

ALZHEIMER EUROPE NEWSLETTER

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WELCOME



To those of you reading this at #28AEC in Barcelona, thank you for joining us for what promises to be another exciting Alzheimer Europe Conference. I would like to give a special mention to co-organisers CEAFA and Fundación Alzheimer España (FAE), and of course express our gratitude to our Honorary Patron Her Majesty Queen Sofía of Spain.

The 28th edition of our Dementia in Europe magazine is being launched today at the conference. It contains an interview with Carlos Moedas, EU Commissioner for Research, Science and Innovation, in which he highlights current and future European priorities for dementia research. You can also read about our most recent European Parliament lunch debate and about the progress being made by ongoing European projects in which we have a hand, including EPAD and the 2nd EU Joint Action on Dementia. The policy pages cover important forward strides in Portugal and Sweden and we also feature our Carers' Survey. On that front, I am delighted to say that the survey findings have just been published in the International Journal of Geriatric Psychiatry. The magazine has a special conference section as well, focusing on the work of our Spanish members, and on dementia research in Spain. Last but not least, there is a special 16-page supplement showcasing the work of the MOPEAD (Models of Patient Engagement for Alzheimer's Disease) project, one of the EU projects we are

currently involved in. MOPEAD is funded by the Innovative Medicines Initiative (IMI), as are many of the projects we partner in.

The IMI is celebrating its tenth anniversary this year and to mark this, it has launched a series of "Project Participant Testimonial" videos, for which I gave our perspective as a patient organisation. We are uniquely placed to share the views and lived experience of people with dementia and to ensure ethical issues are taken into consideration.

Providing a voice to people with dementia and their carers is of huge importance to us as an organisation and we were pleased to hear that a new working group of people with dementia has been formed in Flanders, Belgium this month. Groups like this, as well as our European Working Group of People with Dementia (EWGPWD) help ensure that the work we do duly reflects the needs and priorities of people living with dementia.

Finally, I would like to give a special mention to one of the members of the EWGPWD, Helen Rochford-Brennan (the group's Chairperson), who was awarded an honorary doctor of laws from the National University of Ireland Galway, in recognition of her inspirational dementia advocacy work. Congratulations, Helen!

Enjoy Barcelona, and if you are not here with us, you can follow the event via the hashtag #28AEC.

Jean Georges
Executive Director

Sponsor of the month

Alzheimer Europe would like to express its gratitude to Amgen, a new sponsor for our 2018 activities.

Read more about sponsorship opportunities here:

<https://goo.gl/ckVNeC>



ALZHEIMER EUROPE

11 October: Findings of our carers' survey published in open access article



The article "Timely diagnosis of dementia? Family carers' experiences in 5 European countries" was accepted for publication in the International Journal of Geriatric Psychiatry in September and has now been published online.

The article reports some of the key findings of a study carried out jointly by Bangor University, Alzheimer Europe (AE) and five of AE's member organisations (the Czech Alzheimer Society, Alzheimer Society of Finland, Federazione Alzheimer Italia, Alzheimer Nederland and Alzheimer Scotland).

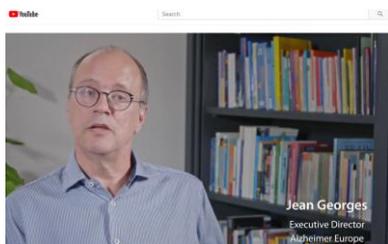
It shows that nearly half of the 1,409 carers who participated in the study felt that an earlier diagnosis would have been preferable. Delaying factors reported by carers included reluctance of the person with dementia, lack of awareness of dementia, the response of professionals and delays within health systems.

The article also highlights that the diagnosis is now often shared with the person with dementia (except in Italy) and that timely diagnosis and higher quality diagnostic disclosure may be associated with better adjustment.

The article is open access and can be downloaded using this link:

<https://onlinelibrary.wiley.com/doi/epdf/10.1002/gps.4997>

16 October: Alzheimer Europe Director Jean Georges interviewed for IMI Project Participant Testimonial videos



The Innovative Medicines Initiative (IMI), is celebrating its tenth anniversary this year and to mark this, it has launched a series of "Project Participant

Testimonial" videos, for which our Director, Jean Georges gave our perspective as a patient organisation, since many of the European projects we partner in are IMI-funded.

Alzheimer Europe is uniquely placed to share the views and lived experience of people with dementia and to ensure ethical issues are taken into consideration.

<https://youtu.be/GnVcMyPGm4w>

29 October: Alzheimer Europe launches new Dementia in Europe magazine at its conference

**DEMENTIA
IN EUROPE**
THE ALZHEIMER EUROPE MAGAZINE



Issue 28
October 2018



On 29 October, the latest edition of "Dementia in Europe" magazine was officially launched, during the 28th Alzheimer Europe Conference #28AEC, in Barcelona, Spain.

This 28th edition of the magazine features an interview with Carlos Moedas, EU Commissioner for Research, Science and Innovation, in which he highlights current and future European priorities for dementia research. Our most

recent European Parliament lunch debate focusing on dementia care also features, as does the progress being made by ongoing European projects in which we are involved, including EPAD and the 2nd EU Joint Action on Dementia. There is an article about our Carers' Survey, and the policy pages cover important forward strides in Portugal and Sweden, among others.

The magazine has a special 28AEC conference section as well, focusing on the work of our Spanish members, and on dementia research in Spain and especially in Barcelona.

This time, the magazine also includes a special 16-page supplement showcasing the work of the MOPEAD project "Models Of Patient Engagement for Alzheimer's Disease". Alzheimer Europe was responsible for producing the project's ethical guidance document and is contributing to the communication activities of this four-year project (2016–2019), founded under the auspices of the Innovative Medicines Initiative (IMI) 2 Joint Undertaking. This special supplement includes a general overview of the project, along with interviews with the project leadership, some of the great educational materials on Alzheimer's disease and dementia the project produced as well as information about each of the project's work-streams and their goals.

You can buy the magazine via our E-shop: <http://alzheimer-europe.org/Publications/E-Shop>.

Past issues can be freely downloaded here:

<http://alzheimer-europe.org/Publications/Dementia-in-Europe-magazines>

29 October: It's time for the 28th Alzheimer Europe Conference!



From 29 to 31 October, the 28th Alzheimer Europe Conference (#28AEC), "Making dementia a European priority" - organised in collaboration with CEAFA and Fundación Alzheimer España - will bring together over 800 delegates at the Hotel Barceló Sants, under the Honorary Patronage of Her Majesty Queen Sofía of Spain. The opening ceremony will take place at 6pm on 29 October and the conference will run until 5.45pm on 31 October.

As every year, Alzheimer Europe (AE) has endeavoured to make its conference as dementia friendly as possible. A meeting room has been reserved for the sole use of people with dementia and their guests - a place to meet, to have a cup of tea or coffee, or just to grab some quiet time. Coffee breaks will also be served in this room. Seats in the front row(s) of all meeting rooms have been marked as "Reserved" for the use of people with dementia. During lunch breaks, a number of places and tables are reserved for the sole use of people with dementia. Those areas are marked as "Reserved" and located on the right hand side of the restaurant. Conference hosts/hostesses will be able to direct you, to find any of these reserved areas.

Among our delegates, we are delighted to be welcoming 35 people with dementia, along with their guests. As always, people with dementia feature prominently in our conference programme - in plenaries, parallel sessions and at the Special Symposium of the European Working Group of People with Dementia.

The full conference programme includes 239 oral presentations and 175 poster presentations. We highly recommend that delegates with smart phones or tablets download the AE conference app, to keep up to date with the programme and find out more about the speakers: <https://attendify.com/app/iaa2wt/>

We also kindly ask you to use the hashtag #28AEC in your conference-related tweets, so that Alzheimer Europe and others can respond to/repost/retweet them as much as possible, making the whole experience more interactive.

