons with dementia to be able to take the time needed and get help when necessary, when paying or packing their groceries.

The government in Sweden has initiated an effort to make grocery stores more dementia friendly. The project has been developed in close cooperation with the Swedish Dementia Association (Demensforbundet), among others.
The aim is to make it easier for people with dementia to be able to continue buying their own groceries for as long as possible. This has become more and more important as this helps people to continue to live at home for longer, after they receiving a dementia diagnosis.

Staff and managers at supermarkets will get a general introduction to what dementia is, how they can best respond to someone with dementia and how they can organise the shop to be as dementia friendly as possible.

Demensforbundet has approximately 120 local offices around Sweden. Step by step, the society will now visit all their local supermarkets in an effort to make Sweden a more dementia-friendly society, and by so doing, hopefully a more friendly society all together.

If you have questions about the supermarket campaign, don’t hesitate to contact rdr@demensforbundet.se

**30 January: Spominčica reports on important events in Slovenia this month**

Alzheimer Slovenia (Spominčica) has listed the following activities as important moments during the month of January 2017:
- Spominčica launched Alzheimer Cafés in five new locations in Slovenia.
- The President of Slovenia, Borut Pahor (pictured, top right) was confirmed as an honourable sponsor of the 9th Slovenian Psychogeriatric Conference on Dementia, on 20-21 October 2017 and dedicated to the association’s 20-year anniversary - it was established by Dr. Aleš Kogoj in 1997.
- A monthly web edition of the Spominčica magazine was published on the web.
- Spominčica continues its monthly show about dementia on local radio.
- During the first week of January, Spominčica participated at a consultation at the Human Rights Ombudsman Office. The president of Spominčica, Štefanija L. Zlobec informed those present about the first signs of dementia, the progression of dementia through each stage, and highlighted some basic guidelines for effective communication with persons with dementia. The main goal of the meeting (pictured, bottom left, alongside Human Rights Ombudsman Vlasta Nusdorfer, bottom right) was to empower people about human rights for individuals with dementia, who should be treated with the same respect and dignity as others.

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**SPOTLIGHT ON: The Alzheimer Society of Finland**

Erratum: In its December 2016 newsletter, Alzheimer Europe published a “spotlight on” section on our Finnish member, The Alzheimer Society of Finland (Muistiliitto). Unfortunately, the published piece was not the most up to date version and contained some old statistics and information. Alzheimer Europe apologises to Muistiliitto for this oversight and is pleased to publish the correct piece in this newsletter:

The Alzheimer Society of Finland is a non-governmental organisation (NGO) aiming to raise awareness of all forms of memory diseases and dementia. It was formed in 1988.

**We have in our network:**
- 44 member associations
- around 270 employees
- around 1000 voluntary workers
- over 14 000 persons as members

**In the central office**, located in Helsinki but also in central and northern Finland:
- 19 persons are working in the central office as at the beginning of 2017
- During a couple of years we have been recruiting four more: one development manager, one legal expert and four other experts of our field.
**Our Board:** The Board consists of one Chair and eight members, including one person from the Working Group of Memory Activists, which is made up of people with memory disorders and their informal carers. Three persons on our board are Members of the Finnish Parliament, from parties on the right, centre and left.

**We are funded mainly by Finland’s Slot Machine Association, called RAY.**

We are not good at collecting money and donations, but we have succeeded in making grant applications to RAY. Our Memory network - the central office and member associations – has been granted in recent years EUR 7 to 8 million by RAY, annually, but this year, nearly 10 million.

We coordinate the network of regional expert and support centres, Muistiluotsi, in order to ensure that centres follow common criteria, which include a commitment to network, customer orientation and evaluation of the work done. So far, a nation-wide network to strengthen voluntary work and cooperation regarding memory-related diseases has been created with it. As a result, services for people with memory disorders have improved. These centres ensure that people with memory-related diseases and their caregivers have the opportunity to influence and participate as full members in their own communities.

**We publish our Memory magazine** four times a year. We are also active on social media (Facebook, Twitter and Instagram)

We give statements on draft laws, opinions and we publish news as well as making news.

