

# ALZHEIMER EUROPE NEWSLETTER

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## WELCOME!



We began the month with a series of meetings in Luxembourg: a Board meeting, a Company Round Table and a Public Affairs meeting. As ever, it was a pleasure to bring together our national members organisations, sponsors and staff, to discuss our projects and plans, and particularly to hear about national campaigning activities and events from all our members.

Regarding our 27th Annual Conference, in Berlin from 2 to 4 October, I am delighted to announce that registrations are now open. Early Bird fees are available until 30 June and the call for abstracts is still open until 30 April, so do get your abstracts in quickly to avoid disappointment! In other good news about the conference, the AE Foundation has decided to launch a call to allocate 10 bursaries of EUR 1,000 to allow people with dementia to attend #27AEC. Please note that bursary recipients must be nominated by our national member organisations.

I am also pleased to announce that our Carers' survey on the diagnosis of dementia is making great progress. I would like to congratulate Finland, as its target has already been exceeded and the online survey closed. If you are a family carer for someone living with dementia in Italy, the Netherlands or Scotland, we would love to hear from you. See the Alzheimer Europe news section for more information and keep an eye out for news about the Czech survey

on our website. It should go live any day now.

March has been a project-heavy month, with no fewer than ten project meetings taking place and fourteen project-related articles in this edition. The list of achievements in each of these projects is truly impressive. It is also fantastic to see the Innovative Medicines Initiative (IMI) recognises the importance of collaboration between these projects, bringing together representatives from the complete portfolio of its projects in the AD/dementia field, as well as other key stakeholders at a meeting in Brussels.

On the Research front, we are pleased to include a "Behind the headlines" commentary from Harvard Medical School Professor, JoAnn Manson, who gives us her thoughts on recent media headlines hinting that chocolate prevents dementia. Also on the research front, I was interviewed by Research Features Magazine this month, on the topic of Alzheimer's disease. Find out more in the AE news section.

I would like to bid a fond farewell to Marc Wortmann, Executive Director of Alzheimer's Disease International (ADI) since January 2007. We work closely with ADI in a number of areas and have come to know Mr Wortmann well in his ten years at the helm. I would like to personally wish him well for the future and also say a warm welcome to Paola Barbarino, who will assume the role of CEO on 15 May.

**Jean Georges**  
Executive Director

## ALZHEIMER EUROPE

### 27 February: Alzheimer Europe Foundation will allocate bursaries for people with dementia to attend AE Conference in Berlin



The Board of the Alzheimer Europe Foundation met in Luxembourg on 27-28 February and approved the 2016 financial accounts of the foundation, which closed with a slight surplus of EUR 20,600 and brought the reserves for the foundation to EUR 170,200.

At the same time, the Board also decided to launch a call to allocate 10 bursaries of EUR 1,000 to allow people with dementia nominated by AE's national member organisations to attend the AE Conference in Berlin. As in previous years, the Board also decided to provide awards for the best posters presented at the Annual Conference.

### 27-28 February: Alzheimer Europe Board looks back on successful 2016



The members of the Alzheimer Europe Board held a meeting on 27 and 28 February in Luxembourg. In particular, the Board looked back on 2016 and approved the Annual Report and

Financial Accounts of the organisation. The Board also approved the report for the European Commission on the activities carried out thanks to the operating grant provided by the health programme of the European Union.

The Board also discussed the programme of the 2017 Alzheimer Europe Conference in Berlin, approved a statement on public and patient involvement in dementia research and discussed the collaboration with the INTERDEM network, the European Union Geriatric Medicine Society and the European Disability Forum, which Alzheimer Europe recently joined as a member.

On 27 February, the Board also met with Marc Wortmann, the outgoing Executive Director of Alzheimer's Disease International to discuss areas for collaboration between the two organisations.

The next Board meeting will take place in June 2017.

[www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Our-Board](http://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Our-Board)

### 28 February: Research Features Magazine talks to Alzheimer Europe's Executive Director about the importance of awareness in dementia



Alzheimer Europe Executive Director Jean Georges was interviewed by Research Features Magazine for an issue with a strong focus on neuroscience.

The full article was published online on 28 February 2017 and will also be featured in the hard copy of the magazine.

<http://researchfeatures.com/2017/02/28/alzheimer-europe/>

### 28 February: AE hosts Company Round Table



Alzheimer Europe (AE) hosted a Company Round Table meeting in Luxembourg on 28 February. In all, 35 people were in attendance, including 8 representatives from sponsor companies and a further 21 from AE member countries.

Policy Officer Vanessa Challinor gave delegates a presentation on "Dementia as a global and European priority" - an overview on EU, WHO and G7 initiatives on dementia; Director for Projects Dianne Give gave an overview of AE participation in EU research projects; and Project Officer Cindy Birck gave an update on AE's Clinical Trial Watch.

Participants also heard about the recent 2nd Alzheimer's Association Academy, which took place in December 2016 and gave feedback on this and discussed ideas for the 2017 edition.

Finally, there was a round-table discussion on the role of Alzheimer associations in providing information on clinical trials and dementia research

### 1 March: Alzheimer Europe hosts Public Affairs meeting in Luxembourg



On 1 March, Alzheimer Europe (AE) hosted a Public Affairs meeting in Luxembourg. 22 representatives from AE member organisations, and 7 AE staff members were in attendance. Iva Holmerová led the meeting, as the newly appointed AE Chairperson.

The agenda focused on:

AE's European Dementia Monitor – feedback from members prior to publication.

The recent 2nd Alzheimer's Association Academy - feedback and suggestions for 2017 (the 3rd Academy will take place in December in Brussels).

The 2017 AE Yearbook on "Care standards for care services" – including presentations from several member organisations regarding the situation in their countries (Scotland, Czech Republic, Malta, Sweden and England).

Representatives from each member attending the meeting also had the opportunity to present their national activities, campaigns and initiatives to the group.

The agenda also included a number of practicalities to support collaboration between members, such as use of the shared intranet.

The next Public Affairs meeting will take place in Brussels on 28 June.

**29 March: Take our online Diagnosis of dementia carers' survey!**



Alzheimer Europe (AE) together with five of its national member organisations, and with the financial support of pharmaceutical company Roche, is leading a project exploring the experiences of carers who support people with dementia.

The survey seeks to provide information about carers' experience of the diagnosis of dementia and the support and help offered after a diagnosis has been made. The project's academic lead is the University of Bangor, Wales (UK).

The survey is being conducted across five European countries: the Czech Republic, Finland, Italy, the Netherlands and Scotland (UK). Feedback is being sought from 1,000 informal carers (e.g. family members or friends) in total (200 per country) via an online survey. Paper copies are also being used when necessary.

The online surveys have been launched and are now live in Scotland, the Netherlands and Italy. The online survey is closed in Finland as they have already exceeded the number of participants needed. Congratulations to our Finnish member the Alzheimer Society of Finland (Muistiliitto), on reaching the target so quickly!

If you are caring for a relative or friend with dementia, live in one of the following countries and wish to participate in the survey, the links are:

**Italy** <https://bangor.onlinesurveys.ac.uk/alzheimer-europe-carers-survey-italy>

**Netherlands** <https://bangor.onlinesurveys.ac.uk/alzheimer-europe-carers-survey-dutch>

**Scotland** <https://bangor.onlinesurveys.ac.uk/alzheimer-europe-carers-survey-scotland>

The **Czech Republic** survey will be launched online shortly. Keep an eye on the Alzheimer Europe website for this information in the coming days

**30 March: Registrations are now open for our 27<sup>th</sup> annual conference**



Alzheimer Europe (AE) and the German Alzheimer's association (Deutsche Alzheimer Gesellschaft - DALZG) invite you to register for the 27<sup>th</sup> AE annual conference, this year to be held in Berlin, Germany from 2 to 4 October.

You can take advantage of the early bird registration fee via our website, until 30 June.

The full conference registration fee includes:

- Admission to all sessions.
- Delegate bag and final programme including the abstract book.
- Opening ceremony and welcome reception.

- Scheduled coffee breaks and lunches on 3 and 4 October. Please note the registration fees for the conference do not include the Gala dinner. Delegates can register for the Gala dinner via the AE website and an early bird fee is also available until 30 June.

AE and DALZG are providing reduced rates for people living with dementia, students, delegates from low and middle income countries (World Bank Categories) and DALZG members and staff.

One day registrations are also available.

See here for further details about registration:

<http://alzheimer-europe.org/Conferences/2016-Copenhagen/Registration-fees>

Please also note that our call for abstracts is open until 30 April, meaning you have less than one month left to submit your abstract!



**EU PROJECTS**

**20 February: EPAD coordinator Craig Ritchie gives Inaugural Lecture "Could a dementia-free world become a reality?"**



Professor Craig Ritchie, EPAD coordinator and Director of the University of Edinburgh's Centre for Dementia Prevention, gave his Inaugural Lecture on 20 February 2017, entitled "Could a dementia-free world become a reality?"

The sold-out event was attended by academics, policy makers, research participants and school students, and provided a fascinating insight into the global landscape of dementia research and prevention.

There has been little progress in developing new interventions to manage the symptoms of dementia over the last 20 years. This has forced a fundamental re-think of our scientific, clinical and epidemiological approach to the condition, culminating in massive, coordinated global initiatives targeting the prevention of dementia and maintenance of brain health.

During his lecture, Prof. Ritchie provided a brief historical perspective of dementia that formed the foundation for a very optimistic vision of the near future (relatively speaking) of how we can beat dementia.

A recording of Prof. Ritchie's Inaugural Lecture is available online: [https://media.ed.ac.uk/media/1\\_h7115jph](https://media.ed.ac.uk/media/1_h7115jph)

**22 February: EPAD ethics paper published in The Journal of Prevention of Alzheimer's Disease (JPAD)**



A paper authored by a dedicated workgroup within the European Prevention of Alzheimer's Dementia

(EPAD) project was published in The Journal of Prevention of Alzheimer's Disease (JPAD) on 22 February.

The article, "Ethical issues in the development of readiness cohorts in Alzheimer's disease research", This paper offers recommendations for the ethical management of re-contact, informed consent and risk disclosure which may be of value to other research collaborations in the process of developing readiness cohorts for prevention trials in Alzheimer's disease and other disease areas.

It is available with open access, here:

<http://www.jpreventionalzheimers.com/2226-ethical-issues-in-the-development-of-readiness-cohorts-in-alzheimers-disease-research.html>

### 23-24 February: EMIF-AD and DPUK Joint Meeting in Manchester, UK is a great success



On 23 and 24 February, approximately 75 participants attended a joint meeting of EMIF-AD and DPUK, with representation from members of EPAD, to

highlight progress to date in the respective projects, as well as in collaboration.

A number of key themes were focused on:

- The development of the respective research platforms and engagement with AD cohorts, incorporating areas of commonality between the respective architectures, as well as overlapping technologies (such as the EMIF catalogue tool)
- Latest developments in the scientific work of the respective projects, especially with regards to biomarkers, including genetic and digital
- A look forward to the IMI2 programme [ROADMAP](#), which EMIF, DPUK and EPAD are contributing to, and which initiated late 2016
- A workshop-based approach to competing for a financial grant for a specific research objective in AD, with two proposals successfully going forward for further evaluation after the meeting

During the meeting, Simon Lovestone announced an award of GBP 20,000 (EUR 23,300) split between EMIF-AD and DPUK, to support a specific area of research as proposed from five groups within the workshops.

Two were selected for further development and then review prior to final selection and the award.

A more detailed report of the meeting will be forthcoming on the EMIF [website](#).