Delegates will be able to register and receive their badges and conference bags from 4pm on 29 October at the conference reception desk on the first floor of the hotel. Speakers can register in the lobby on the ground floor.

Should you have any questions or need support during the event, please speak to a conference host/hostess on site, or find a member of our staff at the Alzheimer Europe stand, during breaks in the programme.

We hope you enjoy your experience in Barcelona!

Alzheimer Europe networking

On 19 September (Brussels, Belgium), Owen met with Irene Oldfather, a member of the European Economic and Social Committee (EESC) to discuss ways in which Alzheimer Europe could work more closely with the EESC.

On 26 September (Brussels, Belgium), Owen attended the Patient Think Thank (PTT) of the European Federation of Pharmaceutical Industries and Associations (EFPIA).

On 27 September (Brussels, Belgium), Owen attended a European Parliament meeting hosted by a range of health bodies including the European Federation of Pharmaceutical Industries and Associations (EFPIA), Medicines for Europe, European patients Forum (EPF) among others, on the subject of the European Parliament's role in prioritising public health and patients after Brexit.

On 1 October (Budapest, Hungary), Alzheimer Europe Chairperson Iva Holmerová attended the Common Speaking Experts 2018 conference, organised by Social Cluster Hungary.

From 3 to 6 October (Novigrad, Croatia), Alzheimer Europe Chairperson Iva Holmerová attended the CROCAD 2018 conference, organised by Alzheimer Croatia.

On 4 and 5 October (Amsterdam, Netherlands), Jean and Cindy attended a meeting of WP6-Dissemination of the EPAD project.

On 8 and 9 October (Madrid, Spain), Chris attended the 6th General Assembly meeting of the ROADMAP project.

On 8 and 9 October (Brussels, Belgium) Owen attended two events: the annual EPF-Medicines for Europe dialogue (which is held to gather the views of patients and pharmaceutical sector on access to medicines) and a multi-stakeholder event on universal access to healthcare.

On 8 and 9 October (Berlin, Germany), Cindy attended the AMYPAD General Assembly Meeting.

On 9 and 10 October (Lausanne, Switzerland), Jean attended the Lausanne V workshop "Taking transformative action to change the course of Alzheimer's disease".

On 11 October, Owen dialled into the European Disability Forum's European Non-Governmental Organisation group meeting.

On 17 October (Esch/Belval, Luxembourg), Jean met with representatives of the Luxembourg Fonds National pour la Recherche.

On 20 and 21 October (Brussels, Belgium), Owen attended the European Patient Forum's Patient Advocacy Seminar.
 On 22-23 October (Brussels, Belgium), Chris and Cindy attended the IMI 10th anniversary scientific symposium.
 From 24 to 27 October (Barcelona, Spain), Jean attended the Clinical Trials in Alzheimer's disease (CTAD) conference
 On 28 October (Barcelona, Spain), the European Working Group of People with Dementia met
 On 29 October (Barcelona, Spain), Alzheimer Europe organised a meeting of its Board and its Annual General Meeting.
 From 29 to 31 October (Barcelona, Spain), the 28th Alzheimer Europe Conference "Making dementia a European priority" took place.

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EU PROJECTS

24 September: The EPAD Academy has officially started its short exchange programme



The European Prevention of Alzheimer's Dementia (EPAD) project launched in 2017 its EPAD Academy that is aiming to efficiently leverage EPAD resources to foster and develop academic research capacity and output in Alzheimer's disease (AD) across Europe for maximum global impact.

The EPAD Academy is first focusing on activities to support early career researchers. For this purpose, a register of "EPAD Fellows" has been established, all of whom are eligible for Academy activities.

On January 2018, the EPAD Academy held its first activity that is to propose online webinars by world-class senior researchers on current topics in AD research for young researchers. The short exchange program, another Academy activity, has started several months ago by identifying potential host institutions and brokering these offers with demands from fellows. On 24 September, Gemma Salvadó from Fundació Pasqual Maragall has started its Academy short exchange program and will be staying for three months at Amsterdam UMC – Locatie VUmc supervised by Prof Frederik Barkhof.

Pictured: Gemma Salvadó (right) with two other EPAD Academy fellows Isadora Lopes Alves (left) and Lyduine Collij (centre) in front of the tulip (waiting room of the Alzheimer Center).

27-28 September: The PRODEMOS project holds its first general assembly meeting in Toulouse



On 27-28 September, the PRODEMOS – Prevention of Dementia using Mobile phone Applications- project held its first general assembly meeting in Toulouse (France). The meeting was chaired by the co-leader of the PRODEMOS study Edo Richard from Academic Medical

Centre Amsterdam (AMC).

The aim of the meeting was to provide the consortium members updates on activities and discuss future plans.

The first day of the meeting was dedicated to crossing cultural barriers and the mHealth platform. Several systematic reviews conducted within the WP2 (Strategies for dementia prevention) were presented to analyse existing research on the effect of mobile health applications in elderly populations for the prevention of cognitive impairment and dementia. Then, activities within the WP3 (crossing cultural barriers) work stream were reported. The University of Sussex (UoS) is in the process of obtaining ethical clearance for the focus groups with people from the local community. In preparation for the mHealth platform, the WP4 (Cultural adaption of a mHealth intervention) is working on the requirements development of the core platform. The team now has defined a target population, defined a higher level functional scope and more detailed functional requirements. Vital Health Software (VHS) showed a clickable demo of what the mHealth platform will approximately look like, including goal setting and population management possibilities.

The second day was focused on the implementation of the trial and practicalities in Sussex, Cambridge and Beijing. Provisional plans for recruitment and data management plans ethic were discussed. Then, a very fruitful session took place on the trial design and research protocol to determine notably the most appropriate modifiable dementia risk score for the PRODEMOS implementation trial. Before the wrap-up session, Linda Barnes (University of Cambridge) and Marieke P. Hoevenaar-Blom (AMC) gave an update of the dissemination work, the coordination and management of the project.

Jean Georges and Cindy Birck attended the general assembly meeting on behalf of Alzheimer Europe (AE). AE is partner in the project and will be representing the patient perspective. AE is involved in the coordination and management, crossing cultural barriers and dissemination and communication work packages of this project. This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 779238.

1 October: Call for abstracts opens for first international MinD conference



The MinD team is preparing for its first international conference, MinD2019, which will take place on 19-20 September

2019 at the Technische Universität Dresden. As of 1 October 2018, MinD invites abstract submissions online. The final date

for full paper submissions and for design proposal submissions is 1 February 2019.

The conference, “Designing with and for People with Dementia: Wellbeing, Empowerment and Happiness”, will provide a trans-disciplinary forum for researchers, practitioners, end-users and policy makers from the design and health care professions to exchange and discuss new findings, approaches and methods for using design to improve dementia care and to support people with dementia and their carers. The conference is supported by the Special Interest Groups on Design for Behaviour Change and on Wellbeing and Happiness of the Design Research Society.

Find out more about MinD2019 and submit your abstract via:

<http://designingfordementia.eu/news/mind-events/mind-conference-2019>

4-5 October: EPAD WP6 team reviews communication strategy and makes plan for 2019



On 4-5 October, the EPAD communication team held a meeting at the VUmc Alzheimercentrum in Amsterdam to review the project's

communication strategy. On the first day, the agenda covered what the members of the EPAD WP6 communication team have achieved so far. The communications activities from 2015-2018 were reviewed to analyse their strengths, weaknesses and opportunities. The team looked back at some of the activities and tools including the website, social media, newsletter, videos and press releases. The next session was focused on the communications capacities at Trial Delivery Centre (TDC) level. Representatives from four TDCs had the opportunity to join the meeting to share their recruitment and retention strategies from a communications point of view. They presented an overview of some of their ongoing communication activities. This session was really useful and a lot of ideas were discussed.

