This month, Alzheimer Europe (AE) launched its European Parliament (EP) election campaign. Together with our members, we call for candidates to make dementia a European priority and join the European Alzheimer’s Alliance (EAA), if elected, by supporting the #DementiaPledge2019. I would like to thank the pledgees so far, as well as our members for helping gather support and for translating the Pledge.

We are also grateful to all 127 members of the 2014-2019 EAA, who have helped make dementia a priority. We look forward to welcoming many back, as well as new members for the next term. EAA members give freely of their time to host our EP lunch debates, the latest of which was hosted by Anneli Jäätteenmäki, MEP. We are hugely grateful to her and her team, as well as to MEP Sirpa Pietikäinen’s team, who helped organise it. The debate was part of a series of AE meetings, including a Board meeting and a round table with sponsors. We also held a public affairs meeting with our members, at which we welcomed speakers from the European Patients’ Forum and the European Disability Forum.

Another important meeting this month was the European Working Group of People with Dementia (EWGPWD) meeting. Aside from its own agenda of work, members consulted on a new project, RADAR-AD. As always, their input was vital and hugely appreciated. EWGPWD members’ care partners do vital work too, addressing stigma and loss of rights. One such person is Jayne Goodrick (wife of Vice-Chairperson Chris Roberts). I would like to personally congratulate her for receiving a Points of Light award this month.

Last week, the Innovative Medicines Initiative (IMI) launched a public-private coordination and support action, NEURONET, to develop an operational platform for its neurodegeneration projects. We are very excited to be involved in this and other collaborations, including EPAD, which has recently announced two major milestones: The launch of its Proof of Concept (PoC) trial and the enrolment of its 1,500th participant.

In European policy news, important progress was made with the European Accessibility Act and Horizon Europe: The EP has passed the Accessibility Act, though the legislation must be formally approved by the Council of the EU before coming into effect. Regarding the Horizon Europe research programme, a partial political agreement was reached, subject to formal approval by the EP and Council.

Unfortunately, there is bad news on the research front, with Biogen and Eisai discontinuing Phase III studies of aducanumab. Failed trials do increase our understanding and bring us closer to success, though, so we remain optimistic. Finally, I would like to remind readers that the call for abstracts for this year’s Alzheimer Europe Conference 29AEC is 30 April, so there is just one month left.

Jean Georges
Executive Director
The Alzheimer Europe Board members convened in Brussels on 25-26 February 2019. The meeting agenda included various financial and operational matters, including preparations for the 29th Alzheimer Europe Conference, which will be held in The Hague from 23 to 25 October 2019. The progress of the organisation 2019 Work Plan was also discussed. The next Board meeting will take place on 24-25 June in Brussels.

26 February: Alzheimer Europe holds European Parliament Lunch Debate

Alzheimer Europe held its first lunch debate of 2019 in the European parliament on 26 February 2019, focusing on dementia as a European research priority. Hosted by Anneli Jätteenmäki MEP, the debate was attended by 64 delegates from across Europe, including the Chair of the European Working Group of People with Dementia (EWGPWD), national Alzheimer’s Associations, research partners, pharmaceutical representatives and Members of the European Parliament (MEPs).

The Executive Director of the Innovative Medicines Initiative (IMI) Pierre Meulien, presented on the work of IMI through both its iterations IMI1 (2008-2013) and IMI2 (2014-2020), highlighting that the public-private model of funding had yielded over EUR 5 billion investment, with over EUR 300 million invested in brain disorders and over EUR 200 million invested in drug discovery, to date. Dr Meulien further identified the shift in approach to include molecular mechanisms, acknowledging that the previous focus on disease-modification in the symptomatic stages of neurological conditions, including dementia, had not been effective. As such, the overarching approach to neurodegenerative conditions focused on four key areas: Underlying causes, populations at greatest risk, improved clinical trial design and brain scanning as a means to improve detection and treatment. Additionally, the value of “big data” projects were also explored within the presentation.

Mikka Hiltunen, Professor of Tissue and Cell Biology at the Institute of Biomedicine, University of Eastern Finland (UEF), presented on current research being carried out within his institute concerning brain health in the older population, with a specific focus on biomarkers as a means of prevention and early detection for dementia. Prof. Hiltunen explained that understanding the genetics of Alzheimer’s disease (AD) was one of the best ways to improve knowledge on the condition. He further outlined the AlzTrans project, which seeks to evaluate the translational aspects, feasibility and applicability of novel AD-associated risk genes/variants, as well as Finland’s involvement in international research collaborations. This included the EU’s Joint Programme on Neurological Diseases (JPND), which involved the European DNA Bank for deciphering the missing heritability of Alzheimer’s disease that collated ~40,000 patients and ~66,000 controls from 13 countries.

Stephane Hogan, Head of Sector for Neuroscience in the Directorate General Research and Innovation at the European Commission, highlighted the EU’s support for dementia research in Europe. Mr Hogan provided an overview of the approach of the European Commission across six areas, including molecular pathogenesis, epidemiology, prevention, diagnosis and monitoring, treatment, and care and support. He also articulated a number of projects across these areas including AETIONOMY, ADDIA and PRODEMOS, as well as collaborative programmes such as JPND and IMI. In addition to being a major funder of research, Mr Hogan noted that the role of the EU included supporting frontier research, providing a network of collaborative projects, as well as providing a framework for efficient research coordination between EU countries. Concluding, Mr Hogan also highlighted the future Horizon Europe and the novel aspects of the forthcoming programme, including specific research missions and an “open science” approach.

Impressions from the lunch debate

Our lunch debate host, MEP Anneli Jätteenmäki addresses the room
Our first speaker, Pierre Meulien presents the IMI Alzheimer’s disease portfolio
Our second speaker, Mikko Hiltunen, University of Eastern Finland, fields a question
Alzheimer Europe Chairperson, Prof. Iva Holmerová, thanked the speakers, MEPs and attendees for taking part in the lunch debate and officially launched two reports by Alzheimer Europe. The first, “The development of intercultural care and support for people with dementia form minority groups”, was the result of an extended piece of work undertaken with the support of partners across Europe, exploring how dementia was experienced by minority communities. The report highlights the need for specific considerations, particularly as cultural differences in the understanding, status and position of dementia, may increase the stigma associated with dementia. Particularly interesting are the recommendations. The second, the Dementia in Europe Yearbook 2018, provides a comparison of national dementia strategies across Europe, comparing the content and policy priorities set out in each document across Europe. The report highlights the strong focus on systems of care and support for people with dementia, whilst also noting the frequency of other areas, such as research, training for professionals and awareness raising.

The session was concluded by an open floor discussion, with questions from attendees on a range of subject matters including forthcoming Horizon Europe research programme, the place of dementia within the research missions, the role of central and eastern European countries in the research agenda and the future of collaborative approaches to research (e.g. IMI3).

26 February: Alzheimer Europe holds a Company Round Table meeting in Brussels

On 26 February, Alzheimer Europe (AE) hosted a Company Round Table meeting in Brussels. It was attended by representatives from Abbvie, Biogen, Essity, Eisai, GE Healthcare, GSK, Nutricia and Roche. Also in attendance, were: 7 members of the AE staff, including Executive Director Jean Georges; 22 representatives of AE member organisations; 1 representative of the European Working Group of People with Dementia (EWGPWD); and 1 representative of the European Patients’ Forum (EPF).

Cindy Birck, AE Project Officer updated sponsors and other delegates on recent developments in our Clinical Trials Watch. Following this, Eleanor Newman from GSK presented some of the implications of Brexit for people with dementia and shared some of the preparations being made by GSK and other pharmaceutical companies for any eventuality at this uncertain time for the relationship between the UK and Europe. Kostas Aligiannis, EPF, talked about the Multiannual Financial Framework (MFF) and its implications for the European health and research programmes. The last speaker of the afternoon was Policy Officer Owen Miller, who presented AE’s European Dementia Pledge campaign, which aims to get MEP candidates for the May 2019 European elections, to commit to making dementia a priority. There was ample time, also, for questions and discussions after each presentation.
We would like to thank our sponsors for participating in this meeting and we look forward to welcoming to the next Company Round Table meeting, in June.

27 February: European Patients Forum and European Disability Forum participate in Alzheimer Europe Public Affairs meeting

On 27 February, Alzheimer Europe (AE) hosted a Public Affairs meeting in Brussels, Belgium.

23 representatives from AE member organisations, 7 AE staff members, 1 representative from the European Disability Forum and 1 representative from the European Patients’ Forum were in attendance.

AE Chairperson Iva Holmerová led the meeting.

The agenda focused on:

- The experience of the European Patients’ Forum in influencing key EU legislative initiatives in the field of health (presented by Kostas Aligiannis, European Patients’ Forum)
- The experience of the European Disability Forum in influencing key EU legislative initiatives in the field of disability (presented by Alejandro Moledo, European Disability Forum)
- Improving the lobbying and campaigning activities of Alzheimer Europe and its national member organisations – Campaigning on the European Dementia Pledge (presented by Owen Miller, AE Policy Officer)
- 2019 Mapping exercise of national member organisations (also presented by Owen Miller, AE Policy Officer)
- Representatives from each member organisation attending the meeting also had the opportunity to present and exchange on national campaigning activities.

The next Public Affairs meeting will take place in Brussels on 27 June 2019.

6 March: Alzheimer Europe calls for European Election candidates to commit to making dementia a priority

Around 9.1 million people in Europe have dementia and these numbers are expected to increase to 14 million people by 2040, due to the ageing of European societies.

With no disease-modifying treatment currently available and varied access to diagnosis, treatment and high quality care across Member States, EU institutions must show leadership by making dementia a priority in the fields of health, research and innovation, and social affairs.

Alzheimer Europe and its members therefore call upon candidates in the 2019 European elections to join this campaign to make dementia a European priority.

Candidates can pledge their support on social media (Twitter and Facebook), simply stating that they support the DementiaPledge2019

Candidates can also download the Pledge as a document to sign and return to AE or the relevant national member association. Finally, candidates can also send their support in an email message.

More information, as well as the Pledge document, can be found here: www.alzheimer-europe.org/Policy-in-Practice2/European-Parliament-Elections-2019

18-20 March: EWGPWD meets in Luxembourg

The first meeting of the EWGPWD in 2019 was held in Luxembourg from 18 to 20 March. The meeting was very productive and members discussed plans for the various projects and activities in which the group will be involved throughout the year and about the support which new members of the group might need to contribute to the meetings.

During the second and third days of the meeting, the members of the EWGPWD and their supporters were invited to provide input on the new IMI project RADAR AD. Interested members and supporters will have the opportunity to join the RADAR-AD Patient Advisory Board. The group provided feedback on the definition and prioritisation of functional domains in Alzheimer’s disease and main features to consider when selecting a device for people with dementia. They also reviewed and provided advice on the protocol for the RADAR AD clinical trial.

