At the start of June, the U.S. Food and Drug Administration (FDA) delivered a highly-anticipated and controversial decision, approving aducanumab for the treatment of Alzheimer’s disease (AD). Biogen’s drug is the first AD treatment to be approved by the FDA since 2003, and is the first potentially disease-modifying therapy to reach the market. Biogen is now required to conduct a post-approval clinical trial and if it does not confirm the drug’s benefit for its target population - people with mild cognitive impairment or mild dementia - the FDA may remove the drug from market.

In another controversial decision this month, which is making waves in the European Health NGO community, the European Commission excluded the operating grants mechanism from its 2021-2022 EU4Health Annual Work Programme. This decision seriously undermines key activities of European health NGOs including Alzheimer Europe, and this, during the greatest public health crisis in living memory. We hope that, as the only DG to have made this regrettable decision rather than following the lead of its counterparts who have not only kept operating grants but increased their scope and funding, that DG Santé and Commissioner Kyriakides will reconsider.

On a more positive note, our AGM has approved a new Strategic Plan 2021-2025 and together with our dedicated team, I look forward to the challenge of fulfilling our ambitious objectives for this five-year period.
COVID-19 SITUATION

18 June: Analysis of UK ONS data shows that communities with a high density of care homes and residential overcrowding experienced higher excess mortality during the COVID-19 pandemic.

During the first wave of the COVID-19 pandemic, severely-affected countries experienced high levels of excess mortality. In England, over 50,000 excess deaths were reported by the UK Office for National Statistics (ONS), with variations in excess deaths between different areas. To understand community characteristics that might influence these patterns, a team of researchers led by Prof. Paul Elliott at the UK Dementia Research Institute applied statistical models to ONS data on excess mortality from the first wave of the pandemic.

Lowest levels of excess mortality were reported in remote rural areas, with the largest increases in mortality in London. Communities with greater environmental and social deprivation tended to have larger increases in excess mortality. Excess mortality risks did not appear to be linked to higher population density; instead, they were related to poverty, overcrowded homes, and non-white ethnicity. Of note, communities with a high density of care homes were linked to a 21-27% increase in excess mortality.

Together, these results underline the importance of bolstering protection for care home staff and residents, and improving public health and healthcare measures that target the communities most at-risk for excess mortality.

https://www.nature.com/articles/s41467-021-23935-x#author-information

24 June: Dementias Platform UK report reveals multiple impacts of COVID-19 pandemic on dementia research

The COVID-19 pandemic has disrupted all aspects of life, as measures aimed at slowing the spread of COVID-19 have interrupted normal ways of working. Many types of research have been put on hold, with restrictions on the numbers of researchers able to work on-site and reductions in face-to-face clinical research visits to limit physical contacts between individuals.

In order to better understand the impacts of the COVID-19 pandemic on dementia research, Dr Natassia Brenman (in collaboration with Dr Richard Milne and a team from Dementias Platform UK/DPUK) held focus group discussions with on-site clinical researchers, off-site researchers using digital and remote methods, and Investigators leading clinical research sites.

Four key themes emerged from these discussions. Firstly, researchers felt that COVID-19 research was being prioritised over research on dementia, increasing academic precarity for early-career researchers and slowing the progress of ongoing studies. Compounding this issue, discussions also identified concerns relating to inclusion and access to dementia research for older people with cognitive impairment or dementia. Investigators highlighted the fact that underrepresentation of certain groups in dementia research (e.g. ethnic minorities) has been exacerbated by the pandemic, in part due to practical issues in accessing clinical sites and also due to lower levels of vaccine uptake in certain populations. Another key theme was centred around practical and ethical challenges to conducting dementia research during a pandemic: for example, maintaining a connection with study participants whilst respecting physical distancing guidelines and wearing face-obscuring personal protective equipment. Finally, the focus group participants expressed differing views on the increasing use of digital technologies for remote assessment and monitoring, with enthusiasm for new and more accessible methodologies on the one hand, and concerns about their scientific and clinical validity on the other.

Commenting on the report, Dr Brenman said: “This research raises even more questions than it answers, highlighting the need to engage with the social and ethical uncertainties about dementia research as well as the practical and scientific challenges. This should be done by listening closely to those navigating these issues day-to-day.”

ALZHEIMER EUROPE

7 June: Alzheimer Europe welcomes FDA decision to approve aducanumab

On 7 June 2021, the US Food and Drug Administration (FDA), in a highly anticipated decision by the global dementia community, authorised aducanumab for the treatment of Alzheimer’s disease and asked Biogen to conduct a post-approval clinical trial to verify the drug’s clinical benefit.

Alzheimer Europe welcomes the approval of the first treatment to modify disease progression, rather than provide symptomatic relief, as currently authorised medicines do. This decision constitutes a significant advance in the treatment of Alzheimer’s disease and gives hope to patients and their families that the cognitive and functional impairments associated with the disease may be slowed or delayed.

Alzheimer Europe also welcomes the decision by the FDA to ask for additional safety and efficacy data to be collected through a post-approval study, as the medicine is being rolled out to patients in the US, addressing concerns raised by the ambiguous results from the two Phase III trials conducted to date.

Alzheimer Europe stresses the need to communicate clearly on which patients will be eligible for treatment, as treatment will be limited to patients with mild cognitive impairment or mild dementia. Additionally, patients will need to have confirmed amyloid presence in their brain which will require a lumbar puncture or brain scan prior to initiating treatment. Regular MRI scans may be appropriate, in order to monitor potential side effects. Treatment eligibility, risks, benefits and costs should therefore be discussed in realistic terms.

European patients will however not receive access to this new treatment yet, as the drug is currently undergoing a full evaluation by European regulators, including the European Medicines Agency or Swissmedic where applications were submitted in October 2020 and April 2021 respectively. Decisions by European regulators are not expected before the end of the year, but Alzheimer Europe hopes for a similarly positive outcome at European level.

Once aducanumab has been approved by the European regulators, pricing and reimbursement discussions will take place at national level and Alzheimer Europe and its national member organisations hope that countries will ensure that this innovative treatment will rapidly be available in all European countries and accessible for patients regardless of their socio-economic background or place of residence.

Whilst encouraged by this important progress in the treatment of people at the earlier stages of Alzheimer’s disease, Alzheimer Europe reiterates its call for continued research into other treatment options including symptomatic treatment for people in more advanced stages and preventative approaches throughout the lifecourse. In addition, Alzheimer Europe remains committed to a holistic approach to Alzheimer’s disease and other types of dementia where new treatment options are included alongside counselling, support and adequate care of people with dementia and their carers at all stages of the disease.

8 June: Alzheimer Europe contributes to paper on “Dementia and COVID-19, a Bidirectional Liaison: Risk Factors, Biomarkers, and Optimal Health Care”

The journal Alzheimer’s and Dementia has published a paper on the possible bidirectional relationship between dementia and COVID-19. Cases of cognitive impairment after a SARS-CoV-2 infection are being more and more recognized as an acute and (possibly) also long-term condition.

The identification of reliable biomarkers for COVID-19-caused cognitive impairment is still in its early shoes, but the researchers report that there is already emerging evidence that SARS-CoV-2 could preferentially target the frontal lobes when spreading in the brain. This is also backed up by “behavioral and dysexecutive symptoms, fronto-temporal hypoperfusion on MRI, EEG slowing in frontal regions, and frontal hypometabolism on 18F-FDG-PET scans,” as the team notes.

Furthermore, they highlight that people with dementia (as well as the people taking care of them), have been greatly impacted by the disruption of their care caused by COVID-19. People with dementia have experienced worsening of cognitive, behavioural, and psychological symptoms, and the rate of COVID-19-related deaths is disproportionately high among cognitively impaired people.

Finally, a multitude of factors, including troubles in remembering and adopting safeguarding procedures, age, comorbidities, residing in care homes, and poorer access to hospital standard of care can play a role in the increased morbidity and mortality. At the same time, the team underlines that non-pharmacological interventions as well as new technologies have shown a potential for the management of patients with dementia, and for the support of their caregivers.

https://content.iospress.com/articles/journal-of-alzheimers-disease/jad210335

14 June: Alzheimer Europe online Annual General Meeting adopts new Strategic Plan 2021-2025

Alzheimer Europe’s Annual General Meeting (AGM) was held online, on 14 June 2021. Alzheimer Europe Chairperson Iva Holmerová chaired the event, which was attended by representatives of Alzheimer Europe’s member associations, the Alzheimer Europe Board and staff, as well as a number of
observers. 30 out of 35 full (voting) member organisations were present, as was one provisional member association. In all, 31 countries were represented at the meeting. The AGM began by adopting the agenda and then the minutes of the previous AGM, of 5 October 2020. Attendees then heard from the organisation’s Honorary Secretary Jim Pearson, about our 2020 activities. Honorary Treasurer Marco Blom followed, sharing details of the finances for 2020, after which the AGM voted to approve the 2020 Annual and Financial Report (publication date: 30 June 2021).

After a short break, the meeting heard an address by the Chairperson of the European Working Group of People with Dementia (EWGPWD), Chris Roberts. He spoke about some of the group’s advocacy and research work during 2020 and about the challenges faced by members of the group, during the global COVID pandemic. He expressed the immense gratitude of the EWGPWD for the support provided by Alzheimer Europe, allowing the group to continue its important work during this difficult time. He said that the work had become a ‘lifeline’, to many in the EWGPWD, during lockdown in particular.

Following this address, was a presentation of our new Strategic Plan 2021-2025, given by Executive Director Jean Georges. The AGM voted to adopt the plan, and the agreed strategic objectives for this five-year period, are:

• Providing a voice to people with dementia and their carers
• Making dementia a European priority
• Changing perceptions and combatting stigma
• Raising awareness of brain health and prevention
• Strengthening the European dementia movement
• Supporting dementia research.

Jean Georges also presented our 2022 Work Plan and budget, both of which were also adopted. In closing, Owen Miller, Policy Officer, gave delegates an update on recent EU developments in the field of dementia.

Thank you to all delegates, speakers and observers who joined our AGM. It is always an inspiration to see the European Dementia Movement in action and while there are some very busy and challenging times ahead, we are optimistic that we can carry out our ambitious plans, by working together.


On 15 June, Alzheimer Europe hosted an online European Parliament Workshop with Charité – Universitätsmedizin Berlin, entitled “The Alzheimer’s spectrum: Changing our understanding of Alzheimer’s disease and dementia”. Alzheimer Europe Chairperson Iva Holmerová chaired the event, which was attended by EU policymakers, representatives from national Alzheimer’s associations, national health ministries, pharmaceutical companies, researchers and members of the European Working Group of People with Dementia. MEPs Deirdre Clune (Ireland), Colm Markey (Ireland) and Roberta Metsola (Malta), were present as well as a representative from the office of Włodzimierz Cimoszewicz (Poland).

