I hope that 2019 was a successful year for you all. The Alzheimer Europe team has every reason to be proud of its achievements over the past 12 months and I would like to thank everyone who supported us in our efforts to ensure dementia remains a European priority. The European Working Group of People with Dementia (EWGPWD), our member associations, partners and sponsors, the MEPs in the European Alzheimer’s Alliance, and the Alzheimer Europe Foundation and Board have all been instrumental. We also owe a debt of gratitude to the EU and its health and research programmes, without which none of this would be possible.

During December, we held a series of meetings in Brussels, including a Board meeting, a lunch debate on improving the diagnosis of dementia, a meeting of the Governmental Expert Group on Dementia, a roundtable with sponsors, the 5th edition of our annual Alzheimer’s Association Academy, and a meeting of the EWGPWD. Thank you to our lunch debate host, Sirpa Pietikäinen MEP (Finland) and to MEPs Dominique Riquet and Younous Omarjee (France) and Matt Carthy (Ireland) who were present/represented. Dominique Riquet made the decision to join the Alliance, and I would like to extend a personal welcome to him and to Tsvetelina Penkova MEP (Bulgaria), who also joined during December. We hope to see them and many of their colleagues at our next lunch debate on 18 February 2020.

The 3rd meeting of our Governmental Expert Group on Dementia welcomed representatives from 15 European countries, and from the 2nd Joint Action on Dementia and the WHO. We are delighted that this initiative, which we launched one year ago, has been such a success, and we look forward to the next meeting, in June. During its meeting, the EWGPWD said goodbye to Miha Kastelic (Czech Republic), a member since 2018. I would like to thank Miha for his contributions and to wish him and his wife Alena all the best.

On the research front, results from several high-profile clinical trials were shared at the 12th annual Clinical Trials in Alzheimer’s Disease (CTAD) conference, which I attended at the start of December. These included the RADAR Phase II trial of Losartan, the HARMONY Phase III trial of Pimavanserin, and the AMBAR Phase IIb/III trial of plasma-protein replacement therapy. A special session focused on the top line results for Aducanumab. Our upcoming “Dementia in Europe” magazine (February 2020) will have an in-depth article on Aducanumab, with opinions from experts in the field, on how results can be interpreted. A special CTAD highlights section can be found on page 22.

Finally, I am pleased to inform you that it is now possible to view the presentations and videos from #29AEC on our website and the videos can also be found on our YouTube channel.

I wish you all an excellent start to 2020!

Jean Georges
Executive Director
ALZHEIMER EUROPE

5 December: Alzheimer Europe continues to comply with EMA’s strict eligibility criteria

On 5 December 2019, the European Medicines Agency (EMA) confirmed that Alzheimer Europe continues to comply with its strict eligibility criteria, as defined by its Management Board, and can continue to be involved in its activities. The list of all the patients’ and consumers’ organisations that are involved in EMA activities can be viewed here:

http://bit.ly/38l1g9o

9-10 December: Alzheimer Europe Board approves 2020 Work Plan and Budget

The Alzheimer Europe Board met in Brussels on 9 and 10 December 2019. The Board reviewed a number of 2019 activities and discussed the evaluation survey of the 2019 conference in The Hague. 279 of 811 contacted conference participants had provided their feedback on the conference and the Board welcomed the fact that the organised plenary sessions were judged to have been good or very good by between 87.57% and 92.54%, whereas the poster exhibition was evaluated as good or very good by 96.17% of participants. Finally, 97.43% of participants would recommend this conference to their colleagues.

The Board also formally approved the work plan and budget for 2020 and discussed various other financial and operational matters. The next AE Board meeting will take place in Brussels on 17 and 18 February 2020.

10 December: Alzheimer Europe holds lunch debate examining diagnosis of dementia

Alzheimer Europe held its final lunch debate of 2019 in the European parliament on 26 February 2019, focusing on dementia as a European research priority. The lunch debate, focused on “Improving the diagnosis of dementia – Findings from European research collaborations”, was attended by around 96 people including national member organisations, government experts on dementia, academics, industry representatives and policy makers.

Sirpa Pietikäinen MEP (Finland), chairperson of the European Alzheimer’s Alliance (EAA) and board member of Alzheimer Europe opened the session, noting that the new term of the European Parliament and the European Commission, highlighting the new challenges and opportunities this presented in making dementia a policy priority in Europe.

Prof. Mercè Boada, the coordinator for the Models of Patient Engagement for Alzheimer’s Disease project (MOPEAD), presented on the findings of the project which ran for three years between 2016 and 2019. She introduced the work of the project which aimed to provide a step change in patient engagement, supporting a paradigm shift from late-stage diagnosis to early diagnosis.

Pierre Krolak-Salmon, work package lead for diagnosis and post-diagnostic support, part of the second Joint Action on Dementia (Act on Dementia), which ran between 2016 and 2019.

The work package head led focused on improving the role of primary care role in diagnosing dementia in a timely manner, including the piloting of an anti-stigma training programme and the development of a graduated dementia diagnosis pathway.

The lunch debate also heard from Dr Gill Farrar, project co-lead for the Amyloid Imaging to Prevent Alzheimer’s Disease (AMYPAD), introduced the 5-year project (2016-2021), consisting of two main studies to deliver on three objectives:

• Evaluate the usefulness of β-amyloid imaging in diagnostic certainty and patient management
• Investigate the natural history of disease and methods to enrich secondary prevention studies
• Quantify treatment-induced changes and patient-specific efficacy.

Alzheimer Europe Chairperson Iva Holmerová closed the session by thanking the speakers for their informative presentations. She also thanked attendees from across sectors and disciplines for attending the meeting, highlighting the importance of collaboration between partners when conducting dementia research, with the political support for programmes such as Horizon Europe being crucial to continue this work.

Impressions from the lunch debate

Our lunch debate host, MEP Sirpa Pietikäinen welcomes delegates

Our first speaker, Mercè Boada presents the MOPEAD project

Our second speaker, Pierre Krolak-Salmon presents the 2nd Joint Action on Dementia
10 December: Alzheimer Europe updates sponsors on its activities

On 10 December, Alzheimer Europe (AE) hosted a Company Round Table meeting in Brussels. It was attended by representatives from Biogen, Eisai, Eisity, Lilly, Lundbeck, Nutricia, and Hoffman-La Roche. Jean Georges, the AE Executive Director, updated the organisation’s sponsors on its 2019 activities with a particular focus on the activities that were sponsored by the companies and sponsors.

Delegates were provided with an update on the European Parliament elections, European Dementia Pledge, relaunch of European Alzheimer’s Alliance, relaunch of the European governmental experts group on dementia, the yearbook dedicated to the prevalence of dementia in Europe, the AE Public Affairs meetings and the Alzheimer’s Association Academy, which brought together the member organisations with capacity building workshops. Attendees also discussed the involvement of AE in EU projects and other corporate affairs activities including the Clinical Trial Watch, the lunch debates, the Dementia in Europe Magazine and the European Dementia Monitor. It was also an opportunity to highlight Alzheimer Europe’s planned activities and sponsorship opportunities for 2020.

10 December: Alzheimer Europe organises its fifth Alzheimer’s Association Academy

On 10 and 11 December 2019, Alzheimer Europe hosted the fifth edition of its annual Alzheimer’s Association Academy. Participants included 24 representatives from AE member organisations; 3 company representatives and 8 AE staff members. There were 15 expert speakers from various institutions and organisations across Europe and from different European projects. The first day began with a session on “Models of patient engagement in dementia” and was moderated by Annette Dumas (ASDM Consulting, Belgium). This session included presentations by Javier Téllez (GMV, Spain), who spoke about citizen science - the role of online cognitive tests for the detection of dementia; Lena Sannemann (University Clinic Cologne, Germany), who discussed involving general practitioners in dementia diagnosis; and Andreea Ciudin (VIHR, Spain), who joined us via tele-conference, to explore the role diabetologists might play in the diagnosis of dementia.

The second session of the day was on “Ethical issues in dementia research” and was moderated by Amy Dalrymple (Alzheimer Scotland). This session included presentations by Marthe Smedinga (Radboud University Medical Centre, Netherlands), who shared some of the ethical challenges in the area of timely detection and disclosure of genetic and biomarker risk; and Dianne Gove (Alzheimer Europe), who looked at ethical considerations for inclusive participation of people with dementia in research.

Day two of the Academy began with a session on “Involvement of patients and patients’ organisations in medicines

Sponsor of the month

Alzheimer Europe would like to express its gratitude to a new sponsor for its 2020 activities.

Read more about sponsorship opportunities here: https://goo.gl/cKVNeC
development and research”, which was moderated by Ana Diaz (Alzheimer Europe). This session included presentations by Camilla Habre (European Patients’ Forum), whose talk was on patient engagement in medicines’ development, in the context of the PARADIGM project; Ana Diaz (Alzheimer Europe), who informed participants about the RADAR-AD project’s Patient Advisory Board; Nicole Goedhart (Athena Institute, VU Amsterdam, Netherlands), exposed some of the existing gaps in patient engagement in medicines’ development; and Lidewij Eva Vat (Athena Institute, VU Amsterdam, Netherlands), who asked participants to consider “what’s in it for me?”. She evaluated the impact of patient engagement within the PARADIGM framework.

The second morning session, was on “The role of new technologies in the diagnosis and prognosis of Alzheimer’s disease” and the moderator was Iva Holmerová (Czech Alzheimer’s Society, Czech Republic and Alzheimer Europe). This session included presentations by Kim Baden-Kristensen (Brain+, Denmark) and Younes Tabi (Oxford University), both of whom presented different aspects of the AD Detect and Prevent project; and Andrew Owens (King’s College London, United Kingdom), with a talk on the potential of mobile and digital technologies to improve the assessment of Alzheimer’s disease, in the context of the RADAR-AD project.

The final session of this fifth Academy was titled “Empowering people with dementia” and was a combination of two presentations and two consultations with the Span+ project. The two speakers, Annemiek Bielderman and Charlotte van Corven, from the Radboud Medical Center in the Netherlands, discussed “defining empowerment for people with dementia from multiple perspectives” and “Development of the SPAN+ empowerment intervention for people with dementia”, respectively. The workshops explored some of the same topics raised during the project’s already-completed Dutch focus groups, so as to cast a wider net, capturing feedback from across Europe.

The two-day Academy was a very interactive event, with many interesting and thought-provoking discussions. Given the success of its Alzheimer’s Association Academies to date, AE will host a sixth edition on 8-9 December 2020.

10-12 December: Members of the EWGPWD meet in Brussels

The last meeting of the EWGPWD in 2019 was held in Brussels from 10-12 December. Prior to the meeting, members of the group and their supporters attended the AE Lunch Debate on the topic of improving the diagnosis of dementia.

On the first day of the meeting, members provided feedback about their involvement at the AE conference and various other events where some members of the group had participated on behalf of the EWGPWD. Different researchers from European projects (MinD, SPAN+, RADAR-AD, PARADIGM) actively participated in the meeting. From the MinD project, two of the researchers presented the outcomes of this project which had focused on the topic of design and mindfulness in dementia and the group was invited to provide feedback on the ‘reflective booklet with mindful exercises: Living the Life’.

On the second day of the meeting, the group worked on the topic of empowerment and initiatives that can promote the empowerment of people affected by dementia. The session was co-moderated by three researchers from the SPAN+ project (Radboud umc) and AE staff. This was followed by a consultation about the RADAR-AD project on the topics of recruitment and retention in the trial that will begin in early 2020. Members of the EWGPWD and their supporters, as members of the RADAR-AD Patient Advisory Board, provided input on these topics. The consultation was co-moderated by AE staff and researchers from the VUmc, King’s College and Lygature. After the meeting, a few PAB members also tested one of the apps which will be used for the study. During the last session of the day, the group discussed the value and impact of patient involvement, and created “trees of impact” which reflected what they hoped to get in return for their contributions to research. This session was led by researchers from the PARADIGM project from VU-Athena and AE staff.