Five members of the RADAR-AD consortium - Irene Kanter-Schlifke (Lygature), Thanos Stavropoulos and Ioulietta Lazarou (CERTH), Nikolay Manyakov (the Janssen Pharmaceutical
Companies of Johnson and Johnson) and Emilio Merlo Pich (Takeda Pharmaceuticals) joined the meeting, and together with Dianne Gove and Ana Diaz (AE) co-moderated the discussions. Jean Georges, Executive Director of AE also contributed to the meeting.

**28 March: One month left to submit your abstracts for #29AEC**

The 29th Alzheimer Europe Conference (#29AEC) will take place in The Hague, Netherlands from 23 to 25 October 2019. Abstract submissions and conference registrations began in February, with the call for abstracts closing in one month, on 30 April and Early Bird registrations set to close on 30 June. Please read the abstract submission guidelines carefully before submitting an abstract: https://www.alzheimer-europe.org/Conferences/The-Hague-2019/Call-for-abstracts

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**Alzheimer Europe networking**

On 25 February (Brussels, Belgium) the Board of the Alzheimer Europe Foundation met. On 25 and 26 February (Brussels, Belgium) the Alzheimer Europe Board met. On 26 February (Brussels, Belgium) Alzheimer Europe organised a lunch debate “Dementia as a European research priority”. On 26 February (Brussels, Belgium) Alzheimer Europe organised a company round table meeting with its corporate sponsors and member organisations.

On 27 February (Brussels, Belgium) Alzheimer Europe organised a public affairs meeting with representatives of its national member organisations.

On 6-7 March (Toulouse, France) Cindy attended the SyDAD annual meeting.

On 18-20 March (Munsbach, Luxembourg) Dianne and Ana attended the quarterly meeting of the European Working Group of People with Dementia.

On 20 March (Brussels, Belgium) Owen attended an event in the European parliament to mark World Down Syndrome Day 2019, hosted by Fondation Jérôme Lejeune.

On 21 March (Madrid, Spain) Jean and Christophe attended the launch of the NEURONET project.

On 22 March (Copenhagen, Denmark) Dianne attended the Steering Committee Meeting of the AD-Detect-Prevent project.

From 26 to 31 March (Lisbon, Portugal) Jean attended the AD/PD Conference.

On 27 and 28 March (Berlin, Germany), Ana attended a series of PARADIGM project workshops.

On 29 March (Lisbon, Portugal), Jean attended a Roche Patient meeting.

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**EU PROJECTS**

**28 February: SPAN+ project launches factsheet about European survey on interventions and projects aimed at empowering people with dementia**

In May-June 2018 the Dutch Radboudumc Alzheimer Centre (RAC), with support from Alzheimer Europe, conducted a European survey on current interventions and projects aimed at the empowerment of people with dementia. Member organisations of Alzheimer Europe participated in this survey.

Many European interventions are considered empowering for people with dementia: the RAC received 99 interventions from 23 different European countries. There is a broad variety in empowerment interventions, ranging from interpersonal interventions aimed at supporting a person with dementia, to societal projects aiming at dementia friendly societies. An overview of the themes of the mentioned interventions and projects can be found in a factsheet, launched on 28 February 2019.

The survey was part of a project called ‘SPAN+: Empowering people with dementia’. This Dutch project aims to develop an effective empowerment intervention, which is applicable for people with dementia at home as well as in care homes.

For more information about the project: www.ukonnetwerk.nl/spanplus/en

For questions and comments, contact the researchers: spanplus.elg@radboudumc.nl

To download the factsheet: https://bit.ly/2TFLDRp

**5 March: EPAD works together towards its PoC platform**

On 5 February, the European Prevention of Alzheimer’s Dementia (EPAD) initiative held its PoC (Proof of Concept) Kick Off meeting in Berlin (Germany). The event brought together more
than 100 delegates including site staff, vendors and the wider EPAD PoC coordination team to showcase the PoC trial platform.

Prof Craig Ritchie, EPAD Co-coordinator (the University of Edinburgh), opened the meeting, thanking IQVIA for the organisation of the event and extending a special welcome to the site staff and study team attending the event. He then introduced the EPAD project, its consortium, flow, structure and the PoC platform. He reported that the recruitment into the PoC is exclusively from the EPAD cohort of at-risk subjects, the Longitudinal Cohort Study, known as the LCS. Following Prof Ritchie, Dr Kristy Draper, the EPAD Global Trial Lead (the University of Edinburgh), emphasised the importance of the master protocol. She highlighted its design and the progress towards the first PoC trial. The negotiations with the first intervention owner are progressing well and it is expected to begin start-up activities for the first PoC appendix in the spring. There was also an exciting announcement that the inclusion of the first participant in will likely happen in Q1 2020. This meeting marked an important stage in the preparations for the PoC with almost all of the study sites coming together to plan and discuss readiness for the first appendix. Two workshop sessions were organised where each site had the opportunity to discuss and work on the PoC readiness. After an energetic workshop session discussing issues across sites and the generation of creative plans, John Tracey from IQVIA presented an overview of 3rd Party Vendors. Finally, Craig Ritchie closed the meeting. Project Officer Cindy Birck attended the meeting.

www.ep-ad.org/2019/02/05/epad-works-together-towards-the-poc-platform/

6-7 March: SyDAD holds its final meeting in Bordeaux

This year, the Synaptic Dysfunction in Alzheimer Disease (SyDAD) project is coming to a close. It is a European training network funded by Marie Sklodowska Curie Actions under the EU-H2020 programme that supports 15 Early Stage Researchers (ESRs) and performs a collaborative research program to reveal the mechanisms behind synaptic dysfunction in Alzheimer’s disease (AD).

On 6 and 7 March, the SyDAD consortium met for a successful final meeting in Bordeaux (France). The meeting hosted by Professor Christophe Mulle and his team was attended by more than 40 participants including ESRs, their supervisors and partner organisations. SyDAD ESRs who are approaching the end of their PhD studies presented their respective work, progress and main achievements. They gave impressive presentations leading to fruitful discussions and scientific questions. In addition, attendees had very interesting reflections on the project’s training programme, out-reach activities, economy, innovation opportunities, research methods and upcoming deliverables. Professor Bengt Winblad (Coordinator) and Susanne Frykman (Project Manager) closed the final meeting by thanking all members for their hard work and scientific collaborations.

The ESRs are distributed in six organisations including Karolinska Institutet (Stockholm, Sweden), University of Bordeaux (Bordeaux, France), University of Milano (Milano, Italy), Deutsches Zentrum für Neurogenerative Erkrankungen (Bonn, Germany), Janssen Pharmaceutica NV (Beerse, Belgium) and Axon Neuroscience (Bratislava, Slovakia). Alzheimer Europe (AE) is a partner organisation in this project. Cindy Birck, AE Project Officer attended the meeting. To learn more: www.sydad.eu

7 March: EPAD passes the mark of 1,500 research participants for its Longitudinal Cohort Study

On 7 March, EPAD has reached a new milestone when the EPAD Longitudinal Cohort Study (LCS) screened its 1,500th research participant in Bristol (UK).

The largest ever public-private partnership in Alzheimer’s disease research, EPAD combines knowledge and expertise from 39 organisations across multiple sectors from academia and industry, bringing together a wealth of experience to its activities. By setting up a trial-ready cohort of research participants, creating a pan-European network of trial sites, developing a platform on which new compounds can be tested in a streamlined and efficient way, EPAD aims to accelerate the development of effective therapies.

Currently, EPAD has 21 study sites up and running across Europe and is adding new participants to the cohort every week. The consortium is now preparing the negotiations with the first intervention owner.

20 March: MinD project writes “Across land and sea, no barriers”

Julie and Binta have travelled from UK to partner INTRAS in Spain to peer review The Good Life Kit with participants of the public and patient involvement group who eagerly share memories during This Is Me and nod delightedly at one another’s recollections.

We demonstrate that with support, and within non-judgmental spaces, anyone can join in game-play. For Clara, this means remembering when and how to throw the dice. Her partner, relieved that mistakes are not stigmatised, sits back and relaxes and stops trying to protect her by limiting her involvement. Clara looks forward to her turn to roll the dice; she is part of the team!

Ana also needs support, throwing counters and cards, until with gentle help, she rolls the dice. When her memory cue is
read, Ana travels back to happy childhood; face creased in smiles, she mimes beautiful bead necklaces young Ana makes to wear around her neck. Now alert and engaged, Ana chats for the first time with other players.

For Ana and Clara; connection, stimulation, engagement, interaction, joy; for their care-givers, relaxation: everyone happily involved in game-play!

This is Me, appears very suitable for people with early stages of memory loss. Participants overall like the idea of playing again, playing with grandchildren, looking backwards and forwards on life and creating new games and reminiscence possibilities from the materials. It could perhaps have a wider use, too, in helping people with less capacity engage and socialise.

The mutual trust generated within our second game, You and Me, frees players up to express pain and longing, to cry, to share, to be understood, heard and held within the heart of the group. Both games have acted as catalyst to unlock experiences otherwise lost, denied or deeply withheld. Game-play is effective in allowing mindful exploration of questions needing to be asked and answered, pasts wishing to be appreciated and futures waiting to be lived.

21 March: Alzheimer Europe collaborates in a new coordination and support action of the Innovative Medicines Initiative

On 21 March (Madrid, Spain), the new Innovative Medicines Initiative (IMI) coordination and support action entitled “Efficiently Networking European Neurodegeneration Research” (NEURONET) held its kick-off meeting.

The main aim of NEURONET is to set up an efficient platform to boost synergy and collaboration across the IMI projects of the Neurodegenerative Disorders (ND) portfolio, assisting in identifying gaps, multiplying its impact, enhancing its visibility and facilitating dovetailing with related initiatives in Europe and worldwide.

The kick-off meeting was attended by 17 consortium partners, including IMI Project Officer, Elisabetta Vaudano who joined remotely. It started with an opening session by Project Coordinator, Carlos Diaz (SYNAPSE Research Management Partners) and Project Leader, Darrel Pamberton (Janssen Pharmaceutical NV) who provided an introduction to the NEURONET concept and vision.

After that, each partner introduced their institution and provided the attendees with an overview of their links to the past, current and future projects of the IMI ND portfolio.

Following the tour-de-table, the leaders of the different work streams introduced the scope of their work package, gave details on tasks that will be conducted throughout the three years of initial project funding and provided insights on how the different work streams depend on each other.

In between, Elisabetta Vaudano provided IMIs perspective on NEURONET. She started her presentation with an introduction to the scope IMI foresees NEURONET to cover and explained that there will already be an interim review of the project after the first year at which the activities of the coordination and support action will be evaluated. She then provided input on various areas where NEURONET should align with IMI activities.