### 5 March: MEETINGDEM; implementation and validation of the Meeting Centres Support Programme in Europe



During the last three years an interesting and successful implementation project, called MEETINGDEM, has been carried out in several countries in Europe, funded by the Joint Programme Neurodegenerative Diseases (JPND) research.

MEETINGDEM (2014-2017) aims to adaptively implement, evaluate and disseminate the evidence-based Meeting Centres Support Programme (MCSP) for people with dementia and their carers in Europe. MCSP consists of a social club for people with dementia, where they can participate in recreational and creative activities as well as in therapeutic interventions, three days per week; informative meetings and discussion groups for their family caregivers and a weekly consultation hour, monthly centre meeting and social activities for both, offered in socially integrated community centres.

The programme is theoretically based on the Adaptation-Coping model (Dröes et al, 2011) and aims to support people with dementia and their caregivers in dealing with the impact of dementia.

MCSP was originally developed in the Netherlands (Dröes et al, 2000) and is now being implemented in other European countries, such as Italy, Poland, The UK and recently also in Spain.

The consortium partners of MEETINGDEM are VU University medical centre (VUMC) in Amsterdam (Netherlands), University of Bologna (Italy), Fondazione Don Gnocchi Onlus in Milan (Italy), Wroclaw Medical University (Poland), University of Worcester (UK) and University College London (UK). They succeeded in successfully preparing and adaptively implementing 13 Meeting Centres in these countries, together with local care, welfare and volunteer organisations who participated in the initiative groups. The implementations were accompanied by research evaluating the implementation process (Mangiaracina et al, 2017), culture-specific adaptations, the effectiveness, cost effectiveness and user experience.

Results of the project are expected to be published in late 2017.

People who are interested in updates on this project, or in setting up Meeting Centres in their own country or region, are advised to sign up for the free project newsletter via [www.meetingdem.eu](http://www.meetingdem.eu) or to contact the researchers via [meetingdem.eu@gmail.com](mailto:meetingdem.eu@gmail.com).  
<https://goo.gl/xb15zL>

### 6-7 March: PredictND management and project team meeting held in Copenhagen

On 6 and 7 March, in Copenhagen, Denmark management and project team meetings for the PredictND project were held, mainly focusing on the upcoming interim review in Brussels (see article dated 14 March).

Partners reported very promising preliminary findings regarding the efficacy of the low-cost approach to detection.

The partners have an impressive list of ongoing and future publications. Neurodegenerative diseases (NDs) are typically diagnosed with a consensus of several experts that have examined the patient and the collected data. The diagnosis will be based on the current guidelines and expertise of the participating specialists. Objective exploitation of data collected from previous patients with similar symptoms is hard. Knowledge of these patients, their tests and outcome should be collected and documented in an intuitive and easy to use form. The first technical objective is to develop a decision support software tool to be used in clinical workflows for differential diagnostics of NDs.

Alzheimer Europe Executive Director Jean Georges and Director for Projects Dianne Gove attended these meetings.



PredictND has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 611005

<http://www.predictnd.eu/>

### 10 March: EPAD project launches introduction video on its website



On 10 March, the European Prevention of Alzheimer's Dementia (EPAD) project launched its first video – an introduction to the project.

The three and a half minute animated video is available on the EPAD website homepage: <http://ep-ad.org/>

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.

### 14 March: Reviewers rate PredictND progress as excellent



On 14 March 2017, the PredictND team attended an interim review meeting with the European Commission and the review board to present the progress and

achievements of the project.

The objectives of the project are to develop a clinical protocol for enabling earlier and objective differential diagnostics of neurodegenerative diseases, a low-cost battery of tests for early detection, a clinical protocol for cost efficient differential diagnostics of neurodegenerative diseases utilising these tests and a decision support software tool to be used in clinical workflows for differential diagnostics of neurodegenerative diseases.

The representatives of the different work packages updated the European Commission and the reviewers about the progress since the last review and gave updates on the overall progress (Mark van Gils, VTT, Finland), the clinical data acquisition and management (Hilkka Soininen, University of Eastern Finland, Finland), the decision support tool requirements (Timo Urhema, VTT, Finland and Jan Wolber, GE Healthcare, UK), the biomarker discovery tools (Daniel Rueckert, Imperial College, UK), the clinical validation studies (Steen Hasselbalch, Rigshospitalet, Denmark) and the business development and dissemination activities (Lennart Thurfjell, Combinostics, Finland). Hanneke Rhodius-Meester (VUMC, Netherlands) gave a demonstration of the developed decision support tool to show how the tool can be used by clinicians and Jyrkie Lötjönen (Combinostics, Finland) updated the reviewers on how the team had addressed the comments of the reviewers from the last meeting. All of these presentations had been prepared and rehearsed at a project team meeting in Copenhagen, Denmark on 6 and 7 March 2017.

The reviewers showed a lot of interest in the different achievements with a number of lively question and answer sessions following the different presentations. All in all, the reviewers were impressed by the progress to date which they rated as "excellent".

Alzheimer Europe supports the dissemination activities of this project and was represented by Jean Georges at the review meeting and by Dianne Gove and Jean at the project team earlier in the month.

NDs are typically diagnosed with a consensus of several experts that have examined the patient and the collected data. The diagnosis will be based on the current guidelines and expertise of the participating specialists. Objective exploitation of data collected from previous patients with similar symptoms is hard. Knowledge of these patients, their tests and outcome should be collected and documented in an intuitive and easy to use form.

Our first technical objective is to develop a decision support software tool to be used in clinical workflows for differential diagnostics of neurodegenerative diseases.

### 15-16 March: Collaboration is key for two-day meeting convened by Innovative Medicines Initiative

"Collaboration in Alzheimer's disease and beyond: the present and future of IMI initiatives in neurodegeneration" was the

theme of the meeting organised by the Innovative Medicines Initiative. It brought together the complete portfolio of IMI projects in the Alzheimer's/dementia field, as well as other key stakeholder organisations and initiatives from Europe and beyond. The goal of the meeting was to discuss existing collaboration and explore future opportunities to work together to advance Alzheimer's research.

During the first day, senior representatives of all currently funded IMI projects in the Alzheimer's field attended to provide an overview of the aims and achievements to date of their projects. The following projects were represented making for a truly impressive portfolio in the field of Alzheimer's research:

- ADAPTED (Alzheimer's Disease Apolipoprotein Pathology for Treatment Elucidation and Development)
- AETIONOMY (Organising mechanistic knowledge about neurodegenerative diseases for the improvement of drug development and therapy)
- AMYPAD (Amyloid imaging to prevent Alzheimer's disease)
- EMIF-AD (European Medical Information Framework – Alzheimer's disease)
- EPAD (European prevention of Alzheimer's dementia)
- IMPRIND (Inhibiting misfolded protein propagation in neurodegenerative diseases)
- MOPEAD (Models of patient engagement for Alzheimer's disease)
- PHAGO (Inflammation and AD: modulating microglia function – focussing on TREM2 and CD33)
- PRISM (Psychiatric Ratings using Intermediate Stratified Markers)
- ROADMAP (Real world outcomes across the AD spectrum for better care: multi-modal data access platform)



These presentations were followed by an open lecture for a broader IMI audience in which Jean Georges from Alzheimer Europe (pictured) gave an overview of current European research

initiatives and presented Alzheimer Europe's campaign to see dementia recognised as a European priority. Craig Ritchie from the University of Edinburgh presented a scientific update with the latest research findings and new understanding of the development of Alzheimer's disease and possible prevention strategies.

The second day was an internal meeting where the different project representatives continued their discussions about potential synergies between projects as well as areas for future research.

**16-17 March: Joint Action Dementia II (Act on Dementia) working group on residential care meets in Sofia**



The working group on residential care of the Joint Action Dementia II project (DEM 2) met in Sofia on 16 and 17 March, to discuss progress with work on end-of-life care and on the management of BPSD (behavioural and psychological symptoms of dementia).

The group worked on the development of guidelines on end-of-life care in residential homes and planned the structure and content of a future report on BPSD. The group also brainstormed on different ways to implement the recommendations.

Director for Projects Dianne Gove represented Alzheimer Europe at this meeting.

**16-17 March: MOPEAD project consortium meets in Brussels**



On 16 and 17 March, the MOPEAD project held its 2<sup>nd</sup> Consortium Meeting in Brussels, Belgium. The meeting was chaired by Mercè Boada (Fundació ACE) and Laura Campo (Eli Lilly on behalf of EFPIA). The aim of the

meeting was to discuss the progress on the four different models of patient engagement for Alzheimer's disease (AD), the strategies and metrics to evaluate run efficiency and AD enrichment as well as design and implementation of advertisement campaigns, followed by the plan for dissemination activities.

The first day concentrated on the discussion of the different models of patient engagement, they include an online platform (citizen science), an open house initiative, primary care-based patient engagement and engagement of potential study participants through endocrinologists' offices. These four models will be implemented and tested in Spain, Sweden, Germany, Slovenia and the Netherlands and were also discussed with regard to the protocols that are implemented in order to ensure comparison of the models.

During the second day, the project partners focussed on both statistical possibilities and strategies. In a parallel discussion, partners from the Work Package on dissemination concentrated on possibilities to empower the campaigns to engage potential participants, and further elaborated the overall plan for dissemination activities throughout the course of the project.

The meeting ended with an overview of outstanding actions that will be followed up by the specific work packages, a summary of decisions and an outlook on the next steps. As a

final prospect for the future, the attendees decided on a date for the next Consortium meeting, to be held on 5 October in Berlin, Germany.

About MOPEAD:

- The Models Of Patient Engagement for Alzheimer’s Disease (MOPEAD) involves fourteen EU partners, coordinated by Fundació ACE and Eli Lilly
- It aims to deliver a step-change in AD patient engagement strategies and a paradigm shift from late-stage diagnosis to early-stage diagnosis
- Multiple regional project sites will be established to identify and test models of efficient early identification of mild AD dementia and prodromal AD patients

**21 March: AETIONOMY finishes busy month with 2nd interim review**



The AETIONOMY project had a busy month in March 2017 with a consortium meeting at the University of Luxembourg in Belval, Luxembourg on 1 and 2 March 2017, as well as

the Interim review in Brussels on 21 March where the project representatives gave an update on the project’s achievements to the Innovative Medicines Initiative and the independent reviewers.

March was also the month where AETIONOMY announced that it had recruited over 200 people into the Parkinson’s disease (PD) portion of the European clinical study on neurodegenerative diseases. This milestone means that the project is 50% completed in both the Alzheimer’s disease (AD) and the PD portion. The portion is being recruited via [EPAD](#) which has now recruited a total of 123 subjects.

Within the project, patients with neurodegenerative diseases and healthy people are providing blood and cerebrospinal samples to undergo detailed molecular analysis at leading European laboratories.

The purpose of AETIONOMY is to propose novel patient classification based on mechanism-based taxonomies, for both PD and AD. “The AETIONOMY study will allow us to validate in real patients two hypotheses for PD and for AD” explains the coordinator of the clinical study within AETIONOMY, Prof. Jean Christophe Corvol of ICM, Paris.

“This will then allow clinicians to stratify patients according to biological mechanisms of the disease and potentially to target specific sub-populations for drug development.”

The interim review meeting ended on a positive note with the reviewers welcoming the progress achieved in the last year.

Alzheimer Europe is involved in AETIONOMY and contributes to the ethics work package coordinated by the Leibniz-University of Hannover as well as the dissemination activities of the project achievements to the wider dementia

community. The organisation was represented by Dianne Gove and Jean Georges at the meetings in Luxembourg and by Jean at the interim review meeting.