The second day placed the emphasis squarely on the communication focus plan for 2019. Very fruitful brainstorming sessions took place in which both internal and external communication goals and expectations were discussed. Particular attention was paid to communication with TDCs and research participants and retention of research participants in the EPAD Cohort. The WP6 team also checked the upcoming project milestones for which external communications may be necessary. It was a successful and productive meeting with a lot of discussions and suggestions. The team is looking forward to implementing them now!

AE contributes as co-lead to the disseminations activities for the EPAD project. Executive Director Jean Georges and Project Officer Cindy Birk attended the meeting.

8 October: The Models of Patient Engagement for Alzheimer's Disease (MOPEAD) project launches video



On 8 October, the MOPEAD project officially launched a video on its YouTube channel. It brings the objectives and goals of MOPEAD in a short animated

infographic to life, supporting the project's clinical sites in their learnings towards finding appropriate ways towards timely diagnosis of Alzheimer's disease. You can watch the video here:

<https://www.youtube.com/watch?v=wPLdlzV7v30>

8-9 October: The AMYPAD project holds its General Assembly Meeting in Berlin



On 8 and 9 October, the “Amyloid imaging to Prevent Alzheimer's disease” (AMYPAD) consortium gathered for its General Assembly (GA) Meeting in Berlin, Germany. The first day placed the emphasis squarely on both the AMYPAD Prognostic and Natural History Study (PNHS) and the Diagnostic and Patient Management Study (DMPS). The GA meeting started with Andrew Stephens (Life Molecular Imaging), Frederik Barkhof (VUmc) and Gill Farrar (GE Healthcare) welcoming more than 60 attendees. They introduced the meeting objectives and reported the two-year progress.

After that, a session was dedicated to the PNHS including its design and scientific challenges. The ethical approval for the AMYPAD PNHS study has been obtained in Amsterdam. There was also an announcement that the second participant has consented for the study and that the First Patient in is planned for October 2018. Over the past quarter, the VUmc team has taken on the role of study sponsor and started to coordinate other sites in their participation into this study. The preparatory work and the operational aspects were shared with the consortium members. There was also an update of the EPAD study as AMYPAD will leverage a Europe-wide network in close collaboration with EPAD to study the earliest stages of Alzheimer's disease in a longitudinal fashion.

The afternoon of the first day hosted a session on the DMPS. The site initiation performed in Geneva and Amsterdam has currently 45 participants in AMYPAD DPMS spread on both active sites. These two centres that have already started recruitment in the DPMS have shared their recruitment experiences and it was valuable to the centres that are preparing to open as they will certainly build their practice upon lessons learned from opened centres.

On the second day, an overview of relatives initiatives such as the IDEAS study and the ABIDE project were presented. A presentation was delivered on the imaging dataflows and quantification pipelines including an update of the work done within the WP2 (Tracer delivery, PET scanning and image analysis). After that the WP5 (Monitoring treatment: Quantify patient-specific efficacy) gave an overview of their activities conducted within the past two years and highlighted the existing datasets and the first results. There was also a presentation on the regulatory strategy update and the ethics. Cindy Birck from Alzheimer Europe (AE) continued with a talk on the AMYPAD communication. AE contributes as co-lead to the communication and dissemination activities for the AMYPAD project. Before the wrap-up session, reporting and financials were also reminded. Gill Farrar and Frederik Barkhof then recapitulated the days' discussions and presented the next steps of the project, after which the GA meeting ended.

Read more about the project [here](#).

9 October: IMI-2 ROADMAP initiative moves into end of Phase 1 as it holds General Assembly Meeting in Madrid



On 8 and 9 October (Madrid, Spain), the Real World Outcomes across the Alzheimer's disease spectrum for better care: Multimodal data Access Platform (ROADMAP) project held its 6th and last General Assembly Meeting. The meeting was chaired by Project Coordinator John Gallacher (University of Oxford) and Project Leader Frédéric Reydet de Vulpillieres (Novartis).

The aim of the meeting was to discuss future plans and to provide the Consortium members with updates on final activities of the different work streams. The project will conclude at end of October 2018.

The first day of the meeting started with a welcome session by John Gallacher during which he recapitulated main project achievements and learnings:

- The project was able to establish a broad-based and evidence-based consensus on the priority outcomes for dementia and treatment pathways.

- It developed a comprehensive database of available European real-world datasets (Data Cube).
- It demonstrated that the current evidence base is inadequate for disease progression modelling and detailed health economic evaluation.
- It made a strong case for the collection of new data that is designed for early detection and disease progression modelling.

After that the work streams gave overviews of their activities conducted within the past two years and highlighted scientific publications that are currently submitted for peer review, and publications that are due to be finalised within the next months. The day concluded with a closed meeting by the project's Executive Committee.

On the second day of the meeting, ROADMAPs communication team provided an overview of the communication activities conducted during the course of the project, their impact, and benchmarked performance with other projects under the Big Data for Better Outcomes umbrella. This included a sustainability solution for access to a repository of open access publications, the project's ResearchGate account.

This was followed by an update from ROADMAPs Ethical, Legal and Social Implications team with an overview of their work throughout the last two years. After that, Gloria Garcia from SYNAPSE (Project Management) presented ROADMAPs Data Cube, which offers a 'landscape' on data availability in Europe. This 3D 'heat map' assessment allows the visualisation of different data sources and how they are able to capture the various Alzheimer's disease-outcomes, together with their relevance for the different disease stages. Discussions revolved around the exposure of the cube on the ROADMAP website. It had been agreed that the project would let data source holders review it before making it public and that the next Expert Advisory Group meeting and Alzheimer Europe Conference would be good occasions to gather feedback before that final step. SYNAPSE will also set up a Data Cube Committee for future updates.

Before the wrap-up session, Frédéric Reydet de Vulpillieres addressed the future of the project regarding a potential Phase 2. He explained that there would be an open call for a future continuation, potentially under a different name, launched no earlier than June with a yet to be decided project duration. John Gallacher then closed the meeting explaining that he envisages a maintenance of the ROADMAP community beyond the end of December, including finalisation of publications and maintenance of website updates.

Read more about the project [here](#).

16 October: The first PARADIGM project newsletter is out!

 On 16 October, the PARADIGM project, which began on 1 March 2018, released its first ever newsletter: <https://goo.gl/s6cPwf>

PARADIGM - Patients Active in Research and Dialogues for an Improved Generation of Medicines - is an IMI-funded European project, running for a duration of 30 months. Its mission is to provide a unique framework that enables structured, effective, meaningful, ethical, innovative, and sustainable patient engagement (PE) and demonstrates the 'return on the engagement' for all players. Alzheimer Europe is a partner and is involved in all work packages of this project.

You can subscribe to receive future newsletters here:

<https://goo.gl/6JatWX>

16 October: AMYPAD publishes a new paper in Alzheimer's & Dementia



On 16 October, researchers from the Amyloid imaging to prevent Alzheimer's disease (AMYPAD) project published an article on its Diagnostic and Patient Management Study (DPMS) in Alzheimer's & Dementia, the journal of the Alzheimer's association.

The publication entitled "AMYPAD Diagnostic and Patient Management Study: Rationale and design" reports the aim and the endpoints of the DPMS study. This Phase IV multicentre, prospective, randomised and controlled study will enrol 900 participants with subjective cognitive decline plus, mild cognitive impairment, and dementia possibly due to Alzheimer's disease. AMYPAD-DPMS will supply physicians and health care payers with real-world data to plan management decisions.