During the last day of the meeting, the group worked on the topics of ethical issues related to dementia research and dementia-friendly communities. They also contributed to work on language use in relation to changes in behaviour associated with dementia (which is being led by the University of Hull). During the meeting, the group and Alzheimer Europe staff bid a fond farewell to Miha Kastelic from the Czech Republic who had been a member of the group since 2018. The members of the EWGPWD as well as everyone at Alzheimer Europe thank Miha for his contributions during his time with the group and also thank his wife Alena for her support and involvement.
12 December: Presentations and videos from #29AEC are online

We are pleased to announce that presentations (all those for which approval has been given by the presenters) and videos from the 29th Alzheimer Europe Conference #29AEC in The Hague are now available on our website.

To see the presentations, first click on the relevant session in the right-hand navigation pane of our detailed conference programme (link hereunder), and scroll to the bottom of the session, to see the attachments.

A selection of our conference photos will also be available online, soon.


Alzheimer Europe networking

From 4 to 7 December (San Diego, USA), Jean attended the CTAD Conference (Clinical Trials on Alzheimer’s Disease).

On 4 December (San Diego, USA), Jean met with representatives of Biogen and AbbVie for an exchange on recent developments.

On 5 December (Brussels, Belgium), Chris attended the EBRA Year 1 Public event.

On 5 December (San Diego, USA), Jean met with representatives of Nutricia to discuss collaboration opportunities on patient reported outcomes.

On 9 and 10 December (Brussels, Belgium), the Alzheimer Europe Board met.

On 10 December (Brussels, Belgium), Alzheimer Europe organised its European Parliament lunch debate “Improving the diagnosis of dementia – Findings from European research collaborations”.

On 10 December (Brussels, Belgium), Alzheimer Europe organised a company round table meeting to present its 2020 Work Plan and 2020 Sponsorship Opportunities.

On 10 and 11 December (Brussels, Belgium), Alzheimer Europe organised its 5th Alzheimer’s Association Academy.

On 12 December (Wavre, Belgium), Jean attended the Health Advisory Board of GSK.

On 17 December (Brussels, Belgium), Angela attended a workshop on the ethical/privacy/data protection certification of ICT solutions, organised by the Active and Assisted Living Programme.

On 18 December (Brussels, Belgium), Jean participated in the sustainability meeting of the EPAD project.

EU PROJECTS

27 November: ROADMAP publishes paper on visualisation of real-world data for AD research

On 27 November, an international team of researchers from the Innovative Medicines Initiative (IMI) ROADMAP project published a scientific article on the ROADMAP Data Cube in the journal Alzheimer’s & Dementia.

The Data Cube is an interactive online tool that visualises availability of Alzheimer’s disease (AD) relevant outcomes in 66 data sources, encompassing 13 outcome domains. The researchers also performed a gap analysis and report that they identified cognitive ability, functional ability/independence, behavioural/neuropsychiatric symptoms, treatment, comorbidities, and mortality as the most collected outcomes.

When considering which outcomes are relevant to the AD research field, the scientists found that data in caregiver-related outcomes were the scarcest. In addition, they also reported that in general, electronic health records covered a broader, but also less detailed data spectrum than research cohorts. The open access publication is available here: https://www.alzheimersanddementia.com/article/S1552-5260(19)35487-1/pdf

More information about the project can be found at: www.roadmap-alzheimer.org
The Data Cube can be accessed here: https://datacube.roadmap-alzheimer.org/

27 November: EPAD project publishes new article on its first formal data release

The European Prevention of Alzheimer’s Dementia (EPAD) project is proud to present its new paper “The European Prevention of Alzheimer’s Dementia Longitudinal Cohort Study: Baseline Data Release V500.0”, published in the Journal of Prevention of Alzheimer’s disease on 27 November. This paper describes the baseline data from the first 500 research participants (V500.0) to assist current and future researchers with their analysis. V500.0 has
been collected, quality checked, released and is now available via secure online tools. To access the data, academic researchers and institutions worldwide will need to make an online request by following this link at http://www.ep-ad.org/erap where a variety of resources can be found.

2 December: The AMYPAD DPMS study hits a significant milestone

The AMYPAD Diagnostic and Patient Management Study (DPMS) aims at better understanding the impact of the utilisation of amyloid PET imaging on diagnostic thinking and patient management. AMYPAD will scan a large population cohort (n=900) suspected of possible Alzheimer’s disease (AD).

The AMYPAD DPMS recently hit a significant milestone as the study has already recruited more than half of the research participants needed to fulfil its goal. The study is fully activated in eight sites including Geneva (Switzerland), Amsterdam (Netherlands), Toulouse (France), Barcelona (Spain), London (UK), Cologne (Germany), Stockholm (Sweden) and Lausanne (Switzerland), with a total of 606 research participants at the end of November 2019. Moreover, this achievement was recently followed by more positive news. Indeed, October 2019 was the best month for recruitment ever, with 60 participants enrolled (the average of the previous six months was 41). This positive trend, together with the recent activation of the last site in Stockholm, gives hope that the enrolment will be finishing during the first half of 2020. While participant recruiting is going relatively well, the data management activities have also been started to ensure a clean dataset for the next step of data analysis.

2-16 December: MinD project visits Alzheimer Europe and presents its designs to the European Working Group of People with Dementia

From 2-16 December, MinD was hosted by Alzheimer Europe for its final secondment. This two-week secondment, was the last of the MinD secondments to be hosted by Alzheimer Europe. It focussed on two important aspects of the project:

The first was drawing together the insights and results of the project for academic, public and policy audiences. This includes guidelines for co-designing, i.e. for working together with people with dementia during the design process. It also includes recommendations for policy providers, funders, voluntary organisations, designers and design academics regarding the recognition, benefits and best practices of applying design in the dementia context. All publications will be available on the project website, on completion of the project: www.designingforbehaviourchange.eu

Secondly, and most importantly, Kristina Niedderer and Kathryn Powell went to Brussels to present and discuss some of the outcomes of the MinD project with members of the European Working Group of People with Dementia (EWGPWD). Following a brief overview of the MinD project, the presentation focused first on the “This is Me” board game and the very positive results from the evaluation with people with dementia in four countries (UK, Netherlands, Germany, Spain). Kristina Niedderer then presented the “Living the Life” booklet which includes a set of six simple mindfulness exercises. First, all together and then in pairs, the group explored some of the exercises. One of the exercises about the appreciation of oneself and others through a hug proved very popular.

The exercises prompted the group to tell about their own rewarding experiences with mindfulness and related training to help in dealing with dementia. The discussion showed how much more common the use of mindfulness had become during the four-year duration of the project.

19 December: Miriade project launches website

The MIRIADÈ (Multi-omics Interdisciplinary Research Integration to Address DEmentia diagnosis) project website is online at miriade.eu

Positions for Early Stage Researchers are open and can be found in this section of the new website: https://miriade.eu/navigatie_level_1/miriade-is-recruiting

Interested candidates can also get in touch via email: miriade@vumc.nl

27 December 2019: MOPEAD project publishes third and final Newsletter

On 27 December, the Innovative Medicines Initiative funded MOPEAD project launched its third and final newsletter. The newsletter brings all the latest news from the project together, including reflections on the 3-year MOPEAD journey from the project leadership Mercè Boada and Laura Campo. It also includes articles on key achievements of the project.

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

The projects in this newsletter with EU funding are:

- AMYPAD - grant agreement 115952
- EPAD - grant agreement 115736
- ROADMAP - grant agreement 116020

**Members of the European Alzheimer’s Alliance**

Currently, the total number of MEPs in the Alliance stands at 98, 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 (EAA):

**Austria:** Monika Vana (Greens/EFA).

**Belgium:** Petra de Sutter (Greens/EFA); Frédérique Ries (ALDE); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE).

**Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D).

**Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR).

**Cyprus:** Costas Mavrides (S&D).

**Czech Republic:** Tomáš Zdechovský (EPP).

**Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D).

**Estonia:** Urmas Paet (ALDE).

**Finland:** Heidi Hautala (Greens/EFA); Mia Petra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP).

**France:** François-Xavier Bellamy (EPP); Dominique Bilde (ENF); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP).

**Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA).

**Greece:** Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Syraki (EPP); Elissavet Vozemberg (EPP).

**Hungary:** Tamás Deutsch (EPP); Ádám Kós (EPP).

**Ireland:** Matt Carthy (GUE/NGL); Ciarán Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke ‘Ming’ Flanagan (GUE/NGL); Billy Kelleher (ALDE); Seán Kelly (EPP); Mairead McGuinness (EPP); Grace O’Sullivan (Greens/EFA).

**Italy:** Isabella Adinolfi (EFDD); Brando Benifei (S&D); Pierfrancesco Majorino (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D).

**Lithuania:** Vilija Blinkevičiute (S&D).

**Luxembourg:** Charles Goerens (ALDE); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Nicolas Schmit (S&D); Isabel Wiseler-Santos Lima (EPP).

**Malta:** Roberta Metsola (EPP); Alfred Sant (S&D).

**Netherlands:** Jeroen Lenaers (EPP); Annie Schrijver-Pierik (EPP).

**Poland:** Elżbieta Lukacijewska (EPP); Jan Olbrycht (EPP).

**Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D).

**Romania:** Cristian Silviu Busoi (MEP); Marian-Jean Marinescu (EPP).

**Slovakia:** Ivan Stefanc (EPP).

**Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Tanja Fajon (S&D); Klemen Grosšelj (ALDE); Irena Joveva (ALDE); Romana Tomc (MEP); Milan Zver (EPP).

**Spain:** Izaskun Bilbao Barandica (ALDE); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens/EFA); Ernest Urtasun (Greens/EFA).

**Sweden:** Jytte Guteland (S&D); Peter Lundgren (EFD).

**United Kingdom:** Martina Anderson (GUE/NGL); Theresa Griffin (S&D); Jude Kirton-Darling (S&D); Claude Moraes (S&D); Rory Palmer (S&D); Alyn Smith (Greens/EFA); Julie Ward (S&D).

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.

10 December: Four MEPs represented at the Alzheimer Europe’s lunch debate

Alzheimer Europe (AE) would like to thank MEP Sirpa Pietikäinen (Finland) for hosting its lunch debate on in Brussels on 10 December. We would also like to thank Dominique Riquet MEP (France) for attending the lunch debate, as well as representatives of the offices of MEPs Matt Carthy (Ireland) and Younous Omarjee (France) for their participation.

All MEPs present or represented are current members of the European Alzheimer’s Alliance (EAA) - a non-exclusive, multinational and cross-party group of MEPs supporting AE and its members in making dementia a public health priority.

You can read a summary of the lunch debate in the Alzheimer Europe section of this newsletter, on page 2.

You can find out more about the European Alzheimer’s Alliance, here:

https://www.alzheimer-europe.org/Policy-in-Practice2/European-Alzheimer-s-Alliance
10 December: Two new MEPs sign up to the European Alzheimer’s Alliance

Alzheimer Europe is delighted to announce that in December, Tsvetelina Penkova MEP (S&D, Bulgaria) and Dominique Riquet MEP (Renew Europe, France) have agreed to join the European Alzheimer’s Alliance, taking the total number of members of the EAA to 98. We are pleased to have the support of Ms Penkova and Dr Riquet, and we look forward to working with both of them during the coming parliamentary term to make dementia a European priority.