The project is set up to focus on five key areas of work:

- WP1 Project and impact analysis (led by NICE/Takeda)
- WP2 Programme integration (led by Synapse/Sanofi)
- WP3 Tools and services (led by SYNAPSE/Parkinson’s UK)
- WP4 Dissemination & Outreach (led by Alzheimer Europe/Roche)
- WP5 CSA Management & Sustainability (Synapse/Eli Lilly)

Alzheimer Europe’s role in this project is two-fold. On one hand, it will be co-leading the communication and dissemination team along with Roche, where they will develop communication tools such as the website as part of the comprehensive communication strategy. On the other hand, it will lead on the development of guidelines and advice on protection of patient privacy, but also other tasks related to the development of tools and services in support of the transition towards a federated neurodegeneration research portfolio.

22 March: AD Detect-Prevent holds first steering committee meeting

Members of the steering committee and project partners met in Copenhagen on 22 March to discuss progress with the AD Detect-Prevent project. This project aims to develop for the clinical and mass market an easily accessible, user-friendly and motivating digital medical device, which can be used on tablets, smartphones and PCs/Mac for the presymptomatic detection of AD. In addition, personalised AD prevention programmes will be developed in the form of computerised cognitive training and behavioural/lifestyle interventions in one seamless product.

The meeting provided an opportunity to align the different work streams, discuss overriding issues related to terminology, motivation, potential target groups and possible areas to focus on for the prevention programmes.

Dianne Gove, Director for Projects, attended the meeting.
The month of March has been very busy for PARADIGM. On 7 and 8 of March, members of WP1 and WP2 met in Oxford for a two-day workshop. Over the first year of PARADIGM, WP1 has been looking at the needs, preferences and expectations of the different stakeholders involved in patient engagement (PE) in the process of developing medicines. The workshop in Oxford focused on how to incorporate the findings of the work carried out by WP1 (online survey, consultations and Delphi study) into the gap analysis which WP2 is conducting. Later on, at the end of the month (27-28 March) a second set of PARADIGM workshops were organised in Berlin. During the first day, delegates discussed about the impact of PE, and how such impact, could be monitored and assessed (work led by WP3). Delegates had the opportunity to learn about the framework that members of WP3 have developed for assessing the impact of patient engagement in the context of PARADIGM. One of the examples to test out the framework was a case presented by Alzheimer Europe linked to work of the EWGPWD. Chris Roberts, vice chair of the EWGPWD and his wife, Jayne Goodrick were present in the workshop and provided very relevant input about their personal experience of being involved in PE in this, and may other activities, at European and national level. On the second day, discussions were focused on WP4 which will be developing a toolbox with tools and templates for PE in medicines development. Ana Diaz, AE project officer, Chris Roberts, vice chair of the EWGPWD and Jayne Goodrick, supporter, participated in the various workshops.

**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:
- **AD Detect-Prevent** - grant agreement 820636
- **EPAD** - grant agreement 115736
- **NEURONET** - grant agreement 821513
- **PARADIGM** - grant agreement 777450
- **RADAR-AD** - grant agreement 806999

**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);

**Cyprus:** Costas Mavrides (S&D); Eleni Theocarou (EPP).

**Czech Republic:** Olga Sehnalová (S&D); Pavel Svboda (EPP);

**Danmark:** Ole Christensen (ALDE); Jens Rohde (ALDE); Christel Schaldemose (S&D).

**Estonia:** Urmas Paet (ALDE); Finland: Lisa Jaakonsaari (S&D); Anneli Jätteenmäki (ALDE);

**France:** Dominique Bilde (ENP);

**Greece:** Dimitrios Papadimoulis (GUE/NGL);

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

**Gibraltar:**

**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); Séan Kelly (EPP); Mairead McGuinness (EPP); Liadh Ní Riada (GUE/NGL).

**Italy:** Brando Benifei (S&D); Nicola Caputo (S&D); Elena Gentile (S&D); Stefano Mauli (EPP); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Serapiotto (EPP); Patrizia Toia (S&D);

**Lithuania:** Vilija Blinkyte-Sakalauskaitė (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); Angelica Niebler (EPP).

**Norway:** Øivind Aadland (EPP); Dagfinn Skjeie (EPP)

**Portugal:** Commendador Costa (S&D); Alice Correia de Sá (NI); Christiane Filipe (EPP); Maria do Carmo Rodrigues (S&D); Rui Abreu (S&D); Paulo Teles (EPP); Catarina Emílio (EPP); Teresa Gomes e da Silva (EPP); Sara Paiva (EPP).

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

**Slovakia:** Miroslav Mikolášik (EPP); Ivan Stefanec (EPP); Anna Záborská (EPP);

**Spain:** Iñigo Errejón (EPP); Ana Mª de la Fuente (S&D); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP).

**Sweden:** Silvia Engström (S&D); Roberto de Masi (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE); United Kingdom: Martin Anderson (GUE/NGL); Richard Ashworth (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claudia Moraes (S&D); Rory Palmer (S&D).

**United Kingdom:**

**Ukraine:** Yuriy Hontaruk (EPP); Olena Zelenska (EPP).

**Victoria:** Heike Christensen (S&D); Marek Krajčí (ALDE); Miroslav Mitrofan (NI)
EUROPEAN ALZHEIMER’S ALLIANCE

29 March: European Parliament election candidates pledge to make dementia a priority and to join the European Alzheimer’s Alliance

Earlier this month, Alzheimer Europe and its members launched the #DementiaPledge2019 campaign, calling upon candidates in the 2019 European Parliament (EP) elections to commit to making dementia a priority. The campaign has already made good progress in its early stages, with 21 candidates supporting the Pledge so far. 18 of these are existing Members of the European Parliament (MEPs) standing for re-election, 1 of whom was not yet a member of the European Alzheimer’s Alliance (EAA), MEP Nicola Caputo (pictured, shaking hands with Policy Officer Owen Miller, left). Alzheimer Europe is delighted to welcome Mr Caputo to the EAA, bringing the total number of members up to 127 for the current 2014-2019 term. The other 3 signatories, if elected, would join the EAA for the 2019-2024 EP term. Alzheimer Europe would like to thank the following candidates for their support:

Belgium
Sara Matthieu (Groen, Greens/EFA)
Bart Staes MEP (Groen, Greens/EFA)
Hilde Vautmans MEP (Open Vlaamse Liberalen en Democraten, ALDE)

Finland
Merja Kyllönen MEP, (Vasemmistoliitto, GUE/NGL)
Sirpa Pietikäinen MEP (Kansallinen Kokoomus, ALDE)

Ireland
Deirdre Clune MEP (Fine Gael, EPP)
Seán Kelly MEP (Fine Gael, EPP)

Italy
Nicola Caputo MEP (Partito Democratico, S&D)
Remo Sernagiotti (Conservatori e Riformisti, ECR)

Netherlands
Annie Schreijer-Pierik (Christen-Democratisch Appèl, EPP)

Portugal
Nuno Morna (Iniciativa Liberal, ALDE)

Romania
Cristian-Silviu Bușoi (Partidul Național Liberal, EPP)
Marian-Jean Marinescu MEP (Democratic Liberal Party, EPP)

Slovakia
Ivan Štefanič MEP (Kresťanskodemokratické hnutie, EPP)

Slovenia
Tanja Fajon MEP (Socialni demokrati, S&D)
Lojze Peterle, (Nova Slovenija – Krščanski demokrati, EPP)
Igor Šoltes MEP (Verjamem, GUE/NGL)
Romana Tomc MEP (Slovenska demokratska stranka, EPP)
Violeta Tomic (LEVICA, GUE/NGL)

Spain
Rosa Estarás Ferragut MEP (Partido Popular, EPP)
Ana Miranda Paz MEP (BNG, EFA).

Candidates can pledge their support on social media (Twitter and Facebook), simply stating that they support the #DementiaPledge2019. Candidates can also download the Pledge as a document to sign and return to AE or the relevant national member association. Finally, candidates can also send their support in an email message to info@alzheimer-europe.org

The Pledge is currently available in six languages: English, French, German, Italian, Luxembourgish and Polish. You can find more information about the #DementiaPledge2019 campaign, as well as downloading the different language versions, here: https://bit.ly/2YbkskH

We are very grateful to our national member associations for their support in translating the Pledge and gathering support from candidates in their countries.

EU DEVELOPMENTS

13 March: European Parliament passes European Accessibility Act

A plenary session of the European Parliament has passed the European Accessibility Act, which aims to ensure that products and services are more accessible for persons with disabilities.

The Act aims to improve the accessibility of products and services for persons with disabilities, including computers, smartphones, tablets, TV sets, banking ATM and services, payment terminals, e-books and e-readers, e-commerce websites and mobile apps and ticketing machines. It also fulfilled two important demands from the disability movement: electronic telecommunications and the 112-emergency number will become accessible to everyone throughout the EU.

The legislation also allows national market surveillance bodies to be given the competence to hold private entities accountable. The requirements of the Act will also support public procurement rules for accessible products and services, so public authorities do not anymore use tax payers’ money in products, services and facilities that are discriminatory of persons with disabilities.
However, the Act does not include the accessibility of buildings or transport, nor does it cover household appliances. As such, a number of products and services may continue to be inaccessible to people with disabilities. Furthermore, microenterprises providing services are exempt from the requirements of the Act. Before coming into effect, the legislation must be formally approved by the Council of the EU, before being published in the EU’s Official Journal. As the legislation is a European Directive, Member States will then have three years to transpose it into national law.

15 March: Usman Khan named as new Executive Director of European Patients’ Forum

On 15 March, the European Patients’ Forum (EPF) named Usman Khan as its new Executive Director. Dr Khan comes to EPF from the European Health Management Association and will take up his new duties on 1 May 2019. He has an established record in European health policy and practice and brings with him significant knowledge of and commitment to patient engagement at all levels.

Nicola Bedlington has stepped down as Secretary General after 13 years and will continue to support EPF in a part-time advisory function. Ms Bedlington said: “I am very pleased to pass on the baton to Usman, to lead the team and support the board in taking EPF into the third decade of the 21st Century and an inspiring new era of change. I know he will do a terrific job.”

Dr Khan commented: “I am really looking forward to taking on the role of Executive Director of the European Patients’ Forum. Nicola leaves a strong legacy and a vibrant organisation, and I am excited by the opportunity to lead EPF in its mission to ensure patient access, patient experience and patient involvement are core to health and social care provision across Europe.”


21 March: Provisional agreement reached on Horizon Europe research programme

The EU institutions have reached a partial political agreement, subject to formal approval by the European Parliament and Council, on the Horizon Europe research programme (2021-2027).