Ms Clune, MEP, Vice-Chair of the European Alzheimer’s Alliance, welcomed everyone to the Workshop and spoke of the importance of keeping dementia as a priority in Europe, particularly in research, with a greater need to take a coordinated and collaborative approach to help improve the lives of people with dementia and of carers.

Philip Scheltens, Professor of neurology and Director of the Alzheimer Centre, VU University Medical Center Amsterdam, presented on the progression in the detection of Alzheimer’s disease, explaining developments from clinical to biological diagnoses. Key to this has been the ability to use biomarkers, detecting the presence of Alzheimer’s disease years before the presence of symptoms. Prof. Scheltens further explained the difference between Alzheimer’s disease and dementia, highlighting that the former denotes the biological changes within the body, whilst dementia represents the symptoms that present at the later stages of the disease spectrum.

Frank Jessen, a Professor and principal investigator at the University Clinic Cologne, introduced developments in the detection and diagnosis of dementia, making use of both clinical and biological mechanisms. As part of this, some of the challenges around the need for enhanced availability, reduced invasiveness, easily interpretable results and sensitivity to early symptomatic changes were explored. In particular, Prof. Jessen identified how blood-based biomarkers are showing excellent potential to be a less invasive, yet accurate indicator in the detection and diagnosis of Alzheimer’s disease.

Miia Kivipelto, Professor of Clinical Geriatric Epidemiology at the Department of Neurobiology, Care Sciences and Society at Karolinska Institutet, Sweden, discussed the potential to be a less invasive, yet accurate indicator in the detection and diagnosis of Alzheimer’s disease. She explained that preventative strategies have a wider impact on dementia than previously thought and shared details of the FINGER trial, of which she is the lead. This is the first randomised controlled trial showing that it is possible to prevent cognitive decline using a multi-domain lifestyle intervention among older at-risk
individuals. The next steps towards successful dementia prevention should include tailoring approaches to specific risk groups in different settings, which she termed “precision prevention”. Prof. Kivipelto stressed the importance of taking a collaborative approach, internationally, in order to achieve this goal and said that initiatives such as EURO- and World-Wide-FINGERS are expected to advance multidomain prevention models focusing on lifestyle and vascular care.

The final speaker to take the (virtual) floor was Anders Gustavsson, co-founding partner at Quantify - a partner in health economics, outcomes research, real-world evidence and market access. Dr Gustavsson presented on behalf of the Project Alzheimer’s Value Europe (PAVE), which is funded by Roche and Biogen. Alzheimer’s disease, he noted, starts 20-30 years prior to the onset of dementia, but this is not taken into account in current population estimates. PAVE therefore decided to conduct a study to estimate the numbers of people with Alzheimer’s disease, across the entire continuum. To do this, they developed a model to estimate numbers and found a lot of evidence on different outcomes and different types of data, covering populations with biomarkers and those with clinical diagnosis. Using these estimates and combining with underlying populations, they concluded that about 25% of the European population over 50 has Alzheimer’s disease. The majority of persons with Alzheimer’s disease do not have dementia, he stressed, but are in the very early stages of disease where prevention may still be possible. These early stages of disease should receive more attention from policy makers and health care planners, he urged and noted that the costs of dementia are comparable to Cancer, while the spending pot is vastly different.

Following the presentations, a lively exchange took place between participants and speakers, with discussions revolving around: communicating about Alzheimer’s disease and dementia considering the changing definitions of both, in recent years; ways to improve detection of the disease in general practice settings; the need for more public health campaigns and messages to raise awareness and reduce stigma, focusing on the fact that this is a brain disease, promoting better brain health and emphasising prevention/risk-reduction strategies; and the need to mitigate the public’s expectations around ‘miracle drugs’ for what is a hugely complex disease. The FDA approval of aducanumab was also mentioned, in this context, with Frank Jessen commenting that it is important to make sure that people understand the benefits of such a drug will not be seen overnight, nor will the benefits of other similar interventions be immediate. Representing the European Commission at the meeting, Nicoline Tamsma (DG Santé) reminded researchers and Alzheimer associations of the importance of registering any new, proven interventions - for example some of the combined prevention methods discussed - on their Best Practice Portal, which the Commission uses to support Members States in rolling out interventions:


Concluding the Workshop, Iva Holmerová thanked presenters and participants for their contributions during the meeting, whilst advising members that the next meeting would take place on 28 September 2021, with a focus on the Innovative Medicines Initiatives (IMI).

Videos from the event are available on Alzheimer Europe’s YouTube Channel:


15 June: Dementia in Europe issue 36 published as an e-magazine

Alzheimer Europe has published a new edition of its “Dementia in Europe” policy magazine, in an electronic format. It highlights our efforts and those of our member associations to make dementia a European priority, and provides updates on the latest national- and European-level policy developments in the dementia field. The first section of the magazine includes coverage of the online European Parliament workshop we co-hosted earlier this year with Charité – Universitätsmedizin Berlin. At the event, which was chaired by Deirdre Clune, MEP (Ireland) and explored the theme of “Digital data for dementia research and innovation”, we launched a report setting out recommendations to improve data sharing in dementia research. We recently published a position paper, also, on the importance of prioritising people with dementia and carers in COVID-19 vaccination programmes, and have dedicated an article to this topic. Other articles in this section share details of a recent Alzheimer’s Association Academy online event about sports and dementia, as well as our involvement in three different European research projects.

In the Policy Watch section, we are delighted to have an interview with EU Commissioner for Equality Helena Dalli, who introduces the EU’s new disability rights strategy. At the national level, we speak to the Coordinator for the Czech Republic’s new National Action Plan for Alzheimer’s Disease and Related Illnesses 2020-2030, Marketa Švejdová Jandová and to Martina Mátlová, Director of the Czech Alzheimer Society, who shares her organisation’s views on the country’s second dementia plan. From the Czech Republic, we head to the Netherlands, where a fourth national dementia strategy has been launched. Anne de Boer, Advocacy Officer at Alzheimer Nederland, examines the strategy from her organisation’s perspective. Ms De Boer also discusses some of the issues surrounding voting for people with dementia in her country, in the Dementia in Society section of this magazine, and highlights some of the work Alzheimer Nederland has been doing to support them in exercising their democratic rights.

Alzheimer Scotland’s Director of Policy and Research, Jim Pearson, then provides an update on the organisation’s Fair Dementia Care Campaign and how this formed the basis of their recent Scottish Parliament Election Pledge Campaign, which sought the support of candidates standing in the Scottish Parliamentary election in May. Finally, at the national level, Mario Possenti, Secretary General of Federazione Alzheimer Italia, highlights the recent commitment from the Italian Government to provide funding for the country’s National Dementia Plan, which was first launched in 2014.

At a global level, the World Health Organization (WHO) is in the process of developing an “Intersectional global action plan on epilepsy and other neurological disorders”, which is discussed in the closing article of the policy watch section of this magazine, by Stéfanie Freel and Katrin Seeher of the WHO.

The third and final section in this edition is the Dementia in Society section, which opens with two articles by members of our European Working Group of People with Dementia (EWGPWD). Each explores aspects of life during the ongoing COVID-19 pandemic. In the first, Helen Rochford-Brennan shares her experience as a person living with young-onset dementia, dealing with bereavement during the pandemic, following the loss of her husband. Petri Lampinen then tells readers what it has been like for him, living with frontotemporal dementia during lockdown and some of the difficulties he faced as well as methods he uses to counter them.

Up next, we hear from a researcher on the MOPEAD (Models of Patient Engagement for Alzheimer’s Disease) project, Lena Sanneman, who was interviewed by the Neuronet initiative (Efficiently Networking European Neurodegeneration Research), as part of its series of interviews with Early Career Researchers.

One of the expert speakers at our previously-mentioned Alzheimer’s Association Academy online event on sports and dementia, Renato Walkowiak, shares details of the “Ping4Alzheimer” initiative which involves giving special table tennis sessions for people with dementia and carers, while a second speaker at the event, Professor Michael Hornberger, rounds off the 36th edition of our magazine with an in-depth look at the link between contact sports-related head injuries and dementia. A big thank you to all the contributing authors, interviewees and to our sponsors, who make our magazine possible. You can download the PDF, here:

http://bit.ly/DementiaInEurope36

17 June: Sponsors and members discuss developments in clinical trials, EU policy, Horizon Europe and EU framework for health technology assessments, at our online company roundtable

On 17 June 2021, Alzheimer Europe (AE) hosted an online Company Round Table meeting, attended by representatives from AbbVie, Biogen, EFPIA, Eisai, Fujirebio, GE Healthcare, Grifols, Lilly, Nutricia, Roche and TauRx. Also in attendance were: 7 members of the AE staff, including Executive Director Jean Georges; 28 representatives of AE member organisations from 22 different countries; and Chris Roberts, Chairperson of the European Working Group of People with Dementia (EWGPWD).

Kicking off the meeting, Alzheimer Europe Project Officer Cindy Birck gave an overview of recent clinical trial developments and an update on our Clinical Trials Watch database, whilst Policy Officer Owen Miller shared some recent policy developments at the EU and global levels.

Following these presentations, attendees heard from Nicolas Creff, Senior Manager Research partnerships at EFPIA (European Federation of Pharmaceutical Industries and Associations), who discussed public-private partnerships in the new Horizon Europe programme, and introduced the Innovative Health Initiative (the new incarnation of what is currently the Innovative Medicines Initiative - IMI). Mr Creff’s colleague Mihai Rotaru, Senior Manager Market Access, EFPIA, delivered a presentation on the new European framework for health technology assessments (HTAs).

Finally, Alzheimer Europe Executive Director Jean Georges updated sponsors and other delegates on Alzheimer Europe’s activities. In closing, he thanked sponsors and members for participating in the roundtable meeting. The next Company Round Table meeting, will take place on 28 September 2021.

25 June: During greatest public health crisis in living memory, European Commission adopts first Work Plan of new EU4Health Programme undermining key activities of European health NGOs

On 25 June 2021, Alzheimer Europe, the umbrella organisation of 37 national Alzheimer’s associations from 33 European countries, supported a call by European health NGOs, asking the European Commission to restore operating grants in the
EU4Health Programme in order to support core activities of European NGOs, such as capacity building, training, networking and the exchange of good practices between national associations.