EU DEVELOPMENTS

28 November: EU Joint Programme - Neurodegenerative Disease Research (JPND) organises international scientific meeting

On 27 and 28 November 2019, leading researchers and stakeholders from 51 JPND supported projects on neurodegenerative disease research gathered at the Royal Flemish Academy of Belgium for Sciences and the Arts, in Brussels, for the JPND1 /JPco-fuND2 Symposium. The aim of the meeting was to disseminate up-to-date research achievements from the projects, to liaise, exchange knowledge and network.

JPND Chair, Professor Philippe Amouyel opened the conference. Project topics presented ranged from Alzheimer’s to Parkinson’s diseases to rarer diseases such as Huntington’s disease, Amyotrophic Lateral Sclerosis (ALS), Prion disease, Spinal Muscular Atrophy and Spinocerebellar Ataxia.

Chris Roberts, Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD) and his wife, Jayne Goodrick attended the event and took part in a panel session (pictured). Jean Georges, Executive Director of Alzheimer Europe was also in attendance at the event.

28 November: European Commission publishes Country Health Profiles

The European Commission has published Country Health Profiles (CHPs) for 30 countries as part of its “State of Health in the EU” programme.

The CHPs provide an in-depth analysis of health systems, looking at the health of the population and important risk factors, as well as the effectiveness, accessibility and resilience of health systems in each Member State.

The profiles have been published alongside a “Companion Report” which shows some of the main trends in healthcare systems, as well as drawing conclusions from the profiles. Some of the key findings include:

- In the digital transformation of health promotion and disease prevention, people who may benefit most from mobile health and other digital tools, may be the least likely to have easy access to them it.
- Gaps in health care accessibility still exist – both the clinical need and socioeconomic characteristics of patients need to be accounted for when measuring access to health care.
- The skill mix of health professionals has the potential to increase the resilience of health systems e.g. by enhancing the role of nurses and pharmacists.

An abridged version of the findings can be found at: https://ec.europa.eu/commission/presscorner/api/files/attachment/858932/EU%20State%20of%20Health%202019%20factsheet.pdf.pdf


3 December: European Disability Forum issues statement on disability and poverty

The European Disability Forum has issued a statement to coincide with the International Day of Persons with Disabilities (3 December), highlighting that 28.7% of people with disabilities living in the EU are in, or at risk of, poverty.
The EDF noted that persons with disabilities are more likely to be in poverty or unemployed than persons without disabilities, as well as facing additional day-to-day living costs. It is also explained that the poverty is greater for people in rural areas, women, younger people and minority ethnic groups.

The statement highlights that since 2010 the rates of people with disabilities who are in or at risk of poverty has increased in 11 countries: Czech Republic, Estonia, Germany, Ireland, Italy, Lithuania, Luxembourg, Malta, Netherlands, Spain and Sweden.

The EDF calls on the European Union, as well as national and local authorities for stronger measures to fight the poverty of persons with disabilities, including:

- Fixing disability assessment by following an approach that looks at a combination of impairment, functional, social and environmental considerations.
- Stopping the “benefits trap” by ensuring disability benefits provide a stable, liveable income.
- Investing in support structures and services through housing-first solutions that allow people with disabilities to live in the community, as well as improving the accessibility of mainstream services.

The statement concludes by calling on the EU and Member States to honour their commitments under the UN Convention on the Rights of Persons with Disabilities (UNCPRD) to ensure that all persons with disabilities are able to live with dignity in the community, with equal access and rights.

4 December: Council of the European Union reaches agreement on Horizon Europe synergies

The Council of the European Union has agreed a partial general approach in relation to Horizon Europe and its synergies with other EU programmes. 14 cross-over areas have been identified, of which three have a particular relevance for dementia policy and research:

- The European Regional Development Fund, which aims to develop regional economies and has a particular emphasis on research, innovation, and technological development
- The European Social Fund Plus, which will pull together a variety of existing programmes to boost employment, job quality and public health
- The Digital Europe Programme, which will see the EU buy advanced digital technologies like AI and high-performance computing and make them available to small businesses and universities.

The agreement will enable the Council to begin negotiations with the European Parliament with a view to adopting the regulation once an agreement is reached on the next multiannual financial framework (MFF). You can read the full text of the agreement at:


10-11 December: Governmental Expert Group on Dementia meets in Brussels

The European Group of Governmental Experts on Dementia held its third meeting on 10 and 11 June 2019 in Brussels, Belgium. 15 European countries were represented at the meeting, in addition to representatives from the 2nd Joint Action on Dementia (Act on Dementia), the World Health Organization (WHO) and Alzheimer Europe.

Over the course of the two-day meeting, the group heard about national programmes of work, as well as European and international workstreams.
The WHO also updated members on the progress made in implementing its “Global action plan on the public health response to dementia 2017-2025”, including progress on the implementation of the Global Data Observatory and the knowledge exchange platform. The group also heard about the first bi-regional workshop on dementia which took place in September 2019.

The first thematic topic discussed by the group related to palliative care, with countries sharing their experiences of implementing policies to ensure that high quality palliative care was accessible for people with dementia and appropriately responded to their needs. Additionally, Professor Lieve Van den Block, the coordinator of the Palliative Care for Older People in care and nursing homes in Europe (PACE) project, presented the findings and policy recommendations following the completion of the project.

The second major theme concerned the use of data registries of people with dementia. As part of this work, Dr Lewis Killin of the University of Edinburgh provided an overview of different data registries in the UK, including providing an overview of the Scottish Brain Health Register, which aims to understand population level trends in brain health, ease research participation and improve clinical care.

The group also heard from the second Joint Action on Dementia which had recently published its conclusions and findings, as the project entered its dissemination phase. The four work package areas covered diagnosis and post-diagnostic support; crisis and care coordination; residential care, and; dementia-friendly communities. The group will meet again in June 2020 in Brussels, Belgium.

On 8 and 9 November 2019, Spominčica (Alzheimer Slovenia) organised the 11th International Conference on Dementia (ASK 2019), entitled “Let’s change the view on dementia”. The event was held at the Perla conference centre in Nova Gorica and brought together local and foreign experts from Belgium, Switzerland, Hungary, Poland, Romania, Italy and Croatia, to present the latest news, achievements and examples of good practice in the dementia landscape.

Some of the topics addressed at ASK 2019 were: Relationships and dementia; Comprehensive treatment; Rights and protection of people with dementia; Innovations in the field of dementia; Safety of persons with dementia; Autonomy and neuropsychological rehabilitation; ICT support for care and treatment (the IONIS project was presented, which consists of a consortium from six European countries; and a transnational meeting of IONIS was also held); Timely diagnosis (the MOPEAD project was presented); palliative care; national awareness-raising campaigns; Slovenia’s “Dementia Friendly Spots”; Incontinence and dementia; and many others.

The conference took place under the auspices of the Prime Minister of the Republic of Slovenia, Marjan Šarec. The most successful aspect of ASK 2019, was its parallel sessions, during which the participants had the chance to participate in some of the parallel sessions.
which participants had the opportunity to attend practical workshops on areas such as relaxation techniques for caregivers, cognitive training, maintaining the autonomy of people with dementia, psychosocial interventions for people with dementia, music, dance and art workshops for people with dementia, sedentary yoga for people with dementia, and finally a Tai Chi Qigong workshop for people with dementia.

11 November: Alzheimer Scotland celebrate 90,000 Dementia Friend milestone

As one of the biggest social action movements to change the perception of dementia, Alzheimer Scotland celebrated a major milestone by reaching 90,000 people becoming a Dementia Friend, one for each person living with dementia in Scotland. Dementia Friends Scotland aims to transform the way the nation acts, thinks and talks about the condition, as well as challenging the stigma of dementia, which still exists for thousands of families living with the illness. Introduced in 2014, the initiative has gone from strength to strength engaging with individuals, communities and businesses across the nation.

Welcoming Dementia Friends Scotland’s latest milestone, Henry Simmons, Chief Executive of Alzheimer Scotland, said: “When we introduced the Dementia Friends initiative to Scotland in 2014, we could never have imagined that by this year we would have reached 90,000 Dementia Friends. It is simply remarkable that so many people in Scotland have become a Dementia Friend, each and every one them playing their part in building a dementia-friendly Scotland and sending a message of support to their fellow citizens who are living with dementia that they care about them.

“It is reassuring, but not surprising, that so many individuals throughout Scotland are willing to make their mark by becoming a Dementia Friend. When we ask the Scottish public for their support we are never let down and this has been exemplified by their support for this movement and by the remarkable number of people who have supported our Fair Dementia Care Campaign, turned out for our Memory Walks, volunteered in our localities and Helpline, signed up to participate in research and helped raise funds to support our work.

“We owe all of our Dementia Friends and supporters a huge debt of gratitude and on behalf of everyone at Alzheimer Scotland, I would like to express our most sincere thanks for helping us achieve this milestone and we look forward with hope to achieving many, many more.”

The Dementia Friendly initiative aims to give people more insight into the condition and the real challenges people living with dementia face. It demonstrates the small changes that can often make a big difference to people living with dementia such as adapting how you speak, giving clear information, removing some of the challenges that can cause confusion and changing behaviour - such as simply being patient in a queue. Find out about dementia and what’s it’s like to live with the condition by becoming a Dementia Friend at www.dementiafriendsscotland.org

27 November: Social Cluster Association wins prestigious Trademarks Prize in Hungary

Every year, the highly regarded “21 Women for Health Foundation” of Hungary holds an award ceremony to celebrate new prize-winning trademarks. This year, the event took place on 27 November and the focus was on a healthy environment. It was a wonderful event celebrating dedicated people working in the field of healthcare.

The awarded programmes all seek out the most important problems in society and try to develop solutions. There is clearly a strong need for good programmes to spread health education and health awareness, but often in the noise of big media the truly credible initiatives are not noticed or recognised. The Foundation tries to achieve some balance through its trademarks prize.

The 2019 winners included “Dementia Hours” by the Social Cluster Association, which provides information hours about understanding dementia and how to care properly for people living with dementia. Other winners included The Green Mature Women Community: mothers who have built communities for thousands of people in need; Nutricia Home Care Service - the only initiative in Hungary to provide assistance for tube-feeding in nursing homes; and a pharmacist who investigates and publishes false promises of medical products.

Anyone can apply for the Trademark Prize, or designate any organisation, programme or association that provides professionally credible solutions to meet the needs of society. It can be a small community, a professional programme, a dedicated professional initiative working anywhere in the country or even across the border. It is important to know about these programmes and share their knowledge to help improve our everyday lives.
Runners from 106 countries and all around Turkey participated in the 41st edition of the Istanbul Marathon, held under the banner "Istanbul is Yours, Don’t Stop, Run". It is regarded as one of the best marathons in Europe, with a route connecting the Asian and European continents, crossing a bridge over the Bosphorus strait. Participants competed in three categories: the full 42 km marathon, a 15 km race and a public run, which was held on an 8 km route.

The marathon primarily aims to attract runners who compete for charities. Last year, charities collected a total of TRY 12.1 million (EUR 1.8 million) in donations and this year this amount reached TRY 17.3 million with 13,286 runners collecting donations from 153,938 donors, which will serve to help 21,697 living beings, (trees, animals, humans, etc.)

The “Adım” (“Step by Step”) initiative is a volunteer-based social initiative in Turkey. Established in 2007 by six social entrepreneurs, it was founded in order to motivate Turkish citizens who did not have the inclination to raise money for a charitable organisation of their own choice, to help address urgent social problems. At that time, nearly 90% of charitable support for non-governmental organisations (NGOs) came from corporate or institutional donations, and NGOs struggled to engage grassroots support for their initiatives.

For the first 8 years, Adım operated within a core group of 8 NGOs. In 2016, they decided to expand. At this point, Türkiye Alzheimer Derneği (the Turkish Alzheimer association) joined Adım, in order to benefit from charitable donations given through the sponsorship of athletes in local sports events. All stakeholders - fundraisers (runners), donors, and NGOs - were connected via a comprehensive online platform.