We work closely with the Memory Club in the Finnish Parliament and participate in the working groups of the Ministry, like the key project of government which is focusing now on home care and informal care (home care for older people will be developed and informal care enhanced in all age groups). In October 2016, the ministry for Social Affairs and Health granted EUR 14.8 million based on key project applications for eight projects on home care and informal care. Out of the eight granted, six involve our member associations.

We coordinate telephone and online help, guidance and support.

We have been developing and are piloting criteria of good care and support - these new guidelines were published in Finnish during 2016.

Guidelines for the diagnosis and medical treatment of Memory diseases are updated every three to four years. The new guidelines will be published at the beginning of 2017. Creating positive attitudes, memory-friendly counties and cities, etc. is important work.

We are also a source of information: Last year we did two studies, surveys: one was the Memory barometer 2015 and the other was a survey of our member associations. We publish our Memory magazine, and monthly newsletter in two languages - Finnish and Swedish.

We are also active in many projects of our own as well as several joint projects; like early onset memory-related disease, help line, voluntary work, and memory park.

In 2012, we set up the Finnish Memory Activists, the Working Group of People with Memory Disorders and their informal carers. The group has been very active and productive.

Our annual Memory Conference was organised in November. Last year there were over 350 participants, including people with memory diseases and their carers, representatives of our member associations, healthcare professionals, academics and researchers, as well as policymakers.

These were just some aspects of our situation in Finland and at Muistiliitto. We have a lot of work to do in lobbing and advocacy in Finland.

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**POLICY WATCH**

1 January: Finnish Ministry of Social Affairs and Health says government steering and joint responsibility are needed

Clearer central government steering and, most importantly, joint responsibility are necessary to carry out the Finnish healthcare and social welfare reform successfully, say Rapporteurs appointed by Finland’s Ministry of Social Affairs and Health. People's wellbeing and health will be promoted, but simultaneously the limited nature of public funding needs to be understood.

The Rapporteurs' task, during 2016, was to consider different ways to reform the steering of healthcare and social welfare services in order to make it more effective.

The funding and strategic steering of healthcare and social welfare services need to be coordinated in a way that reduces
differences in people’s wellbeing and health. This means that central government will steer the autonomous regions to bring into use new, uniform practices for providing services that are more effective than previously, but within the same budget. The aim is to strengthen central government steering when the new autonomous regions start to provide healthcare and social welfare services in 2019.

The Rapporteurs suggest a simple management model, and the model should be the same at all levels of healthcare and social welfare services. The model takes into account which services will be provided, which resources will be used and how the effects of services in promoting wellbeing will be measured. National procedures need to be determined to ensure the budget is adhered to, as well as to provide equal and fair services and it is deemed important to prepare the service policies in an open interaction format, with all sectors of society involved, including citizens.

The report will be used in connection with drafting the act on organising healthcare and social welfare services and preparing legislation relating to counties.


16-17 January: Norway is improving its post-diagnostic support for people with dementia and carers

The Norwegian Directorate of Health has awarded funding to over 15 municipalities to test out and develop new service-delivery models for systematic post-diagnostic support for people with dementia. This Programme will support the delivery of Norway’s “Dementia Plan 2020 - a more dementia friendly society”, which includes the need to improve post-diagnostic support and involve people with dementia and their carers in this work as one of its key aims.

The Norwegian Health Association worked together with the Norwegian Directorate of Health and Norway’s National Centre for Ageing and Health to arrange the first gathering of those municipalities receiving extra funding to discuss their plans for better post-diagnostic support. The discussions took place at a meeting on 16 and 17 January 2017 in Oslo.

Common elements in the different municipalities’ plans include a named co-ordinator to support the person throughout their journey with dementia, opportunities for the person to take part in tailored activities and continue with their interests, engaging more volunteers to support people with dementia in their daily lives and establishing more “carer schools” to improve carers’ understanding of dementia. In addition, many of these municipalities plan to set up a “school” for people with dementia, to provide a forum for giving information about dementia, exchanging experiences and providing mutual support. Currently there are very few municipalities in Norway that have such a “school” for people with dementia in place. Many municipalities’ plans have been inspired by Scotland’s post-diagnostic support programme.