<http://www.aetionomy.eu/en/vision.html>

**21 March: INDUCT project 1 is researching surveillance technology and empowerment**



Early Stage Researcher (ESR) Yvette Vermeer (pictured) explores what people with dementia and family caregivers need in surveillance technology and how using these products could impact them. Ms Vermeer, based at University College London, is part of the Interdisciplinary

Network Using Current Technology in Dementia (INDUCT) project.

Previous research shows that surveillance technologies such as GPS products are increasingly used in dementia care. The market promotes products that increase safety, track people with dementia who “wander”, and support the caregiver.

Many discussions are about how surveillance invades privacy or how increasing safety is chosen over autonomy. However, surveillance products do not always support individual needs, are often unreliable, poorly designed, and do not aid with other behaviours. Yet these products are often seen as the empowering solution. Therefore, the project explores what people with dementia and family caregivers need in surveillance and how these products are designed and marketed.

With more information about surveillance and a raised awareness of needs, people can make informed choices. Also by giving people a say in this research they can start to make demands for designs. Therefore, this research wants to involve people with dementia and family caregivers not only as participants, but as advisers as well. Individuals will be asked about their needs and thoughts on various surveillance products. In addition, advisers are welcome to make recommendations about the research. For instance, on how to run focus groups with various individuals in three different European countries. Preparations have been made for gathering the first findings starting in June 2017. The research project is in collaboration with Alzheimer Europe.

Interested in more information or want to participate? Please email [y.vermeer@ucl.ac.uk](mailto:y.vermeer@ucl.ac.uk)

**23-24 March: ROADMAP project holds 2nd General Assembly in Barcelona, launches website**

On 23 and 24 March, the partners of the ROADMAP project met for the 2<sup>nd</sup> General Assembly Meeting of the project in Barcelona, Spain. The meeting was chaired by John Gallacher (University of Oxford) and Frederic de Reydet de Vulpillieres (Novartis on behalf of EFPIA). The aim of the meeting was to provide an overview of the progress of the project and to

identify opportunities for further cross-Work Package collaboration.

Altogether, ten main topics were presented and discussed. During the first day, these included the recently accepted “D2.1 First list of priority real world evidence relevant outcomes for AD” and progress on the literature review on disease models and Industry/Health Technology Assessment (HTA) economic models, as well as hands-on data extraction pilots from different countries.

During the second day, the current selection of disease models and their validation were discussed. This presentation was followed by a fingerprints demo on data source overview and characterisation. Jacqueline Bouvy (NICE), Christine Gispén (College ter Beoordeling van Geneesmiddelen) and Robin Thomson (Biogen) introduced the work on regulatory and HTA engagement, including the platform to engage with regulators/HTA bodies.

Following on from that, the Ethical, Legal and Social Implications (ELSI) literature review possibilities were discussed with regard to potential scenarios. The presentations ended with an overview of the communications plan and tools, including the launch of the website. The meeting was closed by the members of the Executive Committee with a recapitulation of action items and an outlook on the next meetings.



The official ROADMAP website [www.roadmap-alzheimer.org](http://www.roadmap-alzheimer.org) which was launched during the General Assembly, includes recent news, access to the official ROADMAP twitter handle and an overview of the project’s Work Packages as well as the projects partners. Visitors also have the opportunity to subscribe to the project’s quarterly newsletter.

**24 March: The MinD project works on data analysis**



In March, the MinD project had two parallel secondment visits, one at Fundacion INTRAS in Spain, and one at Queensland University of

Technology (QUT), Brisbane, Australia. The two secondments

are the last in the series of secondments dedicated particularly to the data collection with people with dementia.

Researchers on the two secondments worked hand in hand: MinD colleagues at INTRAS in Spain worked on interview coding and collected the visual diaries. They sent anonymised, digitised versions of the diaries to MinD colleagues working for a month at QUT to analyse the diaries from all three countries involved in the data collection (Germany, Netherlands, Spain). Reading the interviews and diaries, it was clear that people with dementia find it important to still be useful in their setting and active during the day. Their social networks are a really important support for them, including family, caregivers and friends, who are the main point of reference in their life. A workshop on music therapy, attended by researchers at INTRAS, highlighted the importance of self-realisation for people with dementia.

Researchers at QUT participated in an International Symposium on “Designing for Dementia”, organised by the hosts at QUT during the secondment. The symposium was a great success, with 9 international speakers, including the MinD team, other colleagues from QUT, from Sydney and the UK, and from Canada. Speakers presented work, results and insights into various aspects around designing, ethics, methodology and environmental considerations and support available for people with dementia. The symposium was attended by approx. 170 delegates, many from professional backgrounds (architects, formal and informal carers and care professional), which made for a great audience, lively and enlightening discussions, and which highlighted progress in the area of the presented work, as well as much need for further research. The MinD researchers at QUT also presented the MinD project work to a group of about 40 final year design students who were very much interested in some of the methodological and conceptual aspects of the work.

A number of the projects in which Alzheimer Europe is a project partner receive funding from the Innovative Medicines Initiative (IMI) 2 Joint Undertaking. The Joint Undertaking receives support from the European Union’s Horizon2020 research and innovation programme and EFPIA.

The projects mentioned in this newsletter, with funding are:

- AETIONOMY – grant agreement 115568
- EPAD - grant agreement 115736
- EMIF - grant agreement 115372
- MOPEAD - grant agreement 115985
- ROADMAP - grant agreement 116020



## Alzheimer Europe Networking

- On 1 March, Dianne took part in a telephone conference for the ethics work package of the ROADMAP project.
- On 1 March (Luxembourg, Luxembourg), Alzheimer Europe organised a Public Affairs meeting with the AE Board, members and staff.
- On 1 and 2 March (Belval, Luxembourg), Jean and Dianne attended the rehearsal for the AETIONOMY interim review at the University of Luxembourg.
- On 3 March (Brussels, Belgium), Vanessa and Cindy attended an EFPIA Patient Think Tank Meeting.
- On 6 and 7 March (Copenhagen, Denmark), Jean and Dianne attended the PredictND management and project team meetings.
- On 10 March, Dianne took part in the PACE GA telephone meeting.
- On 13 March (Brussels, Belgium), Jean met with representatives of European health NGOs to discuss the future of the EU health programme.
- On 14 March (Brussels, Belgium), Jean attended the PredictND Interim review meeting.
- On 14 March (Brussels, Belgium), Vanessa and Christophe attended a European Brain Council (EBC) lunch debate.
- On 15 and 16 March (Brussels, Belgium), Jean attended the IMI Meeting "Collaboration in Alzheimer's disease".
- On 16 and 17 March (Brussels, Belgium), Jean and Chris attended the 2<sup>nd</sup> MOPEAD Consortium Meeting.
- On 16 and 17 March (Sofia, Bulgaria), Dianne attended the Joint Action Dementia II work package meeting on residential care.
- On 20 and 21 March (Brussels, Belgium) Jean and Dianne attended the AETIONOMY rehearsal and Interim review.
- On 23 and 24 March (Barcelona, Spain), Dianne and Chris attended the 2<sup>nd</sup> ROADMAP General Assembly Meeting.
- On 24 March (Brussels, Belgium), Vanessa attended a European Commission meeting on the European Solidarity Corps
- On 29 March (Munich, Germany), Jean and Heike von Lützu-Hohlbein met with representatives of the Robert Bosch Stiftung for a brainstorming session about dementia and migration at European level.
- From 30 March to 1 April (Paris, France) Gwladys attended the M&I Spring forum.
- On 31 March (Brescia, Italy) Dianne attended the Actifcare meeting.

## 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 Theocharous (EPP). **Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). **Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (ALDE); **Finland:** Liisa 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); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D). **Germany:** Angelika Niebler (EPP); Udo Voigt (NI). **Greece:** Kostas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyraiki (EPP); Eleftherios Synadinos (NI); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Ádám Kósa (EPP). **Ireland:** Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke 'Ming' Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Liadh Ni Riada (GUE/NGL). **Italy:** Brando Benifei (S&D); Elena 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 Blinkeviciute (S&D). **Luxembourg:** Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP). **Malta:** Therese Comodini Cachia (EPP); Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Esther de Lange (EPP); Jeroen Lenaers (EPP); Lambert van Nistelrooij (EPP). **Poland:** Elzbieta Lukacijewska (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 (EPP); 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 Žitňanská (ECR). **Slovenia:** Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Šulin (EPP); Romana Tomc (EPP); Ivo Vajgl (ALDE); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (ALDE); Soledad Cabezón Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estaräs 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

### 21-22 February: EFGCP holds meeting on ethical standards under the clinical trials regulation



On 21 and 22 February 2017, the European Forum for Good Clinical Practice (EFGCP) held its annual conference for 2017 on Meeting the Ethical Standards under the Clinical Trials Regulation (CTR): burning questions and answers (researchers, sponsors and patients) in Brussels, Belgium.

Alzheimer Europe (AE) Director for Projects Dianne Gove chaired a debate on the CTR and vulnerable groups, with a focus on people with dementia, together with Marianne Mamman from Novartis Pharma as rapporteur.

During the debate, members of the audience emphasised the need for effective protection, but balanced with measures to promote respect for the autonomy of people from vulnerable groups. Members of the audience also questioned whether references to vulnerable groups in the CTR were helpful and suggested a greater emphasis on compassion and on seeking to recognise the needs of each participant, so as to maximize each person's potential to participate.

AE Project Officer Ana Diaz also attended the conference and contributed towards this discussion.

### 27 February: The European Patients' Forum officially launches campaign on "Access to Healthcare"



The one-year campaign "Universal Health Coverage For All" was officially launched on 27 February at the European Parliament in Brussels by the European Patients' Forum (EPF) with the "[Patient Access Partnership](#)" (PACT).

The event was co-hosted by MEP Kateřina Konečná, (Czech Republic) and MEP Andrey Kovatchev (Bulgaria). Among the keynote speakers at the event were Isabel de la Mata (European Commission), Agnès Couffinhall Organisation for Economic Co-operation and Development (OECD), Josep Figueras (European Observatory on Health Systems and Policies), Alyn Smith, Platform for Information on Undocumented Migrants (PICUM) and Juan Fuertes, Pulmonary Hypertension Europe (PHA Europe).

The meeting provided an opportunity to present the campaign and to discuss what actions should be taken to achieve universal health coverage at European level.

The EPF campaign is calling on policy makers to adopt an action plan on access to healthcare that improves access to quality health and social care for every patient across Europe.

The five "A's" representing the dimensions of Access are:

- Availability – whether a healthcare service or product is available in the healthcare system of a country.
- Affordability – whether seeking healthcare causes financial hardship to patients.
- Accessibility – whether there are barriers, other than financial (e.g. waiting lists, geographical barriers...), that stop patients from accessing healthcare.
- Adequacy – the quality of healthcare and involvement of patients in shared decision making with their healthcare professionals.
- Appropriateness – whether healthcare meets the needs of different groups in the population.

The purpose of this campaign is to raise awareness among political decision makers and policy makers about the barriers that patients face in accessing healthcare and to foster EU cooperation in the field, to improve the current system.

The outcomes of the campaign will contribute to shaping and developing recommendations and a political document, calling policy makers to commit to the campaign in order to achieve "Universal Health Coverage For All by 2030".

People are encouraged to support the campaign on social media using the hashtag [#Access2030](#).

<http://www.eu-patient.eu/campaign/access-to-healthcare/>

### 27-28 February: JA-CHRODIS Joint Action on Chronic Diseases and Healthy Ageing Across Europe organises final conference



On 27 and 28 February, European and national policy makers, representatives of international organisations NGOs and researchers as well as JA-CHRODIS partners gathered in Brussels to discuss the results of the three-year Joint Action and explore how the outcomes can be rolled out to address the chronic disease challenge across Europe.