This call has been issued in response to the recent publication of the 2021-2022 EU4Health Annual Work Programme by the European Commission. Whilst Alzheimer Europe and other supporting associations welcome the ambitious budget of EUR 312 million for crisis preparedness, disease prevention, health systems and the healthcare workforce and digitalisation, they regret that the operating grant mechanism for European health NGOs has been discontinued by a unilateral decision by the Commission, despite this mechanism having been explicitly included in the EU4Health Programme by the European Parliament and Council of Ministers during the legislative process leading to the adoption of the programme.

In an open letter to Commissioner Kyriakides on 2 June, 56 Members of the European Parliament recognised the crucial role of civil society organisations in supporting global health, acknowledging them as a “vital partner to both European and National institutions to shape and implement public health strategies and policies” and urgently called upon the European Commission “to revise its position on operating grants in the field of health”.

At the 2020 General Assembly of the European Public Health Alliance, Commissioner Kyriakides had herself underlined the value of European health NGOs: “I was President of an NGO myself so I know how important the input of civil society is to the legislative process. We count on civil society to understand the challenges and needs on the ground, and to deliver better health outcomes for all Europeans.”

Despite this political support, and despite the fact that operating grants continue in other policy fields of the European Commission, such as non-discrimination, disability, youth, ageing and the environment, the adopted Work Plan of the EU4Health programme abandons this key funding mechanism of support to health NGOs and risks seriously undermining the outstanding and pioneering work of European organisations in the field of public health.

Jean Georges, Executive Director of Alzheimer Europe, highlighted: “At a time when the health programme has its most ambitious budget yet and when health NGOs are struggling with the impact of COVID-19, it seems inconceivable that the European Commission has chosen this moment to unilaterally discontinue the operating grant mechanism for European health NGOs. We hope that the Commission urgently revisits this position, as it endangers the very existence and sustainability of key European associations and their essential activities.”

30 June: Alzheimer Europe closes call for abstracts for #31AEC online conference

The call for abstracts is now closed for the 31st Alzheimer Europe Conference, taking place online from 29 November to 1 December 2021. We are pleased to have received almost 300 abstracts, all of which will now be reviewed by the Scientific Committee, during July. All submitting authors will be informed of the Committee’s decision from 31 July onwards.

Registrations remain open with the Early Bird reduced fees available until 15 September. Book your place, today!

https://www.alzheimer-europe.org/Conferences/2021-Online/Online-conference-registration

Alzheimer Europe networking (online)

On 1 and 2 June, Jean attended the Patients’ and Consumers’ Working Party of the European Medicines Agency.

On 4 June, Ange, Cindy and Chris organised a meeting of the Neuronet Communication Experts’ Community.

On 7 June, Jean attended the Management Board of the Dementia Panel of the European Academy of Neurology.

On 7, 9, 10, 21 and 29 June, Owen attended meetings with other health civil society organisations to coordination actions around the operating grants in the EU4Health programme.

On 8 June, Jean and Owen attended a meeting with the European Commission on the operating grants in the EU4Health programme.

On 8 June, Ana attended the ADAIR virtual General Assembly.

On 8 June, Angela attended a RECOGNISED meeting with students from the Vall d’Hebron University Hospital.

On 9 June, Angela gave a presentation at the World Dementia Council Dialogue on data sharing.

On 9 June, Dianne, Cindy and Ana attended a meeting organised by EUGMS.

On 10 June, Jean and Owen attended a meeting of civil society organisation with Matthew Hudson of DG SANTE.

On 10 June, Owen attended a meeting of the European Non-Governmental Organisations hosted by the European Disability Forum.
On 10 June, Angela attended an EFPIA/MedTech Europe webinar on the European Health Data Space.

On 11 June, Dianne and Angela attended a meeting of the Neuronet Ethics and Patient Privacy working group.

On 11 June, Jean gave a presentation on collaboration with patient organisations on research and policy at a symposium of the University of Eastern Finland.

On 11 June, Dianne and Ana attended a LETHE workshop.

On 14 June, Alzheimer Europe held its Annual General Meeting.

On 14 June, Angela attended a meeting of the EPND Management Board.

On 15 June, Angela co-moderated an I+HD plenary session on health data access in the EU

On 15 June, Jean attended the Executive Management Board of the EU-Fingers project.


On 15 June, Jean attended a meeting of Project Alzheimer’s Value Europe (PAVE).

On 15 June, Dianne and Ana attended the IMI impact on dementia event.

On 15 June, Dianne attended the webinar “Aducanumab: quels enjeux médicaux et éthiques” organised by l’Espace éthique Ile-de-France, Polethis, le Laboratoire d’excellence DistAlz et la Fondation Alzheimer.

On 16 June, Angela attended the VirtualBrainCloud General Assembly meeting.

On 17 June, Gwladys attended the Spain brings you food for thought meeting.

On 17 June, Alzheimer Europe organised a company round table meeting with members and sponsors.

On 17 June, Dianne and Ana attended a RADAR-AD workshop on regulatory issues.

On 17 June, Angela attended the VirtualBrainCloud General Assembly meeting.

On 18 June, Angela attended a Core Group meeting for the DataSavesLives initiative.

On 21 June, Angela attended the RECOGNISED General Assembly meeting.

On 22 June, Iva and Jean met with the President and a delegation of the European Academy of Neurology.

On 22 June, Jean met with Roche and Janssen.

On 22 June, Dianne and Ana participated in the INTERDEM working group meeting on the use of technology during COVID-19.

On 22 June, Cindy and Angela attended the NEURONET Data Sharing working group.

On 25 June, Jean attended the GSK Health Advisory Board.

On 25 June, Ana and Dianne organised a RADAR-AD Patient Advisory Board meeting.

On 29 June, Jean attended a meeting of the Biogen Alzheimer’s Briefing series.

On 29 June, Dianne, Ana and Cindy participated in the EWGPWD – DISTINCT meeting.

On 29 June, Dianne attended the DZNE webinar on the EU-Atlas: Dementia and Migration.

On 30 June, Jean attended a launch workshop for the DataSavesLives toolkit.

On 30 June, Jean met with the EFPIA AD Platform.

On 30 June, Jean attended a World Dementia Council meeting on “Dementia and an ageing society”.

**EU PROJECTS**

31 May: PRIME project convenes a meeting of its Steering Committee

The PRIME project (Prevention and Remediation of Insulin Multimorbidity in Europe) was launched in early 2020, aiming to unravel the insulin-dependent mechanisms that link diseases such as type 2 diabetes with brain disorders, including Alzheimer’s disease (AD) and compulsivity disorders. Including 17 partners from academia, SMEs and NGOs, PRIME is using a broad range of preclinical, clinical and data-driven approaches to understand how insulin signalling might be involved in these brain disorders.

On 31 May, PRIME convened a meeting of its Steering Committee, composed of researchers leading the 8 different
Work Packages (WPs) of PRIME. Members of the Scientific and Ethical Advisory Board also attended the meeting, with representation from Alzheimer Europe and the International Diabetes Federation-Europe. During the meeting, each WP lead provided an update on progress towards milestones and deliverables, also identifying areas with challenges that need to be addressed. All WPs are making good progress, despite the complexities of undertaking research during the COVID-19 pandemic. The PRIME clinical study has started recruiting participants with Romano-Ward syndrome, a condition linked to insulin resistance and type 2 diabetes. Academic groups in Hungary, Italy and Germany are studying stem cell and animal models of type 2 diabetes and AD, while researchers in Denmark are analysing large clinical datasets to decipher the genetic links between metabolic and brain disorders. PRIME has also been developing materials to increase engagement of patient communities with the project, including webinars and information packs, and has also created an internal mentoring scheme to support the career development of junior researchers working on PRIME.

1 June: The AMYPAD Prognostic and Natural History Study reaches milestone of 1,000 research participants

The members of the Amyloid Imaging to Prevent Alzheimer’s Disease (AMYPAD) initiative reached a significant milestone with the enrolment of the 1,000th research participant in its Prognostic and Natural History Study (PNHS). In this clinical study, researchers aim at understanding the role of amyloid imaging in the earliest stages of Alzheimer’s disease to increase the chances of successful secondary prevention trials. The study recruits individuals suspected of possible Alzheimer’s disease from various ongoing European parent cohorts.

Recruitment started in late 2018 and is expected to continue until March 2022. By the end of May 2021, 1,471 participants have been informed about the study, 1,001 consented, and 835 already underwent their amyloid PET scan. At this moment, the PNHS has 17 active sites and 7 cohorts have been actively enrolling into the study (EPAD LCS, EMIF-AD, ALFA+, FACEHBI, FPACK, UCL-2020-412, Microbiota), with two other confirmed to begin enrolment soon. It has also been very rewarding, since a new cohort (Microbiota) has joined the AMYPAD PNHS study and started recruitment. Finally, the data integration process (from all data sources) and quality check of data has been initiated and the team has also conducted the first exploratory analyses of PNHS data.

9 June: The PRODEMOS project publishes its protocol paper

On 9 June, members from the Prevention of Dementia using Mobile phone Applications (PRODEMOS) project published a paper in the journal BMJ Open, explaining the design of their international randomised controlled trial. The PRODEMOS study is investigating the effectiveness and implementation of a coach-supported mHealth intervention on dementia risk in older people at increased risk of dementia from a low socioeconomic population in the UK and from the general population in Beijing, China.

People aged between 55 and 75 who own a smartphone and have at least two dementia risk factors are able to take part in the study. The intervention and follow-up period are 18 months.

The paper also includes the results of the 6-week pilot study conducted in the UK, aiming to test the mHealth platform functionality and study logistics. The pilot study was evaluated with the participants and coaches. A similar pilot study has been conducted in China. The full trial started in March in the UK and in June in China.

Further information on the PRODEMOS project can be found here: https://www.prodemos-project.eu

11-17 June: NEURONET hosts meetings of its Patient Privacy & Ethics and Data Sharing working groups

Neuronet is an Innovative Medicines Initiative (IMI)-funded coordination and support action, designed to support and enhance collaboration between the diverse projects in the IMI neurodegeneration portfolio. In 2019, Neuronet launched four Working Groups (WGs), cross-project spaces for experts to discuss common issues, priorities and opportunities for synergy and collaboration. Each Neuronet WG is focused on a particular
The EU-funded AI-Mind project has launched a survey regarding the current clinical practices related to the diagnosis of mild cognitive impairment (MCI) and the needs for diagnostic tools to predict, at an early stage, who is likely to develop dementia.

The purpose of this survey is to capture information related to existing clinical guidelines, reimbursement schemes and challenges, as well as to identify the state-of-the-art tools used in European hospitals for screening, diagnosing, monitoring and collecting information on met and unmet needs for the early diagnosis of people with MCI.