<https://doi.org/10.1016/j.jalz.2018.09.003>

23 October: Innovative Medicines Initiative celebrates ten years of breakthroughs during Scientific Symposium



On 22 and 23 October (Brussels, Belgium), Cindy Birck and Chris Bintener attended the Innovative Medicines Initiative (IMI) 10th anniversary scientific symposium.

The symposium started with an opening session by Pierre Meulien (Executive Director, IMI), Jean-Christophe Tellier (Chief Executive Officer and Chairman of the Executive Committee, Union Chimique Belge - UCB) as well as Jonathan Knowles (Professor and Founding Chairman of the IMI Board).

The first day of the scientific symposium was set up to focus on project achievements within key pillars. The first pillar was about the stratification towards personalised medicines and more concretely how IMI project achievements support the striving to bring the right medicine to the right patient at the right time.

The second pillar revolved around patient centric approaches in drug development and how IMI projects involve people living with a condition in their work but also why it is beneficial to do so.

The day concluded with 72 poster presentations structured into four topics:

- New targets, tools and pathways
- From concept to trial
- New clinical and regulatory paradigms
- Patient engagement along the value chain

The second day placed the emphasis squarely on two pillars titled "enablers for discovery and development of new drugs" and "collaborating to fight infections".

Many of the exchanges after the presentations but also within the panel discussions revolved around the innovative potential that can be leveraged from such an unprecedented public-private collaboration, but also the challenges in communicating the work that is being done in the pursuit of delivering a healthier future for all.

Alzheimer Europe is respectively was involved in a range of the projects presented, including

- AETIONOMY (Organising mechanistic knowledge about neurodegenerative diseases for the improvement of drug development and therapy),
- AMYPAD (Amyloid imaging to prevent Alzheimer's disease),
- EMIF (European Medical Information Framework),
- EPAD (European Prevention of Alzheimer's dementia),
- PARADIGM (Patients Active in Research and Dialogues for an Improved Generation of Medicines) and
- ROADMAP (Real World Outcomes across the Alzheimer's Disease spectrum for better care: Multi-modal data Access Platform).

Alzheimer Europe mainly contributes to these projects through public patient involvement, engagement with the dementia community, communication and dissemination activities as well as ethics work.

23 October: INDUCT project is bench-testing a new Cognitive Stimulation App with people with dementia and their family carers



Harleen Rai is the fifth Early Stage Researcher on the Interdisciplinary Network Using Current Technology in

Dementia (INDUCT). She is developing a new cognitive stimulation App for people with dementia and their family carers.

During the development work with a software company in the Netherlands (Eumedianet), Harleen organised several focus groups and interviews in the UK so that people with dementia and their carers could try-out the App and share their thoughts.

Overall, the App was positively evaluated and we received valuable feedback from all the participants. For example, the

navigation of the App was straightforward, but the text could be more concise: "I like bullet points better where it's more segmented, so you've got one thought and the next thought. Instead of a whole jumble of thoughts together".

The content of the App was found to be diverse. Most participants found the App version more interactive than the paper version of the Cognitive Stimulation Therapy: "I think it's more interesting to look at and it's more entertaining, if you like".

Based on their comments, changes have been made to the App and we will now test it in the UK to see whether this App can improve cognition and wellbeing. If you have any questions or might be interested in taking part in this UK-based study, please feel free to contact Harleen on Harleen.Rai@nottingham.ac.uk.

23 October: The MinD team continues to work on the design prototypes and preparing for their evaluation



In October, the MinD team has been working once more in the UK and in Barcelona, Spain. Partners Nottinghamshire Healthcare Trust, University of

Wolverhampton, Picharchitect and University Politechnico Catalunya are hosting researchers from the various partner countries and disciplines to work together.

Researchers are continuing to work on the completion of the design and the realization of the prototypes of the Social Engagement Map, and on preparing for their evaluation. Conceptual development and programming are rapidly progressing for the Social Engagement Map, an interactive platform, which aims to help people with dementia to stay active and socially engaged. Key is to negotiate novel design ideas and user feedback from a further Public and Patient Involvement group. Final touches iron out contradiction and create a shared vision for the new user-friendly interface.

The initial framework for evaluation of the Good Life Kit and the Social Engagement Map with people with dementia, which was developed in Luxembourg in July, is being revisited. Healthcare partners from the four countries (UK, Germany, Netherlands, and Spain) are shaping it to accommodate their local situations.

Looking forward, the MinD team is preparing for its next symposium at INTRAS in Valladolid, Spain, on 20 November 2018. It will bring together related projects and present a first glimpse of the prototypes.

EU project acknowledgement

A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon2020 or from the Innovative Medicines Initiative and Innovative Medicines Initiative 2 Joint Undertakings. The Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.

The projects in this newsletter with EU funding are:

- AMYPAD – grant agreement 115952
- EPAD – grant agreement 115736
- MOPEAD - grant agreement 115985
- PARADIGM - grant agreement 777450
- PRODEMOS – grant agreement 779238
- ROADMAP - grant agreement 116020



Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at **126**, representing **27** Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance:

Austria: Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübiger (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); Elisavet 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 Blinkevičiute (S&D). **Luxembourg:** Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP). **Malta:** Roberta

Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Gerben-Jan Gerbrandy (ALDE); Esther de Lange (EPP); Jeroen Lenaers (EPP); Annie Schreijer-Pierik (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 Estarás Ferragut (EPP); Juan Carlos Girauta Vidal (ALDE); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Ana Miranda (Greens/EFA); Pablo Zalba Bidegain (EPP). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE). **United Kingdom:** Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Rory Palmer (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D).



EU DEVELOPMENTS

15 October: EU countries unprepared to deliver future Alzheimer's treatment into rapid clinical use



A new publication from the Rand Corporation has suggested that healthcare systems in some European countries lack the capacity to rapidly move a disease-modifying treatment for Alzheimer's disease from approval into widespread clinical use.

Researchers examined health systems in France, Germany, Italy, Spain, Sweden and the United Kingdom, modelling the infrastructure challenges from 2020 if confronted with an increase in patients seeking screening. The key findings of the report include:

- The burden of Alzheimer's disease in high-income countries is expected to approximately double between 2015 and 2050.
- The preventive treatment paradigm implies the need to screen, diagnose, and treat a large population of patients with mild cognitive impairment.
- Projected peak wait times range from five months for treatment in Germany to 19 months for evaluation in France. The first year without wait times would be 2030 in Germany and 2033 in France, and 2042 in the United Kingdom and 2044 in Spain.
- Specialist capacity is the rate-limiting factor in France, the United Kingdom, and Spain, and treatment delivery capacity is an issue in most of the countries.
- Any new disease-modifying treatment would potentially face delayed widespread-clinical roll out as a result of the current infrastructure.

The report recommends that:

- In addition to increasing specialist and infusion capacity in each individual country, joint actions and planning in Europe can help provide better coordinated and more-timely care for Alzheimer's patients.

- A combination of reimbursement, regulatory, and workforce planning policies, as well as innovation in diagnosis and treatment delivery, is needed to expand capacity and to ensure that available capacity is leveraged optimally to treat patients with early-stage Alzheimer's disease.

You can read the full report at: <https://bit.ly/2qdqEcs>



MEMBERS' NEWS

28-29 September: Spominčica reports on 10th International Conference on Dementia in Slovenia



On 28 and 29 September 2018 Alzheimer Slovenia (Spominčica) organised a very successful and interdisciplinary 10th International Conference on Dementia at the Faculty of Medicine, University of Ljubljana. With this conference, we commemorated the 20th anniversary of the first psychogeriatric meeting, organised by our founder, Dr Aleš Kogoj. The slogan of the conference was "Dementia – a priority of Slovenian Society". The event was held under the patronage of President Borut Pahor and accredited by the Slovenian press agency (STA).