Horizon Europe will build on the current research and programme (Horizon 2020), continuing with the European Research Council (ERC) and the Marie Skłodowska-Curie fellowships and exchanges, as well as the Joint Research Centre (JRC), the Commission’s science and knowledge service. The programme will contain five mission areas and eight partnership areas. The specific missions and the various public-private and intergovernmental partnerships will be finalised by the commission in its strategic planning stage, before being submitted to the council for approval.

The mission areas will be:

- Adapting to climate change, including societal transformation
- Cancer
- Healthy oceans, seas, coastal and inland waters
- Climate-neutral and smart cities
- Soil health and food

The eight partnership areas will be:

- Faster development and safer use of health innovations for European patients, and global health.
- Advancing key digital and enabling technologies and their use, including but not limited to novel technologies such as artificial intelligence, photonics and quantum technologies.
- European leadership in metrology, including an integrated metrology system.
- Accelerate competitiveness, safety and environmental performance of EU air traffic, aviation and rail.
- Sustainable, inclusive and circular bio-based solutions.
- Hydrogen and sustainable energy storage technologies with lower environmental footprint and less energy-intensive production.
- Clean, connected, cooperative, autonomous and automated solutions for future mobility demands of people and goods.
- Innovative and R&D intensive small and medium-sized enterprises.

A new body, the European Innovation Council (EIC), has also been established which aims to provide breakthrough technological innovations from the laboratory to market application, as well and helping start-ups and SMEs scale up ideas.

Synergies with other future EU programmes and policies will be subject to further discussions, dependent on the progress made in relation to proposals within the EU’s long-term budget. Provisions on international association agreements will also be subject to further discussions.

The preliminary political agreement reached by the European Parliament, Council and Commission is now subject to formal approval by the European Parliament and Council. Horizon Europe’s budgetary aspects are subject to the overall agreement on the EU’s next long-term budget, the Multi-annual Financial Framework (MFF).
22 March: European Economic and Social Committee publishes report on disability and voting rights in Europe

The European Economic and Social Committee (EESC) has published an information report presenting current situation relating to the rights of persons with disabilities to vote in the forthcoming European Parliament elections.

The report is entitled "Real rights of persons with disabilities to vote in EP elections" and shows that despite legal protections around the voting rights of persons with disabilities in the EU, considerable numbers of people are unable to participate in elections. This includes reasons of technical or physical barriers which do not take into account the needs of individuals with disabilities.

In addition, it is estimated that around 800,000 EU citizens with mental health problems or intellectual disabilities will be deprived of their right to vote as a result of national rules in place in 16 Member States. This includes nine EU countries, where persons automatically lose their right to vote when their legal capacity is reduced or when they have a guardian appointed and a further seven whereby voting ability is individually assessed by either courts or medical boards.

The report also highlights further technical barriers including narrow definitions of accessibility, as well as inaccessible or difficult to understand information.

At the plenary session of the EESC, members voted to distribute the report to EU institutions, national governments as well as to NGOs representing persons with disabilities or focusing on human rights.


29 March: EU Commissioner’s Health responsibilities transferred to Commission Vice-President

As of 1 April 2019, the European Commission’s Vice-President for Jobs, Growth, Investment and Competitiveness, Jyrki Katainen, will take over the portfolios of health and food safety from current Health Commissioner Vytenis Andriukaitis.

Mr Andriukaitis is running for the presidency of Lithuania, and will be on unpaid electoral leave from 1 April until 13 May, with the possible extension until 27 May should he make it to the election “run-off” in the country.

MEMBERS’ NEWS

14 February: Alzheimer Austria tells us about its recent “Dementia and the Media” meeting

The first working group meeting on “Dementia and the Media” took place on Valentine’s Day 2019, in Vienna. It was organised by GÖG, Gesundheit Österreich GmbH, which also led on the creation of the Austrian dementia strategy “Living well with Dementia”.

During this meeting, one of the recommendations of the second objective of the strategy was realised: the development of a code of good-practice for media information.

It was agreed upon, at the beginning, that a guideline for dementia-sensitive coverage in the media should be developed. Core messages, structures, contents and any existing background were discussed.

The importance of this project was underlined by some examples from recent articles in newspapers and films that contained images and messages about loss, fading light or darkness, cold winter and only very old people in nursing homes, when covering the field of dementia. The picture of the head with the leaves falling from it was a further stigmatising example of the dementia depiction. The importance of focusing on resources and competences was recorded, as was the need to show the variety of persons with dementia, not only people living with the late stages of the disease.

Living well with dementia depends very much on the context in which people find themselves, and what is associated with them by those surrounding them. Therefore, the media plays an important role in dealing responsibly with the topic, by respecting the dignity of people with dementia. Language guidelines for interviewers and supporters should be included. It is necessary to show the person, not the disease.

Misleading headlines like “Healing Alzheimer’s next year” should be banned, as the contrary is written in small print at the end of the article. It raises unjustified hope in patients and carers. 12 categories were determined for the guide, and members of the working group were invited to contribute to them with examples of good practice, citations and links. A draft should be ready before summer this year and feedback gathered from a variety of stakeholders and discussed at the meeting.

14-17 February: Panhellenic Conference on AD and Mediterranean Conference on Neurodegenerative Diseases organised in Greece

The 11th Panhellenic Conference on Alzheimer’s Disease and Related Disorders (PICAD) and the 3rd Mediterranean Conference on Neurodegenerative Diseases (MeCoND) took
place from 14 to 17 February in Thessaloniki, Greece. These successful events were organised by Alzheimer Hellas, in cooperation with the Panhellenic Institute of Neurodegenerative Diseases.

The two conferences combined were able to host some of the most renowned scientists in the field, who presented and shared the results of the latest scientific research, pharmaceutical and non-pharmaceutical trials and the application of new technologies. The events also provided an opportunity for various health professionals to present their contribution to patients and caregivers.

The 700+ delegates included: clinicians (neurologists, psychiatrists and geriatricians); neuroscientists (molecular genetics, neuropathologists, neurobiologists, neuropsychologists and pharmacists); psychologists; social workers; physiotherapists; representatives from biomedical and pharmaceutical companies; patients; families; and caregivers.

During the conferences, some of the topics that were explored, in relation to dementia were: New Technologies; Newer Data; Legal and Social Issues; Research Programmes; Day Care Centres; Non-Pharmaceutical Interventions.

28 February: Alzheimer’s Disease International (ADI) tells us about its second webinar in global series “Let’s Talk About Dementia Research”

In February, ADI organised the second in a series of global webinars on participation in dementia research and clinical trials. The aim of the series is to demystify the process of clinical trials through an open dialogue between the public, health and social care professional, researchers and the pharmaceutical industry.

Over 200 people from 52 countries joined us to discuss “Global Barriers and Access to Trials, with over half of the participants joining from low- and middle-income countries (LMICs). The conversation built upon the themes of our first webinar and explored the types of advocacy needed to ensure that people living with dementia have the best possible chance of participating in clinical trials both in LMICs and high-income countries.

We were pleased to be joined by an international panel including Professor Miia Kivipelto, who shared insights from the multi-domain intervention The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER). Elizabeth Mutunga, CEO and Founder of the Alzheimer and Dementia Organisation in Kenya, and Rochelle Armour, Research Fellow at the Caribbean Institute for Health Research and Recovery in Jamaica and Assistant Director for Alzheimer Jamaica both joined via video link, as did Behavioural Neurologist, Silvia Rios Romenets, who is currently running the Alzheimer’s Prevention Initiative (API) Autosomal Dominant Alzheimer’s Disease (ADAD) trial in Colombia. Dr Jill Rasmussen, Primary Care Specialist in psychiatry, neurology and learning disability and Independent Consultant in CNS research provided a UK primary care and regulatory perspective. The webinar was co-moderated by Professor Craig Ritchie from the University of Edinburgh and ADI’s CEO Paola Barbarino.

During the discussion, we asked participants which types of research they would like to see prioritised. While the answers were relatively split, it was interesting that over half of respondents (53%) supported multi-domain intervention approaches, closely followed by new therapies and innovation (33%). Other discussion points included how to fund research in LMICs and ensure that it takes place.

Our next webinar will take place on 10 May 2019. Sign up to the ADI mailing list for more information. Recordings of both webinars in the series are available here.

Pictured: Webinar panellists: (L-R) Dr Jill Rasmussen, Professor Craig Ritchie, Professor Miia Kivipelto, ADI CEO Paola Barbarino. Also pictured on laptop screen: Rochelle Amour, Silvia Rios Romenets and Elizabeth Kasimu Mutunga

1-2 March: Thousands unite against dementia at Ready Steady GLOW

Following the popularity of Alzheimer’s Society’s annual Memory Walk events, the charity took a step in a new direction by launching three brand-new walks earlier this month.

Ready Steady GLOW encouraged supporters to shine a light on dementia at the exciting new night time walks in London, Manchester and Bristol. A tide of ‘glow-getters’ across the country took to the streets, raising a remarkable GBP 350,000 (EUR 411,100 approx.) in the process. Many chose to honour the name of the event and dress up in combination of glow-in-the-dark outfits, colourful costumes and accessories.

Transforming Memory Walk into a nocturnal event enabled thousands of people to unite against dementia after dark, taking a moment to reflect on who they were walking for and share the evening with others who are going through or have been through similar experiences to them.
A feature of each walk was a twinkly Memory Tree adorned with messages of love, hope and support; providing an opportunity to remember and celebrate loved ones who are living with dementia or have passed away.

The premise behind Ready Steady GLOW and Memory Walk remains simple – providing a chance for walkers and volunteers alike to come together, share their experiences while taking part in an organised fundraising event.

To find out more about Ready Steady GLOW and other Memory Walk events organised by Alzheimer’s Society please visit: memorywalk.org.uk

7 March: Nicosia branch of Cyprus Alzheimer Association attends International Women’s Day event

The Nicosia District Committee of the Cyprus Alzheimer Association was invited to honour International Woman’s Day celebrations, organised by the Mayor of the Geri Municipality, in a very special way. The event focused on the theme “Is Alzheimer’s disease a Women’s issue?” based on the fact that there is a higher incidence of Alzheimer’s disease among women than men, the ratio being 3:2.

The event was hosted at the Geri Municipality building on the evening of 7 March 2019 and was open to the public. Held under the auspices of the Mayor’s wife Kyproulla Papalazarou, it was attended by a large audience in the presence of three Mayors, namely those of the Geri, Latsia and Tseri Municipalities, and was a big success. Mrs Papalazarou also invited the Geri Municipality Choir to sing during the event; the choir chose melodies from the past which further emphasised the importance of memories.