The Norwegian Health Association is working in partnership with 11 of these municipalities to ensure that the involvement of people with dementia and volunteers is at the heart of their work. The association’s view is that the effective involvement of people with dementia, together with a central role for volunteers, is vital in delivering improved and tailored post-diagnostic services for people with dementia and their carers, and it looks forward to working with these municipalities on their exciting new projects to ensure these two vital elements are in place.

For more information please contact Victoria Sande, project co-ordinator, Norwegian Health Association on visa@nasjonalforeningen.no

16-17 January: OECD Ministerial Meeting on health reforms takes place in Paris


Important developments in health systems, such as new technologies, the emergence of personalised medicine and big data, as well as innovations in workforce arrangements are challenging the governance of health systems in unprecedented ways. Grounded in the reality of tighter budgets and fiscal pressures facing governments across the OECD, Ministers exchanged ideas and experiences of achievements and barriers to the successful implementation of innovative approaches, and identified priorities for future OECD work on health systems.

More information and a full Ministerial statement from the meeting can be read here: [http://www.oecd.org/health/ministerial/meeting/](http://www.oecd.org/health/ministerial/meeting/)

30 January: WHO Global Action Plan on dementia moves closer to approval

During the 140th session of the WHO Executive Board, which took place in Geneva between 23 January and 1 February 2017, the Board approved a report by the WHO Director General recommending that the 70th World Health Assembly (WHA70) endorse the draft global action plan on the public health response to dementia.

The report and accompanying resolution, approved on 30 January, include a set of global targets and indicators to develop practicable and ambitious national implementation strategies, and request the WHO Director General to submit progress reports in 2020, 2023 and 2026 on the plan’s implementation.
The Global Action Plan will now be considered by WHA70 on 22-27 May 2017.

Other topics under discussion at the WHO Executive Board meeting were:

- Non communicable diseases (NCDs) - including dementia
- Medicines and health products
- Health workforce
- Global Vaccine Action Plan 2011–2020
- Poliomyelitis (polio)
- Antimicrobial resistance
- Vaccines

**SCIENCE WATCH**

10 December 2016: New consensual guidelines on vascular cognitive impairment to improve research have been developed

On 10 December 2016, results published in the journal Alzheimer’s and Dementia addressed the vascular impairment of cognition in a classification consensus study. In the past 20 years there has been a lack of a consensual methodology targeting the study of different conditions that influence vascular cognitive impairment (VCI). VCI is characterised by a decline in cognitive abilities that can result in vascular dementia, a severe form of VCI.

The revision of a conceptual model of VCI was initiated by researchers from the University of Bristol, UK. The study was led by Pat Kehoe, Gestetner Professor of Translational Dementia Research and Joint Head of the Dementia Research Group in the School of Clinical Sciences.

The project, called Vascular Impairment of Cognition Classification Consensus Study (VICCCS), consisted of an international consortium invited from around the world to participate. Altogether over 150 researchers from 27 countries contributed to the guidelines.

The project, funded by the Alzheimer’s Society, UK made use of an online consensus-building technique that applies recurring surveys, called the Delphi method.

The study was conducted in two parts: First, the surveys addressed the guiding principles in defining a modern and workable concept of VCI. Second, they looked at how the diagnosis of these conditions can be made in a more standardised way across the world. The results propose new standardised VCI-associated terminology and future research priorities to address gaps in current knowledge.

http://dx.doi.org/10.1016/j.jalz.2016.10.007

1 January: People with dementia could potentially benefit from using tablet devices

The findings of a recent pilot study published in The American Journal of Geriatric Psychiatry, led by Dr Ipsit Vahia, medical director of Geriatric Psychiatry Outpatient Services at McLean Hospital, Massachusetts, US suggest that tablet devices can be a useful tool to offer agitation relief for people with dementia.

The researchers investigated effects of the use of tablet devices by people with dementia. Staff at the geriatric inpatient unit rated agitation in 36 people with dementia, documenting frequency, duration and app usage history.

Due to proper supervision, the engagement rate was almost 100%, regardless of the severity of dementia. Altogether the participants were able to use 70 freely available applications, loaded onto the tablets. The applications differed in complexity, varying from displaying puppy photos to Sudoku puzzles.

Commenting on the study, Dr Vahia said: “We know that art therapy can work, music therapy can work. The tablet, however, gives you the option of switching from one app to another easily, modifying the therapy seamlessly to suit the individual. You don’t need to invest in new equipment or infrastructure.”