The survey is open to all healthcare professionals (e.g. clinicians, nurses, psychologists) working in the field of dementia and MCI across all European countries. The survey is available online and planned to run until 1 August. If you are interested in taking part, please click here: https://nettskjema.no/a/aimindsurvey

If you have any questions, please contact contact@ai-mind.eu

17 June: The VirtualBrainCloud project convenes an online General Assembly meeting

On 17 June, the H2020-funded VirtualBrainCloud project (TVB_Cloud) held its General Assembly meeting online, summarising recent project developments and discussing upcoming plans. Chaired by Prof. Petra Ritter of Charité University Hospital Berlin, the meeting was attended by over 50 project participants, including representatives from the 17 institutions and organisations that make up the TVB_Cloud consortium. Angela Bradshaw (Project Officer) represented Alzheimer Europe at the meeting.

The main goal of TVB_Cloud is to facilitate the personalised prevention and treatment of dementia, by creating a decision support system for clinicians. Based around a cloud platform for personalised brain simulations, this system will integrate data from multiple sources (e.g. brain scans, genetic screens and neuropsychological tests) in a secure online environment.

During the 17 June General Assembly (GA) meeting, TVB_Cloud Work Package leaders provided brief summaries of ongoing activities on data processing, disease progression models, computational brain simulations, and the software development that underlies these activities. The majority of the GA meeting was focused on describing sustainability options for the project, during which follow-up scenarios were outlined and key exploitable outputs were discussed. The next GA will be hosted in the autumn.


21 June: EU-FINGERS and LETHE launch survey to collect views on early diagnosis and prevention of Alzheimer’s disease

The EU-FINGERS and LETHE projects have launched a survey examining the perspectives of European memory clinic clinicians who are involved in the diagnostic work-up for dementia.

The survey is open to physicians (e.g. neurologists, geriatricians, psychiatrists) and other health care professionals (e.g. nurses, psychologists, dietitians) working in memory clinics across all European countries, willing to share their thoughts and experiences on communicating about early diagnosis of Alzheimer’s disease, biomarkers, dementia risk and prevention.

The survey is available online and planned to run until 20 August. If you are interested in taking part, please click here: https://vumc.datacoll.nl/ogyvcwhbpj?l=en
Your views are extremely important and will be much appreciated. If you have any questions about the survey, please contact Heleen M.A. Hendriksen at:

h.hendriksen@amsterdamumc.nl

21 June: Innovative Medicines Initiative publishes videos from its “Impact on dementia” event

Meet the speakers

Luc Truyen
Global Head Development and External Affairs | Xencor, Inc.

Helen Rochford-Brennan
Member of the EU Joint Research Programme on Alzheimer's Disease (JPND) | Alzheimer Europe

Carlos Diaz
CEO | SYNOPSIS Research Management Partners, S.L.

Rachel Steeg
Project Manager | Fraunhofer UK Research Ltd

Gill Farrar
Global Medical Leader | GE Healthcare Medical Affairs

Professor Olivier Ribot
Head of the Clinical Pharmacology & Pharmacoepidemiology Department | Aix-Marseille University

On 21 June, the Innovative Medicines Initiative (IMI) organised an event called “IMI impact on dementia”, as part of its series of online live sessions on the impact of IMI in various areas. During these impact events, key actors explored the challenges faced, and demonstrated how IMI contributed towards overcoming them. Dementia was one of three specific areas in which the IMI showcased its impact, with the others being diabetes, and the relatively new field of data management.

The IMI is a partnership between the European Union and the European pharmaceutical industry. It facilitates open collaboration in research, to advance the development of, and accelerate patient access to, personalised medicines for the health and wellbeing of all, especially in areas of unmet medical need. Dementia projects account for around 10% of IMI’s budget, most of which are focused on Alzheimer’s disease (AD).

The presentations given during the IMI impact on dementia event included the topic of “The challenge, the vision and the value”, which was explored by Luc Truyen from Janssen and Helen Rochford-Brennan, a member of the European Working Group of People with Dementia (EWWGPD). Helen Rochford-Brennan highlighted the importance of involving people affected by dementia in research and projects and the value of collaboration. She and her EWWGPD colleagues have been involved in several IMI projects, including EPAD, ROADMAP, AMYPAD, RADAR-AD, PARADIGM and AETIONOMY, as part of the public involvement (PI) work.

The next topic explored at the event was “How IMI projects have addressed the challenge & ’moved the needle’, Solutions from IMI projects”, which was discussed by Carlos Diaz, Neuronet project coordinator, Rachel Steeg, Fraunhofer UK Research Ltd, and Gill Farrar of GE Healthcare Medical Affairs. Carlos Diaz highlighted the importance of moving towards a system leadership approach in order to efficiently coordinate neurodegeneration research. Rachel Steeg introduced the European Bank for induced pluripotent Stem Cells (EBiSC), and Gill Farrar spoke about a collaborative research initiative aiming to improve the understanding, diagnosis and management of AD through the utilisation of β-amyloid PET imaging (AMYPAD). The presentations were followed by a ‘questions and answer’ round. Find the recordings here:

https://www.youtube.com/embed/Ju_bM2SlTKo?list=PLvrEEDAAI_jEtY9t4EmRr2wuLSvSgAlv

21 June: The eye as a window to the brain: RECOGNISED convenes an online General Assembly meeting

On 21 June, partners working on the H2020-funded RECOGNISED project met during an online General Assembly meeting, chaired by Profs. Rafael Simo (Vall d’Hebron University Hospital, Barcelona) and Noemi Lois (Queen’s University, Belfast). Attended by representatives of the 21 Institutions participating in RECOGNISED, including academic institutions, SMEs and patient organisations, the General Assembly (GA) meeting summarised recent project developments and provided a forum for discussing upcoming plans.

RECOGNISED aims to determine the usefulness of eye tests to identify people with type 2 diabetes with cognitive impairment or at risk of developing dementia. The 10 Work Packages of the RECOGNISED project involve studies that span preclinical research on animal models of disease, to clinical studies in which participants will undergo retinal scans alongside neuropsychological tests, brain scans and genetic screening. During the 21 June GA meeting, RECOGNISED Work Package leaders provided brief summaries of ongoing activities, updating project partners on recent advances and discoveries. Despite interruptions caused by the COVID-19 pandemic including the temporary closure of laboratories, preclinical research on animal models of diabetes and Alzheimer’s disease are progressing well, with efficient collaborations between laboratories based in different countries, generating extensive genetic, behavioural, cognitive and imaging datasets for analysis. Of note, RECOGNISED partners highlighted the successful start of the RECOGNISED clinical studies, which are recruiting participants from 11 centres based in 8 different countries. Clinicians described the ways in which recruitment and follow-up processes have been adapted to ensure compliance with COVID-19 sanitary measures, such as offering evening and weekend appointments, and condensing visits to
different services to allow participants to complete their visits in a shorter period of time than originally anticipated. The final session of the GA was focused on exploitation, dissemination and communications, highlighting some of the considerations for business development and underlining the importance of disseminating RECOGNISED outputs to relevant stakeholders.

https://www.recognised.eu/

29 June: Members of the EWGPWD and ESRs from DISTINCT meet online

Five Early Stage Researchers (ESRs) from the DISTINCT project met the members of the European Working Group of People with Dementia (EWGPWD) to discuss issues related to their research. The research projects involved the use of technology to improve the lives of people with dementia and their carers. The meeting consisted of a plenary discussion and three breakout sessions, all of them online. The discussion focused mainly on methodological issues linked to the design of an online survey and face-to-face interviews at home and in residential care settings.

The sessions were very dynamic and inspiring. Members of the EWGPWD provided important feedback about how to interact with people with dementia and how to make research questions more meaningful and accessible to possible participants. The members of the EWGPWD and their supporters were very enthusiastic about the session.

Dianne, Ana and Cindy organised and supervised the meeting.

29 June: AI-Mind joins forces with EBRAINS research infrastructure to tackle the challenge of brain diseases

The EU-funded AI-Mind project, led by Prof. Ira Haraldsen of Oslo University Hospital, was one of only thirteen projects worldwide that were successful with their applications to the Human Brain Project’s (HBP) EBRAINS Research Infrastructure Voucher Call. With this, the AI-Mind project gets access to the EBRAINS research infrastructure and digital tools that have been developed with, by and for researchers to address challenges in brain research.

The Voucher covers the work of an expert team led by Prof. Petra Ritter of Charité University Medicine Berlin, which will help to implement tailor-made workflows that are compliant with the General Data Protection (GDPR) to enable AI-Mind to best use the EBRAINS infrastructure. The third element that completes the alliance triangle is The Virtual Brain Cloud Project (TVB-Cloud), a programme of the European Open Science Cloud that develops virtual brain simulations. The collaboration of these initiatives not only aligns with the European Digital Health strategy in using digital technologies for the benefit of patients, but is also the first with the potential to take a critical step towards an artificial intelligence (AI) revolution in brain healthcare. Moreover, the alliance of AI-Mind, TVB-Cloud and HBP is timely because the European Commission recently proposed the very first legal framework on AI in healthcare.


EU project acknowledgements

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 are:

- **AI-MIND** – grant agreement 964220
- **AMYPAD** – grant agreement 115952
- **LETHE** – grant agreement 101017405
- **Neuronet** – grant agreement 821513
- **PRIME** – grant agreement 847879
- **PRODEMON** – grant agreement 779238
- **RECOGNISED** – grant agreement 847749
- **VirtualBrainCloud** – grant agreement 826421
EURO-FINGERS is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project. The project is supported through the following funding organisations under the aegis of JPND www.jpnd.eu: Finland, Academy of Finland; Germany, Federal Ministry of Education and Research; Spain, National Institute of Health Carlos III; Luxemburg, National Research Fund; Hungary, National Research, Development and Innovation Office; The Netherlands, Netherlands Organisation for Health Research and Development; Sweden, Swedish Research Council. Grant agreement: INTER/JPND/19/BM/14012609.

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 92, representing 26 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: Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe).
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 Tomasić (ECR).
Cyprus: Costas Mavrides (S&D).
Czech Republic: Tomáš Zdechovský (EPP).
Denmark: Margrethe Auken (Greens/EFA); Christel Schaldemose (S&D).
Estonia: Urmas Paet (Renew Europe).
Finland: Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D);
Czech Republic: Tomáš Zdechovský (EPP).
Denmark: Margrete Auken (Greens/EFA); Christel Schaldemose (S&D).
Estonia: Urmas Paet (Renew Europe).
Finland: Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP).
France: François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillame (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP); Chrysoula Zacharopoulou (Renew).
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Greece: Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE-NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Syparaki (EPP).
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Netherlands: Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP).
Poland: Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP).
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Slovakia: Ivan Stefanec (EPP).
Sweden: Jytte Guteland (S&D); Peter Lundgren (ECR).