We hosted many special guests and speakers from more 8 countries around the world: Paola Barbarino, CEO, ADI; Iva Holmerova, Chairperson, Alzheimer Europe; Charles Cherri, Vice-Chairperson, Alzheimer Europe; Darina Sedlakova, Head of the WHO Country Office Slovenia; Dr Peter Hagell, Professor of Neurological Caring Science, Faculty of Health Science, Kristianstad University, Sweden; Assistant Professor Dr Agnes Egervári, Social Cluster Association, Hungary; Vidya Shenoy, Secretary General, Alzheimer's & Related Disorders Society of India (ARDSI); Alexander Kurz, INDEED (Interreg, Danube transnational Programme); and many more. Some of the special Slovenian guests at the conference were: Štefanija Lukic Zlobec, President of Spominčica; Prof. Dr Zvezdan Pirtošek, Neurology Clinic Ljubljana, Faculty of Medicine; Dr Milica G. Kramberger, Neurology Clinic Ljubljana; Ksenija

Klampfer, Minister for Social Affairs; Dr Igor Švab, Dean of the Faculty of Medicine, Ljubljana; and Vlasta Nussdorfer, Slovenian Ombudsman. During the opening ceremony, attendees had the opportunity to listen to the words of Samo Fakin, Minister of Health, read from a letter of support he sent in his absence (he was attending the UN meeting in New York). Lectures, symposia and poster presentations highlighted important current information about ongoing dementia research and clinical trials, timely diagnosis, risk factors and prevention, the challenges of home care, types of help, technological supports, dementia-friendly communities, legal and ethical issues around dementia, and palliative care.

We received a special letter of gratitude from Paola Barbarino, stating:

“It is an honour to be here today and we will look forward to seeing Slovenia increasing its influence in the global regions and national effort to face and beat the dementia epidemic. Slovenia is one of the few countries in the world which have a national action plan for dementia and is alone to have one in the Balkans. Slovenia is showing the world what can be done when you have energy, commitment, political will and funding. Being small is no impediment to dream big.”

Also during World Alzheimer’s Month (September), Slovenia held a number of other important events: On 14 September, at the Social Chamber of Slovenia, Spominčica opened its 55th “dementia-friendly spot”. It has been a hugely successful year on this front, with 50 new spots in 2018 alone; On 19 September a press conference was held at the Medical Chamber of Slovenia, and a press release sent out to all national media; Spominčica organised more than 30 Memory Walks around Slovenia, including the 7th annual walk in Ljubljana, on 22 September; and finally, on 25 September, Spominčica and the Slovenian Association of GPs organised a symposium on dementia, with 25 % of Slovenia’s GPs in attendance.

17 October: Helen Rochford Brennan awarded Honorary Degree from NUI Galway, reports The Alzheimer Society of Ireland



The Alzheimer Society of Ireland was delighted that a pioneer in dementia advocacy Helen Rochford Brennan has been awarded an Honorary Degree from NUI Galway at a special

ceremony on 17 October.

Helen has encouraged the medical profession and community to look beyond the solely medical model of care for people with dementia and to focus on the person, ever since her diagnosis with dementia at the age of 62 in 2012.

Since her diagnosis, Helen has campaigned to raise awareness of dementia through a rights-based approach, speaking at

international conferences, giving media interviews, engaging with scientists, clinicians, educators and research projects.

Helen has written very personally about living with the Alzheimer’s type of dementia and this year she has contributed to two books on human rights and she hopes her participation in research will one day help to find a cure and create a better quality of life for people living with dementia.

Helen, who is from Tubbercurry in Co Sligo, is the current Chairperson of the European Working Group of People with Dementia and is the group’s nominee to the Board of Alzheimer Europe; she is former Chair of the Irish Dementia Working Group and continues to sit on the steering committee.

Helen is on the Monitoring Committee of Ireland’s first National Dementia Strategy, she is also an (Alzheimer type) Dementia Consultant and a Global Dementia Ambassador.

17 October: Demensförbundet aims to have 5,000 Dementia Friends in Sweden by the end of the year



At the beginning of May this year, the Swedish Dementia Foundation (Demensförbundet) launched its Dementia Friends campaign, Demensvån, to inform the general public about dementia. It aims

to help people understand how to recognise the signs that might indicate a person has dementia and, more importantly, how they can help support that person.

More and more people with dementia live at home for longer, so it has become very important that people have at least some basic knowledge and understanding about dementia. Most likely, every Swede will meet someone with dementia in their daily life and need to have the basic knowledge to be able to help if needed, says Demensförbundet.

Sweden already has more than 4,500 Dementia Friends and the aim is to reach 5,000 friends by the end of the year. Next year, Demensförbundet plans to expand the campaign by involving Swedish pharmacies as well. Following diagnosis, this is in many cases one of the first places people go, if prescribed a medication. Therefore, the pharmacies is a natural next step.

Demensförbundet is grateful to Alzheimerforeningen (Denmark) for all the help and support given, in developing the Swedish concept, which is based on the Danish material.

The campaign site is in Swedish: <https://demensvan.se/>

24 October: Alzheimer’s Society (UK) tells us about new GameChanger project



In September Alzheimer’s Society and the University of Oxford launched a new research project ‘GameChanger’.

The project highlights the increasing opportunities smartphone and wearable technology offer to study cognition

in large groups of people without the need for a laboratory or clinic.

The team at Oxford, led by Dr Chris Hinds, have developed a smartphone app with a series of games, designed to test specific aspects of memory and thinking that are affected in the early stages of Alzheimer’s disease.

Over the next 6 months Alzheimer’s Society will be supporting this game changing project to collect data from thousands of people without dementia. Participants will sign up to play brain games for 5 minute a day, every day, over a month. This invaluable data will help the research team to build a comprehensive picture of healthy ageing. Following up with the same participants in a year will give us an even clearer picture of changes in cognition over time. In the first month over 12,000 people signed up and have been playing the games.

The very early signs of Alzheimer’s disease can appear more than 10 years before diagnosis, but today we have no way to effectively detect these tiny changes. It can take a long time for people to receive the diagnosis they need to access support, and means there is a delay in people entering into clinical trials at the very early stages of the condition when new treatments could be effective.

More and more, technology gives us the change to study cognition ‘little and often’ building a comprehensive understanding of how cognition changes as we age. The first stage is to test and validate this technology to understand what ‘healthy ageing’ looks like. GameChanger aims to do just that.

In the future this vital information will help us to identify the early changes in people who will go on to develop dementia. Researchers and doctors will be able to make sure people showing early signs of dementia can take part in the latest and most promising research studies and clinical trials. Ultimately, making best use of this latest technology will give us the best chance of supporting research that could prevent, slow down or even stop the progression of dementia.

24 October: Alzheimer’s Society reports on engaging politicians on the cost of care



Last month, Alzheimer’s Society attended the Labour and Conservative Party Conferences, the two main political parties in England. We spoke to Members of Parliament (MPs), local councillors and other delegates who attended our exhibition stand. The stand was designed in the form of an interactive

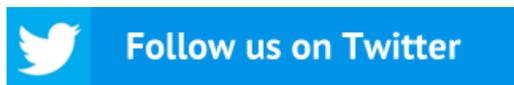
shop and delegates were invited to step into the shoes of a person with dementia to see what care was available for them. Delegates shopped for care support and the experience highlighted that cost, quality and access to care are all issues that people with dementia face in England. Delegates were presented with a bill for all the items that they had chosen, representing the extortionate amount people with dementia spend on their care.