There are stringent conditions to become a member of this platform: a transparency manifesto must be signed; the NGO’s balance sheets for the last three years must be published on the web; and finally, it is necessary to present a project for the marathon, with all financial details.

This year, the Turkish Alzheimer association proudly announced its participation in its 5th consecutive marathon. 127 runners collected approximately EUR 56,000 from 2,192 donators. Over the five marathons, 787 runners have collected a total of EUR 154,000. The first two marathons raised funds for home care services and the last three have raised funds for the daycare centre in Istanbul.

In Bosnia and Herzegovina, less than 3% of those affected by dementia are actually diagnosed. The rate of diagnosis through the initiative of the national primary health care system is extremely low due to lack of funding and attention. Udruženje AiR, the Alzheimer’s association in Bosnia and Herzegovina, has promised to increase this diagnosis percentage.

At the beginning of October, the Association published a handbook entitled “Dementia from the angle of Primary Health Care”. It marks the beginning of an ambitious project to increase the country’s dementia diagnosis rate.

The Association has also organised successful masterclasses (pictured) for GPs and nurses. There is an urgent need to have up-to-date information about dementia, in the areas of prevalence, causes, types, medical therapies, the importance of the non-pharmacological post-diagnostic support, and palliative care. As part of this training, certain protocols have been developed which show the need to prepare personal disease progression histories for each patient, in preparation for accurate diagnosis. To date, 2 masterclasses have been organised and attendance was high, at 250 participants, showing the level of interest in this type of training. Each participant received a free handbook to use as a reference guide in their daily work.

Spominčica (Alzheimer Slovenia) is a partner in a new Erasmus+ project, called Super Lingo. The project consortium consists of five European countries: Scotland (Lingo Flamingo), Ireland, Slovenia, Greece and Romania.

The kick-off meeting took place in Dublin, Ireland on 28 and 29 November 2019. Project partners will develop linguistic memory games and role-playing games for older adults with Subjective Cognitive Decline (SCD) or Mild Cognitive Impairment (MCI). The games aim to help them enhance their
cognitive functioning, and to assist users in acquiring new knowledge of foreign languages.

Alzheimer Slovenia will carry out focus groups, where they will find out which way of studying foreign languages is the most convenient, suitable and what are the potential benefits for choosing specific methods of learning.

Bilingualism can delay the onset of dementia by up to five years, says Alzheimer Slovenia, and research is actively being done into the areas of foreign language training as cognitive therapy, impacting decision-making, multitasking, concentration and communication.

2 December: Deutsche Alzheimer Gesellschaft organises conference on dementia and migration

In Germany, approximately 108,000 people living with dementia come from a migrant background. Along with their family carers, these people often have difficulties gaining access to the healthcare system.

At a conference organised by the German Alzheimer association Deutsche Alzheimer Gesellschaft (DAlZG) on 2 December 2019, the question of how support could be better opened up for people from a migration background and how more information and education can be provided, was discussed in depth.

An important finding of the meeting was that it is not about looking at migrants as a closed group, but that each individual and their family must be considered individually, along with existing needs and resources. In addition to gender, education, religion or social class, culture is just one criterion that shapes people. The combination of these different characteristics is crucial as it can inhibit or encourage the activation of self-management skills. It quickly becomes clear that, in general, people have very few differences that matter and in fact have a great deal in common, points out DAlZG. Nevertheless, access to individual target groups remains different.

The conference, held in Berlin, was part of the project entitled “Dementia and Migration”, which is funded by the German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth. Further information for stakeholders as well as people with dementia and a migration background is available on this website, operated by DAlZG:

www.demenz-und-migration.de

4 December: Polish Alzheimer’s Association calls on MEPs to join the European Alzheimer’s Alliance

This autumn, the Polish Alzheimer’s Association launched a call to try to increase the number of Polish members in the European Alzheimer’s Alliance (EAA). On its website, the Association writes: “We hope that Polish MEPs will increase their support and join the Alliance to more actively express their support for dementia to become a health priority.”

The EAA is a non-exclusive, multinational and cross-party group that brings together Members of the European Parliament (MEPs) to support Alzheimer Europe and its members in making dementia a public health priority in Europe.

The number of EAA members currently stands at 97, of which only 2 are from Poland, out of a possible 51 MEPs representing the country in the European Parliament. The two current members are Elżbieta Łukacijewska and Jan Olbrycht.


5 December: Societatea Alzheimer Romania participates in project on the use of creative arts and storytelling for people with dementia

The first output from this project is a booklet entitled “Creative Drama and Storytelling in Dementia Care: Information for Practitioners”. This booklet provides an overview of how creative drama and storytelling are being used within the dementia care field and the benefits they may have for the well-being of people living with dementia and their care partners. It draws on theoretical understandings of social inclusion, to illustrate how researchers and practitioners across the globe, including within the ERASMUS partner countries, are using these creative initiatives to promote this important facet for people affected by dementia. The booklet is aimed at dementia practitioners who are currently using drama and storytelling within their practice or have an interest in doing so in the future.
The booklet is divided into four chapters. The first provides an overview of dementia and the current global political focus on supporting people to live well with the condition, paying particular attention to the social inclusion agenda and developing dementia-friendly communities. The second chapter discusses the use of creative drama and storytelling within the dementia care field, focusing on where these initiatives are currently being employed, how they are being used, as well as the benefits for people with dementia and the wider social inclusion agenda. The third chapter provides an overview and examples of creative drama and storytelling initiatives within each of the partner countries. The final chapter draws comparisons across the ERASMUS partner countries and summarises the information contained within the booklet. Based on these conclusions, it then outlines recommendations for policy and practice within this field.

Cătălina Tudose, President of the Romanian Alzheimer society (Societatea Alzheimer Romania) advises that: “The focus of care must be on the needs of the whole person and the family, as perceived by the individual, at that point of time in their lives. Instead of expecting the person with dementia to ‘function’ in our world, through these therapies we will validate their experience of the world.”

In coordination with the ERASMUS+ partners, the booklet was prepared by the Ageing and Dementia Research Centre (ADRC) at Bournemouth University, UK and can be found at:

www.story2remember.eu

The booklet has been translated into Romanian, Bulgarian and Greek and can be downloaded from the project website:


5-6 December: Alzheimer Croatia holds 5th educational conference on Alzheimer’s disease “EdukAl 2019”

EdukAl 2019, an educational conference on Alzheimer’s disease, was the 5th consecutive annual conference successfully organised by Alzheimer Croatia. The event achieved a record number of speakers and poster presentations. The conference also attracted increased international attention. The two-day conference, on 5 and 6 December 2019, was attended by 250 participants, with more than 100 presenters from Croatia, Bosnia and Herzegovina, Montenegro, Slovenia and Serbia presenting 40 papers on news in the fields of medicine, social work, psychology, physical and occupational therapies, as well as caregiver and nursing skills.

Conference participants reiterated their plea to the Government of Croatia to start the process to create and adopt a national dementia strategy. They also called on the relevant government ministries to improve the regulations governing the recognition of disabled persons with dementia and to simplify the route by which family caregivers can obtain official carer status.

In a feedback survey on the value of the conference, two-thirds of participants said that they would return to EdukAl next year and almost 90% expressed the opinion that they would recommend it to their colleagues and friends. The EdukAl 2019 conference was supported by Alzheimer’s Disease International, Alzheimer Europe, the Croatian ministries for health, demography and social affairs as well as the Municipal City of Zagreb.

11 December: Slovak Alzheimer’s Society looks back at its main activities in 2019

Focus on general public: Brain Week

2019 was the 12th year of the World Brain Week campaign. The Slovak Alzheimer’s society (Slovenská Alzheimerova spoločnosť) organised campaign events involving 194 organisations and 8,027 participants from all regions of Slovakia. A wide range of activities took place, aiming to improve understanding of the functioning of the brain and also to explore the possibilities of stimulation and development of the brain at any age. Open days, creative workshops, lectures and discussions were carried out by medical facilities, schools, libraries, facilities for older people, non-profit organisations, and regional public health authorities.

Focus on professionals: International conference on non-pharmacological interventions

In September, for World Alzheimer’s Month, in what has now become a tradition, the Slovak Alzheimer’s society organised the conference “Senior’s training and non-pharmacological intervention for Alzheimer’s disease”. Over 2 days, 132 participants took part in 16 lectures and 8 workshops. These are the numbers from the 11th year of this conference. Each year, the conference provides a great opportunity to exchange up-to-date information in the field of non-pharmacological interventions, among professionals from the health and social sectors.

Focus on families: Support of family caregivers

An important focus of the Slovak Alzheimer’s society is providing support for people with dementia and their families. Currently, in seven regions of Slovakia, dementia support groups are regularly organised for family caregivers of people with dementia, by volunteer workers from the Slovak Alzheimer’s society. Also, education for family caregivers was developed by workers at the SAS-MEMORY Centre, which
created videos and organised face-to-face workshops for family caregivers who are providing home care for people with dementia.

http://www.centrummemory.sk/alzheimerforum/index.html

15 December: Alzheimer Croatia develops the first dementia-friendly nursing school in Croatia

Alzheimer Europe

Alzheimer Croatia reports that Vrapče Nursing School in the municipal City of Zagreb became the first dementia-friendly school in Croatia, in early December 2019. The association has kick-started the process of creating the first dementia-friendly generation of students and fully educated specialists in dementia care in Croatia.

Alzheimer Croatia has a longstanding and fruitful collaboration with this unique school. Their members lead lectures and workshops in the school and as a return gesture, the students provide volunteering assistance during various events aimed at raising public awareness of dementia. Almost all of the students are Dementia Friends and have set up their own school club.

The curriculum of this five-year nursing school is divided into two parts. The first two years are general and aligned with the compulsory high school programme, and the next three years are devoted to vocational education. It is planned that basic knowledge about dementia will be achieved during the first year of education, and professional education programmes for future nurses and technicians will be supplemented with topics related to the recognition of dementia and ways of caring for people living with this disease.

16 December: Foundation Compassion Alzheimer Bulgaria continues its mission to provide information and support, with funding from the Waldensian Church

The Waldensian Church receives public funds through Otto per Mille ("eight per thousand") law in Italy, for the purpose of social programmes, both within Italy and abroad. Italian citizens have the option to donate 0.8% (or an eight-per-thousand portion) of their annual taxes to a charitable organisation of their choice.

With the support of funds from the Waldensian Church of Italy, Foundation Compassion Alzheimer Bulgaria has implemented a project in the cities of Sofia and in Varna, to provide centres for information and support for people with Alzheimer’s disease or dementia. The main objective of this project is to provide much-needed services, including psychological and legal consultations for the families and people living with dementia, but also to implement awareness-raising activities. Monthly project activities, including Alzheimer cafés and self-help groups, are important tools for social support.

As part of this project, the Foundation recently visited the buildings of the Italian organisation, Rifugio Re Carlo Alberto, which includes a nursing home for people living with dementia and a day care centre. In May 2019, in the city of Varna, the Italian Rifugio team conducted a training session for practitioners engaged in the work of providing settings and services for people with dementia. The Rifugio team also presented the Italian experience about the services provided at the day care centre and their work in the community. In order to further this cultural exchange of ideas and experience, a second training will be organised in Bulgaria in the first half of 2020.

Thanks to various media events, the Foundation continues to spread the message for the urgent need for adequate policies and services for people living with dementia. The Foundation takes part in a working group to map strategic directions for the improvement of the diagnosis, prevention and treatment of dementia, in line with the 2020 Bulgarian National Health Strategy. This work group is composed of representatives of various institutions, experts and NGOs.