EU DEVELOPMENTS

1 June: EU Commission launches public consultation on the European Health Data Space

One of the key priorities of the EU Commission in the area of health is the creation of a European Health Data Space (EHDS) which, it is hoped, will facilitate exchange of health data between organisations and across borders, supporting collaborative decision-making between Member States and enabling research on new treatments and care. The EHDS will be supported by a new regulatory framework - the Data Governance Act - that will govern the conditions for access to health data.

In developing the EHDS, the EU Commission wants to ensure that the rights, needs and values of individuals are respected, whilst also enabling personal, health data to be shared for greater benefit. To this end, a public consultation on the EHDS has been launched, aiming to collate the views and experiences of a broad range of stakeholders including members of the public, health organisations, NGOs, industry and academic...
researchers. The consultation will remain open for responses until 26 July, and can be accessed via the link below.


16 June: European Group of Governmental Experts meets online

The European Group of Governmental Experts on Dementia has met online, exchanging updates and knowledge on the most recent and relevant developments in relation to dementia. The meeting was attended by representatives of 24 countries, Austria, Belgium (Flanders), Bulgaria, Czech Republic, Estonia, Finland, France, Germany, Ireland, Italy, Latvia, Malta, Netherlands, Norway, Portugal, Poland, Slovenia, Slovakia, Switzerland, United Kingdom (England) and United Kingdom (Scotland). Representatives from the European Commission (DG SANTE and DG RTD) and the World Health Organization (WHO) were also present in the meeting.

A number of presentations were heard on the day, including on:

- Recent developments on the work of the World Health Organization, such as its recent launch of the Global Dementia Observatory Knowledge Exchange and the forthcoming strategy on epilepsy and other neurological conditions.
- Brain research which has taken place at an EU level, as well as the future of the Horizon Europe programme.
- The publication and implementation of the new Czech National Dementia Strategy which will run between 2020-2030.
- Austria’s work on involving people with dementia and other stakeholders in the implementation of the country’s national action plan on dementia.

In additional, a round table discussion was held in relation to the ongoing COVID-19 pandemic. Themes arising from the discussion included:

- Good uptake levels in relation to vaccines across different European countries.
- Some countries revisiting the issue of prioritisation of individuals within vaccine strategies, with more countries prioritising dementia to some degree (either as a condition in itself or through inclusion as a chronic disease).
- Continued caution by care homes in some countries in relation to visitation, even where measures have been eased.

The next meeting of the group is expected to take place on 7 December 2021.

16 June: European Commission publishes Horizon Europe Work Programme 2021-2022

The European Commission has adopted its work programme for the Horizon Europe research programme, covering the period 2021-2022. The work programme outlines the objectives and specific topic areas that will receive a total of EUR 14.7 billion in funding (from an overall funding package of more than EUR 95 billion across 7 years). Under the health cluster, there are six “destinations” which under which specific calls are made:

- Destination 1 -Staying healthy in a rapidly changing society.
- Destination 2 -Living and working in a health-promoting environment.
- Destination 3 -Tackling diseases and reducing disease burden.
- Destination 4 -Ensuring access to innovative, sustainable and high-quality health care.
- Destination 5 -Unlocking the full potential of new tools, technologies and digital solutions for a healthy society.
- Destination 6 -Maintaining an innovative, sustainable and globally competitive health-related industry.

The first calls for proposals will open on the Commission’s Funding and Tenders Portal on 22 June. Details of the health cluster and calls under this section of the programme can be found at:


The full work programme can be found at:


18 June: European Commission publishes EU4Health work programme 2021-2022

The European Commission has adopted its first annual work programme for EU4Health, covering the period 2021-2022. The work programme outlines the objectives and specific topic areas that will receive a total of EUR 312 million in funding (from a funding package of more than EUR 5.1 billion across 7 years). The programme will be managed by the European Commission and the Health and Digital Executive Agency (HaDEA).

The work programme covers a number of areas from the EU4Health remit, including crisis preparedness, disease prevention, support for health systems and the healthcare workforce, and digitalisation. Grant-funded work within the programme has a considerable focus on cancer-related topics,
with additional thematic areas including the mental health impact of COVID-19, work on support for Member States in developing digital health, as well as funding for the Organisation for Economic Cooperation and Development (OECD) to support implementation of best-practices related to non-communicable diseases.

The work programme provides no operating grants for civil society organisations, with a limited number of calls open to civil society organisations to participate. The full work programme can be found at:


**22 June: EU Parliament and Council reach political agreement on the Health Technology Assessment Regulation**

After months of negotiations, the EU Parliament and Council have reached a political agreement on the proposed Health Technology Assessment (HTA) regulation.

HTA involves the systematic assessment of the effects, costs and benefits of medicines, medical devices and tests, and aims to inform decision-making on market access and clinical guidelines. Currently, HTA processes are performed by around 50 different HTA agencies based in different Member States. The new regulation on HTA will create a framework for greater collaboration between Member States on clinical assessment and scientific consultations for new health technologies. Member States will still be responsible for assessing non-clinical aspects of HTA (e.g. economical, ethical, and social concerns) and will ultimately decide on pricing and reimbursement based on national criteria.

It is hoped that this framework will help accelerate access to new medicines and support Member States in meeting unmet clinical needs, boosting innovation and improving competitiveness of the EU healthcare sector. The regulation will now have to be formally adopted by the EU Council and Parliament before it can enter into force.


**28 June: European Commission adopts UK data adequacy decision**

The European Commission has adopted two adequacy decisions for the United Kingdom - one under the General Data Protection Regulation (GDPR) and the other for the Law Enforcement Directive. This means that personal data can now flow freely from the European Union to the United Kingdom where it benefits from an equivalent level of protection to that guaranteed under EU law.

The adequacy decisions facilitate implementation of the EU-UK Trade and Cooperation Agreement, which foresees the exchange of personal information, for example for cooperation on research collaborations. However, both adequacy decisions include safeguards in case of future divergence, including time limiting the duration of adequacy to four years.

The key points from the adequacy decisions include:

- The UK’s data protection system continues to be based on the same rules that were applicable when the UK was a Member State of the EU, meaning that the UK has fully incorporated the principles, rights and obligations of the GDPR and the Law Enforcement Directive into its post-Brexit legal system.
- For the first time, the adequacy decisions include a so-called ‘sunset clause’, meaning that the decisions will automatically expire four years after their entry into force. After that period, the adequacy findings might be renewed, however, only if the UK continues to ensure an adequate level of data protection which the Commission will continue to review.

The adequacy decision can be found at:


**POLICY WATCH**

**3 June: France publishes Neurodegenerative Diseases Roadmap 2021-2022**

On 3 June, the French Government published a Neurodegenerative Diseases Roadmap 2021-2022, outlining next steps which will be taken across different fields. Following the completion and evaluation of the French Neurodegenerative Disease Plan 2014-2019, France Alzheimer worked with other civil society organisations in France to engage with the French Government, emphasising the need
for continued prioritisation of neurodegenerative diseases across different areas of health policy.

In the response, the French Ministry of Health committed to publishing a shorter “Roadmap” identifying focused policy measures for continued work. A total of 18 actions are identified in the Roadmap, around the following 10 axes:

- Consolidation of achievements in terms of entry into the pathways
- Better response in situations of disruption of care due to psycho-behavioral disorders
- Pathways and responses adapted to young patients
- Better access to research
- Adaptation of hospital care (avoidance of inappropriate hospitalisations with upstream work and creation of resources for adapted hospital care)
- Adaptation of the Parkinson’s patient’s pathway (in particular neuro-stimulation)
- Promoting French efforts in Europe and exchanging best practices
- Prevention
- Medical and social care
- Democracy in health.

Within the report, the government commits to continued participation of France in the European Group of Governmental Experts on Dementia, as well as citing Alzheimer Europe’s 2019 prevalence estimates for the number of people living with dementia in France. The Roadmap can be downloaded (in French) at: https://solidarites-sante.gouv.fr/IMG/pdf/plan_pmnd_version_longue.pdf

**12 May: New Chairperson elected at Alzheimer Iceland AGM**

The Annual General Meeting (AGM) of Alzheimer Iceland was held on 12 May in unusual circumstances, but the meeting took place online for the first time.

The agenda included traditional general meeting functions. Árni Sverrisson, who has been Chairperson of the association for the past 7 years, did not give the option of re-election to the position of Chairperson, but instead takes a seat on the Board. In his place, Ragnheiður Ríkharðsdóttir was elected. She has served on the Board for the past year.

Others on the Board include Brynjólfur Bjarnason, Vice-Chairperson, Friða Proppé, Secretary and Guðbjörg Alfredsdóttir. New in reserve are Ragnheiður Elín Árnadóttir and Sigurjón Pórdarson.

Alzheimer Iceland thanks Árni Sverrisson for his invaluable contribution to the association, and congratulates the new Chairperson on her appointment.

**25 May: NGO Living with Dementia reports on Estonian conference “Technologies and the surrounding environment in supporting daily coping of people with dementia”**

A conference on “Technologies and the surrounding environment in supporting daily coping of people with dementia” was held in Estonia on 25 May, aiming to offer solutions for how people who need care could lead an independent and active life for as long as possible. Independent life is what helps to delay the symptoms of dementia. Technology forms a part of our lives, also when it comes to dementia and care. The conference focused on answering the questions of whether and how technologies can help families, whether technology could “replace” a human being, or if it should do it at all.

The opening speaker of the conference was Hunn Wai – a designer and co-founder of the design company Hack Care from Singapore – who gave tips on how to create a home that would not confuse people with dementia, be comfortable and assist

**MEMBERS’ NEWS**

**10 May: Dementia Jersey has a new CEO**

Claudine Snape is the new CEO of Dementia Jersey, since 10 May 2021. Ms Snape, who was born in Jersey and has a number of years of experience working for major charities in the United Kingdom, joins Dementia Jersey from The National Deaf Children’s Society, where she was Director of Communications. She built her career in the charity sector in London working for major charities, including Cancer Research UK and now takes over from Sean Pontin, who has taken the role of CEO of disability charity Enable.

Dementia Jersey Chairman, Chris Renouf said: “We’re delighted that Claudine is joining us. She brings a wealth of charity sector knowledge with a focus on fundraising and marketing. She’ll be a big help to build on our recent name change and boost our profile and income in order to support more people with dementia”.