We spoke with nearly 100 MPs, sharing key messages ahead of an upcoming Green Paper on social care reform. At Labour Conference, Tommy Dunne and Paul Hitchmough, both of whom are living with dementia, were there to talk to MPs and Shadow Ministers about their experiences directly. It was reassuring and positive to see MPs engaging with them about their diagnosis and the issues they felt strongly about. Tommy said, ‘I was able to tell them how it’s wrong that people living with dementia are facing catastrophic costs to pay for their care and support. I told them that just because we have dementia, it shouldn’t mean we should be penalised compared to if we had cancer or another medical condition.’ At Conservative conference, Sandy Sweet, whose mother has dementia, told her family’s story to MPs and Ministers, including the Prime Minister Theresa May, managing to convey the importance of reforming the care system for people with dementia in an incredibly impactful way.

Alzheimer’s Society CEO, Jeremy Hughes, and other members of the team also spoke at various roundtables, panel events and meetings throughout both conferences, making sure our messaging on social care and dementia was heard by key stakeholders.

We are now working to follow up on the contact we had with delegates, to ensure that the success of party conferences leads to meaningful change for people with dementia and their families. To find out more about Alzheimer’s Society’s activity Party Conferences, visit:

<https://blog.alzheimers.org.uk/campaigns/party-conferences-2018/>



POLICY WATCH

1 October: Largest ever Alzheimer’s funding increase signed into law in US



National Institutes of Health

The largest-ever funding increase for Alzheimer’s and dementia research at the National Institutes of Health (NIH) was signed into force in the US, having passed the Senate and House of Representatives in recent weeks.

The passage of the budget for 2019 represents a USD 425 million increase in funding for Alzheimer’s and dementia at the NIH, taking the total annual expenditure to USD 2.3 billion, up from USD 448 million in 2011.

Alzheimer's is the most expensive disease in the USA, costing an estimated USD 277 billion - including USD 186 billion in direct costs to Medicare and Medicaid - in 2018. More than five million Americans are living with the disease and by 2050 this number is projected to rise to nearly 14 million. The increased funding will be used to advance basic disease knowledge, explore ways to reduce risk, uncover new biomarkers for early diagnosis and drug targeting, and develop potential treatments.

1 October: Ageing Equal campaign emphasises ageism as a human rights violation



On 1 October (International Day of Older Persons) AGE Platform Europe, with the support of its partners and fellow civil society organisations, launched a 70-day campaign against ageism. The "Ageing Equal" campaign, which aims to raise awareness of how ageism, as a human rights violation, affects different groups in society across the whole life span, marks the 70th anniversary of the Universal Declaration of Human Rights. It will close on 10 December (UN Human Rights Day).

You can follow and support the campaign on social media using the hashtag #AgeingEqual

<http://ageing-equal.org/>

9 October: Alzheimer Society of Ireland frustrated by Irish Government decision not to designate a specific budget for dementia



The Alzheimer Society of Ireland was frustrated following the Irish Government's decision not to designate a dedicated ring-fenced budget for dementia supports and services in

Budget 2019 which was announced on 9 October, but insists that this is addressed in the Irish Health Service Executive's (HSE) 2019 National Service Plan.

Investment announced on the day of the Budget 2019 simply maintains the status quo and does not address the scale of dementia which affects 55,000 people in Ireland and the significance of the issues that requires a specific budget.

"We are very disappointed that the Government has yet again decided not to make specific funding available for people with dementia and their family members in Budget 2019," The Alzheimer Society of Ireland CEO, Pat McLoughlin.

"There are thousands of families up and down the country who have been struggling to access basic minimum level of supports and services for loved ones with dementia, and as a society we are failing to provide these people with the supports they need.

"A number of times over the past 12 months alone, we have had a number of high-profile reports that have suggested additional community supports are needed for people with dementia and their family members - the mid-term review of the National Dementia Strategy (NDS), which was launched in May 2018, acknowledges that people with dementia and their families are still dealing with inadequate services and supports and states that additional funding is required.

"Budget 2019 represented a great opportunity to address this issue. The Government now has an opportunity in the HSE's National Service Plan later this year to direct funds for dementia-specific supports and services to address the pressing issue of dementia in Ireland."

Over 5,000 letters were sent to members of the Irish parliament around Ireland and the support that everyone has given the campaign over the last few months has been incredible.

The ASI will keep working hard until people with dementia and their families are given access to the community supports they need and deserve across Ireland.

Pictured: Dementia Advocate Dolores Power, The ASI CEO Pat McLoughlin at the launch of The ASI Pre-Budget Submission 2019 launch in Dublin, June 2018.

15 October: Alzheimer Italia launches petition calling for dementia funding



The Federazione Alzheimer Italia (FAI) have launched a petition calling on the Minister of Health, Giulia Grillo, to commit to providing greater support for people with dementia, their families and carers in Italy.

Specifically, the petition calls on the Minister to allocate funding for the Italian National Dementia Plan which was approved four year ago, which has not received funding to implement its commitments during that time. The petition highlights the importance of ensuring that every person with dementia, their families and carers have access to pathways of care which will improve their lives and the need to overcome poor services for a condition which is rooted in social stigma. The petition also includes a three-minute supporting video minute video from Kate Swaffer, CEO of Dementia Alliance International (DAI) talking about the need to see the person, not the illness.

You can read FAI's full petition, watch the video and sign-up at: <https://bit.ly/2yZ9x1L>



SCIENCE WATCH

7 August: Gene editing technique may help to identify new AD biomarkers



On 7 August, a Spanish team of scientists published an article on a potential new biomarker for Alzheimer's disease (AD) in the October edition of the Journal of Molecular Medicine.

About 5% of the causes for AD can be linked to a familial respectively hereditary type, for which animal models exist. The remaining 95% of cases remain of unknown origin and there are no animal models available yet, helping to better understand the disease. Due to this absence, the team aims to develop a new model to study AD of unknown origin.

In their study, the scientists from the University of Extremadura first analysed brain tissue from six deceased humans that had AD and compared it to six that were diagnosed with non-AD degenerative conditions. Using a genome editing technique (CRISPR - Clustered Regularly Interspaced Short Palindromic Repeats), they observed a significant loss of the STIM1 protein in the human tissue of the samples with AD. From that point on, the team conducted tests on other samples in which they inhibited the expression of the STIM1 gene and observed alterations that were very similar to the ones observed in tissues with AD.

In their conclusion the scientists stated that STIM1-KO cells constitute an *in vitro* model with which the study of the disease development could be possible. Furthermore, they stated that the model will be useful to help understand the role of STIM1 in the modulation of additional channels and pathways involved in neurodegeneration, with a possible impact on the search for new therapeutic targets.

You can find the article [here](#).

18 September: Sosei and Allergan suspend clinical activities of HTL0018318 in AD

On 18 September, Sosei and Allergan announced the suspension of the clinical development activities with HTL0018318. The decision to temporarily halt this investigation is due to toxicology results from an animal study in non-human primates examining different dosing levels of HTL0018318 over a nine-month period.

The experimental compound HTL0018318 is a small molecule in clinical investigation as a new symptomatic treatment for cognitive impairment in people with Alzheimer's disease (AD) and other dementias including dementia with Lewy bodies (DLB).

The experimental drug is in Phase I clinical development in the US and in a Phase II clinical trial in Japan. It has been investigated in around 310 participants from EU and US including people with AD and healthy volunteers. First findings

found that HTL0018318 was well tolerated and with no serious adverse effects at the tested doses.