The keynote speaker was Professor Savvas Papacostas, Neurologist at the Cyprus Institute of Neurology and Genetics in Nicosia and the founding consultant of the Nicosia District Committee of the Cyprus Alzheimer Association. Prof. Papacostas gave an interesting and informative presentation, explaining what Alzheimer’s disease and dementia is about and how it can be medically addressed and prevented.

The President of the Cyprus Alzheimer Association, Antigoni Diakou also addressed the public and presented the activities of the Association and how its volunteers can help those in need. The public was reminded that the relevant medication is provided for free by state hospitals thanks to the Association’s persistent efforts. Ms Diakou asked the public to fight the stigma that exists around Alzheimer’s disease and dementia. Ms Diakou also invited the three Mayors present to consider creating Dementia Friendly Communities in their respective municipalities; an invitation that the Mayors welcomed!

8 March: On International Women’s Day, the Alzheimer’s Society (UK) highlights the need for a better balance in dementia research

International Women’s Day was on 8 March, and to mark the occasion we reflected on the need for a better balance in dementia research.

The number of women in science, technology, engineering and mathematics (STEM) occupations is beginning to increase. Analysis of the UK labour force survey for 2018 by WISE records around 900,000 women in STEM occupations, but this still only makes up only 22% of the total STEM workforce and only around 13% of management roles are held by women. We know that the majority of women with STEM qualifications do not work in STEM careers, unlike their male counterparts. This means that the field is haemorrhaging talent.

Alzheimer’s Society is working hard to attract excellent researchers to dementia research and to keep them there. We have done this through taking part in establishing the UK Dementia Research Institute, as well as building supportive relationships with and rewarding our excellent researchers through our Dementia Research Leaders Programme. Crucially we have most recently become one of the few charitable funders who provide maternity/paternity/adoption and sick pay and leave for our PhD students as well as providing guidance and support for more senior researchers. Our researchers have told us that lack of work life balance and support from research institutes is a major factor contributing to women leaving research.

At Alzheimer’s Society we believe that research funding organisations have a key role to play in keeping excellent female researchers in the field. We are continuously evaluating our research funding schemes to remove any gender based bias and support women in research. Of our 154 active research projects 85 are led by women, representing 55% of the current portfolio. More can always be done as research has shown that studies with at least one female contributor are more likely to tackle women’s health issues and difference between the sexes and we know that dementia is an issue that disproportionately affects women.

11-17 March: Alzheimer Croatia marks Brain Awareness Week 2019

To mark Brain Awareness Week (BAW) 2019, Alzheimer Croatia conducted public lectures on brain health and dementia and offered free testing of cognitive abilities. BAW is a global campaign to increase public awareness of the progress and benefits of brain research and this year’s edition took place from 11-17 March.
The main theme of the lecture was approaching people with dementia in a way which enables communication to be established at moments when their attention is absent. Specifically, following problems experienced by family caregivers in communication with people with dementia, Alzheimer Croatia has realised that communication techniques are not their only obstacle. Moreover, misguided approaches to approaching communication with people with dementia can even cause a person with dementia to refuse to communicate or to become agitated. That is why understanding the non-verbal and para-verbal expressions can make a big difference.

A new opportunity to test the cognitive abilities of senior citizens in the capital of Croatia, Zagreb confirmed previous results. Half of those tested expressed some form of cognitive impairment. People for whom these impairments are significant are then referred to their general practitioner (GP) for further treatment.

These activities were realised as part of the programme “City of Zagreb is becoming a Dementia Friendly Community”.

**13 March: France Alzheimer’s post-diagnosis support programme for people with dementia gets good feedback**

In early spring 2018, France Alzheimer launched a programme dedicated specifically to people with dementia. With this programme, the French organisation hopes to provide new answers to those recently diagnosed.

One of the main objectives of this programme is to improve the quality of life for people with dementia and their caregivers and especially to enable the newly-diagnosed person to be proactive in dealing with what they are going through, by helping them to process the situation. During these sessions, the people with dementia are invited to mobilise their own resources to enable them to adapt their daily lives to the new situation.

Furthermore, the pilot of the programme suggests they share their experiences and needs within the group, in order to find appropriate answers, strategies and compromises to maintain relationships with family, friends and other social relationships.

France Alzheimer has identified three main admission criteria for the programme, for future beneficiaries. First of all, the diagnosis must already have been made and announced. Then, essentially, the person concerned must be interested in the programme, wish to participate and express a will to share their experiences within a group.

This programme, in which the caregiver may not participate, is threefold:

- A personalised group information session to identify the needs and define priorities for people with dementia.
- Several group workshops lasting two hours each:
  - Workshop 1: Share my experience and knowledge of the disease
  - Workshop 2: Emphasize my skills and share my solutions
  - Workshop 3: Identify my available tools to help in my daily life
  - Workshop 4: My family and social environment, and me
  - Workshop 5: Managing my stress
  - Workshop 6: What are my wishes?
  - A final individual overview led by the workshop moderator, who will be able to assess the impact of the programme on the quality of life of the person concerned and those around them.

The evaluations carried out after the first programmes have shown a high level of satisfaction among the beneficiaries. They mention in particular:

- Less frequent feelings of isolation and a higher level of self-esteem
- Benefits from supporting each other and sharing strategies
- A resumption of activities and a feeling of success.

**13 March: For 30 years, France Alzheimer has been organising vacation retreats for families affected by dementia**

In order to help families affected by dementia, France Alzheimer organises adapted vacation retreats for the past 30 years.

Organising holidays can be so taxing for people with dementia and their families that it sometimes seems easier not to go. And yet, the very people who are struggling are those most in need of a vacation! Time off is an essential respite in combatting the illness and can help give families affected by dementia the energy to face the daily challenges it poses. And those who are living with dementia want and have the same chance to holiday as anybody else. Hiking and sunbathing on the beach are examples of the little things, which are highly appreciated by families who face this illness.

To make it possible, they need the appropriate assistance. This is why vacation retreats have been one of France Alzheimer’s priorities for the past 30 years.

Every year, between April and October, about 15 trips are organised by the association, in centres adapted for people with dementia and their caregivers. The retreats last for 10 or 11 days and accommodation, full board, activities and excursions are all covered.

Thanks to France Alzheimer’s volunteers, guests can all relax while receiving the care they need. Stigmatising the families is...
out of the question; on the contrary, since the objective of these retreats is to focus on other things than dementia. In order to reduce vacation access inequalities and to grant this opportunity to as many people as possible, France Alzheimer offers five pricing plans. They are proportional to the participants’ yearly income tax. In other words, the cost is adapted to the income of those who wish to benefit from the retreat. The difference between the actual cost and the paid amount is covered by the Association. 6,000 people have benefited from vacation retreats over the past 30 years.

15 March: Alzheimer Society of Ireland writes “Irish online Erasmus+ dementia training garners European Commission praise”

The Alzheimer Society of Ireland’s Home-Based Care-Home-Based Education online course for family carers looking after a loved one with dementia recently received high praise from the European Commission.

This online course was one of the products of our Erasmus+ project which was coordinated by The ASI with partner organisations Ic Dien a further education college in Belgium and Flexible Education Norway. The course has proven to be a great success, and features the same content as our existing face-to-face course Insights into Dementia. But is held exclusively online and can be completed from the comfort of your own home.

The European Commission wrote to The ASI’s Learning and Development team last week to praise the project and to explain that it has been selected as a “success story” by a panel of experts from the Directorate-General for Education, Youth, Sport and Culture of the European Commission. It is understood that praise of this nature is extremely rare.

“Success stories” are finalised projects that have distinguished themselves by their impact, contribution to policy-making, innovative results and/or creative approach and can be a source of inspiration for others. The selection of this course as a success story was made on the basis of rigorous criteria regarding its quality, relevance and results.

Fergus Timmons ASI External Learning and Development Manager said: “We are absolutely delighted to receive this recognition from the Commission. It really validates the approach we have taken to delivering person centred online education courses for family carers. And of course, thanks to Erasmus+ for the funding which we used to develop the programme.”

The course also won a National Training Award for Excellence in Digital Learning at the Irish Institute of Training and Development (IITD) Gala in 2018.

For more information, go to www.alzheimer.ie


16 March: Pancyprian Alzheimer Association introduces new children’s book “My grandpa and Mr Alzheimer”

On behalf of the Pancyprian Alzheimer Association, Dr Sideris Bakouras, Neurologist – Psychiatrist, has written the following summary of a new children’s book called “My Grandpa and Mr. Alzheimer: a fairy tale for the young and the old”.

The strange, incomprehensible and multi-symptomatic clinical picture of Alzheimer’s disease poses problems of a professional, economic, social and family nature. The present book deals with the tangible and intangible nature of these problems in the most creative way. The understanding of the strange nature of Alzheimer’s disease, especially in families with patients, is a prerequisite for patient support and assistance and for a balanced living for the carers as well as for the patients.

The author succeeds with clarity, simplicity, comprehensiveness and a flowing narration to describe the symptoms of Alzheimer’s disease. She succeeds in a very inventive way, through a fairytale and through a grandson’s dream, to describe and interpret all the symptoms and strange behaviour of a beloved grandfather who is also an Alzheimer patient.

In the first part of the story, besides the description of the disease and how its various manifestations affect the family life, the author gives a general but accurate explanation of the malfunction of their normal activity.

The second part offers brief and clear explanations and interpretations of the related scientific terms for the understanding of the symptoms of the disease. In the last part of the book, we see creative exercises and quizzes to help the young readers understand the meaning of the story. It is also worth mentioning that every scene of the book is illustrated expressively and clearly by Mrs Theodosia Kotsika, so the reader dives into a trip in the centre of the human brain and visually explores the Alzheimer disease.

Because of all the above, this book is recommended to all readers, particularly to those who have to deal with situations similar to the ones described in the story, as well as to carers of Alzheimer patients and health professionals.

The book is also available to buy online.
18 March: Malta Dementia Society tells us about two important new initiatives

The beginning of this year saw two important initiatives being launched in Malta:

Firstly, on 18 February, the Maltese Parliament met to discuss current and future dementia policy. Members of Parliament, from both sides of the house, met with professionals working in the various fields of dementia research, management and care to debate on how Maltese policy makers can enhance their contribution towards the dementia cause. The parliamentary session was opened by the speaker who, in his speech, made special reference to the need to make dementia a national priority. Other contributions came from Members of Parliament who, prior to being elected to parliament, practiced the medical profession. They stressed the difficulties that relatives face in taking care of a community-dwelling individual with dementia and the need to continue developing services to meet the ever-increasing demand. Other topics discussed included dementia as a disability, technology, community and long-term care.