18 December: Alzheimer’s Society celebrates being “United against dementia” for 40 years

Alzheimer Europe

Alzheimer’s Society celebrated its 40th anniversary on 6 November 2019. It was founded as the then Alzheimer’s Disease Society in 1979, by a small group of determined volunteers who shared an ambition to make life better for care supporters of people living with dementia. This group of volunteers, which has now grown to over 20,000, together with the employees of Alzheimer’s Society, is challenging perceptions of dementia, funding research and providing vital care and support. The Society is united in the aim of reaching everyone affected by dementia, so that no one will face dementia alone. Dementia is now recognised as the UK’s biggest killer. There were only 3,021 recorded deaths in 1979, in 2017 there were over 76,000. With 850,000 people estimated to have the condition, dementia is the biggest health and social care
challenge faced by UK society, and Alzheimer’s Society is committed to defeating it.

Alzheimer’s Society’s has created over 3 million Dementia Friends and over 400 dementia-friendly communities where people feel understood, respected and supported and can continue to live in the way they want to and in the community they choose.

Alzheimer’s Society also hosts the Global Dementia Friends Network, supporting countries to develop their own Dementia Friends programmes and fostering a global network. There are over 60 Dementia Friends programmes in more than 50 countries and 18 million Dementia Friends, raising awareness and reducing stigma around dementia on a global scale.

In 1990, the Society established its own research programme and has invested more than GBP 60 million (EUR 70.5 million) in over 400 research projects and funded hundreds of researchers. Alzheimer’s Society is committed to investing at least GBP 15 million (EUR 17.6 million) over the next decade including GBP 50 million (EUR 59 million) for the ground-breaking UK Dementia Research Institute, co-founded in 2015. The Society’s national services, including the Helpline, Talking Point online community, local service finder and publications, are accessed over 2.7 million times a year. Alzheimer’s Society’s new Dementia Connect service will connect people with the right support, at the right time, in the right way.

In 40 years’ time, more than 2 million people will have dementia in the UK. Alzheimer’s Society wants to ensure those living with the condition have the care they need by providing simple and universally accessible support for everyone affected by dementia.

Morella Kayman MBE, co-founder of Alzheimer’s Society, provides a personal account on: www.alzheimers.org.uk/blog/morella-kayman-husband-lawrence-40-years-alzheimers-society

18 December: Greek Alzheimer society in Chalkida organises in-home care services in rural areas

Since 2009, the Greek Society for Alzheimer Disease and Dementia-related Diseases of Chalkida has been spreading useful knowledge in order to improve the quality-of-life of people with dementia, caregivers and families.

In May 2018, they started an innovative psychoeducational “In-Home Care Program” for 56 families of people with dementia, using a grant from the TIMA Charitable Foundation. Professionals engaged in this programme are: a project manager, a social worker, a psychologist, a physical therapist and a nurse. The team visits families with mobility and socio-economic problems, every week, to discuss care planning, hygiene, physical exercise and supporting caregivers to prevent issues such as depression.

Today, the “In-Home Care Program 56 PLUS” is in progress for a total of 96 families (including follow-up) until October 2020.

During September 2019, a “Dementia Consult Mobile Station” was launched, as part of the Program, in order to support people with dementia in rural areas of North and South Evia. The Mobile Station maximises the impact of the Program, offering early-detection of memory deterioration. Families have difficulties detecting early signs of dementia and there is fear and stigma about memory loss too. Mobile services are a good way to allow people in rural areas to consult a mental health professional, in order to assess memory deterioration and potential negative consequences. Early detection can also be a good way to reassure people who are afraid of memory loss, says the Chalkida society.

In order to provide high-quality memory support services, the Society contacted local authorities and established partnerships using town halls in two towns and one village. The “Dementia Consult Mobile Station” serves about 30 families per month.

18 December: Alzheimer’s Society celebrates 2019 Dementia Friendly Awards in England, Wales and Northern Ireland

Alzheimer’s Society’s Dementia Friendly Awards ceremonies took place in November 2019, with the Northern Ireland ceremony in Belfast on 25 November and the England and Wales ceremony in London on 27 November. The awards celebrated people, organisations and communities who make a real change to the lives of people with dementia.

Around 150 guests attended both ceremonies including finalists, judges, special guests and sponsors. The England and Wales awards were hosted by journalist Jane Moore and in Northern Ireland, they were hosted by Alzheimer’s Society Ambassador and television personality, Sarah Travers.

There was an exceptionally high standard of nominations this year across England, Wales and Northern Ireland, Alzheimer’s
Society said, with 500 nominations received. Industry judges and judges affected by dementia had a very difficult job to shortlist the nominations down to the 10 award categories and choose the winners.

Amongst the inspirational winners in England and Wales was the Lifetime Achievement Award celebrating the 40th Anniversary of Alzheimer’s Society which went to Morella Kayman MBE, Dr Anne Hunter OBE and Professor Gordon Wilcock, founders of the then Alzheimer’s Disease Society, in 1979.

In Northern Ireland, the Lifetime Achievement Award went to Liz Cunningham, who has transformed the landscape of dementia in Northern Ireland since her diagnosis 10 years ago at the age of 48.

Awards host and journalist, Jane Moore, said: “I’m delighted to have hosted this year’s Dementia Friendly Awards 2019 in London. This year’s awards celebrated individuals, organisations and communities leading and inspiring a change that will transform the lives of people living with dementia across the country forever, challenging misunderstandings, changing attitudes and taking action. My own mother-in-law had dementia so I understand what a heart-breaking condition it can be, stripping people of their memories. All of the winners and nominees have done incredible and inspiring work to help people living with dementia and they should all be incredibly proud.”

More details on the awards and a full list of winners can be found online at:

alzheimers.org.uk/dementiafriendlyawards

18 December: BRIDGE project organises workshops for people with dementia and young people in Greece, Romania and Italy during 2019

The Panhellenic Federation of Alzheimer’s Disease and Related Disorders is the coordinator of the Erasmus+ KA2 project entitled “BRIDGE”. In the first phase of this project, three important workshops were organised.

The coordinator of the Bridge project in Greece organised a 2-day workshop in May 2019. A variety of people were involved: 3 healthcare professionals, 3 game designers, 3 caregivers, 13 older people and people with dementia, and 14 young people as volunteers. All 36 participants gave positive feedback not only for the well-organised sessions, but also for the chance to collaborate with different people and to exchange ideas and feelings. The final outcome of this collaborative workshop was that three new games were created.

On 29 and 30 May, in Elias Hospital in Bucharest, a co-creation workshop took place, organised by Asociatia Habilitas-CRFP, within the framework of the BRIDGE project. The participants included people with dementia, carers, healthcare professionals and young volunteers, who all worked together to create five new “serious games” which target the improvement of different cognitive areas.

In Carpi, on 13 May, Anziani e non solo (ANS) organised a workshop focusing on caregiving issues. A follow-up workshop was also organised for “Caregiver Day”, on 21 May. 13 people took part in the first workshop: 8 healthcare professionals, 2 game designers, 2 young volunteers and 1 carer. Participants were divided into 3 groups and began the day by playing existing games. All participants took part in the games, had fun playing and challenging themselves and the other participants. The atmosphere was relaxed and playful. During the workshop, three new concept ideas were developed: two were physical games and one was a digital game. During the follow up workshop, 32 people attended, 7 of whom were carers of people with dementia. During the second workshop, the concept ideas (developed during the first workshop) were presented and feedback was collected in order to re-design or improve them.

https://projectbridge.eu/

19 December: Scottish missing person app for people with dementia hits 10,000 downloads

Purple Alert, the first app of its kind in the UK which helps find people with dementia when they are lost reached 10,000 downloads on World Alzheimer’s Day (21 September 2019).

Developed by Alzheimer Scotland, in partnership with Police Scotland and partners from across the public sector, the Purple Alert app is designed to support the families and carers of people living with dementia during an immediate missing person search.

The app supports a Police Scotland’s National Persons Unit search, by sharing key information about the missing person at the point of crisis and alerts all users of an active local search, aiding to more eyes and ears on the ground helping with the search. Since going live in 2017, the app has assisted with 13 missing person searches resulting in all being found safe and well within four hours.

Joyce Gray, Deputy Director of Development for Alzheimer Scotland said: “As people age in a digital world we must be ready to provide solutions that enter seamlessly into their existing lives. From the outset our aim was to create a solution
for when someone with dementia fails to return home or becomes missing. It’s a really distressing time for families, so having vital information to hand relieves some of that pressure and helps focus searches on places that are meaningful to the individual concerned.

“We have been blown away by the reaction to the app from families and communities who have downloaded the app or came on board to help us share information about the app since going live. To reach 10,000 downloads ahead of our two-year anniversary on World Alzheimer’s Day, was a big success for us as we continue with our vision to unify communities and help create a dementia-friendly Scotland where nobody faces dementia alone.”

Purple Alert is a free-to-download app for iOS and Android smartphones enabling information to be shared at the touch of a button to empower communities to raise an alert and share information of a missing person.

To find out more about Purple Alert or to download the app, visit: purplealert.org.uk

POLICY WATCH

30 November: Ireland’s Health Service Executive publishes implementation evaluation of Dementia post-diagnostic Support Scheme

To increase staff capacity to deliver dementia post-diagnostic supports (PDS) and to make them more equitably available, the Irish National Dementia Office (NDO) recently ran a PDS grant scheme. The scheme is part of a broader dementia post-diagnostic programme of work which supports the implementation of the National Dementia Strategy.

Following a review of the literature, the grant scheme focused on three interventions - cognitive stimulation therapy (CST), cognitive rehabilitation (CR) therapy and psychoeducational (PE) interventions. An open competition was held and grants covering staff costs were awarded; with a geographical spread across the country.

An independent evaluation of the PDS Grant Scheme focused on issues related to: intervention implementation; the subjective impact of interventions for participants; and how these programmes address the post-diagnostic care/support gap.

Data was collected between January and June 2019, across 17 sites implementing 19 PDS interventions:

- The number of people participating, across 7 CST programmes was 89 people with dementia (not applicable for carers)
- The number of people participating, across 6 CR programmes was 80 people with dementia and 64 family carers
- The number of people participating, across 6 PE programmes was 63 people with dementia and 63 family carers
- The total number of people with dementia participating in the 19 programmes was 232 and the total number of family carers participating was 127.

The findings show that implementation was impacted by the:
• confluence of staff experience, skills, readiness and know-how;
• choice of intervention - adopting an existing intervention or developing a new one;
• embeddedness of staff within their organisation and within the wider health system;
• management support;
• local context e.g. level of demand among people with dementia;
• need for ongoing supervision, mentoring and feedback for less experienced staff.

The vast majority of participants rated interventions very positively. They particularly welcomed the focus on social interaction and peer support within group interventions e.g. CST and CR. For group CR it was also more cost effective.

Further investigation is needed to assess efficacy where there were adaptations to existing models, specifically in the case of CST, where all grant sites made changes.

Evidence on the impact of PE is less well established. Developing new PE programmes took significant time and resources; requiring high levels of expertise. Although the "Next Steps Guidance Document on Psychoeducational Programmes", was an important and practical tool to guide programme development.

As a result of the evaluation findings, all grant sites that wished to continue their programmes into 2020, have received co-funding to do so. The findings are also informing the content of a National Dementia Post-diagnostic Framework for Ireland.

For more information about the PDS programme contact emer.begley@hse.ie

The evaluation report is also available to download:
https://www.understandtogether.ie/Training-resources/Helpful-Resources/Publications/An-Evaluation-of-the-HSE-s-National-Dementia-Post-Diagnostic-Support-Grant-Scheme-2019-.pdf

12 December: Post-General Election Alzheimer’s Society hopes UK Government will keep promises on funding and cross-party talks

On 12 December 2019, the United Kingdom (UK) went to the polls and elected the Conservative Party into Government. The issues of social care and dementia were mentioned by the main political parties - Labour and the Conservatives.