The JA-CHRODIS addresses "Chronic Diseases and Healthy Ageing Across Europe". Chronic diseases like diabetes, cardiovascular disease, cancer and mental disorders affect 8 out of 10 people aged over 65 in Europe.

The first half day of the conference gave participants the opportunity to learn more about the key outcomes of the Joint Action, which include:

- the “Multimorbidity Care Model” which is already being piloted in The Netherlands,
- the “Policy Brief on National Diabetes Plans”
- in the area of health promotion, good practices from the local, regional and national level have been identified, alongside the success factors, which enable their transfer or scaling-up,
- the CHRODIS platform, an IT tool which supports the selection of best practices and hosts a digital library.

On the second day, high-level speakers, including European Commissioner for Health and Food Safety Vytenis Andriukaitis and WHO Regional Director for Europe Zsuzsanna Jakab discussed the potential of JA-CHRODIS’ work within the framework of current EU and WHO priorities on chronic diseases.

Further highlights of the conference included the [launch of the 12 steps](#) to reduce the burden of chronic diseases. The document, including the 12 steps, developed by the JA-CHRODIS Executive Board comprises recommendations based on JA-CHRODIS work for the scaling up, transfer and implementation of practices in order to ultimately reduce the burden of chronic diseases.

JA-CHRODIS is the first Joint Action on chronic diseases co-financed under the EU Public Health Programme. It has brought together tens of partners from 25 European countries, who have worked since 2014 to identify, validate, exchange and disseminate good practices on chronic diseases across EU Member States and to facilitate their uptake across local, regional and national borders.

<http://chrodis.eu/ja-chrodis-final-conference/>

## 2 March: MEPs adopt report to make medicines more affordable



On 2 March, MEPs adopted a European Parliament report calling for transparency and clarity of public funding on research, improved access to medicines and development of new drugs. It also recognised that a number of vital drugs

were overpriced due to abuse of patent rules by pharmaceutical companies as well as the imbalance in the price negotiations among the pharmaceutical industry about the individual Member States.

The text was approved by 568 votes to 30, with 52 abstentions.

MEPs say that the high level of public funds used for R&D is not reflected in the pricing of medicines, impeding a fair return on public investment. They call for greater clarity on R&D costs, including the share of publicly-funded research, and on the marketing of medicines. They call on the Council and the Commission to strengthen the negotiating capacity of Member

States in order to ensure affordable access to medicines across the EU.

MEP Soledad Cabezon Ruiz (Spain), who drafted the resolution stressed “Public health systems in Europe are a key part of the identity of the EU and something which we value highly. Access to medicines must be guaranteed and in order to achieve that, we need to rebalance the negotiating power of EU member states compared to that of the pharmaceutical industry.”

<http://www.europarl.europa.eu/news/en/news-room/20170227IPR64157/meps-propose-ways-to-make-medicines-more-affordable>

## 2 March: Future IMI Calls for proposals include more emphasis on Alzheimer’s disease



innovative medicines initiative

On 2 March, the Innovative Medicines Initiative (IMI) announced the next topics under consideration for inclusion in an upcoming Call for proposals, including one on Alzheimer’s disease:

- Development and validation of technology enabled, quantitative and sensitive measures of functional decline in people with early stage Alzheimer’s disease (RADAR-AD) – read the indicative text here.
- Fairification of IMI and EFPIA data .
- Development of sensitive and validated clinical endpoints in primary Sjögren’s syndrome (PSS).
- European screening centre: unique library for attractive biology.
- Exploitation of IMI project results.

Interested in applying? Read IMI’s [tips for applicants](#) and [advice on finding project partners](#).

Please note that all information regarding future IMI Call topics is indicative and subject to change. Final information about future IMI Calls will be communicated after approval by the IMI Governing Board.

<http://www.imi.europa.eu/content/future-topics>

## 3 March: EFPIA hosts Patient Think Tank Meeting



On 3 March, the European Federation of Pharmaceutical Industries and Associations (EFPIA) held a Patient Think Tank Meeting in

Brussels. On the agenda was a draft white paper - “Patient Organizations and Industry Working together”. The paper was drafted by a working group from the Patient Think Tank (PTT).

During the meeting, the group discussed the content and made suggestions for next steps. One of the next steps discussed was the roll out of the white paper in different European countries.

EFPIA also gave a presentation entitled “Incentives review”, which showed the current understanding of the background to, and challenges of the Commission’s study on the economic impact of SPCs, pharmaceutical incentives and rewards in Europe. EFPIA then presented a “Pipeline Review &

Introduction of new technologies in the Healthcare System". This included a discussion around what the different stakeholders of the healthcare systems can do for innovation and to provide access.

Alzheimer's disease was used as an example of high unmet needs, where even a moderate efficacy would have a big impact on patients, showing how a disease-modifying therapy offers great hope and benefits to patients, their families, caregivers, healthcare systems and society.

Finally, EFPIA gave a policy update on developments around Member State cooperation on pricing and reimbursement.

Alzheimer Europe Policy Officer Vanessa Challinor and Project Officer Cindy Birck attended the meeting.

**6 March: Demonstration calls for strong and effective European Accessibility Act**



On 6 March, a group of around 200 people, including dozens of people with disabilities, demonstrated outside the European Parliament in Brussels. The demonstration, organised by the European Disability Forum (EDF), was held to highlight concern about the recently published draft report of the European Parliament's Internal Market and Consumer Protection Committee (IMCO) on the Accessibility Act, and called on the European Parliament to adopt a stronger and more ambitious Accessibility Act

Helga Stevens, MEP (Belgium), who was present at the demonstration said:

"The committee's report is watering down the proposal for the act to such an extent that fundamentally important parts of it may be lost."

The European Accessibility Act, already some seven years in the making, is a proposal for a law that could make several products and services in the EU accessible for all citizens, including 80 million persons with disabilities 190 million people aged 50 and older, and also people with dementia.

The European Disability Forum (EDF) was also out in force at the demonstration.

EDF President, Yannis Vardakastanis stated:

"Accessibility is a prerequisite to live independently and be included in society. We are calling on the European Parliament to keep its role as the front runner for the rights of its citizens and support a strong and ambitious Accessibility Act that will bring a real change in the lives of all people in Europe."

Igor Šoltés, MEP (Slovakia), who was also supporting the demonstration said that "millions of people in Europe are still excluded from using basic products and services that are taken for granted by others. These, included withdrawing money from a cash machine, entering a bank or any public building and using the metro."

<http://www.edf-fehp.org/newsroom/news/activists-demonstrate-strong-law-accessibility-europe>

**14 March: European Brain Council hosts Lunch debate "Expanding brain research in Europe - A societal need?"**



On 14 March in Brussels the European Brain

Council (EBC) hosted a lunch debate. The meeting was part of a series of events held throughout the week for Brain Awareness Week 2017, during which EBC raised awareness of the important issues of brain research and the burden of brain disorders across Europe.

The first speaker was Frédéric Destrebecq (Executive Director, EBC) who gave an overview and introduction on EBC activities including an update on EBC's "Value of Treatment" research project in which Alzheimer Europe has been involved. Ms Hilikka Karkkainen (President, GAMIAN-Europe) spoke about "The burden of mental disorders and the patients' experience and expectations as a partner in EU research projects". Alexander Schubert (Executive Director, European College of Neuropsychopharmacology (ECNP) discussed "The challenges to innovation in brain research". Lars Kristiansen (Federation of European Neuroscience Societies (FENS)-Kavli Network of Excellence) talked about "The need to strengthen brain research in Europe to better respond to societal needs". Finally Stéphane Hogan (DG Research and Innovation, European Commission) gave an overview of the European Commission's work in brain research, "The perspective from the European Commission's DG research & Innovation".

To keep up with future events, EBC has created the #ILoveMyBrain logo as a communication tool for promoting and connecting all the work being done to promote brain health and prevent and treat brain disorders in Europe.

Policy Officer Vanessa Challinor and Project Officer Christophe Bintener represented Alzheimer Europe at this meeting.

**14-15 March: EMA Patients' and Consumers' (PCWP) and Healthcare Professionals' (HCPWP) Working Parties meet in London**



The European Medicines Agency (EMA) PCWP and HCPWP met for a two-day meeting in London on 14 and 15 March.

The first day of the meeting was a workshop dedicated to the topic of personalised medicines, where delegates could hear about how the work of the EMA related to this topic. Delegates were also invited to discuss the role of patients, consumers and healthcare professionals on personalised medicine. Delegates commented on the need to have well-educated patients, who can contribute to personalised medicine, and agreed on the relevance of involving patients in a meaningful way.

On the second day, there were a number of presentations on the EMA's activities, including its interaction with patients, consumers and healthcare organisations during 2016, the work plans for 2018-2019 and an update of the work of the

Topic Groups and their recommendations on social media and risk minimisation measures. Delegates heard about a pilot project, which aimed at further involving patients on EMA benefit/risk considerations. Based on the positive evaluation, the EMA plans to continue this type of involvement on a case-by-case basis. The different scientific committees of the EMA also provided updates on their activities.

Project Officer Ana Diaz attended the meetings on behalf of Alzheimer Europe.



## MEMBERS' NEWS

### 1 March: SPOMINČICA reports on a busy month

On 1 March, our Slovenian member Spominčica sent us the following report of some of its important activities during February 2017:

- Spominčica started with an Alzheimer Cafe in one new location in Slovenia.
- Monthly web edition of Spominčica magazine was published on our website.
- Spominčica has continued with monthly show about dementia on radio Bob (heard in Ljubljana and surroundings).
- On 28 February, we started a new cycle of our training programme "Forget me not" for caregivers of individuals with dementia.
- We organised an education course for public workers (tradesmen), who works at information points at the BTC shopping centre in the City of Ljubljana.

Also, in collaboration with the company Pristop we published a poster about dementia in 26 different Slovenian media to raise public awareness about dementia. The motif of a pencil with the shadow of a screwdriver represents a typical problem with perception in dementia. It warn us that individuals with dementia have some difficulties to recognise objects and their functions, which leads to uncertainty and confusion. As caregivers, we have to be aware of cognitive decline, so taking care of their safety should be our number one priority. We believe that a campaign like that would contribute to a better dementia-friendly environment in Slovenia.



Finally, Spominčica is also part of the Erasmus project AD-GAMING (Development of Training Program for the Improvement of Quality of Life of Persons with Alzheimer through "serious games"). Our partners in this project are Spain, UK, Greece and Romania. The basic goal of "serious games" (pictured) is improving cognitive skills and developing a training programme for health professionals and caregivers to use the game not just for fun, but also as an opportunity for mental activity. In February, Spominčica conducted 3 co-

creative sessions at nursing homes across Slovenia. According to focus groups, all participants showed interest for participation and positive results such as better social skills, making new friends, reviving memory and general knowledge, improving orientation, recognition, language skills and perception.

### 2 March: All-Party Group on Dementia grows in the Irish Parliament



Ireland's first All-Party Oireachtas Group on Dementia was launched in October 2016. This group - co-convened by Deputy Mary Butler and Senator Colette Kelleher- is run in partnership with The Alzheimer Society of Ireland (ASI)

and now has 19 members, representing all the main political parties in Ireland.

The All-Party Group has been busy in recent months, hosting regular meetings and undertaking a study visit to Scotland, where Deputy Butler and Senator Kelleher met with senior staff from Alzheimer Scotland, members of the Scottish Dementia Working Group and key political representatives and stakeholders. The Group also hosts regular Dementia Awareness Sessions for members of the Irish Parliament, which are delivered by the ASI.