<http://v4.eir-parts.net/v4Contents/View.aspx?cat=tdnet&sid=1630265>

26 September: Theranexus receives approval to start Phase Ib study for AD drug THN201



On 26 September, Theranexus, a French biopharmaceutical company developing drug candidates for the treatment of nervous system diseases announced that it has received approval by the French regulatory authorities to initiate a Phase Ib clinical trial investigating the drug candidate THN201 for the treatment of cognitive disorders in Alzheimer's disease (AD). THN201 is a combination of donepezil (a cholinesterase inhibitor) and mefloquine (an antimalarial compound).

This Phase Ib clinical trial will be a double-blind, randomised, parallel and placebo-controlled study evaluating the activity, safety and pharmacokinetics of THN201. The study is expected to recruit 150 healthy volunteers in eight French research centres.

<https://bit.ly/2D69NAt>

28 September: Scientists publish article on a combination of computer models to better predict MCI



On 28 September, researchers from the Boston University School of Medicine published an article on an investigation in which they aimed to find out if a combination of brain imaging and neuropsychological testing could help in distinguishing between people with normal cognition and those with mild cognitive impairment (MCI). Currently MCI often remains undetected and may be a sign of a progressive disease course. The cause of which may be reversible and therefore more accurate methods are in need. The team of US scientists developed three computer models using data from 386 people. The first model was based on a fusion of computer programs that were trained in predicting MCI through "deep learning" on brain scan slices. The two other models (so-called multilayer perceptron models) were developed using for each, either a pen-and-paper global cognition test (MMSE) or the logical memory test results. These three models were then again combined using majority voting. The scientists reported that their fusion model was better at predicting MCI than the models used alone and that it reached an overall accuracy of 90.9%.

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<https://www.sciencedirect.com/science/article/pii/S2352872918300654>

1 October: Finnish study underlines high psychotropic polypharmacy in AD

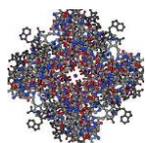


In a recent study, Finnish scientists published findings on how often psychotropic drugs are administered for people with Alzheimer's disease (AD) in the

journal European Neuropsychopharmacology. The study includes data from over 70,000 community-dwelling Finnish people who received a diagnosis of AD from 2005 to 2011. The publication underlined that the use of antipsychotic drugs was more than seven times more common in people with AD than other groups as well as that the use of more than one psychotropic was three times more common among persons with AD four years after the diagnosis.

<https://linkinghub.elsevier.com/retrieve/pii/S0924977X18302906>

1 October: Researchers describe a new mechanism that may contribute to AD



In a recent article published in the journal Cell Death & Disease, US researchers from Rutgers University reported that a potassium channel called KCNB1 may contribute to Alzheimer's disease (AD) and traumatic brain injury.

In the published study, researchers found that under conditions of oxidative stress, the build-up of KCNB1 was much higher in post-mortem brains of AD donors compared to control brains. They also showed that this mechanism contributed to inflammation, cognitive impairment and amyloidosis in AD mouse models.

<https://go.nature.com/2D5GvC9>

9 October: Researchers explore a novel model for amyloidogenesis in Alzheimer's disease



On 9 October, researchers from the University of Edinburgh as well as the Massachusetts General Hospital and Harvard Medical School published an

article on a rational framework incorporating recent findings on the antimicrobial role of β -amyloid in the journal Alzheimer's & Dementia.

Alzheimer's disease (AD) is characterised by a deposition and clustering of amyloid- β ($A\beta$) proteins in the brain that contribute to cell death. However, it is argued, that surfacing findings also show beneficial roles of $A\beta$ as recent evidence suggests that $A\beta$ shows antimicrobial activity and even inhibits the infectivity of viruses.

In this theoretical publication, the researchers aim to provide a rational framework for incorporating these seemingly independent findings on the antimicrobial role of β -amyloid and emerging experimental, genetic, and epidemiological data, suggesting innate immune-mediated inflammation propagates AD neurodegeneration. You can find the article [here](#).

9 October: Researchers initiate a new Phase IIb trial for AD in UK



Previous findings showed that a specific protein called serum amyloid P component (SAP) could contribute to the formation of amyloid and that brains of people with Alzheimer's disease (AD) have more SAP compared to the brains of people without

the condition. Researchers at the UCL have developed a drug called miridesap in order to target and remove SAP.

On 9 October, these scientists announced the start of a new Phase II trial to access miridesap for AD. The Depletion of serum amyloid P component in Alzheimer's disease (DESPIAD) trial will investigate the safety, tolerability and potential effectiveness of miridesap in people with AD. The double-blind placebo controlled randomised Phase IIb study is being conducted in London and recruits people with mild Alzheimer's disease. Participants will receive the experimental drug for one year and will be tested for changes in brain structure and function. Funded by the National Institute for Health Research, the trial is sponsored by University College London.

<https://bit.ly/2CEIXXA>

12 October: Researchers develop a new computer model mapping how AD could spread through the brain



On 12 October, a team of researchers from the Stevens Institute of Technology (New Jersey), Stanford University and University of Oxford published an article on the development of a new computer model that simulates how toxic

proteins could spread through the brain. The study was published in the journal Physical Review Letters.

The simulations focused on Alzheimer's disease (AD), Parkinson's disease and amyotrophic lateral sclerosis. These neurodegenerative diseases are known to produce misfolded proteins that build up in the brain. Scientists analysed the brain from people who died after developing these three diseases. Using mathematical models, they looked at the location, progression and accumulation of toxic proteins including tau and amyloid beta proteins. They suggested that brain geometry, transport anisotropy and mechanics play a central role in neurodegeneration.

<https://bit.ly/2SiLPqI>

16 October: Study reports on association between risk of incident dementia and aortic stiffness



On 16 October, scientists from the University of Pittsburgh published an article, introducing aortic stiffness as a potential predictor of dementia in the Journal of Alzheimer's disease.

The scientists analysed data from 356 elderly people who were followed-up with tests (cognition, arterial stiffness and brain scans among others) during 15 years as part of the Cardiovascular Health Study.

Aortic stiffness was measured by carotid-femoral pulse wave velocity. The stiffness reduces the blood flow and damages small arteries in the brain. The scientists found that it predicts incident dementia in older adults, independent of confounders such as age, hypertension and diabetes.

Although the study could not address whether or not interventions to slow arterial stiffening can reduce the risk of developing dementia, the scientists reported that there is a relation between lower physical activity, higher blood pressure heart rate and waist size five years in advance.

<https://bit.ly/2ORHAnh>



LIVING WITH DEMENTIA

21 September: Petri Lampinen, member of the EWGPWD, tells us about his speech at the Alzheimer Society of Finland’s 30th anniversary gala



It was a great honor to say the opening remarks in the 30th anniversary gala of the Alzheimer Society of Finland (Muistiliitto) on World Alzheimer’s Day this year. I got this opportunity as the Chairperson of the Finnish working group of people with dementia, the Memory Activists. A large group of volunteers from the local memory (or dementia) associations were also invited to the gala. It was a great way to show appreciation to the volunteers. The gala, which included a lot of musical entertainment, was a big success. Awards were given to people with extensive and particularly valuable experience in the field of dementia. I was also happy to see that, despite my dementia, I have developed into a better public speaker and enjoy facing bigger crowds as well.

I have also participated in a video interview by another Finnish NGO, working in cooperation with the Alzheimer Society of Finland. I was told about this opportunity through my local memory (or dementia) association. In the interview, I shared my experience of living with the disease. The NGO will use the recording in their work, promoting the welfare and social protection of the older population. I can also use the video as part of my future speeches. While looking at this recording first time, I noted that my positive attitude is an important resource for me and that I live a good life. I feel that I am helping many people with the wide-ranging dementia work that I am able to do. My work has lot of meaning for me.