During the election, Health Secretary Matt Hancock published an article pledging that, should the Conservatives win the election, they would increase funding for social care by GBP 1 billion per year. Additionally, he committed to implementing cross-party talks to address the need for social care reform and ensure that no one will have to sell their home to pay for their care any longer.

Once elected, Boris Johnson also promised that he would set up the cross-party talks into social care reform within the first 100 days of his administration. Alzheimer’s Society will continue to engage and pressure Government to ensure that this timetable is adhered to.

Further to this, the Conservative Government has pledged to double investment in dementia research throughout the next ten years.

Fiona Carragher, Alzheimer’s Society’s Chief Policy and Research Officer, said “This positive funding announcement would approximately double what is spent now and could make a huge difference.

"Every year dementia costs the economy GBP 34 billion. We have called for 1% of this to address the problem long term, so this announcement does fall short of that, but is still a big step in the right direction.

"Dementia research is behind other disease areas and we urgently need research to fund new drugs, but we also need to fund research into care - accompanying this with radical reform of the broken social care system."

In 2020, Alzheimer’s Society will be working relentlessly to engage officials in the Prime Minister’s Office, sharing recommendations on how new investments should be spent to best support people affected by dementia.

23 December: Alzheimer Scotland’s Fair Dementia Care campaign secures over 7,000 signatures

Alzheimer Scotland premiered a short documentary film back in October 2019 to support its Fair Dementia Care campaign. The campaign seeks to end the inequalities faced by people with advanced dementia, their families and carers, in terms of access to appropriate health care and the disproportionate impact of social care charges.

The Fair Dementia Care report highlights that dementia is caused by progressive and terminal neurological diseases, such as Alzheimer’s disease, yet people with advanced dementia do not currently have equality of access to free health care that people with other progressive and life limiting illnesses rightly have.
The short film “Dementia: the true cost” explores the experiences of three carers and has been produced in partnership with author and retired journalist, Mike Edwards, who has reported on the work of Alzheimer Scotland over the past two decades.

Alzheimer Scotland locality staff have hosted film screening and engagement events all over Scotland over the past few months to discuss the issues raised in the film and to increase public support and to date over 7,000 people have signed up to support this campaign. Two of Scotland’s political parties have also committed to include Fair Dementia Care in their political manifestos for the forthcoming Scottish Parliamentary elections in May 2021. In the meantime, Alzheimer Scotland continues to engage with the public and with politicians and other decision makers to step up the urgent need to bring about free dementia care in Scotland.

Pictured: Former First Minister Henry McLeish (left) and Alzheimer Scotland Chief Executive Henry Simmons (right)

**SCIENCE WATCH**

4 December: Study shows reduction in seizures and cognitive impairment in aged mice treated with a TGFβ inhibitor

On 4 December, Vladimir Senatorov, Aaron Friedman and colleagues reported the results of their study on blood-brain barrier breakdown in aging, showing that treatment of aged mice with a TGFβ inhibitor drug can reduce seizures and cognitive impairment. This study, which also evaluated blood-brain barrier breakdown and TGFβ signalling in the brains of aged adults, was published in the Science Translational Medicine journal.

The blood-brain barrier (BBB) is a semi-permeable barrier that separates circulating blood from the brain. It is composed of specialised vascular cells and the ‘feet’ of astrocytes, which together form a protective sheath around small blood vessels in the brain. In healthy young adults, the BBB effectively filters out blood-borne pathogens and controls the access of different molecules and growth factors to the brain. However, aging is associated with BBB dysfunction and leakiness, letting in toxic blood-borne molecules and pathogens. Previous studies in aging individuals have shown that BBB breakdown is strongly correlated with cognitive decline and Alzheimer’s disease (AD). Preventing or reducing BBB breakdown could therefore have therapeutic benefits in AD and other aging-associated conditions. However, there are still gaps in our understanding of the BBB: in particular, we don’t yet know which biological mechanisms cause BBB breakdown in old age. In this study, Senatorov and Friedman set out to evaluate BBB dysfunction in samples from aged adults and in rodent models of aging. First, they looked at BBB leakage in aging mice, checking which cell type within the BBB showed signs of dysfunction. They found that astrocytes within the BBB appeared to be particularly dysfunctional, taking up more and more albumin (a protein that circulates in the blood) as animals aged. Analysis of these dysfunctional astrocytes revealed enhanced TGFβ signalling, while functional assays showed that BBB breakdown was linked to seizure activity and cognitive impairment in aged mice.

To check whether this observation in mice could be clinically relevant in humans, the researchers performed MRI scans on 113 individuals aged between 21 and 83 years. Of these 113 individuals, they observed that over 50% showed signs of BBB dysfunction by the age of 60. Importantly, brain gene expression analysis using a publicly-available data resource showed increasing TGFβ expression from 123 individuals as they aged. Finally, the researchers returned to their animal models of aging and BBB breakdown to see whether inhibiting TGFβ signalling could be beneficial. After 7 days of treatment with a drug that inhibits TGFβ signalling, aged mice performed better on cognitive tests and had reduced seizures.

Taken together, this work indicates that preventing TGFβ signalling in astrocytes can reduce age-related BBB dysfunction in mice. It also provides tentative clues suggesting that increased TGFβ signalling may be related to BBB leakiness in humans, although it remains to be seen whether TGFβ plays a causative role in this pathological process from a clinical perspective.

https://stm.sciencemag.org/content/11/521/eaaw8283

5 December: ACADIA Pharmaceuticals presents positive topline results from Phase III clinical trial of pimavanserin

On 5 December, ACADIA Pharmaceuticals Inc. presented topline results from its Phase III HARMONY clinical trial of pimavanserin, designed to evaluate the efficacy of pimavanserin. Pimavanserin is an antipsychotic drug that is currently approved for Parkinson’s disease (PD)-related psychosis, under the trade name NUPLAZID. Pimavanserin functions by blocking the 5HT2A serotonin receptor and is classified as a selective serotonin inverse agonist.

The Phase III HARMONY trial was designed to evaluate the efficacy of pimavanserin in treating dementia-related psychosis, enrolling 392 participants with dementia (vascular, frontotemporal or Alzheimer’s disease dementia, dementia...
with Lewy bodies or dementia associated with PD) having previously experienced dementia-related psychosis. HARMONY comprised a 12-week open-label pimavanserin treatment period prior to a 26-week long randomisation period. Strong results presented by Erin Foff, Senior Director of Clinical Research at ACADIA Pharmaceuticals Inc., showed that pimavanserin had met its primary endpoint, significantly reducing the risk of relapse of psychosis by 65% during the double-blind, randomisation period. Psychotic symptoms were meaningfully reduced and pimavanserin was well-tolerated by the trial participants, with no worsening in cognition or motor symptoms. ACADIA Pharmaceuticals are now in the process of applying for FDA approval for pimavanserin, with submission anticipated in early 2020.

5 December: PREVENT-Dementia study identifies association between midlife dementia risk factors and longitudinal brain atrophy

On 5 December, UK researchers published a paper showing that dementia risk factors are associated with longitudinal brain atrophy. Brain atrophy, which involves the loss of neurons, is a common feature of many diseases that affect the brain. Findings were published in the journal of Neurology, Neurosurgery & Psychiatry.

In the published study, scientists investigated the relationship between dementia risk factors and subsequent brain atrophy in middle aged participants. A total of 193 participants aged 40 to 59 at baseline were recruited from the UK PREVENT Dementia programme and underwent an MRI scan at baseline. 168 of them had a repeat scan approximately two years after. 53% of the participants recruited in the study had a parental family history of dementia. Dementia risk factors were calculated for each participant at baseline using the Cardiovascular Risk Factors, Aging, and Dementia (CAIDE) risk score. This dementia risk score is a tool to estimate late-life dementia risk, based on midlife vascular risk factors. Longitudinal rates of brain atrophy, including the percentage brain volume change between the two scans, were measured. Findings showed that increased CAIDE score (> 6) in midlife was associated with greater rate of brain atrophy over a two-year period. No relation was found between brain atrophy and people with a parent with and without dementia. The presence of APOE ε4 was also not related to brain atrophy. In addition, the scientists reported a strong correlation between age and brain atrophy.

http://dx.doi.org/10.1136/jnnp-2019-321652

7 December: Cortexyme presents data from its Phase 1b trial of gingipain inhibitor, showing reduced ApoE fragmentation

On 7 December, Cortexyme Inc. presented data from a Phase 1b trial of its investigational product COR388, showing that participants treated with COR388 had reduced levels of fragmented ApoE proteins in samples of their cerebrospinal fluid (CSF).

COR388 is a small-molecule inhibitor of gingipains, which are proteins that are released by bacteria species (p.gingivalis) that commonly reside in the mouth. Previous studies have shown that people with bacterial gum disease have a higher risk of developing Alzheimer’s disease (AD), and that people with AD have elevated levels of gingipain in their brains, associated with infiltrating p.gingivalis bacteria. Cortexyme believe that gingipains cleave proteins such as ApoE and Tau, inducing neurotoxicity – and that inhibiting gingipains may therefore confer therapeutic benefits.

The Phase 1b trial of COR388 was designed to test the safety and initial clinical efficacy of the drug in a small number of participants with AD compared to healthy controls. In this trial, six participants with AD received a 50mg dose of COR388 twice daily for 28 days, while 3 participants received a placebo. After this dosing period, the participants who received COR388 showed substantial reductions in ApoE fragments in their CSF. Alongside, in vitro experiments showed that cells infected with p.gingivalis bacteria had much higher levels of ApoE cleavage activity. Treatment of infected cells with COR388 blocked ApoE fragmentation, suggesting that it can effectively inhibit gingipain activity in vitro.

A large, international Phase 2/3 Trial of COR388 (the GAIN Trial) is currently underway. The GAIN Trial is evaluating the efficacy, safety, and tolerability of COR388 in participants with mild to moderate AD. Top-line results are expected in late 2021.


17 December: Amylyx Pharmaceuticals announces top-line results from the CENTAUR Phase II clinical trial for amyotrophic lateral sclerosis

On 17 December, Amylyx Pharmaceuticals, a pharmaceutical company developing a novel therapeutic for amyotrophic lateral sclerosis (ALS) and other neurodegenerative diseases such as Alzheimer’s disease, announced top-line results from the CENTAUR Phase II clinical trial evaluating the safety and tolerability of AMX0035 for the treatment of ALS. AMX0035 is a combination therapy designed to prevent neuroinflammation and nerve cell death.

CENTAUR was designed as a randomised, double-blind and placebo-controlled Phase II study, enrolling participants between 18 and 80 years of age. Over a period of 24 weeks, participants received AMX0035 or placebo twice daily. The company reported that the study met its primary endpoint of demonstrating a significant treatment benefit for AMX0035 of slowing disease progression as measured by the ALS Functional Rating Scale-Revised (ALSFRS-R) in participants with ALS, as compared with placebo.
Detailed results will be presented at forthcoming conferences. Additionally, nearly 90% of the participants who completed the study were enrolled in an ongoing open-label extension study. Interim data are expected to be presented in 2020.

http://bit.ly/2ME3KGM

18 December: Eleusis reports results from Phase I trial of LSD in older healthy participants

The clinical stage life company Eleusis announced results from its Phase I clinical trial evaluating the safety, tolerability, pharmacokinetics and pharmacodynamics of low doses of lysergic acid diethylamide (LSD), a hallucinogenic drug, in older healthy participants.

The double-blind, placebo-controlled and randomised study was conducted in London. In this trial, 48 healthy participants (average age of 63 years old) received orally and repeated doses of LSD (5, 10 or 20 μg) every four days. Over a 3-week period of dosing, researchers monitored the participants’ health and the adverse events. Measures included clinical laboratory evaluations, physical and psychiatric health exams, blood pressure, heart rate, electrocardiogram, cognition and proprioception.