The group is focused on several key priority issues for 2017, including the implementation of Ireland's National Dementia Strategy, the needs of key groups affected by dementia, timely diagnosis and the creation of a statutory scheme for home care in Ireland.

Pictured: Kathy Ryan, Vice-Chair of the Irish Dementia Working Group, addressing member of the Irish Parliament at the All-Party Group Dementia Awareness Session on 2 March.

### 8 March: Alzheimer Bulgaria celebrates International Women's Day with dementia seminar for women



March is the month of the International Women's Day. Alzheimer Bulgaria celebrated this holiday together with the "pensioners' female singing group" in Gorna Mitropolia village, Pleven District.

During the organised meetings, older women from the village were informed about the diseases that can lead to dementia; what the first symptoms are and when to seek medical advice; the advantages of early diagnosis as well as where they can consult specialists.

Some of the women shared their experiences on taking care of relatives living with dementia. Together, they researched useful information about the problem on the Internet but, unfortunately, found hardly any in Bulgarian.

As it was a holiday, the women sang some songs. "Singing helps them to feel healthier, even if they are not very young" said Alzheimer Bulgaria.

**9 March: France Alzheimer launches campaign on AD during Presidential elections**



On 9 March, France Alzheimer announced a new campaign, which will run during the French Presidential elections:

With our national mobilisation campaign called "Tous candidats à la maladie" (all candidates for the disease), our Association intends to participate in the electoral debate. But let's be clear: France Alzheimer is not pursuing any electoral aim. The objective is elsewhere: to encourage reflection among the candidates and to generate, via the Internet and especially social media such as Twitter, the mobilisation of the general public around a cause that concerns us all.

Who says Presidential election, also says electoral programme. France Alzheimer has made 23 concrete commitments to improve dementia care and the situation of millions of families. And, there is some urgency: in 2025, 1 French person in 4 over the age of 65 will have dementia. The next five years are crucial.

<http://www.touscandidatsalamaladie.fr/>

**13 March: Alzheimer Slovenia talks about its participation in MOPEAD project during Brain Awareness Week**



Spominčica - Alzheimer Slovenia is participating in a new project, MOPEAD – Models of Patient Engagement for Alzheimer's Disease, which started in October 2016.

Dr Milica Gregorič Kramberger, neurologist, (from Neurology Clinic, University Medical Centre Ljubljana, project partner) presented MOPEAD during Brain Awareness Week, 13 to 19 March, in Ljubljana.

This 33-month project aims to deliver a step-change in Alzheimer's disease (AD) patient engagement strategies and a paradigm shift from late-stage diagnosis to early-stage diagnosis.

Multiple regional project sites will be established to identify and test models of efficient early identification of mild AD dementia and prodromal AD patients.

**21 March: Norwegian Health Association reports on summit meeting on brain health in Norway**



The Norwegian Health Association recently took part in a summit meeting on brain health in Norway. At the meeting, the Norwegian

Government announced plans for a national strategy on brain

health. Brain diseases affect one in three people during their lifetime. At the summit, Prime Minister Erna Solberg and Minister of Health, Bent Høie, met with researchers, clinicians and representatives of patient groups. The topic was "How Norway can contribute to increased knowledge about brain diseases". Head of the Norwegian Health Association's dementia research programme Anne Rita Øksengård (PhD, MD) spoke on behalf of the organisation, putting forward three proposals:

- To establish a national, multidisciplinary programme on dementia research and substantial funds for this.
- Research on the causes, diagnosis and treatment of dementia should be intensified.
- A requirement for cooperation between research groups carrying out basic research and those involved in clinical research. In basic research there should be cooperation in all neurodegenerative brain diseases, such as dementia, ALS and MS.

The government will provide better services for people with neurological diseases, therefore we will create a national strategy for brain health. We see the need for more research so that we can better prevent these diseases and treat patients as well as possible, Prime Minister Erna Solberg said.

<https://www.regjeringen.no/no/aktuelt/hjerneehelse-far-egen-nasional-strategi/id2544438/>

**24 March: First Dementia Nurse Specialist Training in Croatia**



On 24 March, the first comprehensive, specialist education programme for carers of people with dementia, began in Umag (peninsula Istria), Croatia. The programme, which

falls within the context of the EU project Dementia aCROsSLO, is aligned with the latest trends in specialist education for formal caregivers. It covers 12 topics and 33 "school hours", i.e. lectures and workshops.

Introductory themes will present the basics of dementia and neurodegenerative diseases, as well as practical ways of recognising signs of Alzheimer's disease (AD), the principles of psychosocial work and basic forms of care for people with dementia.

The second block of lectures is directed at mental and behavioural disorders and practical ways to help with these; communicating with people with dementia and their relatives; and non-pharmacological and pharmacological therapies.

The third and last block of lectures is aimed at senior executives and will focus on planning work with people with dementia and the monitoring of their psychosocial and health status.

The development of this educational plan was led by the Alzheimer Croatia, the head partner of the Working Group for Education of the Croatian-Slovenian project Dementia

aCROcSLO, which is co-funded by EU funds from the project Interreg.

Lectures will be performed by well-known experts from Croatia and Slovenia. They are being held on a weekly basis, in retirement homes in Izola (Slovenia) and Umag (Croatia), and will end in late spring of this year.

Pictured: The first lecture in a retirement home in the City of Umag, Croatia.

**24 March: Finland provides personalised advice on memory-related issues over the phone**



A phone service called Memory Advice has been in its pilot phase for about a year now in Finland. The service is targeted for people

with memory-related diseases, their carers and professionals in the field. The service is available three days a week. Calls are cheap; the caller pays only 8 cents / minute + local network charge.

On the basis of the one-year pilot phase, the Alzheimer Society of Finland (Muistiliitto) says that the service is needed: In the past year the phone line received 349 calls and many calls were left unanswered, because of the congestion of the phone line.

The most common questions received by the Memory Advice phone service were on specific issues having to do with nursing, symptoms of memory-related diseases, studies on memory-related diseases, as well as legal advice. The most common questions on legal advice were related to continuing power of attorney and advance directives.

The vast majority of callers were women and people with memory related diseases. Most of the callers were between 41 and 65 years of age, though the age range was large, ranging up to more than 80 years of age.

The Memory Advice phone service calls are received by professionals working in the Memory Pilot centers. Memory Pilots are expert and support centres maintained by the member associations of the Alzheimer Society of Finland.

The Society is pleased to note that people are aware of and have been using the Memory Advice phone service. Phone calls have been received from all the regions of Finland.

The Memory Advice phone service will now be expanded and calls are answered in each region of Finland. There will thus be 18 professionals on duty in total.

**28 March: UK Alzheimer’s Society tells us about “State of the Nation” consultation**



State of the Nation is the largest consultation of people affected by dementia that we have ever undertaken to capture the experiences and attitudes of those living with dementia today.

We want to gather in-depth information on what life is really like for many different people living with dementia across

England, Wales and Northern Ireland. With this information we can find out what we can do, and how best we can support those living with dementia.

This is certainly not the first time that the Alzheimer’s Society has carried out surveys of people with dementia; previous surveys have supported the development of policy reports from Dementia 2012 through to Dementia 2015. However, State of the Nation seeks to give a totally new approach to how we gather evidence, significantly increasing our knowledge of people’s experiences, and increasing the quality of information gathered around the views of people affected by dementia.

We are recruiting local trained volunteers to go in to services and identify people that will be able to complete or be helped to complete the survey. Furthermore the survey questions have been refined over several versions with the input of different groups of people affected by dementia, and have been developed in a way that they feel they are able to complete, or can have assistance to complete in a way that still captures only their own views. We have now completed online surveys of 500 carers and 2,356 members of the public, as well as 33 in-depth interviews with people affected by dementia. Our research partner is analysing emerging themes. Finally a quantitative survey of 1,000 people with dementia, is being carried out - there is only one other piece of quantitative research in people living with dementia globally!

Speaking to people with dementia on this scale - and importantly at this level of detail – will provide us with a rich tapestry of stories which will feed in to the work that we do and help us all to unite against dementia.

**28 March: Alzheimer Scotland calls for its supporters to get on board with a campaign for its Election 2017 Pledge on Dementia**



No group of elected politicians has more say on the decisions that directly affect people with dementia and their families, than local councillors. They are the only democratically accountable members of the Integrated Joint

Boards that now run all adult health and social care in Scotland. And even the councillors that don’t sit on those boards have a job to do to scrutinise those who do.

4 May 2017 will see council elections in all 32 of Scotland’s local authorities, with the people of Scotland set to elect 1,222 councillors across the nation. Alzheimer Scotland needs your help to make sure that each one of the newly elected councillors understands what needs to be done to make sure that people with dementia and carers receive the support and care they need.

Alzheimer Scotland has worked together with members, people with dementia and carers to develop six priorities that we want all candidates to sign up and work towards, if

elected. With over a thousand councillors due to be elected and many more candidates standing, Alzheimer Scotland needs all its supporters to support the campaign and contact their candidates!

**Get on board – get involved**

Find your local candidates: Council website, local press, political parties, or ask [publicpolicy@alzscot.org](mailto:publicpolicy@alzscot.org)

Tweet them, email them, write on their Facebook pages, attend hustings, speak to them when they campaign and ask them to support our [#AlzScot2017](#) Pledge, below

- Encourage them to take pledge selfies!
- Tell them why this issue is important to you, how you or those close to you are affected.

Get them to email their support to [publicpolicy@alzscot.org](mailto:publicpolicy@alzscot.org) or tweet using the hashtag [#AlzScot2017](#)

Read the full Pledge we want our councillors to sign up to here: <http://www.alzscot.org/election>

**28 March: Norwegian Health Association talks about the way forward for its dementia research programme**



Researchers involved in the Norwegian Health Association’s dementia research programme met in March 2017, to discuss processes and results midway.

The programme, launched after the Norwegian Broadcasting Corporation’s telethon in 2013, has received approximately EUR 10 million.

Themes covered in the programme are: research into the causes, prevention, diagnosis and treatment of dementia.

<http://nasjonalforeningen.no/forskning/demensforskning/>

**28 March: UK Alzheimer’s Society reports on its shared learnings with Japan**



In January 2016, UK Secretary of State, Jeremy Hunt and Japanese Minister Yasuhisa Shiozaki agreed to work together to progress their shared commitment for age- and dementia-friendly communities.

The Alzheimer’s Society is proud to be the UK delivery partner, working with the Japanese National Centre for Geriatrics and Gerontology (NCGG) towards mutual learning to improve our national programmes and to share this knowledge to support the development of dementia-friendly communities worldwide.

Partnering with Japan is particularly meaningful, as in 2012 we were greatly inspired by the way Japan had raised awareness of dementia through their volunteering programmes – primarily their Ninchisho (dementia) Supporter Caravan programme. Following this the Dementia Friends programme

was developed, which has now over 1.8 million Dementia Friends in England and Wales, and which has captured the imagination of people globally.

Over the past year, we have taken part in various learning exchange visits and sharing opportunities to build on the support and information we currently provide to improve the lives of people living with and affected by dementia. From coordinating a special Dementia Friends/Ninchisho Supporter Caravan session with the Alzheimer’s Association Japan to WHO Director General Dr Margaret Chan, to looking at dementia care and services in Japan and learning from their focus on respect for individuality and freedom.

Our collaboration continues with a pre-conference symposium at ADI’s 2017 conference “Building a Dementia Friendly World”, which is a coordinated effort between the Alzheimer’s Society, WHO Kobe centre and ADI.