Building on the outcomes of the findings, the clinical team is increasing the provision of tablet devices in order to offer a way to help find calm and empower people with dementia.

https://doi.org/10.1016/j.jagp.2016.07.011

1 January: Selected mushrooms could be of future use as Brain Food

On 1 January, findings arising from a literature review assessing the consumption of certain mushrooms with regard to their anti-dementia/AD active compounds were published in the Journal of Medicinal Food.

Scientists from the University of Malaya, Kuala Lumpur, Malaysia reviewed findings on eleven mushrooms that could potentially lead to improved nerve regeneration. They summarised results from different studies examining the effects of various extracts on the outgrowth activity of neurites in rodents.

The researchers concluded that selected edible and medicinal mushrooms may effectively enhance outgrowth in the brains of mammals.

So far none of the identified mushrooms can be bought in regular European supermarkets. Only a few of the benefits were tested in humans and pursuing assumptions should
therefore be made with care. Further and clear benefits could be clarified based on suitable study designs including humans. 

https://doi.org/10.1089/imf.2016.3740

3 January: FDA approves Phase 2/3 trials of Axsome AD agitation drug

On 3 January, the company Axsome Therapeutics, which develops therapies for the management of central nervous system disorders, announced the approval of its Investigational New Drug Application by the US Food and Drug Administration (FDA) for AXS-05 in the treatment of Alzheimer’s disease (AD) agitation. Its product AXS 05 is an oral AD agitation drug combining dextromethorphan and bupropion.

This clearance permits Axsome to launch its Phase 2/3 studies to evaluate the efficacy and safety of its drug in people with AD agitation. In the planned clinical trial, approximately 330 participants with AD agitation will be randomly assigned to receive AXS-05, placebo, or bupropion. The company said its AD candidate drug is already planned to be tested in Phase 2/3 in the first half of 2017 and will be evaluated using the Cohen-Mansfield Agitation Inventory, which is a 29-item scale to systematically assess agitation.

http://phx.corporate-ir.net/phoenix.zhtml?c=254022&p=irol-newsArticle&ID=2233285

4 January: Are people living near heavy traffic at higher risk of developing dementia?

Results published in the journal The Lancet on the 4 January 2017, showed a trend towards a higher incidence of dementia in people living within 50m of a major traffic road.

Researchers from the University of Toronto, Canada investigated the association of living near heavy traffic and the incidence of cases of dementia, Parkinson’s disease and multiple sclerosis.

The study sample consisted of two cohorts between 2001 and 2012, including 6.6 million people between the ages of 2050 and 55-85.

The findings also suggested that there is no association of living near major roads and the incidence of Parkinson’s disease and multiple sclerosis.

Even though air pollution and stress are related to general health, these findings should be noted with care. The results of the study that showed an increased risk of dementia of 7% in people living within 50m of a busy road do not mean that 7% of the population living near major traffic roads will develop dementia, but rather that the risk is heightened by 7% which is not that high considering the fact that physical activity reduces it by 14%.

http://www.thelancet.com/journals/lancet/article/PII/S0140-6736(16)32399-6/abstract

9 January: Phase 1 study of γ-secretase modulator from NeuroGenetic Pharmaceuticals shows positive results in healthy volunteers

On 9 January, the biopharmaceutical company NeuroGenetic Pharmaceuticals, which develops innovative drug therapies for Alzheimer’s disease (AD), announced the accomplishment of a Phase 1 clinical study for its γ-secretase modulator NPG 555. NPG 555, a clinical candidate selected to treat and prevent AD, targets the γ-secretase enzyme complex by converting the production of Aβ42 to non-toxic forms such as Aβ37.

The Phase 1a study was conducted in healthy and young subjects with a single ascending dose (25 mg – 300 mg). The 14-day Phase 1b multiple ascending dose clinical trial was a randomised and placebo-controlled study in healthy volunteers (40-65 years old) dosed at 100 – 400 mg. Participants received the drug through a capsule.

No major side effects were observed. NPG 555 was found to be safe and well-tolerated. Interestingly a reduction in Aβ42 level was noticed. The announced results revealed a 51% favourable change in Aβ37/Aβ42 ratios at Day 14 compared to baseline pre-drug levels for 400 mg.