The company found that low doses of LSD were safe and well-tolerated, and it plans to support further clinical development of the drug for the treatment and prevention of Alzheimer’s disease. Findings were presented at the 12th Clinical Trials in Alzheimer’s Disease (CTAD) conference and published in the journal Psychopharmacology. Scientists reported that it was the first clinical trial evaluating low doses of LSD.


CTAD NEWS

The 12th edition of the Clinical Trials on Alzheimer’s Disease (CTAD) Conference took place from 4-7 December San Diego, California. In this section, we highlight some of the key research developments which were presented during the conference. The 13th edition of CTAD will take place from 4-7 November 2020, in Boston.

4 December: CTAD Lifetime Achievement Award goes to Zaven Khachaturian for his work on the foundations of AD clinical trials

On 4 December, the Lifetime Achievement Award in Alzheimer’s Disease Therapeutic Research was awarded to Zaven Khachaturian at the 2019 Clinical Trials on Alzheimer’s Disease (CTAD) conference. Zaven Khachaturian is the President of Prevent Alzheimer’s Disease 2020, as well as a Senior Science Advisor to the Alzheimer’s Association (US). He is also the Editor-in-Chief of Alzheimer’s & Dementia: Journal of the Alzheimer’s Association.

Dr Khachaturian has made many important scientific contributions to our understanding of Alzheimer’s disease (AD). Following his training in neurophysiology at Yale and Case Western Reserve University, he was one of the first scientists to propose a connection between altered calcium homeostasis and AD. He also contributed to the earliest diagnostic criteria for AD, working as Associate Director then Director of the Office of Alzheimer’s Research at the US National Institutes of Health (1977-1995).

Previous awardees of the CTAD Lifetime Achievement Award include Rachelle Doody (Global Head of Neurodegeneration for Genentech and Roche), Gordon Wilcock (Professor of Gerontology at the University of Oxford) and Bruno Dubois (Professor of Neurology at Pitié-Salpêtrière University Hospital).

https://www.ctad-alzheimer.com/lifetime-achievement-award

4-7 December: 12th Annual “Clinical Trials in Alzheimer’s Disease” Conference held in San Diego, California

Between 4-7 December, the 12th annual Clinical Trials in Alzheimer’s Disease (CTAD) conference was held in San Diego, California. Since its inception in 2008, the CTAD conference has brought together clinical researchers in academia and industry, providing a platform for delegates to share data on clinical studies, diagnostics and tools at all stages of the development pipeline. This year, over 1000 attendees from a wide range of stakeholder groups were present.

The conference was structured around five educational symposia, focused on blood pressure control and cognitive function (1), predictive platforms for advancing drug combination approaches (2), epigenetics and the BET-system in dementias (3), results from the AMBAR albumin replacement Phase 2b/3 trial (4) and AD in Down Syndrome (5). Oral communications sessions, roundtable discussions and keynote presentations were held alongside the educational symposia.

https://www.ctad-alzheimer.com/lifetime-achievement-award
At the start of the conference, the CTAD Lifetime Achievement Award in Alzheimer’s Disease (AD) Therapeutic Research was awarded to Zaven Khachaturian, acknowledging his key role in founding AD research programmes run by the US National Institutes of Health. Following the award ceremony, oral communications sessions covered the results of several high-profile clinical trials, including the RADAR Phase 2 trial of Losartan to improve brain blood flow in AD, the HARMONY Phase 3 trial of Pimavanserin for dementia-related psychosis, and the AMBAR Phase 2b/3 trial of plasma-protein replacement therapy for mild-to-moderate AD. A special hour-long session focused on the topline results from the EMERGE and ENGAGE Phase 3 trials of Aducanumab, Biogen’s candidate immunotherapy drug. Keynote lectures provided an overview of the US National Institute of Aging-sponsored clinical trials and perspectives on new frontiers for AD drug development, while roundtable discussions addressed (among other topics) how AD clinical trial design could be improved, taking into account sex and gender considerations. Jean Georges, Executive Director of Alzheimer Europe, attended the CTAD conference. Further details on the CTAD conference programme can be found here: https://www.ctad-alzheimer.com-final-program-now-available

Oral and poster abstracts can be found here: https://www.ctad-alzheimer.com/abstracts

5 December: Biogen announces topline results from the EMERGE and ENGAGE Phase III clinical trials of Aducanumab

On 5 December, Biogen presented the topline results from its Phase III clinical trials of Aducanumab, during a special opening session for day 2 of the 12th Clinical Trials in Alzheimer’s Disease (CTAD) conference. Aducanumab is an antibody that binds specifically to aggregated amyloid-beta proteins, facilitating their clearance by inflammatory cells in the brain. A previous Phase Ib clinical trial showed that Aducanumab could reduce brain amyloid-beta in a dose- and time-dependent manner, also slowing clinical decline in participants receiving monthly intravenous infusions of the drug.

EMERGE and ENGAGE were two global Phase III trials designed to validate the results of this Phase Ib trial, evaluating the safety and efficacy of Aducanumab in participants in the early stages of Alzheimer’s disease (AD). Together, they enrolled 3,285 participants with mild cognitive impairment due to AD or mild AD, as diagnosed by a positive amyloid PET scan. The two trials had identical designs and enrolment criteria, comparing monthly infusions of high- or low-dose Aducanumab or a placebo control over an 18-month period.

The presentation was particularly high-profile as EMERGE and ENGAGE were originally halted in March 2019, due to negative futility analyses that suggested neither trial would reach its pre-specified primary endpoint. However, in October 2019 Biogen and its partner Eisai announced that new data showed EMERGE had, in fact, met its primary endpoint; a subgroup of ENGAGE participants also met the primary endpoint. This turnaround was the focus of Biogen’s presentation at CTAD, which was delivered by Samantha Budd Haeberlein, VP for Late State Development at Biogen.

Dr Haeberlein started by providing an overview of the design used for the two trials, with a particular focus on the dosing regimen. In both trials, participants were titrated up to a low dose (3mg/kg) or high dose (10mg/kg) of Aducanumab or placebo. She underlined the fact that a new protocol (Pv4) was instituted in March 2017, 18 months into the trial enrolment process. The Pv4 protocol was instituted so that carriers of the ApoE4 risk allele could receive the high dose of 10mg/kg. Prior to this amendment, concerns about an adverse effect known as ARIA (amyloid-related imaging abnormalities) had meant that ApoE4 carriers could only be titrated up to 6mg/kg. However, a by-product of this protocol change was that participants who enrolled early in the ‘high dose’ arm received a lower median cumulative dose of Aducanumab over the duration of the trials (116mg/kg) compared to those who enrolled under the changed protocol (153mg/kg).

Next, Dr Haeberlein showed the final results for the primary and secondary endpoints in the EMERGE trial, for participants who completed 78 weeks on trial. These endpoints consisted of four cognitive and functional tests: CDR-SB, MMSE, ADAS-Cog13 and ADCS-ADL-MCI. In the high-dose group, there was a statistically significant reduction in clinical decline as measured by each of these scores, ranging between a 22% reduction in decline as measured by CDR-SB score and a 40% reduction in decline as measured by ADCS-ADL-MCI score. This cognitive and functional benefit of Aducanumab treatment was accompanied by reduced brain amyloid levels, as measured by PET scans. Together, these results confirmed that the March futility analysis of EMERGE was wrong, and that Aducanumab treatment did in fact confer a cognitive benefit for participants enrolled in this particular trial.

Dr Haeberlein then moved on to the ENGAGE trial results, which were much less clear-cut. In ENGAGE, unlike in EMERGE, there was no obvious benefit of Aducanumab over placebo when analysing the final cognitive test datasets from all participants who had completed 78 weeks on the trial. To understand why two identical trials could have such different results, Biogen went back to the full dataset and did a detailed analysis of the dosing regimens. Their aim was to see whether there was a difference in the total amount of Aducanumab received by participants in EMERGE (which had positive results) compared to those enrolled in the ENGAGE trial (which had negative results). In particular, they wanted to see whether the timing of the protocol change to Pv4 might account for this difference.

In her presentation, Dr Haeberlein showed that when Pv4 was initiated, ENGAGE had already recruited ~800 participants, whereas EMERGE had only recruited ~600 participants. She highlighted that for pre-Pv4 participants, 21% in EMERGE and 15% in ENGAGE received the full possible 14 doses of 10 mg/kg. After Pv4 was started, 51% in EMERGE and 47% in
ENGAGE received the full possible 14 doses of 10 mg/kg. This means that fewer participants in ENGAGE received the highest dose of Aducanumab for a sufficiently long duration; this difference may account for ENGAGE not meeting its endpoints. In other words, for Aducanumab to be effective, Biogen believes that it needs to be taken in sufficiently high doses, for a sufficiently long duration.

Biogen now plans to file a regulatory submission for Aducanumab to the US Food and Drug Administration to discuss a clinical trial with placebo. According to the release, the enrolment in ENGAGE was completed in the second quarter of 2020. Biogen now plans to file a regulatory submission for Aducanumab to the US Food and Drug Administration to discuss a clinical trial with placebo. According to the release, the enrolment in ENGAGE was completed in the second quarter of 2020.

AMBAR II trial in order to deepen and complement the concluded study.


9 December: Athira Pharma presents results from Phase I/II trial of NDX-1017 in mild to moderate Alzheimer’s disease

On 9 December, Athira Pharma, a drug development company aiming to improve human health by advancing new therapies for neurodegenerative diseases like Alzheimer’s disease (AD), presented initial data from its Phase Ia/Ii clinical trial of NDX-1017 at the 12th Clinical Trials in Alzheimer’s Disease (CTAD) conference.

The Phase Ia/Ii trial was designed as a randomised, placebo-controlled and double-blind study to evaluate the safety, tolerability and pharmacokinetics of NDX-1017 in healthy participants and participants with AD dementia. The company reported that the study enrolled 88 participants. In all treated cohorts, results showed dose-dependent and consistent changes in brain activity. NDX-1017 was reported to enhance key brain circuitry and normalise brain activity in people with mild-to-moderate AD.

“We are encouraged that we were able to show a robust and statistically significant improvement in an objective measure of a cognitive process in Alzheimer’s patients,” said Hans J. Moebius, MD, PhD, Chief Medical Officer, Athira Pharma.


LIVING WITH DEMENTIA

17 December: Idalina Aguiar, member of the EWGPWD, participates in “Musiquence” study

In December 2019, a group of students presented their innovative work in the field of technology and cognitive stimulation for the dementia population, at the 9th “Mental Health and Psychiatry” meeting in Madeira, Portugal. A novel framework was presented, to engage people with dementia. The development processes and the framework are based on several experimental trials conducted in different healthcare centres in Madeira. The framework is called Musiquence (music + sequence) and is a software tool that uses music and reminiscence cognitive-based stimulation activities to provide mental stimulation to people with dementia. Also, the framework allows healthcare professionals and informal caregivers to customise the activities to the individual’s profile in terms of multimedia content and different technology (such as desktop computers, tablets, augmented reality, and interactive tables). Currently, the framework is being used to add new knowledge regarding the effect of music and reminiscence in the dementia population. Soon, the framework will be available to the public to equip both healthcare professionals and informal carers, using novel approaches to engage people living with dementia. It was a pleasure to be a part of this study with my colleagues in “Lugar de Memórias” at the Garouta do Calhau” daycare centre, and with Alzheimer Portugal on Madeira Island. Idalina is supported by her daughter Nelida, to whom we are grateful for her help in translating Idalina’s words to English.
18 December: Tomaž Gržinič, member of the EWGPWD, gives lecture for students at Slovenian Faculty of Social Work

On 18 December 2019, I, Tomaž Gržinič, Slovenian member of the European Working Group of People with Dementia (EWGPWD), gave a short lecture for students at the Faculty of Social Work, in Ljubljana.