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

“Dementia is the biggest health crisis facing the world today with over 47 million people living with the condition, and this number is set to rise to over 100 million by 2050. Collaboration between countries is crucial to create a global change and a worldwide societal shift towards acceptance, inclusion and support for people living with dementia and their carers.”

You can read about our Director of Marketing and External Affairs learning exchange in Japan here:

<https://blog.alzheimers.org.uk/personal-stories/dementia-care-japan-independence-choice/>

**31 March: The Alzheimer Society of Finland updates us on its activities and other news from Finland**



**New Strategy 2017 - 2020**

Our new strategy pilots our work until 2020. The vision is a memory-friendly Finland.

We have three main points:

People with memory diseases (MD) can live their life of his/her own as active members of society, included not excluded according their own capacities, abilities and resources.

Not many want to live in isolated villages.

Our goal, as an NGO, is to improve public awareness and also to promote and support people w MD to become an accepted, visible part of society.

**Promotion of Brain health, prevention of memory-related diseases and everyday changes of life**

Healthy habits - healthy brain.

We underline what Professors Mia Kivipelto and Timo Strandberg say: “As the options of prevention of arterial diseases are well known, this will also provide possibilities for extensive prevention of memory diseases.

Central measures include physical activity, a healthy diet and intervention in risk factors - early enough, of course. What is good for the heart is generally good for the brain as well."

The strategy underlines the need for health and social services that genuinely/really 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.

Influencing together (effectively): We work together with our 44 member associations and their 14 000 members, 1000 voluntary people and 260 employees. We think that we are quite strong actor with our partners.

**The Criteria of Good Care and Life -workbook**

The Alzheimer Society in Finland has been coordinating and implementing the National Memory program (2012-2020) in NGO sector since 2013. As a part of this work, we have published a workbook for professionals:

The Criteria of Good Care and Life for the homecare services and nursing homes to help develop and evaluate their work with people diagnosed with memory related disease and their care partners.

The workbook will be presented at the ADI conference in Kyoto.

**Current Care Guideline of Memory Diseases**

The working group appointed by the Finnish Medical Society Duodecim, Societas Gerontologica Fennica, the Finnish Neurological Society, Finnish Psychogeriatric Association and the Finnish Association for General Practice updated Care Guidelines of Memory Diseases in Finland on 27 January.

Examples of key messages:

- This guideline was published in 2006 under the name Diagnosis and pharmacotherapy of Alzheimer's disease. In connection with updating 2010, the guideline was extended to cover other common memory disorders and now 2017 also non-pharmacological treatment.
- Memory disorders, including Alzheimer's disease (AD), can probably be prevented by modifying known risk factors, such as hypertension.
- One in three persons above the age of 65 reports having memory symptoms. In Finland, there are as many as 200,000 people with slightly deteriorated cognitive function, and 100,000 with mild symptoms of dementia and 93,000 with moderate or severe dementia.
- In Finland, about 14,500 new cases of memory related diseases are diagnosed each year.
- A significant proportion of memory disorders remains undiagnosed.
- The cause or reason for memory symptoms expressed by the patient must be determined.
- The cornerstones of examination are clinical interview and examination performed by a physician, memory questionnaires and tests, laboratory tests, and brain imaging scanning.

- If signs of progressive memory disorder are observed before a diagnosis can be made, the patient should be monitored every 6-12 months.

This guideline aims at:

- promoting the prevention of the most common memory disorders, recognition of their risk factors, and their treatment, and
- intensifying and unifying the diagnosis and pharmacotherapy of memory related diseases and progressive memory disorders as part of their holistic treatment and rehabilitation.

**Municipal Elections in Finland**

Municipal Elections will take place in April this year. We have organised pledge campaign like AE did during European election or like we did our Parliament election campaign.

Our main message is Memory friendly community is great for everyone. We have increased the awareness of candidates and In three weeks we have received nearly 300 signatures in our website. We are active with our local associations and there are active with local candidates.

The pledge and number of Finnish signatories are mentioned several times in our Facebook (over 7000 followers) and Twitter.

Two big issues will be discussed in Parliament:

- Citizens' initiative on euthanasia proceeds to Parliament
- A recently-launched citizens' initiative to legalize euthanasia has already gathered the 50,000 signatures required for lawmakers to consider the proposal.

I think it is going to be, this citizens' initiative will raise a massive discussion, debate and dialog in Finland.

Finland passed legislation in 2012 to guarantee citizens' constitutional right to influence democracy by way of the citizens' initiative. It means that initiatives that gather the required 50,000 signatures automatically qualify to go before Parliament for consideration.

Self-determination, restrictions or deprivation of freedom

Once again in Finland we are trying to draw up a law on self-determination for the people with MrD, the first attempt started 2010 and did not end well/successfully.

Now Social Affairs and Health Ministry officials have prepared on this issue during the spring.



**POLICY WATCH**

**28 February: Ireland forges ahead with important legislation for people with dementia**



While talk of a new Taoiseach and possible election rumbles on, several pieces of legislation have been moving through the Oireachtas that are important for people with dementia.

The [Criminal Law \(Sexual Offences\) Bill 2015](#) has been passed by both Houses of the Oireachtas. This Bill provides clarity on the definition of consent and recognises people's right to sexual autonomy, while providing safeguards for those who cannot consent to a sexual act.

The Alzheimer Society of Ireland (ASI) input into the Bill through its submission on Sexual Offences against Vulnerable Persons, which you can read [here](#)

Another important Bill is the [Disability \(Miscellaneous Provisions\) Bill 2016](#), which was debated in the Dáil at the end of February. This Bill will make legislative changes that are needed before Ireland can ratify the UN Convention on the Rights of Persons with Disabilities (UN CRPD). Ireland signed the Convention in 2007, but is the only country in the European Union that has failed to ratify it. The ASI will continue to monitor this legislation to ensure the needs of people with dementia are represented.

**8 March: Global Alzheimer's and Dementia Action Alliance (GADAA) release new report: "Women & Dementia: A Global Challenge"**

 Global Alzheimer's and Dementia Action Alliance states a new report released by the [Global Alzheimer's & Dementia Action Alliance](#) (GADAA). The impact of dementia is much greater for women than men the world over,

The report publishes research on the issue of women and dementia and highlights that the prevalence, care burden and stigma of dementia disproportionately affects women, making it a global women's health, social care and rights challenge that can no longer be ignored.

The full findings can be read [here](#).

**28 March: The Organisation for Economic Co-operation and Development (OECD) reports on its recent Health Ministerial Statement**

 On 17 January 2017 Health Ministers of OECD and partner countries gathered in Paris to discuss the next generation of health reforms. A key topic was the need to make health services more people- and patient-centred in the quest to improve effectiveness and value for money. Ministers agreed that a critical part of this transition is how we measure performance. Here is an extract from the Ministers' statement:

"The shift from a health system that is centred on providers to one that is centred on people's individual needs and preferences has important implications for how we measure health system performance. The OECD has long played a leading role in benchmarking health system performance. Internationally comparable indicators have provided a powerful reference for countries seeking to understand the impact of policy reform. However, we recognise that data generated in health systems are still too often concentrated on

health activities and inputs, limiting opportunities for gaining new insight into the impact of policies." see <http://www.oecd.org/health/ministerial/ministerial-statement-2017.pdf>

The OECD is commencing a new programme of work to collect and report measures that are valued by users of health services. The programme is called the Patient-Reported Indicators Survey - or PaRIS. The aim is to gather systematic information on outcomes and experiences of care as perceived by patients, their carers and surrogates, in order to drive improvements in policy and practice throughout healthcare systems.

<http://www.oecd.org/health/paris.htm>

**28 March: Local elections are coming up in Scotland – want to know more about voting with dementia?**



Our friends at Alzheimer Scotland have kindly provided the following information for people interested in learning more about voting with dementia in Scotland:

People with dementia and carers often have questions about how to vote with dementia. The most important thing to remember is that the right to vote is a legally protected human right. People with dementia retain the right to vote, wherever they live, including if they are temporarily staying somewhere that isn't their usual residence. People with dementia have the right to vote so long as they are able to clearly express their voting choice.

Registering to vote by post or appointing someone to vote on your behalf - a proxy - can help reduce the potential stresses of an unfamiliar environment like the polling station.

For all information relating to voter registration, deadlines and voting preferences, visit [www.aboutmyvote.co.uk/register-to-vote](http://www.aboutmyvote.co.uk/register-to-vote).

Contact the Alzheimer Scotland Dementia Helpline on 0808 808 3000 or visit [www.alzscot.org/vote](http://www.alzscot.org/vote) to access full information and guidance on voting with dementia in Scotland.

Alzheimer Scotland is also campaigning for candidates in the Scottish Local Government Elections to support its [#AlzScot2017](#) Election Pledge. You can read more about this in our Members' news section.



## BEHIND THE HEADLINES

### 28 March: Dr JoAnn Elisabeth Manson comments on recent headlines claiming chocolate may prevent dementia



There have been a number of recent media headlines, about chocolate pills and other forms of chocolate being able to prevent dementia. We asked Dr JoAnn Elisabeth Manson, Professor of Medicine at Harvard, to provide her comments.

Dr JoAnn Elisabeth Manson is Professor of Medicine, Harvard Medical School and Chief, Division of Preventive Medicine, Department of Medicine, Brigham and Women's Hospital.

The focus of Dr Manson's research has been women's health, randomised clinical trials in cardiovascular disease prevention, and population health/translational research.

Find out more about Dr Manson here:

<http://researchfaculty.brighamandwomens.org/briprofile.aspx?id=4718>

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

The headlines suggest that chocolate has the ability to prevent Alzheimer's. Like many other news headlines these days, the "headline" allegation is not directly linked to the findings of the [study](#). The results of the investigation published in the journal *Neurology*, did not assess the effect of the consumption of hot chocolate on the conversion rate to Alzheimer's, which would be needed in order to be able to make statements about "prevention".

More specifically the scientists examined the participants' performance in cognitive tasks and evaluated the relationship between local neural activity and subsequent changes in cerebral blood flow before and after the consumption of cocoa for 30 days and compared the results between participants that had consumed flavanol-rich cocoa (609 mg), and flavanol-poor cocoa (13 mg flavanols). Blood flow and blood pressure changes were not significantly different between the two cocoa groups. Therefore, the researchers evaluated whether or not the response to cocoa (without taking the amount of cocoa flavanols into account) differed depending on neurovascular coupling (NVC) status, indicating that there was a significant improvement for 17 people with a poor NVC status at baseline. Considering the small sample size, the findings should be regarded as indicative rather than definitive.

This is another small study that suggests that the naturally occurring flavanols in cocoa beans may improve blood flow. But the first large long-term study to assess whether cocoa flavanols can lower the risk of heart attacks, strokes, memory loss, and other illnesses is on its way.

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

"Cocoa flavanols look promising," said Dr Manson. "The next logical step is to move from the small randomised trials looking at mechanisms like changes in blood flow and blood pressure to testing whether cocoa flavanols can reduce the risk of clinical events—heart attacks, strokes, cardiovascular deaths."

"People have had so many misconceptions about the study," says Manson. "They think we're testing chocolate or that the trial is a signal that they should eat more chocolate. It isn't. "People can still eat chocolate for their enjoyment, but we don't recommend that they eat more of it to get more flavanols."

To get 750 mg of flavanols a day, you'd have to eat nearly 1,000 calories' worth of dark chocolate or thousands of calories of milk chocolate every day. A more reasonable source: an unsweetened cocoa powder you can mix into your coffee, milk, yogurt, hot cereal, or other food - that is, if the cocoa hasn't been processed in a way that destroys flavanols.