9 January: Recruitment of Phase 2a study for drug candidate PQ912 from Probiodrug is complete

Probiodrug is a biopharmaceutical company developing novel therapeutic solutions to treat Alzheimer’s disease (AD). Probiodrug’s product candidate PQ912 represents a molecule approach to reducing amyloid beta (Aβ) generation. PQ912 blocks the activity of Glutaminyl Cyclase, an enzyme that participates in the formation of Aβ. This molecule showed therapeutic benefits in AD animal models in preclinical studies as well as good tolerability in a Phase 1 trial study with healthy volunteers.

In March 2015, the company started the patient enrolment to initiate a Phase 2a study for its product candidate PQ912. This clinical trial is a randomised and double-blind study assigned for patients in the early stages of AD. The objectives are first to investigate the safety and then to assess the pharmacodynamics profile of PQ912 compared to the placebo.

On 9 January, Probiodrug announced the recruitment of 120 participants for this Phase 2a study. The group includes 64 females and 56 males, with a mean age of 73 years.

The company hopes to obtain the full unblinded results in the second quarter of 2017.

13 January: Accumulation of tau protein damages the brain's spatial orientation in AD

In a study published on 13 January in the journal Nature, scientists at Columbia University Medical Center (CUMC) in New York reported a new link between Alzheimer’s disease (AD) symptoms and an excess of tau protein in the brain.
Previous findings have underlined that tau, a protein found in a normal mature neuron, is abnormally hyperphosphorylated and present in excess in brains with AD. Indeed, tangles composed of hyperphosphorylated and aggregated protein tau are one of the hallmarks of AD.

In the published study, researchers reported that the accumulation of tau protein in the brain of an AD mouse model disrupted the function of specific neuronal cells called grid cells (pictured). These cells are found in the medial entorhinal cortex (MEC), a part of the brain involved in navigation. Interestingly, in the earliest stages of AD, tau tangles appear first in the MEC. The researchers showed that aged transgenic mouse models expressing mutant human tau protein in the MEC presented excitatory neuron loss. In addition, excess tau protein lead to grid cell dysfunction and spatial memory deficits.  

http://www.cell.com/neuron/fulltext/S0896-6273(16)30996-5

13 January: Calcium channel enhancer may provide a new therapeutic target for AD

On 13 January, Japanese researchers announced the development of an experimental drug SAK3, a calcium channel enhancer that could help treat the most common form of dementia.

Acetylcholine, a neurotransmitter found in the brain, plays an important role in attention, memory and motivation. Previous findings have shown that a dysfunction in the acetylcholine system is believed to be one of the main causes of Alzheimer’s disease (AD) and vascular dementia.

In the study, published in the journal Neuropharmacology, mouse models received an oral SAK3 administration. The scientists reported that SAK3 could stimulate the release of acetylcholine in the hippocampus - the brain region responsible for memory. In addition, they also reported that SAK3 could improve cognition deficits.

Currently, SAK3 is in the preclinical stage of drug development and has been shown to be safe and well-tolerated in mouse models. The researchers concluded that this experimental AD drug must be now tested in clinical trials, which are expected to begin in the next few years.

https://www.ncbi.nlm.nih.gov/pubmed/?term=Pharmacological+properties+of+a+calcium+channel+enhancer

17 January: England dementia training hospital survey launched

The DEMTRAIN study in England aims to develop the evidence base for dementia training in NHS hospitals. This study is part of the UK ESRC/NIHR funded Neighbourhoods and Dementia Programme, which was funded as part of the first Prime Minister’s Challenge on Dementia and is led by the research team at Lancaster University. Viewing the acute hospital as a neighbourhood space increasingly occupied by people living with dementia, the DEMTRAIN study will examine the impact of dementia training on staff skills, knowledge, confidence and satisfaction, and improved outcomes for patients living with dementia in these settings. Over four study phases, including analysis of hospital episode data and economic cost modelling, this mixed method study is examining quality and effectiveness of training programmes in acute hospital settings and their impact on length of hospital stay and re-admissions for people living with dementia. The hospital survey questionnaire has been developed with support and guidance from DEMTRAIN’s member involvement groups, including invaluable discussions with the Scottish Dementia Working Group: Neighbourhoods and Dementia Programme Research Group.