The second initiative is a 10-week training programme for informal caregivers and relatives of people with dementia living in the community. The programme is composed of a two-hour session per week for ten weeks and focuses on topics related to promoting independence, dementia-friendly environment, assisted activities of daily living and taking care of yourself if you are a caregiver. The sessions will also give the opportunity for caregivers to share their experiences of care.

20 March: Hungary launches new project, based on findings from earlier INDA project

Our friends at Hungary’s Social Cluster Association have sent us the following report about the recent conference of the INDA project:

In Hungary, the population has hardly any knowledge about dementia. Having been diagnosed, the patient with the family is overwhelmed with information and has little understanding about whom to ask for help. The knowledge of the experts and professionals has to be upgraded as they need to become competent in new methods in order to support in a complex way the family and the patient as well.

The Interprofessional Dementia Approach (INDA) project, run between 2015 and 2017, was a complex, innovative programme developed and implemented by the Social Cluster Association and Catholic Charity Service in Hungary. The project was intended to reveal the needs for services in dementia care, to develop a multifaceted care programme and to raise awareness about people living with dementia, as well as the opportunities of early diagnosis. The experiences from the INDA project form the foundation for a new project with the title “Adaptation of Interprofessional Services related to Dementia: Knowledge Expansion and Awareness-Raising through Local Communities”.

The opening conference (pictured) of the new project took place on 20 March 2019 in Győr, Hungary. The project consortium consists of three partners: the Catholic Charity Service, the Unified Health and Social Institution of Győr, and ‘Fazeekas Gábor’ Residential Home for the Elderly in Hajdúbőszörmény.

The main focus of the activities within the project is to increase the awareness of the population around dementia, through well-structured communication activities, and to realise professional adaptation to enable high-level caregiving for older people living with dementia.

The programme is aimed at discovering the problems of non-professional family members of a person living with dementia in different types of towns and villages, and at elaborating methods that will be of service to them later on. Taking into account the differences among settlements is a key element of the project, because the societies of a small community and a larger city have, no doubt, significant differences. Diverse settlements are well represented by the consortium partners, to allow for well-founded formulation of recommendations.

Dr Ágnes Egervári, director general of the Catholic Charity Service, added that the new project aims not only at ensuring information and support for families, but also at preparing an interprofessional dementia programme. An education, research and information campaign is necessary to raise public awareness, to dissolve taboos and to stop exclusion of people with dementia, as well as to gain wide political backing before the end of the project.

21 March: Ireland’s “Dementia: Understand Together” campaign goes from strength to strength as politicians get involved

Over 60 Members of Parliament (TDs), Senators and representatives attended a recent dementia awareness session in the Irish Parliament (Dáil Éireann) that focused on taking action to make their constituencies dementia inclusive as part of the Dementia: Understand Together campaign.

Since the launch of Ireland’s Dementia: Understand Together campaign at the end of 2016, 2.3 million people in Ireland (63% of the population) have seen the TV ads. The campaign, which also includes radio ads and a social media presence,
aims to increase awareness and understanding of dementia. The campaign is run by the Health Services Executive (HSE) and the Alzheimer Society of Ireland is a proud partner on the campaign.

Early market research on the campaign’s impact shows a positive increase in adults’ understanding of dementia (one third of those surveyed). In addition, a majority said they had now taken some action, from making a mental note to be empathetic and to get in touch, to calling in to see someone with dementia.

The Dementia: Understand Together campaign is now shining a bright light on its other goal: to inspire individuals and communities to take steps to embrace and include people affected by dementia in Ireland.

The Irish parliament’s cross-party group on dementia (The All Party Oireachtas Group on Dementia), for whom the Alzheimer Society of Ireland acts as secretariat, is playing its part and hosted an awareness session for politicians that focused on taking community action.

The March session focused specifically on the Dementia: Understand Together Community Activation Programme by showcasing the campaign and asking politicians to take actions in their constituency to make them more dementia inclusive. Over 60 Members of Parliament (TDs), Senators and representatives attended, which was the highest turnout achieved for one of these sessions.

Speakers included Fiona Foley, Dementia: Understand Together in Communities National Coordinator; Linda Jordan a Community Champion in Co Cork; and Kevin Quaid, a member of the Southern Dementia Working Group and who lives with Lewy Body Dementia. At the session Mr Quaid said: “It is not an option not to talk about dementia, ask how you can help and take actions”.

With 200 community champions registered and 40 business partners, actions taken to date include: local awareness talks and coffee mornings; talking to businesses and politicians; starting support groups; developing inclusive choirs; working with schools and sports clubs and creating networks of champions in local community.

Pictured: Some members of the All Party Oireachtas Group on Dementia with speakers, at the Dementia Awareness Session held in March, in Dáil Éireann.

21 March: English NHS book on dementia care in hospital settings is translated into Croatian

Following the recommendation of the Croatian Alzheimer Alliance, a Croatian edition of a 2016 book by Imperial College Healthcare NHS Trust has been published. The original text, “Caring for People with Dementia in Hospital - A Best Practice Guide” was written by Jo James, Beth Cotton, Jules Knight and Rita Freyne. The Croatian translation was done by Mario Gros, MD, PhD. The editor of the Croatian edition, entitled “Najbolja skrb za osobe s demencijom u bolničkim uvjetima – praktični vodič” (ISBN 978-953-176-875-7), is Professor Ninoslav Mimica, MD, PhD, of Alzheimer Croatia. He also wrote the Foreword. The hardcover book, illustrated in colour, is 108 pages long and was published by Medicinska naklada Zagreb, University Psychiatric Hospital Vrapče and the Croatian Society for Alzheimer's Disease and Old Age Psychiatry.

The original text was written by a Dementia Expert Team of highly educated and specialised nurses, practitioners working in the hospital and developing ways to recognise, understand and help people with dementia during their treatment in general hospitals, which occurs most often for some medical reason other than dementia. The practical guide includes 15 chapters, from the introduction, describing what dementia is, to advice on how to improve communication or deal with the changed behaviour of people with dementia. There are chapters on mental capacity, deprivation of rights, advanced care and end of life care. Other topic areas include delirium, estimates of pain, mobility, nutrition and hydration, as well as hand massage, and there is a particular emphasis on the ethics of care. Special attention is also paid to informal caregivers i.e. families living with dementia. At the end of the book, additional literature is provided for each of the above-mentioned topics.

This book is a guide for all those who are in dealing with people with dementia in a hospital setting. It is useful both for people working in the healthcare profession, as well as others. It aims to give the reader a better understanding of people living with dementia and their needs, fears, struggles, wishes and preferences. In the absence of a cure, non-pharmacological approaches to dementia management are particularly important. This book, which is a guide to best practices and practical approaches through comprehensive care for people with dementia, helps provide this, as well as demonstrating the effectiveness of the techniques and practices covered.

22 March: ADI reports on STRiDE meeting in South Africa this month

In March, ADI’s Research and Policy Project Lead Wendy Weidner and Honorary Vice President Dr Nori Graham travelled to South Africa for the annual STRiDE (Strengthening responses to dementia in developing countries) stakeholder meeting and training workshop in Cape Town.

STRiDE is a research project funded by the Research Council UK (RCUK) and led by the Personal Social Services Research Unit (PSSRU) at London School of Economics (LSE), in
partnership with ADI, Dementia Alliance International (DAI) and the Universities of Sussex and Cape Town. The project aims to help improve dementia care, treatment and support in seven lower-middle income countries (Brazil, Jamaica, India, Indonesia, Kenya, Mexico and South Africa) by strengthening capacity to generate and use research to support policies - especially the development of national dementia plans - to improve dementia care for people with dementia and their families. The meeting was a great success and provided an important opportunity for cross-learning and knowledge exchange.

Researchers and Alzheimer associations provided country updates and progress on project work packages. Wendy Weidner gave an update on Work Package 8, speaking on the importance of collaborative work between Alzheimer associations and researchers in each of the country STRIDE teams. Their joint-working will pave the way for using STRIDE’s research findings to recommend policy for developing national dementia plans tailored to the unique culture and demographics of each country.

Attendees came from over 20 countries and included people living with dementia and their care partners, researchers, representatives from the WHO South Africa, South Africa Human Rights Commission, Ministries of Social Development and Health, the South African Older Persons Network, and civil society. Find out more about STRIDE here.

Pictured: STRIDE meeting: (L-R) Elizabeth Kasimu Mutunga (Kenya), Tara Puspitarini Sani (Indonesia), Petra Du Toit (South Africa), Elaine Mateus (Brazil), Narendhar Ramasamy (India), Rosa Farres (Mexico), Rochelle Amour (Jamaica), Anji Mehta (London School of Economics).

22 March: NGO Living with Dementia updates us on some recent positive developments in Estonia

Dementia Helpline

The first dementia information phone-line (helpline) in Estonia was opened in January this year. The Helpline is open for 4 hours on working days. People with dementia and their family members, as well specialists (social workers, service providers, etc.) are welcome to call in with any questions related to dementia. The Dementia Helpline is managed by the Dementia Competence Centre.

Dementia support groups for family members

In 2017, the first dementia support groups for family members of people with dementia were started in Estonia, by NGO Living with Dementia. The growth of these new support groups has been very fast and today there are support groups in 17 different places throughout the country. In March this year, the first support groups for the Russian speaking population were launched (in Narva and in Tallinn). Given the huge demand for information and support, there are at least 10 more support groups planned in the next few years. The dementia support group leaders are volunteers and are mainly members of NGO Living with Dementia.

Memory Cafés

In February this year, the first Memory Café was opened in Estonia. While the above-mentioned support groups exist mainly to help the family members of people with dementia, Memory Cafés are established to help people with dementia feel better supported and allow them an opportunity to socialise and to enjoy time together with family and friends, as well as with those in their community interested in helping and understanding dementia better. Memory Cafés also try to offer an interesting cultural element, by taking place, for example, at Tallinn TV Tower or in the KUMU Art Museum. As Memory Cafés are proving to be very popular, there are also plans to spread these throughout Estonia. The Memory Cafés are run by NGO Living with Dementia.

Dementia conference (pictured)

In March this year, more than 150 persons participated in the conference “Journey towards dementia-friendly services”. Presentations gave a good overview of the development of the dementia field in Estonia. They covered topics such as which services, for people with dementia and their carers, are offered by local governments or care homes. There were very inspirational and impassioned speeches by family members of people with dementia, as well as international speakers from Slovenia, Finland and Belgium, who spoke about dementia-friendly movements in their countries and about designing the environment, as well as palliative care. Indeed, the final session was devoted to palliative care. Speakers from Belgium were joined by some from Estonia, who presented the current situation and future plans for palliative care in Estonia. The conference was organised by the Dementia Competence Center.