#### What are the next steps?

Dr Manson is co-directing the new trial - the COcoa Supplement and Multivitamins Outcomes Study (COSMOS) - which will give cocoa flavanols (750 mg a day) or a placebo to 18,000 women (aged 65 or older) and men (aged 60 or older) for four years. The trial is co-led by Howard Sesso, Associate Professor of Medicine at Harvard Medical School. "We'll also look at cognitive function, diabetes, physical performance, and other outcomes," explained Dr Manson.

But it's not worth signing up so you can eat chocolate in the name of science. "It's not a randomised trial of chocolate or even dark chocolate," noted Dr Manson. "It's a randomised trial of cocoa flavanols—bioactive plant-based nutrients with virtually no calories, sugar, or fat." Why can't you get the same 750 mg of flavanols from chocolate? "It would require an enormous amount," she said. "And for many forms of chocolate, it would be virtually impossible because the cocoa flavanols are destroyed in processing."

“In COSMOS, we’ll be giving people cocoa flavanols that were protected from the time that they were harvested from cocoa beans,” says Manson. “They come in a capsule, which makes it possible to do a long-term placebo-controlled trial and not add a load of sugar, saturated fat, and calories to the diet.”

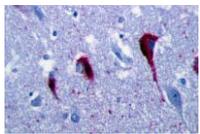
(The study is funded by Mars Symbioscience, a division of Mars, Inc., with partial support from the National Institutes of Health.)

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

The study will lead to a better understanding of the potential effects but also limits of cocoa consumption and add new knowledge to the scientific evidence that is gathered in the combat of diseases.

## SCIENCE WATCH

### 20 February: US scientists reveal link between tau neurofibrillary tangles and neurodegeneration in AD



In a study published in the journal JAMA neurology on 20 February, researchers from Massachusetts General Hospital in Boston, US reported that tau accumulation could be associated with cortical atrophy and Alzheimer’s disease (AD) symptoms.

Previous post-mortem studies of AD brain tissue have demonstrated that neurofibrillary tangles are closely associated with an AD clinical state.

In the published study, the tau pathologic findings were measured by positron emission tomographic (PET) imaging in a small number of subjects (3 women and 3 men) with a mean age of 61.8 years.

Researchers associated the distribution of the imaging signal with the clinical AD symptoms. In addition, the localisation and magnitude of cortical atrophy was also associated with Tau imaging results.

<http://jamanetwork.com/journals/jamaneurology/article-abstract/2604134>

### 28 February: Accera’s experimental AD drug fails to meet its primary endpoint in Phase 3 study

On 28 February, US company Accera, which develops therapies for central nervous system disorders, announced results of its first Phase 3 NOURISH clinical trial study for the treatment of mild to moderate Alzheimer’s disease (AD).

The NOURISH Phase 3 trial is a 26-week, double-blind and randomised trial assigned for people with mild-to-moderate AD. Accera’s product candidate AC-1204 is an orally administered therapy inducing a mild state of ketosis, thereby providing an alternative energy source to the brain. Participants received daily doses of AC-1204 or a placebo.

After a successful Phase 2 trial, Accera decided to tweak AC-1204’s formulation. Although the experimental drug was reportedly safe, it failed to demonstrate a statistically significant improvement at 26 weeks compared with participants treated with placebo in Phase 3.

Accera plans to present detailed results at the Alzheimer’s Association International Conference (AAIC) in London in July

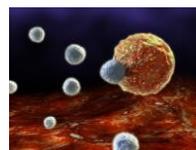
2017. Furthermore, the company said its AD candidate drug was already planned to start a second late-stage study. Due to the results from the first Phase 3, Accera has now fixed the formulation and will discuss next steps with the U.S. Food and Drug Administration.

### 28 February: Genentech starts a second Phase 3 Trial for AD drug crenezumab

On 28 February, the Swiss-based biopharmaceutical company AC Immune announced that its partner Genentech, a member of the Roche group, had decided to start a second Phase 3 trial of crenezumab as a treatment for Alzheimer’s disease (AD). The study is investigating the drug crenezumab, which is a monoclonal antibody that specifically recognises amyloid beta (Aβ).

Although the design details of this new study CREAD2 are not yet available, this trial will recruit 750 participants with prodromal to mild AD. This new clinical trial follows the current Phase 3 CREAD trial. In fact, the company is currently evaluating the clinical efficacy and safety of crenezumab in a Phase 3 clinical trial in another 750 people with prodromal to mild AD. This trial started in January 2016 and is expected to run until 2020.

### 1 March: Study explores possible link between autoimmune conditions and dementia



In a study published on 1 March in the Journal of Epidemiology & Community Health, researchers from the University of Oxford, UK assessed whether hospital admission for autoimmune disease is associated with an elevated risk of future admission for dementia.

Autoimmune diseases can affect almost any part of the body and they are usually identified through inflammation (redness, heat, pain and swelling). The inflammation is caused by the immune system of the body, confusing some of the body’s own cells with intruders, trying to eliminate them.

The retrospective cohort study was conducted using national hospital care and mortality administrative data from the years 1999 to 2012. The scientists constructed cohorts of people admitted to hospital with a range of autoimmune diseases and analysed the data to see whether or not they developed dementia over time.

Based on their statistical analyses, the team concluded, that out of 25 autoimmune diseases studied, 18 showed

associations with dementia. These included conditions such as, Addison's disease, Multiple Sclerosis, polyarteritis nodosa and psoriasis. The increased risk varied from 29% in psoriasis up to 97% in Multiple Sclerosis.

According to the researchers that led the study, these findings should be considered as indicative rather than definitive, for various reasons. One high impact factor could be that the study is restricted to people who were admitted to hospital or who received day case care.

On one hand, findings could be distorted due to the possibility that people admitted to a hospital with an autoimmune disease are likely at the severe end of the disease spectrum, which could lead to a higher risk of developing dementia. On the other hand, people with an autoimmune disease and also with subsequent dementia might be more likely to be admitted than others.

Further, the scientists stated that even though their findings were statistically significant, the effect sizes found in the study were small. In spite of that, they stated that clinicians should be aware of the potential coexistence of autoimmune diseases and dementia in individuals.

<https://doi.org/10.1136/jech-2016-207809>

### **6 March: Roche initiates two new Phase 3 trials for gantenerumab in people with prodromal to mild AD**

On 6 March, German biotechnology company MorphoSys AG announced that its partner Roche plans to launch two new Phase 3 trials of gantenerumab for Alzheimer's disease (AD). This experimental AD drug is a monoclonal antibody, which targets amyloid beta plaques to remove them.

Unfortunately, in 2014, gantenerumab failed both its primary and secondary Phase 3 efficacy endpoints. More than two years after MorphoSys announced it was discontinuing this Phase 3 clinical study, Roche restarted new gantenerumab tests. In fact, in 2016, Roche initiated two new Phase 1 trials in healthy participants testing the safety of higher doses of gantenerumab.

Roche expects to start the enrolment of the Phase 3 trials later this year for people with prodromal to mild AD, but the company has not yet published the design details.

### **13 March: Neurim announces enrolments in phase II clinical trial of Piromelatine for mild AD**



On 13 March, Israeli biotechnology company Neurim Pharmaceuticals, which develops neuroscience drugs, announced the launch of a Phase II clinical study for its experimental drug, Piromelatine. This novel compound is under development for sleep and cognition in the treatment of insomnia, as well as neurological disorders such as Alzheimer's disease (AD).

Previous findings suggested that Piromelatine, which has sleep promoting effects, may improve cognitive function and slow the progression of early-stage AD. The company announced

thus the start of enrolment for a phase II clinical trial evaluating Piromelatine in AD patients. The trial, named ReCOGNITION, aims to determine the safety and efficacy of Piromelatine.

In the planned clinical trial, approximately 500 US participants with mild AD will be randomly assigned to receive different oral doses of the drug (5, 20 and 50 mg daily for 6 months). For this purpose, the company is recruiting participants aged 60 to 85, who have been diagnosed with mild AD and who must have been treated with stable doses of acetylcholinesterase inhibitors.

### **13 March: Researchers suggest new approach to investigate how to halt Alzheimer's disease progression**

On 13 March, a research team from Lund University, Sweden published an article in the journal Nature Communications, highlighting a possible new approach to halt Alzheimer's disease (AD) progression.

The scientists used the MAX IV synchrotron in transgenic mouse models of AD to shed light into the predate formation of beta-amyloid. This method to look at the development of AD has never been used before in this context.

Based on the images, the team realised that the progression in the development of the disease is slower than anticipated and that there are steps that they do not know much about yet.

Using biochemical identification, the researchers were able to further analyse the so far underinvestigated phase, which revealed that the beta-amyloid did not appear, as previously thought, as a single peptide, but rather as a unit of four peptides (a tetramer).

These findings led the team to the conclusion of a new hypothesis of the disease cause, concentrating on the possible early development of the amyloid precursor protein (APP) through the abnormal separation of the four peptides.

The next step towards investigation of the new approach will be to try to understand the interaction patterns of beta-amyloid before it clumps together to form plaques and ultimately find a way to stop the formation of amyloid plaques proactively.

<https://doi.org/10.1038/ncomms14726>

### **15 March: Two Phase 2 studies of cancer drug for Alzheimer's and Parkinson's diseases launched in the US**

Georgetown University Medical Center in the US announced the start of enrolment for two Phase 2 clinical trials evaluating Nilotinib in people with Alzheimer's (AD) and Parkinson's diseases (PD).

This drug is approved by the US Food and Drug Administration (FDA) and it is already on the market at much higher doses for the treatment of leukemia, a type of blood cancer.

Scientists have supposed that this drug could also eliminate the brain toxic proteins including beta-amyloid plaques and

Tau tangles, which are both AD hallmarks. For this purpose, one new study is currently recruiting participants to evaluate the safety and efficacy of low doses of Nilotinib in people with AD. In the planned clinical trial, participants with mild to moderate AD will be randomly assigned to receive the drug (1 capsule of 150 mg daily for 6 months followed by 2 capsules of 150 mg each daily for the subsequent 6 months).

In addition, the researchers also conducted a new Nilotinib clinical trial in people with PD. Although it was a small trial with no placebo control, previous data presented in late 2015 by Georgetown University Medical Center reported clinical improvements with small doses of Nilotinib in people with PD.

**20 March: Can vitamin E or selenium prevent dementia in asymptomatic older men?**



On 20 March, researchers from the University of Kentucky (Lexington), US published an article in the journal JAMA Neurology, in which they describe their assessment of whether antioxidant

supplements (vitamin E or selenium) used alone or in combination can prevent dementia in asymptomatic older men.

So far, we know that oxidative stress is an established dementia pathway, but it is still unclear if the use of antioxidant supplements can prevent dementia. Therefore, the Prevention of Alzheimer’s Disease by Vitamin E and Selenium (PREADViSE) trial, which began as a double-blind randomised trial, was transformed into a cohort study to further investigate this.

The PREADViSE trial consisted of 7540 men, of whom 3786 continued into the cohort study, conducted from 2009 to

2015. Participants were randomized to either a vitamin E, selenium, vitamin E and selenium or placebo group. During the study, participants were assessed using a telephone-based cognitive screening.

The results were somewhat sobering, leading to the conclusion that neither of the supplements nor their combination led to a statistically significant change in the conversion rate to dementia compared to placebo.