Claudine Snape said: “I’m excited to be coming back to the Island after 20 years to take on this important role. It’s one close to my heart as my grandmother had vascular dementia and my best friend’s dad has Alzheimer’s.”

"Dementia Jersey plays a key role in supporting the quality of life and dignity of people with dementia in the local community and I hope to be able to extend their reach and impact.”

https://dementia.je/people/claudine-snape/

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https://dementia.je/people/claudine-snape/
with activities. The Singaporean design studio’s speciality is dementia-friendly furniture, tableware, etc.

Up next, Dympna Casey from the National University of Ireland, Galway (NUI Galway) explored questions around who social robots are developed for. Can a robot take the place of a carer? What is the role of robots and where should they be used?

The Head of Koeru Care Home, Terje Teder introduced the first-ever social robot in Estonia, Paro the harp seal, being used at a care home. The therapeutic robot responds to voice, touch, temperature and communicates by making a sound. The presenter also noted that smart assistance in care can also come in the form of smaller, simpler and inexpensive solutions, such as guideposts and signs, as well as simple movement-activated light solutions, all of which are readily available.

Activity Therapist and PhD student Aisling Flynn, from Ireland, introduced memory technology research rooms, one of which she works in herself. In addition to introducing assistive technologies in these places, free assessment and counselling are also provided. An activity therapist decides, based on each client’s individual characteristics, which technological assistive tools and minor modifications might be of help to that particular person. Clients are also referred on, or receive follow-up assessments, if needed.

Kimberley Littlemore is a documentary maker from the United Kingdom. She shared her very personal experience with delegates: she filmed her parents, who live with dementia, to show what domestic life looks like through their eyes. Her parents agreed to make this film because they want to help people to understand how people with dementia live and to grasp what kind of challenges they face on a daily basis.

Following this, Viktor Saaremets, Head of the Prevention Department at the Estonian Rescue Board, shared some experiences of accidents in the home, showing that people living with dementia are also at risk in their own homes and highlighting how, with a little help from the technological tools available, a home can be made a safer place. Families and carers of people with dementia buy smartphones to use with monitoring devices and keep an eye on people with memory impairment who might become lost. Ene Jõeveer, a family member of a person with dementia, shared her user experience. Urban space sets some limits to the use of GPS devices as they might lose the signal on public transport or in staircases; the accuracy of location becomes critical in a tight network of streets.

A city is age-friendly if the entire community contributes to considering the needs of the elderly. The city of Tartu is set to become age-friendly by 2030. Mihkel Lees, the Deputy Mayor of Tartu, stated that all people of Tartu should be able to lead a long, independent and full life in their hometown and noted that the local government should think about preventing a need for assistance from early on. A well-designed public space contributes to that, he stressed.

The moderator, Tiina Tambaum said that people with dementia want to carry on with their normal day-to-day lives and that, despite remembering things from their childhood more clearly, as the disease progresses, this does not mean they become children. People with dementia want to engage in meaningful activities, no different from anyone else. None of their needs disappear. They want to hear their names spoken, feel touches. The settings – rooms and people – must create an opportunity to use what the brain still has left. Technologies can help but will never replace care provided by another person, she concluded.

A short film about dementia was presented at the conference. It can be watched, here (with English subtitles): https://vimeo.com/568427982

The full conference report is available, here (in Estonian): Tehnoloogia on hea, aga ei asenda inimest | Elu Dementsusega

18 June: A new brain bank has opened in Prague

On 18 June 2021, a new brain bank in Prague officially opened its doors. It is the first of its kind in the CEE countries - EU member states which were part of the former Eastern bloc - and is located in the Fakultní Thomayerova nemocnice (Thomayer University Hospital), in its Neurology and Pathology departments.

A brain bank is a repository of brains that have been donated for research. When a person decides to donate their brain for biomedical research, the brain bank gathers the tissue post-mortem, prepares it for future use in research, and stores it according to the highest standards. The opening of this new facility was attended by Iva Holmerová, founder of the Czech Alzheimer Society and Chairperson of Alzheimer Europe, Radoslav Matej, Chief of Pathology and Robert Rusina, Chief of Neurology. The Dean of the 3rd Medical
Faculty was also present at the opening, as these departments are a teaching base for Medical Faculty students.

Pictured: Iva Holmerová with Radoslav Matej (chief of pathology) and Robert Rusina (chief of neurology).

28 June: France Alzheimer welcomes neurodegenerative diseases roadmap 2021-2022, but demands stronger commitments from the French Government

The French neurodegenerative diseases roadmap 2021-2022 was officially launched on 1 June 2021. The associations which are stakeholders of this road map and worked with the French Ministry of Health to build it, acknowledge this essential step, as the country’s former neurodegenerative diseases plan (PMND) ended more than a year ago. They remain cautious, however, and demand strong commitments from the French Government on the dedicated budget (still unknown), the deployment schedule and the continuous assessment of the different measures.

Indeed, the roadmap has been introduced as a work plan “not intended to cover the entire scope of measures necessary to meet the needs of people living with neurodegenerative diseases. It is targeted on the measures of the former PMND for which the non-completion or the need for appropriation requires that the efforts be continued”.

This is not ambitious enough for France Alzheimer, which asks for a strong, long-term commitment from the Government to address this major public health issue and allow concrete improvements for people living with dementia and their carers.

1 June: Researchers identify changes in novel plasma proteins that may signal increased dementia risk many years before disease onset

According to a new study published in Nature Aging, people at higher risk of developing dementia in later life could be identified by screening for abnormal levels of specific blood proteins.

Using blood samples from over 4,100 participants in the Atherosclerosis Risk in Communities (ARIC) study, which began in 1987, a team of researchers led by Prof. Joseph Coresh (Johns Hopkins Bloomberg School of Public Health) used the SomaScan platform to analyse the levels of over 5,000 different plasma proteins. Evaluating blood samples from healthy participants in late middle age, the researchers identified 38 proteins that were linked to the development of dementia within 5 years. Looking at blood samples taken from a much younger group of over 11,000 participants almost 20 years previously, a similar association was identified for 16 proteins, predicting the development of dementia over 20 years later. A validation study
using samples from a different, Icelandic cohort found similar changes for 6 of the 16 proteins, one of which was a protein called SVEP1, which has previously been linked to the development of Alzheimer’s disease in analyses of genetic risk.

https://www.nature.com/articles/s43587-021-00064-0

4 June: Alzheon initiates a new Phase III trial with ALZ-801 for early Alzheimer’s disease

On 4 June, Alzheon Inc., a clinical-stage biopharmaceutical company focused on developing new medicines for neurodegenerative disorders such Alzheimer’s disease (AD), announced the dosing of the first participant in its new APOLLOE4 Phase III study.

The study is a randomised, double-blind and placebo-controlled trial evaluating the efficacy and safety of ALZ-801 in people with early AD carrying two copies of the €4 allele of the apolipoprotein E gene (APOE4/4 homozygotes).

The company received a USD 47 million grant from the US National Institute on Aging (NIA) to advance this Phase III study. Approximately 300 participants from US, Canada and Europe will receive either placebo or ALZ-801 twice daily for 78 weeks. The primary objective of the APOLLOE4 study is to measure the impact of ALZ-801 on cognition using the Alzheimer’s Disease Assessment Scale – cognitive subscale (ADAS-cog). Secondary outcomes include assessments of function, ability to perform daily activities and neuropsychiatric symptoms.


7 June: FDA approves aducanumab, a first disease-modifying treatment for Alzheimer’s disease

In a hotly-contested and keenly-awaited decision, the U.S Food and Drug Administration (FDA) has approved aducanumab for the treatment of Alzheimer’s disease (AD). Aducanumab, which will be sold by Biogen under the name “Aduhelm”, is the first AD treatment to be approved by the FDA since 2003, and is the first potentially disease-modifying therapy to reach the market. Aducanumab, a monoclonal antibody to beta-amyloid, has been evaluated in several trials on mild cognitive impairment and mild AD. These trials, which included the Phase 3 EMERGE and ENGAGE trials, were designed to test whether aducanumab could help clear amyloid plaques from the brain, and reduce the progressive cognitive impairment associated with the development of AD. Although the cognitive test data from these clinical trials were ambiguous, data from brain imaging scans consistently showed a reduction in amyloid plaque load following intravenous (IV) administration of high-dose aducanumab. In their press release, the FDA stated that their decision to approve aducanumab via the “Accelerated Approval” pathway was primarily based on this reduction in amyloid plaques, which, it is hoped, will also result in clinical benefit. Rather than limiting the approval to people with mild cognitive impairment or mild AD, the FDA has chosen to approve the therapy broadly, for people at all AD stages.

Biogen are now required to conduct a post-approval clinical trial to verify the anticipated benefit of aducanumab, which is delivered via monthly IV infusions and involves regular monitoring via brain scans. If this trial does not confirm that aducanumab is beneficial for people with AD, the FDA has the possibility of removing the drug from the market. Biogen has determined a list price of USD 56,000 per year for the drug, with this price set for the next four years.

Aducanumab is currently under review at the European Medicines Agency (EMA) and at Swissmedic, following submissions by Biogen in October 2020 and April 2021, respectively.


8 June: Anavex completes enrolment of its Phase II/III clinical trial in people with Alzheimer’s disease

On 8 June, Anavex Life Sciences Corp - a clinical-stage biopharmaceutical company developing therapeutics for the treatment of neurodegenerative diseases including Alzheimer’s disease (AD) – announced that it has completed enrolment for its ongoing Phase IIb/III study evaluating blarcamesine (formerly known as ANAVEX 2-73) for AD.

The 48-week Phase 2II/III double-blind, randomised and placebo-controlled trial is evaluating the safety and efficacy of blarcamesine for the treatment of early AD. The recruitment has exceeded the company’s initial target and recruiting 450 participants at 52 sites across US, Europe and Australia. Participants will receive once daily oral doses of either blarcamesine or placebo. Primary and secondary endpoints will assess safety and both cognitive and functional efficacy, measured through ADAS-Cog, ADCS-ADL and CDR-SB. The company expects to announce topline results by mid-2022.


14 June: Results of Phase II ADAMANT trial of AADVac1 for mild Alzheimer’s disease published in Nature Aging

On 14 June, Dr Petr Novak and colleagues at Axon Neuroscience published the results of the ADAMANT Phase II clinical trial, in
the Nature Aging journal. ADAMANT was a 24-month randomised, placebo-controlled trial that aimed to assess the safety and efficacy of AADVac1 in participants with mild Alzheimer’s disease (AD).