More information about NGO Living with Dementia: www.eludementsusega.ee
Facebook: https://www.facebook.com/eludementsusega/

10 February: Portugal has new legislation on the rights of people with incapacity

After some decades trying to get legislation in place promoting the autonomy and the rights of people with incapacity (due to dementia, or for any
other reason) the “Regime do Maior Acompanhado” came into force on 10 February 2019. This means a complete change of paradigm in line with the Convention on the Rights of Persons with Disabilities (CRPD). Now, the Portuguese legal framework “ensures that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests”, as stated in Article 12, n°4 of the Convention.

Capacity is no longer seen as an ‘all or nothing’ phenomenon, but is now assessed according to the person’s concrete needs and with the different categories of acts people may wish to perform (making a will, driving, choosing where to live, taking financial or property decisions).

Interdiction and incapacitation have been replaced by “meidas de acompanhamento” (accompanying measures). These can be of very different types and are decided in order to promote autonomy and rehabilitation.

People who may need help to take financial or property decisions, in principle, preserve their autonomy to take personal decisions such as getting married, choosing where to live, appointing a healthcare proxy, having children and taking care of them, making a will or voting.

People may choose, in advance, the person or persons who will help them to make decisions or act on their behalf, if and when needed and a court ruling must take these advance decisions into account.

These are very important steps towards the promotion of people with incapacity legal rights. It is also a huge challenge to judges, public attorneys, lawyers, doctors, people with incapacity and their families but also to nursing homes and other facilities. All of them need to be well informed and prepared to explore all the opportunities arising from this new legal framework.

It is also very important to make wider society aware of the main advantages of it: the recognition of decisions of any kind taken in advance and the principle of limiting autonomy as little as possible.

Unfortunately, however, stresses Alzheimer Portugal, the new legal framework has omitted a very important issue - there are still no professional guardians, which means there is a very large number of people with incapacity and no guardian. They may be cared for by their families, who may act in good faith, but with no legitimacy to act on their behalf. And what’s worse, a growing number of people with mental incapacity are living alone in very poor conditions (lack of food, hygiene, home), because there is no one appointed to protect them and to act on their behalf. Some of them have money and property but are not able to manage them.

Overall, Alzheimer Portugal is very happy with this change of paradigm and has been developing several training programmes on this issue, for professional and family carers, to make them aware of the importance of informing people with dementia of their right to decide in advance and to have a voice in the judicial process that will ultimately decide the most adequate measures in each situation for each person, as the need arises.

20-22 February: Turkey holds its 1st Council on Ageing

Under the auspices of the Presidency of the Republic of Turkey, the first Council on Ageing was held on 20-22 February 2019 in Ankara. The main themes of the 1st Council on Ageing, as announced by the President of the Turkish Republic, Recep Tayyip Erdogan in his speech at the United Nations (UN) General Assembly on 25 September 2018, was “supporting active ageing” and “strengthening the rights of the elderly”. The inauguration of the 1st Council on Ageing was commenced with an opening ceremony on 20 February at the Convention and Culture Centre of the Presidency of the Republic of Turkey and the programme continued in Ankara Green Park Hotel on 21-22 February.

The commissions within the scope of the Council continued their studies under six topics including “Active Ageing”, “Care Economy”, “Elderly Care Services and Quality of Life”, “Age-Friendly Cities and Local Governments”, “The Rights of Older Persons” and “Economics of Ageing”.

Two parallel activities were held, one being a photography contest with the theme “Bridge: Intergenerational Solidarity”, organised by the Ministry of Family, Labour and Social Service. The aim was to strengthen family bonds, communication and solidarity between generations and to create a sustainable identity for studies raising social awareness and transferring cultural values between generations.

The second activity was named “Centennial Sycamores”, which had been planned to celebrate Turkey’s centenarians (people who are 100+ years old) living in 7 different regions of the country. The Council was closed on 22 February, following the declaration of Council recommendations.

21 February: French families hit hard by government’s decision to stop reimbursing anti-dementia drugs

It has been seven months since the French Government took the decision to stop reimbursing the four anti-dementia drugs currently approved in Europe. Since then, France Alzheimer has repeatedly raised the alarm, drawing attention to the growing distress caused to the 3 million families affected. To
2,463 caregivers and 84,000 people with dementia responded.

France Alzheimer has shared the same sense of incomprehension and abandonment as people with dementia and their families, since the decision was taken in June 2018. Given no alternative, the people affected are suffering the full consequences of the total delisting of “anti-Alzheimer’s” drugs. In response to the French Government's intransigence, the survey aimed to raise awareness of the issue.

Its results identify three immediate and worrying consequences:

- The sudden cessation of treatment is causing a brutal increase in cognitive impairments. This deterioration was reported by 52% of respondents.
- Families already under pressure now have to pay considerably more for these treatments, out of their own pockets: 2 out of 3 respondents were taking at least one of the four drugs when the announcement on delisting was made. 70% of them have no plans to stop their treatment. The main reason given, by 62.5% of the respondents was the effectiveness of their treatment. 20% have stopped their treatment and 10% expect to stop soon, mainly because of the excessive cost, especially given that VAT on these drugs has increased by 8 percentage points.
- The therapeutic relationship between doctor and patient has broken down. Only 55% of those who have decided to stop taking their treatment will continue to see a specialist, 38% have already stopped doing so, and 7% are considering it.

For the sake of people with dementia and their families, the Government must now prioritise research, France Alzheimer stresses. Part of the financial effort must be devoted to clinical research required to offer patients long-term solutions that are fully funded and appropriate for their needs. This vision is shared by 68% of the caregivers who responded and 77% of the people with dementia.

With a resounding silence on this subject from the French Government, France Alzheimer has decided to provide EUR 200,000 to fund a clinical trial. It will study the impact of daily doses of Donepezil on participants’ cognitive abilities over a three-year period, in the hope of finding new and concrete results that could reverse the decision to delist these drugs and resume funding for them.

22 March: Estonian State to fund adjustments to physical environment for persons with dementia in care homes

The Estonian Ministry of Social Affairs will provide support to the tune of EUR 1.5 million, taken from the state budget, for care homes wishing to create a more dementia-friendly environment. A total of 38 applications were received for this funding. They are now being evaluated and decisions about support will be made by the end of April 2019.

The State will support the costs of making adjustments such as design, construction, interior or landscape architectural works, installation of stationary furniture, and equipment suitable for persons with dementia. In particular, projects with different technological solutions were expected; for example, those wanting to use remote monitoring systems and fall sensors to ensure the safety and quality of life of residents.

The terms and conditions of the grant and the evaluation methodology were based on an expert analysis conducted by NGO Living with Dementia in 2018.

SCIENCE WATCH

15 February: Denali Therapeutics begins recruitment in Phase Ib trial of DNL747 for AD

On 15 February, Denali Therapeutics, a biopharmaceutical company developing a broad portfolio of therapeutic candidates for neurodegenerative diseases, announced that it has dosed its first participant in a Phase Ib clinical trial evaluating DNL747 for Alzheimer’s disease (AD). DNL747, being developed with collaboration partner Sanofi, is a brain-penetrant small molecule inhibitor of RIPK1 that plays a key role in inflammation and cell death.

The randomised, double-blind and placebo-controlled Phase Ib clinical trial is evaluating the safety, tolerability, pharmacokinetics and pharmacodynamics of multiple oral doses of DNL747 in people with AD. About 26 participants from 55 to 85 years old will be randomised to receive either DNL747 or placebo. Data readout is expected during Q4 2019. https://www.denalitherapeutics.com/investors/press-release/denali-therapeutics-announces-first-patient-dosed-in-phase-1b-study-of-dnl747-for-alzheimers-disease

20 February: Genentech starts a Phase II trial in moderate AD

On 20 February, the Swiss-based biopharmaceutical company AC Immune announced that its partner Genentech, a member of the Roche group, has started a second Phase II trial of RO7105705 in moderate Alzheimer’s disease (AD).

The trial is a Phase II multicentre, randomised, double-blind, placebo-controlled and parallel-group study evaluating the
efficacy, safety, pharmacokinetics and pharmacodynamics of RO7105705 in people with moderate AD. The primary outcomes are change from baseline in both cognitive function (as measured by the Alzheimer’s Disease Assessment Scale, Cognitive Subscale, 11-item version) and functional capacities (as measured by the Alzheimer’s Disease Cooperative Study-Daily Living Inventory). The company plans to recruit 260 participants with moderate AD.

RO7105705 is an anti-Tau monoclonal antibody, also being studied by Genentech in a separate Phase II trial evaluating its efficacy and safety in people with prodromal to mild AD.


28 February: Researchers describe five new risk genes for AD

According to a study published on 28 February in the journal Nature Genetics, a genetic analysis conducted in the US and Europe has reported five new genes that increase the risk of developing Alzheimer’s disease (AD). The international team of researchers analysed data from 94,737 people with late onset AD collected by the four groups that make up the International Genomic Alzheimer’s Project. In addition to confirm the know association of 20 genes with AD risk, the team identified 5 new risk genes for late-onset AD (QCK, ACE, ADAM10, ADAMTS1 and WWOX). They also identified cellular pathways which might be implicated in the process of the disease such as the immune system, lipid metabolism, tau binding proteins and amyloid precursor protein (APP) metabolism. Genetic variants affecting APP and Aβ processing have been showed to be associated with both early-onset autosomal dominant AD and with late onset AD. Scientists suggested that therapies developed for early-onset disease could also be applicable to the late-onset form of the disease.

https://www.nature.com/articles/s41588-019-0358-2

4 March: Observational study assesses relationship between type 2 Diabetes treatment status and AD-related outcomes

On 4 March, researchers from the Alzheimer’s Disease Neuroimaging Initiative (ADNI) published an article on the differences in Alzheimer’s disease (AD)-related outcomes depending on the profile of type 2 Diabetes treatment in the journal Diabetes Care.

The researchers drew on information from 1,289 dementia-free ADNI participants, out of which 900 underwent a lumbar puncture and provided the study with information on AD-related biomarkers (including levels of phosphorylated tau (p-tau), total-tau (t-tau) and β-amyloid, which are connected to the development of AD-dementia). Information on 331 participants who progressed to dementia was available after follow-ups of participants (up to 120 months succeeding initial assessment). The researchers then grouped participants’ information into four groups, differentiating between those who initially had normal blood glucose levels (762 participants), people who had a fasting blood glucose of 100-125 mg/dL classified as “prediabetes” (353 participants), people with diabetes that did not take treatment (78 participants), as well as people with diabetes who received treatment (96 participants).

The researchers noted, that the untreated group of people with diabetes progressed more rapidly towards dementia and exhibited higher levels of the AD biomarker p-tau than participants with normal glucose levels.

Furthermore, they suggested that since participants with treated diabetes seemed to not differ from people with normal glucose levels as well as those with prediabetes, pharmacotherapy for type 2 diabetes might have attenuated the risk for diabetes-associated dementia.