I was invited to share my story about how my life has changed since my diagnosis of Alzheimer’s disease. I am pleased that my thoughts and positive attitude towards life was so well-received. I was told that I literally gave the attendees goose bumps! I try to always be open-minded and optimistic and to see the future in the brightest way possible.

In my introduction, I told participants how I coped with the diagnosis and managed to reorganise my daily routine in order to live life to the fullest.

I stressed that I nothing has made me happier than realising what great friends I have. Even though orientation is still the biggest challenge, on an everyday basis I continue with my leisure time activities, just as I always have done – playing tennis, ping pong, editing magazines, hiking, painting, and gardening. Currently, I am more worried, due to changes in my medical therapy, but I remain passionate about all the things I love. I gave the students a take-home message that I believe we all should take into account: “Even with dementia life is still beautiful”.

I also told participants that I support all campaigns and awareness-raising events about dementia, but am convinced that timely diagnosis is not the only key to promote a healthy and active lifestyle with dementia. I think we should improve prevention techniques as well as improving screening tests to detect mild signs of dementia in preclinical stages. In conclusion, I said that the sooner we know what we are dealing with, the better the outcome would be.

In the closing session, a few cognitive exercises were also done. The students were impressed and grateful to hear my story and to put a face to dementia. It was an honour to be invited.

DEMENTIA IN SOCIETY

5 December: Helen Rochford-Brennan is narrator of newly-launched “hear/say” book of stories on ageing and dementia

The hear/say project began as a collaboration between the Memory and Aging Center (MAC) at the University of California, San Francisco (UCSF) and Voice of Witness, in 2016. The goal was to create a space for people with dementia, carers, doctors, family members, researchers, nurses, artists, and others to share “stories of aging, dementia, art, work, and life”. They wanted to shed light on the personal and rarely heard day-to-day experiences of ageing and dementia, and help reduce the stigma and “othering” that occurs by perpetuating a “single story”.

The project expanded in 2018 to include the Global Brain Health Institute (GBHI) and work directly with the Atlantic Fellows for Equity in Brain Health, an international cohort dedicated to protecting the world’s ageing populations from threats to brain health. The expansion also included the making of a documentary film, in collaboration with Cynthia Stone Media.

A second volume of hear/say has now been published, for which GBHI partners at Trinity College Dublin were brought in to incorporate a global perspective on healthcare, memory, and ageing. The stories in this volume contain themes of loss, love, joy, compassion and more, with Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (EWGPWD) as narrator. As part of her involvement in this project, she was filmed during the 29th Alzheimer Europe Conference in The Hague, in October 2019 (pictured). This footage forms part of the upcoming documentary.

Helen Rochford-Brennan expresses the rationale for the book, thus: “So many times people have come up and said, ‘You’re telling my story. That is how my life is, but I’ve always been afraid to say it.’ And I say to them, ‘You know, you go and become an advocate just like me because you are going to help somebody else. Your voice is just as important as my voice.’”

The book launch took place in Dublin on 5 December 2019.

The hear/say team is a collaboration between the Global Brain Health Institute and Voice of Witness which include Cliff Mayotte, Jennifer Merrilees, Lorina Naci, Caroline Prioleau, Cynthia Stone, Dominic Trépel & Erin Vong.
6 December: Alzheimer Slovenia President becomes congress ambassador and earns 2019 award for accomplishments in social care

The Association of Slovenian congress ambassadors was established in 2019 as a department of the Tourist Association of Slovenia, which belongs to the International Tourist Association. Its broader goal is to better promote Slovenia as an international congress/conference host. Moreover, the association seeks opportunities for social-networking with foreign partners, to exchange experiences, as well as ideas and innovations. It also endeavours to maintain long-lasting partnerships.

In 2019, 26 people in Slovenia were named honorary congress ambassadors. One of them was Štefanija L. Zlobec, President of Spominčica (Alzheimer Slovenia), on the basis that she has organised a number of international conferences, including the 25th Alzheimer Europe Conference (#25AEC) in Ljubljana in 2015. She is a highly active advocate in the dementia field, being involved in many roundtables and public debates about dementia; and authoring many reference texts and materials about dementia in Slovenia and worldwide.

Her special interest is collaborating with various organisations in social care and is very enthusiastic about creating dementia-friendly communities and improving post-diagnostic support for caregivers of people with dementia in Slovenia. Her boundless energy is constantly focused on developing numerous social services to make life with dementia easier.

The Ministry for Social Affairs recognised Štefanija L. Zlobec for her special achievements during 2019, in the social care field. On 6 December 2019, she received her award at the Congress Centre Brdo pri Kranju, presented by Ksenija Klampfer, Minister for Social Affairs.

EDUCATION

3 December: Free online course in “Foundations in Dementia” is available for professional and family carers

A six-week, free course, called “Foundations in Dementia” is available online, aiming to help participants to understand people with dementia and to care appropriately for them, as professional or family supporters.

The course spans six main topics, one each week:

- Week 1 - Inside the brain
- Week 2 - Assessment and treatment
- Week 3 - Law and ethics
- Week 4 - Communication skills
- Week 5 - Family and friends
- Week 6 - Living well with dementia and end of life care

It also offers insights from recent research. Some of the material is specific to England and Wales, such as the legal context and health service provision, but much of it is applicable beyond those borders.

NEW PUBLICATIONS AND RESOURCES

5 December: British Deaf Association Scotland launches resource for Deaf people with dementia who use British Sign Language

The British Deaf Association (BDA) Scotland has created a toolkit for Deaf people who use British Sign Language (BSL) and who are living with dementia, as well as their families, carers, and any staff who are supporting them. The toolkit was created by Deaf people who are carers or former carers and use BSL.

The toolkit closely aligns with BDA Scotland’s vision of ensuring equality of access and services for Deaf people living with dementia; that is; the fundamental citizenship right to language and culture.

Find out more:

Download the toolkit:

18 December: Alzheimer’s Society launches Dementia-friendly emergency services guide

Alzheimer’s Society (UK) has launched the “Dementia friendly emergency services guide”, which sets out best practice for emergency services looking to support and assist people with dementia.

In 2017, emergency services across the United Kingdom (UK) made a strategic commitment to become more dementia friendly and
Support people in their local community affected by dementia. Since 2017, 28 services have signed up to become dementia friendly and the sector now has over 35,300 Dementia Friends. The release of the guide will help support services across the country in meeting this goal.

The guide has been created alongside services across the country and with representatives from the National Police Chiefs’ Council, National Fire Chief’s Council and the Association of Ambulance Chief Executives.

The new resource sets out three areas where organisations can collaboratively develop their people, places and policies to support people affected by dementia. All emergency service providers, whether police, fire and rescue, ambulance services, or other services, may find it useful.

Jeremy Hughes, Chief Executive of Alzheimer’s Society, said: “There are 850,000 people living with dementia in the UK and this number is increasing. Having emergency services that understand the complexities of dementia and can respond to often distressed and frightened individuals is a lifeline.

“Defeating dementia will take a societal response, where individuals, organisations and whole sectors are changing the way they think, talk and act about dementia. I would encourage every other fire, ambulance and police service to take a look at our Dementia Friendly emergency services guide to create even more change.”

To download a copy of the guide visit: alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/resources-organisations/dementia-friendly-emergency-services

## JOB OPPORTUNITIES

### 5 December: Demensförbundet seeks a consultant to southern Sweden

Demensförbundet (Swedish dementia association) is looking to recruit a consultant to southern Sweden. The duties of the successful applicant will include supporting and assisting the local dementia associations in their nonprofit work, to improve conditions for people with dementia and their families.

The position is a full-time job with access as soon as possible. Applicants must be fluent in Swedish.

The application deadline is 15 January 2020. Find out more: https://www.demensforbundet.se/vart-uppdrag/lediga-tjanster/

### 5 December: Barcelonaßeta Brain Research Center seeks PhD student in Clinical, Biomarker and Risk Factors Research Group

Barcelonaßeta Brain Research Center (BBRC) invites applications for a full-time PhD student position within the context of the “Brain resilience and vulnerability during midlife” Alzheimer’s Association-funded project lead by Dr Eider Arenaza-Urquijo. The project will be carried out within the Clinical, Biomarker and Risk Factors Research Group of the Alzheimer Prevention Program headed by Dr José Luis Molinuevo. Applications close on 12 January 2020.

https://www.barcelonabeta.org/en/bbrc-research-center/job-offers

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

Alzheimer Europe Board:
Chairperson: Iva Holmerová (Czech Republic); Vice-Chairperson: Charles Scerri (Malta); Honorary Secretary: James Pearson (UK - Scotland); Honorary Treasurer: María do Rosário Zincke dos Reis (Portugal). Members: Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (Ireland), Stefanie Becker (Switzerland), Marco Blom (Netherlands), Sabine Jansen (Germany), Pat McLoughlin (Ireland), Sirpa Pietikäinen (Finland), Jesús Rodrigo (Spain), Karin Westerlund (Sweden).

Alzheimer Europe Staff:
Executive Director: Jean Georges; Communications Officer: Kate Boor Ellis; Conference and Event Coordinator: Gwladys Guilloty; Director for Projects: Dianne Gove; Project Officers: Christophe Bintener, Cindy Birck, Angela Bradshaw, Ana Diaz; Policy Officer: Owen Miller; Finance Officer: Stefanie Peulen; Administrative Assistants: Aideen O’Brien; Grazia Tomasin.
### AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>13-15 January</td>
<td>Kick-off meeting for the PRIME project (Frankfurt, Germany)</td>
<td>Angela</td>
</tr>
<tr>
<td>15-16 January</td>
<td>ADAIR Kick-off meeting (Prague, Czech Republic)</td>
<td>Jean</td>
</tr>
<tr>
<td>21 January</td>
<td>EFPIA Alzheimer’s Roundtable (Brussels, Belgium)</td>
<td>Jean</td>
</tr>
<tr>
<td>27 January</td>
<td>Meeting with France Alzheimer (Paris, France)</td>
<td>Jean</td>
</tr>
<tr>
<td>27 January</td>
<td>Kick-off meeting for the RECOGNISED project (Barcelona, Spain)</td>
<td>Angela</td>
</tr>
<tr>
<td>28 January</td>
<td>Neuronet Scientific Coordination Board (Madrid, Spain)</td>
<td>Jean, Chris, Angela</td>
</tr>
</tbody>
</table>

### CONFERENCES

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>26-29 March</td>
<td>14th World Congress on Controversies in Neurology (CONy), <a href="http://cony.comtecmed.com/">http://cony.comtecmed.com/</a></td>
<td>Vienna, UK</td>
</tr>
<tr>
<td>2-5 April</td>
<td>International Conference on Alzheimer's and Parkinson's Diseases and related neurological disorders (AD/PD), <a href="https://oat-wdp.kenes.com/general-information/">https://oat-wdp.kenes.com/general-information/</a></td>
<td>London, UK</td>
</tr>
<tr>
<td>11-12 June</td>
<td>Care in the Age of Outrage, <a href="https://dementiaconference.com">dementiaconference.com</a></td>
<td>Sydney, Australia</td>
</tr>
<tr>
<td>26-30 July</td>
<td>Alzheimer’s Association International Conference (AAIC), <a href="https://www.alz.org/">https://www.alz.org/</a></td>
<td>Amsterdam, Netherlands</td>
</tr>
</tbody>
</table>
30th Alzheimer Europe Conference
Building bridges
Bucharest, Romania
20–22 October 2020

www.alzheimer-europe.org/conferences #30AEC