The hospital survey was launched on the 17 January 2017 (End date: 17 March 2017). Survey invitations were sent to 193 acute NHS hospitals in England. So, if you are a hospital dementia lead or have a key dementia role within your acute hospital do not forget to check your inbox for a unique online survey link, and please feel free to contact the DEMTRAIN study team on idclancaster@lancaster.ac.uk.

DEMTRAIN researchers are working with a number of key stakeholders to facilitate this research and to develop a better understanding of dementia training in acute NHS hospitals across England. The survey has endorsement from national UK stakeholders and organisations including Professors Alistair Burns, Old Age Psychiatry and Consultant Old Age Psychiatrist, Manchester Mental Health and Social Care Trust, and Martin Vernon, National Clinical Director for Older People and Integrated Care at NHS England, Dementia Action Alliance, and the Royal College of Nursing.

If you have specific questions regarding the study, please do not hesitate to contact a member of the research team on idclancaster@lancaster.ac.uk or for further information, please visit:  

http://www.neighbourhoodsanddementia.org/work-programme-5/

18 January: Meditation and music could help improve memory and cognitive function, study finds

In a study published on 18 January in the journal of Alzheimer’s disease, scientists have claimed that meditation and music may help reverse early memory loss in adults at risk for Alzheimer’s disease (AD).

In this randomised controlled trial, 60 participants with subjective cognitive decline were assigned to a Kirtan Kriya meditation or music listening programme for 12 minutes daily during 3 months and then at their discretion for
the ensuing 3 months. The average age of participants in the study was 60.6 years. 92% of participants completed the 3-month procedure and 88% the full 6-month programme. After 3 and 6 months, memory and cognitive function were measured through specific tools including a memory functioning questionnaire, a trail-making test and a digit-symbol substitution test. Interestingly, at 3 months participants in both groups showed significant improvements in subjective memory function and objective cognitive performance. In addition, researchers observed that this progress was maintained or further enhanced at 6 months.

Results published on 18 January in the journal JAMA Psychiatry assessed the association between delirium and cognitive decline. Researchers from University College London and Cambridge University, UK, examined whether the accelerated cognitive decline observed after delirium is independent from the pathologic processes of dementia.

"If delirium is causing brain injury in the short and long-term, then we must increase our efforts to diagnose, prevent and treat delirium. Ultimately, targeting delirium could be a chance to delay or reduce dementia" said Dr Daniel Davis (MRC Unit for Lifelong Health and Ageing at UCL), who led the research while at the University of Cambridge.

Best wishes and kind regards to everyone,
Carol Hargreaves, EWGPWD member.

Living with dementia means staying active and raising awareness about our still existing abilities. The ability to talk, to write, to be on stage and spread a positive message.

As a keynote speaker I was very impressed that my English speech was translated into Finnish and also sign language was used.

A highlight was the meeting with the Finnish Working Group of People with Dementia. I was impressed by my tough working colleagues, who even cover 300km just to take part in the meeting.

My message: “Dementia knows no borders together people with dementia are stronger than ever!”
EDUCATION

23 January: Registrations now open for KU Leuven’s 3rd Summer Course on Ethics in Dementia Care

The Centre for Biomedical Ethics and Law at KU Leuven is organising the 3rd edition of its “Summer Work on Ethics in Dementia Care”, to take place in Leuven, Belgium, from 5-7 July 2017. The objective of the course is to foster exchanges on foundational, clinical-ethical and organisational-ethical approaches to dementia care practices.

During the Summer Course, national and international experts will give presentations on various ethical topics in the domain of dementia care and there will be ample time for intensive discussions.

The Summer Course, which is taught in English, is of interest to participants from diverse professional backgrounds, such as medicine, nursing, psychology, social work, gerontology, health care administration, philosophy and theology, and to PhD students undertaking courses of study in these areas.

Further information can be found here: https://gbiomed.kuleuven.be/english/research/50000687/50000697/Summer_Course/summer-course

NEW PUBLICATIONS AND RESOURCES

16 January: INTERDEM publishes position paper on Assistive Technology

A collaborative position paper on Assistive Technology, written by members of INTERDEM, has been published in the journal JMIR Rehabilitation and Assistive Technologies.