AADVac1 is a peptide vaccine directed against an area of the tau protein that is involved in the formation of tau tangles, which accumulate in the brain during the development of AD. Preclinical studies of AADVac1 showed that rats which received regular doses of AADVac1 had much less evidence of AD pathology in the brain, with substantially fewer tau tangles and improved performance on cognitive and functional tests. Results of a Phase I clinical trial of AADVac1 revealed that the treatment was safe and well-tolerated by participants, with a trend towards improved performance in certain cognitive tests.

ADAMANT initiated recruitment in 2016, enrolling 196 participants with mild to moderate AD, 117 of whom received AADVac1 (11 doses over the 24-month trial period). Similar to the results of the Phase I trial, ADAMANT found that AADVac1 was safe and well-tolerated, with similar numbers of adverse events reported by the treatment and placebo groups. AADVac1 was able to stimulate the immune system to produce high levels of antibodies against tau. This was associated with significant reductions in the levels of biomarkers of neurodegeneration, including neurofilament light chain (NFL) and pTau217. The researchers did not observe any substantial overall improvements in cognitive or functional tests following treatment with AADVac1, although closer analysis of participant subgroups identified a 30% reduction in cognitive and functional decline (measured by CDR-SB and ADAS-MCI-ADL tests) among those with a confirmed AD biomarker profile.


15 June: European Alzheimer’s Disease Consortium (EADC) responds to FDA approval of aducanumab

Following the news that the FDA had approved aducanumab for the treatment of Alzheimer’s disease, the European Alzheimer’s Disease Consortium (EADC) published a position statement, on 15 June 2021.

It begins by noting that the FDA approval is subject to the drug’s manufacturer, Biogen, conducting an additional clinical trial at Phase IV, to verify the drug’s clinical benefit, and that if the study were to fail, the approval may be revoked. The EADC also highlights that the drug is currently only approved in the US, and emphasises that aducanumab trials only enrolled a group of patients with a narrow disease–specific stage, namely mild cognitive impairment (MCI) due to Alzheimer’s disease (AD) or early-stage Alzheimer’s dementia, and that aducanumab should therefore only be given to this group of patients.

It also stresses that, given that the FDA followed a different regulatory pathway, i.e. that of a surrogate endpoint (approval on the basis of the evidence of reduction of amyloid deposits), the approval may open the door for many other applications based on amyloid reduction, but without solid evidence for clinical efficacy. Due to the absence of convincing clinical benefits, this is and will remain controversial, pending further evidence. Indeed, the EADC points out that further research is needed to better understand which patients and at what disease stage they respond best, what the optimal duration of treatment is (current data do not span more than 18 months) and what side effects may occur after long-term use.

In conclusion, the statement says that, while doctors and patients have been hoping for a new and improved drug for AD, for many years now, caution is advisable in view not only of the high cost and of the expectations surrounding the new drug, but also of the uncertainty around the lack of clear clinical proof of efficacy, at this stage. On a more positive note, the EADC points out that despite these uncertainties, this first treatment against the pathophysiology of AD is of great importance and if eventually proven to slow the progression of cognitive decline in people in the MCI stage of AD or early Alzheimer’s dementia, will be a major advance in the field. It also expresses the hope that the use of aducanumab will represent a breakthrough for more AD therapies and encourage more pharmaceutical companies to resume their research activities, including into targets other than amyloid. Read the EADC’s full position statement, here:


16 June: The TANGO Phase II study evaluating gosuranemab in AD did not meet its primary efficacy endpoint

On 16 June, the global biotechnology company Biogen announced topline results from its Phase II study of gosuranemab (BIIB092), an investigational anti-tau antibody that was being evaluated as a potential treatment for Alzheimer’s disease (AD).
The TANGO Phase II trial was a 78-week double-blind, placebo-controlled and parallel-group study evaluating the safety and efficacy of gosuranemab in people with mild cognitive impairment (MCI) due to AD or with mild AD. A total of 654 participants (50-80 years old) received gosuranemab or placebo once every 4 weeks across 97 sites in US and Europe. Top-line results showed that the study did not meet its primary endpoint, which was a change on the Clinical Dementia Rating Scale-Sum of Boxes (CDR-SB). Although gosuranemab was well-tolerated overall, no treatment benefit was seen on exploratory efficacy endpoints, including the Alzheimer’s Disease Assessment Scale–Cognitive Subscale (ADAS-Cog 13), the Alzheimer Disease Cooperative Study Activity of Daily Living (ADCS-ADL), the Mini-Mental State Examination (MMSE) and the Functional Assessment Questionnaire (FAQ).

Based on these top-line results, the TANGO study has been terminated. Analyses of additional data are ongoing and the company plans to present the findings at upcoming events.


21 June: Results from the DIAN-TU trial show that gantenerumab reduces key biomarkers in inherited form of Alzheimer's disease

On 21 June, researchers have published results from the Dominantly Inherited Alzheimer Network Trials Unit (DIAN-TU) Phase II/III study in the journal Nature Medicine.

It was announced last year that the study failed to meet its primary endpoint, which was a slowing cognitive decline as measured by multiple tests of thinking and memory.

The adaptive platform trial is a randomised, double-blind and placebo-controlled clinical trial assessing the safety, tolerability and efficacy of two drugs, solanezumab (made by Eli Lilly) and gantenerumab (made by Roche), in people at risk for and with a type of early-onset form of Alzheimer’s disease (AD) caused by a genetic mutation, called autosomal dominant AD. The trial, testing two investigational drugs to slow or prevent the progression of AD in autosomal dominant AD families, recruited participants in Australia, China, Europe and US. 52 participants were assigned to receive gantenerumab, 52 solanezumab and 40 placebo. They were followed for up to seven years.

In the published study, analyses of secondary endpoints and biomarkers are reported. Participants who received gantenerumab showed a significant reduction of amyloid plaques and tau protein in the brain, compared to placebo. The solanezumab-treated group showed a greater cognitive decline on some measures and did not show benefits on biomarkers.

https://www.nature.com/articles/s41591-021-01369-8

23 June: Eisai and Biogen have been granted US FDA Grants Breakthrough Therapy designation for lecanemab in AD

On 23 June, Eisai and Biogen have announced that the US Food and Drug Administration (FDA) has granted Breakthrough Therapy designation for lecanemab in AD (also known as BAN2401), an investigational antibody targeting amyloid beta, for the treatment of Alzheimer's disease (AD).

According to the FDA, the Breakthrough Therapy designation is a process designed to expedite the development of drugs that are intended to treat a serious condition. The benefits of a Breakthrough Therapy designation include more intensive guidance on an efficient development program as well as eligibility for rolling review and potentially priority review.

The FDA's decision on lecanemab is based on the recently published results of the Phase Iib clinical trial named Study 201. This 18-month multi-centre, double-blind, placebo-controlled and parallel-group study of lecanemab enrolled 856 participants with mild cognitive impairment (MCI) due to AD and mild AD with confirmed presence of amyloid pathology from US, Europe and Asia. In this study, pre-specified analysis showed a consistent reduction of clinical decline across several clinical and biomarker endpoints at the highest doses.

In addition, the Phase III clinical study, AHEAD3-45, is currently evaluating lecanemab in people with preclinical AD. In March 2021, Eisai and Biogen completed enrolment of their Phase III Clarity AD study of lecanemab in people with mild cognitive impairment due to AD or mild AD dementia with confirmed amyloid accumulation in the brain. The study's primary endpoint is expected to be completed by the end of September 2022.


24 June: Eli Lilly receives US FDA Breakthrough Therapy designation for donanemab in AD

On 24 June, Eli Lilly has announced that the US Food and Drug Administration (FDA) has granted Breakthrough Therapy designation for donanemab, an antibody that targets a form of modified amyloid protein, for the treatment of Alzheimer's disease (AD).
The Breakthrough Therapy designation aims to expedite the development and review of drugs that are intended to treat a serious condition when preliminary clinical evidence indicates that the drug may demonstrate substantial improvement on a clinically significant endpoint(s) over already available therapies that have received full FDA approval.

The FDA agency based this decision on a randomised, placebo-controlled and double-blind Phase II study evaluating the safety and efficacy of donanemab in people with early symptomatic AD. This TRAILBLAZER-ALZ study enrolled 272 participants and showed a significantly slower decline in cognition and daily function compared to placebo. Donanemab met the primary endpoint of change from baseline to 76 weeks in the Integrated AD Rating Scale (iADRS). In addition, the study reported that donanemab showed consistent improvements in secondary endpoints measuring cognition and function as compared to placebo.

Donanemab is also being evaluated in an ongoing randomised, placebo-controlled, double-blind and multi-centre Phase III study, named TRAILBLAZER-ALZ 2, to evaluate the safety, tolerability and efficacy of donanemab in people with early symptomatic AD.


30 June: Andrew Feigin discusses results from phase 2 Huntington’s disease trial of anti-semaphorin 4D antibody pepinemab (SIGNAL)

TouchNEUROLOGY recently spoke with Andrew Feigin (Department of Neurology, NYU Grossman School of Medicine, New York City, NY, US), to discuss the results from the phase 2 Huntington’s disease trial of anti-semaphorin 4D antibody pepinemab (SIGNAL). The interview was filmed at the virtual 15th International Conference for Alzheimer’s & Parkinson’s Diseases (ADPD), earlier this year. You can watch it, here:


30 June: Article on design and rationale of RECare study published in Journal of Alzheimer’s Disease

The REspectful Caring for AGitated Elderly (RECare) project is trying to tackle one of the most challenging symptoms of the clinical course of dementia: the so-called Behavioural and Psychological Symptoms of Dementia (BPSD). The major objective of RECare is to adapt and upscale the implementation of a particular intervention aimed at controlling BPSD, the special medical care unit for persons with dementia and BPSD (SCU-B), an intervention that has already been implemented in some European countries.

The mission of the SCU-B is to have a positive impact on patients’ behaviour with the ultimate goal being to allow, when possible, their return home. The therapeutic approach in most existing SCU-Bs is a mix of cautious pharmacological treatment and non-pharmacological therapies, such as occupational therapy, physiotherapy, doll therapy, sensory rooms, etc. The specific objectives of RECare are:

- To start a prospective cohort study, comparing the activity of the centres endowed with a SCU-B of both types, with that of the other centres lacking this structure.
- To adapt the model in accordance with the results of the cohort study, not only regarding the main endpoints, but also comparing the experience and the different working methods of participating centres and the different socio-political context in which they act.
- To scale up the intervention in the countries taking part in the study, but where SCU-Bs are absent, or sporadic, such as Italy and Greece.