21 September: Idalina Aguiar, member of the EWGPWD, tells us how she marked World Alzheimer’s Day 2018



Last month, and mainly on World Alzheimer’s Day (21 September) I was once again fighting against the stigma of dementia. Much has been done in support of people living with dementia in recent years, and many campaigns have been launched. Much has changed, but there is still much to do. We need to change the way society still sees the 182,000 people with dementia who live in our country (Portugal). Those affected by dementia know how important it is that society become more accepting, and integrate and help people with dementia. Together, we can contribute to the building of a Dementia-Friendly Community. Together we can make society “friendlier” for people with dementia!

Alzheimer Portugal is 30 years old this year and to mark this anniversary, as well as World Alzheimer’s Day itself of course, several “Memory Walks” are being carried out around Portugal and its islands. I participated in some of these, to help raise awareness.

I have also been involved in campaigning, to ask people in Portugal (especially politicians) to realise the importance of approving the Caregiver’s Statute, which would help create a more inclusive, fairer society.

Idalina is supported by her daughter Nélida, to whom we are grateful for her help in translating Idalina’s words to English.

15 October: Carol Hargreaves, member of the EWGPWD, shares some positive aspects of her dementia



I would love to let the world know that, although I have dementia and don't know what the future holds for me, I can only say I have a new purpose in life. We are all given our crosses to bear and life has to go on.

I have learned so much, firstly from my national group, the Scottish Dementia Working Group (SDWG). The SDWG put me forward for the European working group (EWGPWD), which was an honour. It's a privilege to meet all my friends and work colleagues and, believe me, we work very hard to make the lives of people with dementia easier. If I can help even one person, I will feel I have done something right.

I worked all my days, and my family brought me joy, but now I feel like a different person, in a good way. I know I am more open minded and take

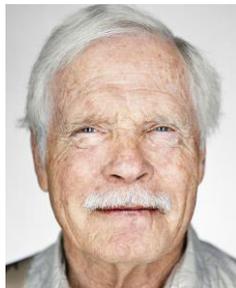
nothing for granted. Things can go wrong, but I don't (or try not to) blame my illness.

I have been honoured to open big, important conferences and was able to speak about my life before and after my diagnosis. I do get very nervous every time I speak, but somehow the nerves disappear and it goes well.

That's it, I just wanted to say how passionate I am, and to say that we can live well with dementia, we just need a little help sometimes.

DEMENTIA IN SOCIETY

30 September: CNN founder Ted Turner reveals he has Lewy body dementia



79-year-old US billionaire media mogul Ted Turner, the founder of CNN, has revealed he has been diagnosed with Lewy body dementia, a neurodegenerative disease that affects memory, mood, motor skills and behaviour. He was misdiagnosed with depression before doctors identified dementia with Lewy bodies as the real

underlying cause of his symptoms, which include forgetfulness and exhaustion.

11 October: New Flemish working group of people with dementia holds its first meeting



On 11 October, the first meeting of a brand new working group for people with dementia' in Flanders, Belgium, took place.

The positive energy of the "real experts", the people with dementia and their loved ones

was wonderful to behold, reported the Expertisecentrum Dementie Vlaanderen (Flanders Centre of Expertise on Dementia), on social media.

Providing a voice to people with dementia and their carers is of huge importance to us as an organisation and we were delighted to see this new group form. Groups like this, as well as our European Working Group of People with Dementia (EWGPWD) help ensure that the work we do duly reflects the needs and priorities of people living with dementia.

JOB OPPORTUNITIES

8 October: University of Salford seeks Senior Lecturer in Ageing



The School of Health and Society at the University of Salford, Manchester, UK is looking to appoint a Senior Lecturer to take a lead in its response to the Ageing agenda. The successful candidate will also be responsible for the production and

delivery of the educational offerings within the Institute of Dementia, which is housed in the School.

The Senior Lecturer will plan, design, develop and deliver a range of high-quality programmes of study at all levels, ensuring that programme design and delivery comply with the academic quality standards and regulations of the University. The successful candidate will also undertake research of international quality and, where required, to co-ordinate or supervise the work of research assistants and students.

For further information please contact: Dr Julia Ryan Director of Health (+44) 0161 295 2790 j.ryan@salford.ac.uk or Brian Boag, Associate Dean (Operations & Strategic Planning) (+44) 0161 295 2480 b.r.boag@salford.ac.uk Job description: <https://bit.ly/2RztR2f> Application: <https://bit.ly/2RyjuvC>

23 October: Oxford University Dementia and Ageing Research team seeks two trials coordinators



Oxford University is looking to appoint two trials coordinators to work with the Oxford Dementia and Ageing Research (OxDARE) clinical trials team, conducting a growing portfolio of dementia-orientated studies, including the MRC/NIHR funded Deep and

Frequent Phenotyping (DFP) and European Prevention of Alzheimer’s Dementia (EPAD) studies. The posts are based in the Department of Psychiatry at the Warneford Hospital. The posts are full-time, however consideration would be given to candidates looking to work part-time (minimum of 80% FTE) on a pro rata basis. Whilst the roles are for experienced Trials Coordinators, the university would be willing to consider candidates at an early stage of their career who are seeking a development opportunity, for which an initial appointment would be at Grade 6 the responsibilities adjusted accordingly.

This would be discussed with applicants at interview/appointment where appropriate.

The posts are for a fixed-term (funded to 31 December 2019) The closing day for applications is 12.00 midday on 5 November 2018.

For further information please contact the HR Administrator on vacancies@psych.ox.ac.uk and use Vacancy ID 137201

<https://bit.ly/2QzRGFV>

AE CALENDAR

Date	Meeting	AE representative
22 November	European Parliament Informal Carers Interest Group (Brussels, Belgium)	Jean
26-27 November	30 th Anniversary Conference of Israel’s Alzheimer’s Association - EMDA (Tel Aviv, Israel)	Jean
29-30 November	AETIONOMY Final Symposium (Bonn, Germany)	Jean

CONFERENCES 2018

Date	Meeting	Place
1-4 November	CNS Summit, http://cnssummit.org/	Boca Raton, Florida, US
11-14 November	11 th International Conference on Frontotemporal Dementias, https://www.dconferences.com.au	Sydney, Australia
21 November	ADI webinar on “Let’s Talk About Dementia Research: Demystifying Trials, Access and Understanding” https://www.alz.co.uk/webinars-research-participation	Online
23 November	First annual meeting ‘Herinneringen’ (‘Memories’), https://herinneringen.eu/nl	Leuven, Belgium
14-15 December	EDUKAL 2018 – Fourth educational conference on Alzheimer’s disease, https://www.edukal.alzheimer.hr	Zagreb, Croatia
16-18 January 2019	13 th Human Amyloid Imaging, http://www.worldeventsforum.com/hai/	Miami, Florida
14-17 February 2019	11 th Panhellenic Conference on Alzheimer’s Disease and Related Disorders, http://www.alzheimer-conference.gr	Thessaloniki, Greece
20-23 March 2019	13 th Göttingen Meeting of the German Neuroscience Society, https://www.nwg-goettingen.de/	Göttingen, Germany
26-31 March 2019	The 14 th international conference on Alzheimer’s & Parkinson’s diseases, https://bit.ly/2Jyvw3t	Lisbon, Portugal
4-7 April 2019	13 th World Congress on Controversies in Neurology, http://www.comtecmed.com	Madrid, Spain
19-20 September 2019	International MinD Conference 2019, http://designingfordementia.eu	Dresden, Germany
22-25 October 2019	29 th Alzheimer Europe Conference “Making valuable connections”	The Hague, Netherlands

29th Alzheimer Europe Conference

Making valuable connections

The Hague, Netherlands

23–25 October 2019

www.alzheimer-europe.org/conferences

 #29AEC