<http://jamanetwork.com/journals/jamaneurology/article-abstract/2612477>

**21 March: US scientists develop a genetic test to predict age of AD onset**

In a study published on 21 March in the journal Plos Medicine, US scientists reported the development of a genetic test to calculate the age at which people develop Alzheimer’s disease (AD).

This test was based on 31 genetic markers such as the APOE gene, which is known to be implicated in 20-25% of AD cases. The other markers have been identified to have a small effect on disease risk. This new screening test crossed the genetic data with the age of the people with AD in order to estimate the probable age of onset of the first symptoms. For this purpose, researchers analysed a large database of approximately 70,000 participants including people with AD as well as healthy people to calculate a risk score.

The authors said that people with high scores were found to get the disease 10-15 years earlier than those with low scores. In addition, the score detected was a predictor of AD onset with 90% accuracy.

<http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002258>

**LIVING WITH DEMENTIA**

**7 March: “Awareness Activities as a member of the EWGPWD” - by Idalina Aguiar**



This month (March 2017), I participated, as a member of the EWGPWD, in two important activities as a Delegation of Madeira Alzheimer Portugal guest.

First, on my birthday, 7 March, I participated in a Caregivers Support Group. In this group, we broach the main issues related to daily activities of people with dementia and their caregivers. It was important to me to know their (caregivers’) opinions and I had the opportunity to share what a person like me would feel in

some situations.

On 15 March I took part in an awareness activity aimed at the general public, with the theme: “What is Alzheimer’s disease?” I was invited to talk about the EWGPWD, to share our activities and I gave my personal examples.

During both activities, I felt comfortable and I realised how important my presence was there and how important it is to the community to listen to people with dementia.

**17 March: Living with dementia in Finland – my experience**



I have been happy to join the Alzheimer Europe European Working Group of People with Dementia. The first meeting I attended with my wife Päivi was in Copenhagen last autumn and it strengthened my dedication to the cause. I see us, the members of EWGPWD, as musketeers working towards improvements in common European challenges facing people with dementia.

My personal experiences with dementia started when my wife noticed problems with my memory. I started to forget to turn the coffee maker off or take keys with me while going on errands. I got my diagnosis of Alzheimer’s

at the beginning of 2016. It was the first time ever to hear the name of the disease and a great shock. Our reaction was to be as open as possible about my condition and to look online for more information.

However, around the time of my diagnosis, I faced also some physical illnesses. I am still, three years later, trying to figure out (with help from my doctors) what are the root causes to my symptoms of dementia. The process has been long and I have met several leading doctors in the Finnish field of Alzheimer's.

One of the effects living with dementia has on me is that my sense of direction has deteriorated. Last autumn we moved to a new home, and I have found it difficult to get accustomed to the new environment. But luckily as long as I have a map with me I have been able to keep up daily jogging, my dear hobby.

## DEMENTIA IN SOCIETY

### 30 March: ADI announces new CEO



Alzheimer's Disease International (ADI) is pleased to announce that Paola Barbarino has been appointed as its new CEO. She will assume the role on 15 May 2017.

Ms Barbarino is currently the Managing Director of Opaline Limited, a consultancy company specialising in strategy and governance. Until September 2016 she was the CEO of LIFE, a London-based membership organisation gathering Lebanese financiers in the diaspora, running an educational charity and supporting an enterprise-promoting NGO.

<https://goo.gl/SSQ0zv>



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## EDUCATION

### 6 March: UCL offers full-time MSc Dementia Scholarship



**UCL**  
MSc in Dementia: Causes, Treatments and Research at UCL

University College London (UCL) is currently advertising a Full time MSc Dementia Scholarship of GBP 31,000 (EUR 36,100).

[Dementia: Causes, Treatment and Research Mental Health MSc](#)

is offered jointly by the UCL Division of Psychiatry and Institute of Neurology and provides research-oriented and cutting-edge training in the study of dementia and its scientific basis, led by international leaders in the science and practice of dementia.

Find out more about the [Jost Leuschner MSc Dementia scholarship](#).

### 16 March: University of Stirling offers International Masterclass on design for dementia and ageing

The Dementia Services Development Centre (DSDC) and the Dementia and Ageing Research Group at the University of Stirling, together with Alzheimer Scotland, are excited to announce an International Masterclass on design for dementia and ageing.

This event, planned for 1 June 2017, will provide the chance to learn from and network with thought leaders and those with practical experience of creating environments and designing for an ageing population from across the world. It will showcase the latest research alongside innovative approaches and practical experience on how design for dementia and ageing can positively inform the development of our communities for today and in the future.

You can register here: <http://dementiaevents1.blogspot.lu/>



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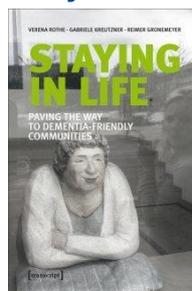
Help us make dementia a priority

## NEW PUBLICATIONS AND RESOURCES

### 1 March: EMA publishes report on Big Data workshop

A report on the workshop on big data held by EMA in November 2016 has been finalised and is now available on the EMA website under the 'Documents' tab here: [http://www.ema.europa.eu/ema/index.jsp?curl=pages/news\\_and\\_events/events/2016/08/event\\_detail\\_001314.jsp&mid=WC0b01ac058004d5c3](http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/events/2016/08/event_detail_001314.jsp&mid=WC0b01ac058004d5c3)

### 22 March: New book suggests how we can create spaces to allow people with dementia to "stay in life"



On 22 March, the German book "Staying in Life: Paving the Way to Dementia-Friendly Communities" was published in its English version by transcript Verlag. The book, written by Verena Rothe, Gabriele Kreutzer and Reimer Gronemeyer of the German dementia initiative Aktion Demenz, brings together the experiences of 78 local dementia projects in Germany, aiming to show "what we can do to create spaces where one can stay in life - rather than just staying alive."

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How can we turn the individual environments of people with and without dementia into “places of human warmth”? This was the key question for the organisers of the 78 local initiatives, supported by three editions of the Aktion Demenz funding programme “People in the Community Living with Dementia”, financed by the Robert Bosch Foundation.

Verena Rothe, manager of the programme, said:

“We would like to express our gratitude to all those committed individuals from politics, art, churches, social and volunteer work that have been and are creatively working towards dementia-friendly communities. It is only through them that we were able to collect and combine all these different approaches to dementia.”

You can find more information at [www.transcript-verlag.de/978-3-8376-3890-5/staying-in-life?c=1041](http://www.transcript-verlag.de/978-3-8376-3890-5/staying-in-life?c=1041)

You can also contact Aktion Demenz on tel. +49 641/992 32-06 or via [info@aktion-demenz.de](mailto:info@aktion-demenz.de)



## JOB OPPORTUNITIES

### 31 March: Bangor University seeks Professor in Dementia – one week left to apply



The School of Healthcare Sciences at Bangor University invites applications for the role of Professor in Dementia. The successful candidate will play a significant role in leading the development of applied research and implementation across the field of dementia. This role represents a significant opportunity for a leading applied researcher to develop their work and reputation.

The successful candidate will join a successful academic programme of dementia research, innovation, service improvement and education. This programme is underpinned by excellent relationships with health and social care services, and a strong research infrastructure in the Bangor Institute for Health and Medical Research

The deadline for applications is 7 April 2017.

<https://jobs.bangor.ac.uk/details.php.en?id=QLYFK026203F3VBQB7V68LOTX&nPostingID=3219&nPostingTargetID=3466&mask=stdext&lg=UK>



### Contact Alzheimer Europe:

Alzheimer Europe: 14, rue Dicks (L-1417), Luxembourg;  
[info@alzheimer-europe.org](mailto:info@alzheimer-europe.org), [www.alzheimer-europe.org](http://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 do Rósario 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), Jesús 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 Challinor; Finance Officer: Stefanie Peulen; Administrative Assistants: Grazia Tomasini, Ute Corail.

## AE CALENDAR 2017

Date	Meeting	AE representative
3-5 April	Site inspection, The Hague and Rotterdam, Netherlands e	Gwladys
6 April	Eurodiaconia meeting (Brussels, Belgium)	Vanessa
10-11 April	European Patients' Forum (EPF) AGM (Brussels, Belgium)	Vanessa
11 April	Meeting with the European Parliament Interest Group on carers (Brussels, Belgium)	Jean
24-25 April	AETIONOMY/PRECISESADS joint legal and ethics meeting (Berlin, Germany)	Dianne, Cindy and Chris
26 April	First ethics working group meeting on dementia and disability (Amsterdam, Netherlands)	Dianne
27-28 April	European Alzheimer's Disease Consortium (EADC) meeting (Bucharest, Romania)	Jean

## CONFERENCES 2017

Date	Meeting	Place
26-29 April	32nd International Conference of Alzheimer's Disease International, <a href="http://www.adi2017.org">www.adi2017.org</a>	Kyoto, Japan
11-13 May	5th Venusberg Meeting on Neuroinflammation, <a href="https://www.dzne.de/en/science-society/public-events/venusberg-meeting.html">https://www.dzne.de/en/science-society/public-events/venusberg-meeting.html</a>	Bonn, Germany
14-17 June	Mechanisms of Neurodegeneration, <a href="https://www.embo-embl-symposia.org/symposia/2017/EES17-04/">https://www.embo-embl-symposia.org/symposia/2017/EES17-04/</a>	Heidelberg, Germany
16-29 June	Royal College of Psychiatrists' International Conference, <a href="http://www.rcpsych.ac.uk/traininpsychiatry/conferencetraining/internationalcongress2017.aspx">http://www.rcpsych.ac.uk/traininpsychiatry/conferencetraining/internationalcongress2017.aspx</a>	Edinburgh, Scotland
24-27 June	3rd Congress of the European Academy of Neurology (EAN), <a href="https://www.ean.org/amsterdam2017/">https://www.ean.org/amsterdam2017/</a>	Amsterdam, Netherlands
16-20 July	Alzheimer's Association International Conference (AAIC), <a href="https://www.alz.org/aaic/">https://www.alz.org/aaic/</a>	London, UK
26 July	The First Montessori Aging & Dementia Symposium Prague 2017, <a href="http://agingsymposium.com/">http://agingsymposium.com/</a>	Prague, Czech Republic
16-21 September	XXIII World Congress of Neurology, <a href="http://www.2017.wcn-neurology.com/">http://www.2017.wcn-neurology.com/</a>	Kyoto, Japan
17 September	Innovations and state of the art in dementia research, <a href="http://alzheimers-dementia.org/">http://alzheimers-dementia.org/</a>	Rome, Italy
2-4 October	27 <sup>th</sup> Alzheimer Europe Conference, <a href="http://www.alzheimer-europe.org/Conferences/Berlin-2017">http://www.alzheimer-europe.org/Conferences/Berlin-2017</a>	Berlin, Germany
2-4 November	Clinical Trials on Alzheimer's Disease (CTAD), <a href="http://www.ctad-alzheimer.com/ctad-2017">http://www.ctad-alzheimer.com/ctad-2017</a>	Boston, US
16-19 November	CNS Summit, <a href="http://cnssummit.org/">http://cnssummit.org/</a>	Boca Ratòn, Florida, US
22-25 March 2018	12th World Congress on Controversies in Neurology (CONy)	Warsaw, Poland
7-11 July 2018	11th FENS Forum of Neuroscience, <a href="http://www.forum2018.fens.org/">http://www.forum2018.fens.org/</a>	Berlin, Germany

# 27<sup>th</sup> Alzheimer Europe Conference

## Care today, cure tomorrow

### Berlin, Germany

### 2-4 October 2017

[www.alzheimer-europe.org/conferences](http://www.alzheimer-europe.org/conferences)

 #27AEC



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Selbsthilfe Demenz



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