Nevertheless, the team also reported on the limitations of their study, explaining that due to the nature of the ADNI study, the studied group may not be representative of the aging population with diabetes. In addition, they stated that it is not possible to determine the effect of diabetes treatment on AD due to the observational nature of their study.

Future research through clinical trials is therefore be needed to shed further light into this, preferably with enough power to analyse for sex differences, provided the samples are large enough to reach the needed statistical power.

http://care.diabetesjournals.org/content/early/2019/02/25/dc18-1399

11 March: Researchers compare changes in the eyes of people with AD, MCI and control participants

On 11 March, researchers from North Carolina (US) published findings on comparisons between the retinal microvasculature of participants with Alzheimer’s disease (AD), Mild Cognitive Impairment (MCI) and control participants in the journal Ophthalmology Retina.

There is a growing interest in possibilities to identify people at risk of developing dementia as early as possible. In this context, conscious efforts are being made to identify faster and more accessible screening techniques that are neither invasive nor too costly. Recent studies have found indications that changes in the eyes could be possible indicators of cognitive changes as well.

The current study involved 39 people living with AD, 37 participants with MCI and eye scans of 133 healthy control participants. All participants were aged 50 or older. The study team reported that out of 235 imaged participants, 42 eye
scans had to be excluded either due to poor scan quality or due to motion artefacts, explaining that some of the participants with AD were fatigued easily and more prone to fixation errors.

Looking at the results of their analyses, the team noted that indeed there were significant observable differences between the measures for people with AD, MCI and the control participants. Furthermore, the analyses also showed significant correlations between some of the parameters used and scores in a pen and paper test for global cognition among all participants. Although interesting, further research is needed since this study did not investigate if there are changes over time.

12 March: Results from cohort study do not show association of midlife diet and subsequent risk for dementia

On 12 March, an international team of researchers published an article on an investigation about midlife diet and subsequent risk for dementia in the Journal of the American Medical Association (JAMA) Neurology.

The researchers used information from 8,225 participants who took part in the observational study that started in 1985. Out of all participants, with available follow-up information, 344 developed dementia over the course of the study. In order to see if a healthier diet coincides with lower rates of dementia, the scientists derived an Alternative Health Eating Index (AHEI) from food frequency questionnaires the participants were asked to fill out during follow-up examinations that took place approximately every five years throughout about twenty-five years.

For their analyses, the researchers leveraged on information from three time points for which the AHEI were calculated (1991-1993, 1997-1999, and 2002-2004). Participant information was grouped for each time point into a tertile depending on how healthy the person’s diets were. The team then looked at the incidence of dementia by participant group and were unable to find a significant correlation between a healthy midlife diet and incident dementia.

The researchers nevertheless explained that it remains unclear whether a healthy diet plays a role in influencing cognitive outcomes in a combination with other behaviours that promote health as well as that their study does not warrant about the influence of diet in subgroups at increased risk for dementia. Lastly, the team also underlined that as it is the case for all observational studies that it is impossible to rule out all factors that might have had an influence but were not included in the analyses.

13 March: Scientists investigate links between extended family history and relative risk of developing AD

On 13 March, researchers from the United States published a paper on the estimated relative risk for Alzheimer’s disease (AD) based on extended family history constellations in the journal Neurology.

Research focus on AD moves more and more to the earlier stages of the condition and possibilities to assess who is at higher risk of developing AD dementia in future. Previous evidence has shown that people whose close family members had AD may be at an elevated risk of developing AD dementia.

This new investigation aimed at finding out whether it would help to also include a more extended family history in order to better estimate relative risk, encompassing first- to third-degree relatives.

The study team therefore leveraged on data from people with deep ancestry information available in the Utah Population Database. Overall, the study included information on more than 270,000 individuals and analysed their ancestral genealogy along with their death certificate to estimate population rates for AD.

After this, the researchers set up different estimations of the relative risks depending on the family history constellation. Including the number of first-degree relatives (parents, offspring and siblings), second-degree relatives (grandparents, grandchildren, aunts and uncles but also nieces and nephews) and third degree relatives (great-grandparents, great-grandchildren, great nieces, and nephews, great uncles and aunts as well as cousins) but also age at death, sex as well as maternal vs paternal inheritance.

The results supported previous findings showing a significant increase in risk of AD for any affected first-degree relatives, but also that there is an increased risk for those whose second and third-degree relatives had AD.

Furthermore, the researchers reported on mixed results depending on the inheritance from fathers and mothers showing that family history on the mother’s side came with an elevated risk as compared to family history on the father’s side.

14 March: Study on mice investigates if auditory and visual stimulation can help to reduce AD-related proteins

On 14 March, researchers from the United States of America published an article on a trial assessing the effect of auditory stimulation in Alzheimer’s disease (AD) mouse models in the journal Cell.

The specific process the researchers used is entitled “auditory gamma entrainment using sensory stimuli”
(GENUS) and the researcher’s motivation to further explore possible beneficial effects on mice came from their previous research that showed that this non-invasive light flicker method positively affected pathology in a part of the brain of mice that is strongly associated with visual functions.

The team induced the special tone stimulation throughout seven days especially targeting the animal’s gamma frequency (brain waves that are part of the communication between neurons) in the auditory cortex and a sub field of the hippocampus, the CA1, which is associated with memory functions.

The results showed, that the mice did not only showed positive activation in brain cells such as microglia, astrocytes and even vasculature but that in addition to that, that phosphorylation of tau (which is also connected to the death of brain cells in AD) was reduced.

The scientists furthermore reported that a combination of auditory and visual GENUS led to decreased amyloid (which is also associated with the death of brain cells) in the frontal part of the brain (prefrontal cortex) and neocortex. In addition to this, the researchers noted that the mice showed an improvement in cognitive function and spatial recognition tasks.

Since this is a study with mouse models, the authors clearly stated that these results cannot be translated to humans but warrant future research to determine possible translatable effects.

https://doi.org/10.1016/j.cell.2019.02.014

21 March: Biogen and Eisai discontinue Phase III ENGAGE and EMERGE studies of aducanumab

On 21 March, the pharmaceutical companies Biogen and Eisai announced the decision to discontinue the ENGAGE and EMERGE Phase III studies of aducanumab in Alzheimer’s disease (AD).

ENGAGE and EMERGE are Phase III multicentre, randomised, double-blind, placebo-controlled and parallel-group studies designed to evaluate the efficacy and safety of aducanumab in people with mild cognitive impairment due to AD and mild AD dementia.

The decision to halt the trials is based on results from a futility analysis conducted by an independent data monitoring committee, which reported that the trials were unlikely to meet their primary endpoint in the Clinical Dementia Rating-Sum of Boxes (CDR-SB) score upon completion. Detailed data from the ENGAGE and EMERGE studies will be presented at future meetings.

As a result of this decision, the EVOLVE Phase II safety study and the PRIME Phase Ib long-term extension study of aducanumab will also be discontinued.


22 March: Eisai initiates a Phase III clinical trial of BAN2401 in early AD

On 22 March, Eisai announced the launch of a Phase III clinical trial of BAN2401, an anti-amyloid beta protifibril antibody, in people with early Alzheimer’s disease (AD). BAN2401 is developed under a partnership with Biogen.

The Clarity AD Phase III trial is a placebo-controlled, double-blind, parallel-group and randomised study evaluating BAN2401 in people with mild cognitive impairment due to AD or mild AD dementia with confirmed amyloid accumulation in the brain. Around 1,566 participants will receive either BAN2401 (10mg/kg bi-weekly) or placebo. The primary endpoint is the change from baseline in a scale called Clinical Dementia Rating–Sum of Boxes (CDR-SB) at month 18.


25 March: Otsuka reports Phase III results for AVP-786 in agitation in people with Alzheimer’s dementia

On 25 March, Otsuka Pharmaceutical Co., Ltd. announced that its subsidiary Avanir Pharmaceuticals reported results from its Phase III clinical trial evaluating AVP-786 for the treatment of agitation in people with Alzheimer’s dementia.

The Phase III trial (15-AVP-786-301) is a multicentre, randomised, double-blind and placebo-controlled study evaluating the efficacy, safety and tolerability of AVP-786 for the treatment of moderate-to-severe agitation in people with Alzheimer’s dementia. The study enrolled 410 US participants aged 50 to 90 with moderate-to-severe agitation and probable Alzheimer’s dementia.

Data showed a significant improvement on the primary endpoint on the Cohen-Mansfield Agitation Inventory for one of the two doses being evaluated. Similar improvements were also reported on the secondary outcome measures. The most common side effects that occurred in participants receiving AVP-786 versus placebo were falls, urinary tract infection, headache and diarrhoea.


DEMENTIA IN SOCIETY

1 March: Jayne Goodrick receives Points of Light award for her work advocating for people with dementia and carers

Jayne Goodrick, hailing from Rhuddlan in Wales (UK), received a “Points of Light” award on 1 March, in recognition of her work as an advocate for people with dementia and their carers.
Following her husband Chris Roberts’ diagnosis with early onset dementia at age 50, Ms Goodrick has worked as a carer herself and as an advocate, fighting for the empowerment of carers and the rights of people with dementia. She has consulted with the UK and Welsh governments, giving input on the Welsh Dementia Action Plan, for example.

Mr Roberts, Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD) and an international speaker on the subject of dementia, is supported every step of the way by his wife and the couple also featured in a BBC Panorama documentary in 2016, looking at their family’s life since the diagnosis.

Ms Goodrick was presented with her award by the Secretary of State for Wales, Alun Cairns MP (pictured, left), at number 10 Downing Street, the British Prime Minister’s Office (Pictured, right: Ms Goodrick and Mr Roberts outside the door to Number 10).

In a personal letter, Prime Minister Theresa May said: “You have shown remarkable resilience and dedication in so openly sharing your personal experiences of caring for your husband Chris with his diagnosis of dementia. Your expertise by experience is providing invaluable support to thousands of carers across the UK and to the work of government and charities in tackling this terrible condition.”

Ms Goodrick said: “I am truly honoured to have been awarded the Points of Light award for doing what we do. I say we, because the work around highlighting and addressing the stigma, the inequality, and the loss of rights for all people affected by dementia, is a team effort.”
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<td>4-7 April</td>
<td>13th World Congress on Controversies in Neurology, <a href="http://www.comtecmad.com">http://www.comtecmad.com</a></td>
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<td>Alzheimer’s Society Annual Conference, <a href="http://www.alzheimers.org.uk/conference">www.alzheimers.org.uk/conference</a></td>
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29th Alzheimer Europe Conference
Making valuable connections
The Hague, Netherlands
23–25 October 2019
www.alzheimer-europe.org/conferences   #29AEC