Alzheimer Europe’s Director for Projects Dianne Gove was involved in the paper “Technologies to Support Community-Dwelling Persons w

19 January: Dr Shibley Rahman’s book “Enhancing Health and Wellbeing in Dementia” published

On 19 January, experienced dementia researcher Dr Shibley Rahman’s book, “Enhancing Health and Wellbeing in Dementia – a person-centred integrated care approach” was published.

The key aim of the book, for which the main foreword was written by Professor Sube Banerjee is to enable the provision of outstanding quality care and services for people living with dementia regardless of care setting.


Contact Alzheimer Europe

Alzheimer Europe: 14, rue Dicks (L-1417), Luxembourg; info@alzheimer-europe.org, www.alzheimer-europe.org

Alzheimer Europe Board:

Chairperson: Iva Holmerová (Czech Republic); Vice-Chairperson: Charles Scerri (Malta); Honorary Secretary: James Pearson (UK - Scotland); Honorary Treasurer: Maria de Rosario Zincke dos Reis (Portugal); Members: Stefanie Becker (Switzerland), Helen Rochford Brennan (Ireland), Marie-Odile Desana (France), Sabine Henry (Belgium), Sabine Jansen (Germany), Sirpa Pietikäinen (Finland), Jesus Rodrigo (Spain), Štefanija Lukič Zlobec (Slovenia).

Alzheimer Europe Staff:

Executive Director: Jean Georges; Communications Officer: Kate Boor Ellis; Conference and Event Coordinator: Gwladys Guillory; Director for Projects: Dianne Gove; Project Officers: Christophe Bintener, Cindy Birck, Ana Diaz; Policy Officer: Vanessa Chalilnor; Finance Officer: Stefanie Peulen; Administrative Assistants: Grazia Tomasini, Ute Corail.
## AE CALENDAR 2017

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 February</td>
<td>Meeting with World Dementia Council (London, United Kingdom)</td>
<td>Jean</td>
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<tr>
<td>1 February</td>
<td>NILVAD Steering Committee (London, United Kingdom)</td>
<td>Jean</td>
</tr>
<tr>
<td>6 February</td>
<td>Human Brain Project (webinar)</td>
<td>Dianne</td>
</tr>
<tr>
<td>7 February</td>
<td>&quot;Mental Health &amp; Active Ageing Ensuring opportunities and participation in society at all ages&quot;, (Brussels, Belgium)</td>
<td>Vanessa</td>
</tr>
<tr>
<td>13-14 February</td>
<td>EPAD Meeting for WP6 Dissemination (Basel, Switzerland)</td>
<td>Jean, Kate and Cindy</td>
</tr>
<tr>
<td>21-22 February</td>
<td>EFGCP Annual Conference “Meeting the Ethical Standards under the Clinical Trials Regulation: The Burning Questions (and Answers) for Researchers, Sponsors and Patients” (Brussels, Belgium)</td>
<td>Dianne and Ana</td>
</tr>
<tr>
<td>22 February</td>
<td>Romanian National Alzheimer Conference (Bucharest, Romania)</td>
<td>Helga Rohra, EWGPWD (Speaker)</td>
</tr>
<tr>
<td>22-24 February</td>
<td>EMIF-AD/DPUK Joint Meeting (Manchester, United Kingdom)</td>
<td>Jean</td>
</tr>
<tr>
<td>27-28 February</td>
<td>AE Board (Luxembourg, Luxembourg)</td>
<td>AE Board and staff</td>
</tr>
<tr>
<td>28 February</td>
<td>Company round table meeting (Luxembourg, Luxembourg)</td>
<td>AE Board, members, staff and sponsors</td>
</tr>
</tbody>
</table>

## CONFERENCES 2017

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>24-25 June</td>
<td>3rd Congress of the European Academy of Neurology (EAN), <a href="https://www.ean.org/amsterdam2017/">https://www.ean.org/amsterdam2017/</a></td>
<td>Amsterdam, Netherlands</td>
</tr>
</tbody>
</table>
27th Alzheimer Europe Conference
Care today, cure tomorrow
Berlin, Germany
2–4 October 2017

www.alzheimer-europe.org/conferences  #27AEC