RECare is a three-year, prospective study enrolling 500 people with dementia. Particularly, 250 community-dwelling people presenting with severe BPSD will be recruited by five clinical centres across Europe, equipped with a SCU-B; while the second similar group of 250 people will be followed by six other centres without SCU-Bs. The endpoints include short and long-term SCU-B clinical efficacy, quality of life of patients and carers, cost-effectiveness of the SCU-B, psychotropic drug consumption, carers’ attitudes towards dementia, and time until nursing home placement. A first publication on the design and rationale of the study was recently published in the Journal of Alzheimer’s Disease:

Rationale, Design, and Methodology of a Prospective Cohort Study for Coping with Behavioral and Psychological Symptoms of Dementia: The RECare Project - IOS Press
LIVING WITH DEMENTIA

11 June: Petri Lampinen, member of the European Working Group of People with Dementia, manages to overcome the limitations imposed by COVID

The past time has made my work as an expert by experience more difficult. The COVID-19 pandemic has cancelled many events over the past year, at which I was supposed to go to talk about my experiences of having dementia.

I had enough of the silence in the spring and decided to do everything I could, so I could be able to continue in my active role, taking part in these types of activities. I know that it’s necessary for me, to function.

I first made a self-made video, talking about me and the memory issues that have affected me. I sent it to a good friend, who is a memory professional. I’m glad he has used the video in memory nurse training.

Immediately after that, I drafted an article for Alzheimer Europe’s Dementia in Europe magazine. My writing also attracted interest in the press in my homeland, where it will be published this autumn.

I also asked the South Ostrobothnia Memory Association, in which I am involved, if they would have some tasks for me and I suggested that I could lecture online, talking about independent rehabilitation, memory disorder experiences, and relationships with a memory disorder. I was glad these all happened this spring. I gave many lectures and this put me back into gear for my activities, and it was no longer a reverse gear. The lectures will continue this autumn and I have agreed to participate in these.

I also gave a remote reading to the students of Seinäjoki high-level gerontology class. This event provided good contact with the educational institution with which I will continue to work.

I was also invited to speak as part of a training for health care personnel, organised by the Hospital District of South Ostrobothnia. The main theme was memory disorder and a vulnerable older person at an on-call reception. A psychologist from the geriatric ward interviewed me at Seinäjoki Central Hospital. Some of the audience was in the auditorium and the other group listened remotely online. I felt like I was able to share my thoughts well. They were particularly interested in cognitive accessibility, which is one of my favorite subjects.

My wife and I gave talks together, about memory disorders and relationships, at events in Kurikka and Alavus. The organisers were the Memory Society of South Ostrobothnia and the Family Carers’ Organisations. These two events brought us a great deal. We were able to share a positive and open picture of living with a memory disorder.

The Finnish Memory Association has made a video project with people with memory disorders and their loved ones. Filming has often been postponed due to this pandemic. My wife Nina and I are a part of this project. With the precise design, we were able to complete the filming. As far as we are concerned, the filming was done safely at my parents’ summer house in Hämeenlinna and Nina and I were happy to be invited to join this project.

Now I’m sitting, taking a well-deserved rest in my garden swing, listening to birds singing and enjoying the green summer. I am grateful to everyone who has supported me and my wife during the spring.

DEMENTIA IN SOCIETY

21 June: Dementia Lithuania forms partnership with Lithuanian Sports University

Dementia Lithuania, which is a newly founded organisation that aims to represent the rights of people living with dementia and their carers in Lithuania, is pleased to have started a new partnership with the Lithuanian Sports University. This new partnership will look to implement a range of activities that promote physical activity in dementia care, support and prevention, mainly focused on:

- developing a training for students at the Lithuanian Sports University, about the development of applied physical activity for people living with dementia in community settings
- implementing a training programme for the carers of people living with dementia about the application of physical activity exercises in care, to support their loved ones’ health and well-being
- developing and implementing a workshop programme that will introduce diverse questions to support the health and well-being of people living with dementia and their carers.
Dementia Lithuania looks forward to working on all of these actions, which it hopes will meaningfully contribute to the supports that are currently available for people living with dementia and their carers. It also expects that the collaboration will help to raise awareness about dementia in wider society. This cooperation was inspired by the knowledge and good practices presented at Alzheimer Europe’s recent online Alzheimer’s Association Academy (18 May 2021), which looked at various aspects of sports and dementia, including discussions about how sports can be integrated into community-based services and initiatives.

www.demencijalietuvoje.org

Pictured: Aida Gažauskienė, lead of the Science and Innovation Guidance Department, Prof. Dr Diana Reklaitienė, President of the Lithuanian Sport University, and Ieva Petkutė, lead of Dementia Lithuania.

NEW PUBLICATIONS & RESOURCES

24 June: As part of “Nature’s Building Blocks” video series, Fujirebio has created a video highlighting the importance of early diagnosis of Alzheimer’s disease

The importance of early diagnosis of Alzheimer’s disease (AD) is highlighted in a new series of documentaries that were presented under the name “Nature’s Building Blocks” on 16 June, during the BIO International Convention. Initiated by the ICBA (International Council of Biotechnology Associations), the series aims at exploring innovations and partnerships that are driving biotechnology industries forward, through the personal stories of the people behind the science and those whose lives and livelihoods depend on it. The ICBA has invited a number of biotechnology companies to participate in the series of documentaries, all of which are produced by BBC StoryWorks.

Fujirebio, the in vitro diagnostics company with a long history of AD diagnostic solutions and partnerships, was invited to participate in the series. It decided to do so with a video dedicated to AD testing. The video, released on 24 June 2021, follows 53-year-old Daniel Du Rietz, who has been diagnosed with AD dementia. He is from Stockholm, Sweden. He and his wife, Sophia, share their experiences from the earliest doubts and symptoms, through the diagnosis and adapting their lives to Daniel’s condition. They also share their firm hopes for the future.

The neurologist following Daniel, Dr Silke Kern, talks about the importance of early testing for AD, and Dr Henrik Zetterberg, University of Gothenburg, and Geert Jannes, Scientific Director at Fujirebio, discuss the latest evolutions in AD testing and open doors to how the disease could be detected and monitored in the future. The six-minute video can be watched, here:http://www.bbc.com/storyworks/natures-building-blocks/an-early-diagnosis

25 June: World Dementia Council publishes collection of essays on dementia care

On 25 June 2021, the World Dementia Council published a collection of essays on dementia care. It is a series of reflections from international leaders looking at better care, supporting carers, the impact of COVID-19, as well as national perspectives from India and Chile. You can find the publication, here:

https://worlddementiacouncil.org/DLP/global-dia

JOB OPPORTUNITIES

30 June: EPF launches Call for Tender for Consultant to help map the patient organisation situation in Western Balkans

With the scope of the European Patients’ Forum (EPF) growing beyond the EU, it has amended its Constitution, now allowing organisations based in all of Europe to become EPF members. This aims to include work towards a Wider
Europe as a geographical continent rather than as a purely political entity. This includes the EPF’s goal to strengthen patient groups in areas where it currently lacks exhaustive information of the patient condition, the visibility of the regional patient organisations, and their relationship with the local governmental authorities.

With this in mind, the EPF has launched a Call for Tender for a Consultant to help map the current patient organisation situation in the Western Balkans.

The deadline for applications is **15 July 2021**. Find out more and apply, here: EPF Calls for Tender page.

**30 June: University of Nottingham Faculty of Social Sciences seeks Research Associate/Fellow**

Applications are invited for the post of Research Associate/Fellow in the Faculty of Social Sciences, School of Sociology and Social Policy (SSP), at the University of Nottingham. The research associate/fellow will be based in the Institute of Mental Health: [https://www.institutemh.org.uk](https://www.institutemh.org.uk). The person appointed will work closely with Professor Justine Schneider (School of Sociology & Social Policy) and Professor Martin Orrell (University of Nottingham Medical Faculty).

The purpose of this role is to implement the UK arm of a cross-national trial involving five countries: Norway, Germany, Netherlands, Turkey and UK. Music Interventions for Dementia and Depression in Elderly Care (MIDDEL) will provide internationally-generalisable results concerning the effects of Music Therapy and Group Recreational Singing in care homes. The role holder will have operational responsibility for delivering MIDDEL in the UK - geographically, this is likely to be in The Midlands and East of England. The role holder will be expected to implement the protocol, conduct the research, be an active member of the research team and be jointly responsible for writing up the study for publication. The deadline for applications is **11 July 2021**.

Find out more and apply, here: [https://www.nottingham.ac.uk/jobs/currentvacancies/ref/SOC19792](https://www.nottingham.ac.uk/jobs/currentvacancies/ref/SOC19792)

**EDUCATION**

**30 June: touchNEUROLOGY announces new learning activity focused on Alzheimer’s disease**

TouchNEUROLOGY has launched a new learning activity focused on Alzheimer’s disease, featuring behavioural neurologist and neuroscientist Dr Brad Dickerson discussing recent advances and future directions in neuroimaging technologies in Alzheimer’s disease.

This activity, part of the “touchTALKS” series, is provided by touchIME and has been made possible by an independent medical education grant from Biogen.

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<td>EWGPWD</td>
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<td>1 July</td>
<td>Patients’ and Consumers’ Working Party of European Medicines Agency</td>
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<td>26-30 July</td>
<td>Alzheimer’s Association International Conference</td>
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<td>8 August</td>
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### CONFERENCES 2021

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<td>26-30 July</td>
<td>Alzheimer’s Association International Conference (AAIC), <a href="https://www.alz.org/aaic/overview.asp">https://www.alz.org/aaic/overview.asp</a></td>
<td>Amsterdam, Netherlands &amp; Virtual</td>
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<td>23-26 September</td>
<td>15th World Congress on Controversies in Neurology (CONy), <a href="https://cony.comtecmed.com/">https://cony.comtecmed.com/</a></td>
<td>Dubai, United Arab Emirates</td>
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<td>26-29 October</td>
<td>Digital transformation of healthcare: the added value of patient partnerships (EPF), <a href="https://epfcongress.eu/">https://epfcongress.eu/</a></td>
<td>Virtual</td>
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<td>29 Nov-1 Dec</td>
<td>31st Alzheimer Europe Conference, <a href="https://www.alzheimer-europe.org/Conferences/2021-Online">https://www.alzheimer-europe.org/Conferences/2021-Online</a></td>
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31st Alzheimer Europe Conference
Resilience in dementia: Moving beyond the COVID-19 pandemic
Virtual Conference
29 November - 1 December 2021
www.alzheimer-europe.org/conferences #31AEC