WELCOME

Neurological disorders are the leading cause of disability-adjusted life years and second leading cause of death globally. With this in mind, delegates at the 75th World Health Assembly have approved a new intersectoral “Global action plan on epilepsy and other neurological disorders” (including dementia), aiming to improve access to care and treatment, prevention, and brain health.

An online session of our popular Alzheimer’s Association Academy series was held this Monday, focusing on dementia as a disability. Speakers, including Helen Rochford-Brennan, member of the European Working Group of People with Dementia (EWGPWD), highlighted the importance of taking a human rights-based approach to dementia, of implementing the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), under which dementia counts as a disability, and of ensuring equity, empowerment and inclusion.

We also co-organised a webinar with the European Federation of Neurological Alliances (EFNA) and GAMIAN-Europe, on "Patient involvement in Brain Health: Safeguarding the future of Brain Health for patients". During the meeting, a joint Call to Action was launched, highlighting the need for improved Patient Involvement in brain health research in Europe. Expert-by-experience Helen Rochford-Brennan was again among the speakers, this time highlighting that people with dementia must be equal partners in research, who are truly listened to and whose opinions impact outcomes.

Involvement in research is a topic that is close to the hearts of the members of the EWGPWD and when they met face-to-face this month, for the first time in over two years, they worked on several projects, within the framework of Public Involvement. At the meeting, which was held in Luxembourg, Chris Roberts was re-elected as EWGPWD Chairperson, for the next term of office (starting from October). The group also discussed the organisation of its special symposium at the 32nd Alzheimer Europe Conference.

Speaking of the conference, the call for abstracts is now closed and the almost 270 abstracts received are now being reviewed by the Scientific Committee. Submitting authors will be informed of the Committee’s decision in mid-June.

It has been 20 years this month since the last approval of an Alzheimer’s medicine by the European Medicines’ Agency, meaning that people living in Europe affected by Alzheimer’s disease (AD) have been waiting to gain access to better treatments for two decades. With Biogen’s recent withdrawal of its marketing authorisation application for aducanumab, the wait goes on. We continue to monitor clinical trial developments with great interest and note the welcome announcement by Biogen of its upcoming phase IV trial of aducanumab. We hope that this trial and ongoing trials by other companies will lead to positive results soon.
The impact of patient engagement in healthcare decisions is crucial. Specifically, it is imperative that all stakeholders ensure the involvement of patients to:

- Implement policies to ensure early and meaningful patient involvement.
- Safeguard the future of brain health for patients, it is imperative that all stakeholders ensure the involvement of patients to:
- Engage patients in the discussion on brain health.
- To date, patient involvement has largely not been used to a satisfactory degree in research into brain health and innovation, meaning there has been relatively little impact on patient care and diagnosis. The patient community needs precision medicine in the prevention and diagnosis of brain diseases. To achieve this goal, those working in the fields of neuroscience, neurology and psychiatry need to cooperate further, align themselves more closely and transform their framework, in a similar way to what has been done in oncology.

The meeting of 12 May was opened by Joke Jaarsma, President of EFNA. The keynote speech was delivered by Guendalina Graffigna from the Università Cattolica del Sacro Cuore, Milan, Italy. Prof. Graffigna discussed "The impact of patient involvement in research, policy and practice", emphasising that "Patient Engagement can (and should) be achieved in many different settings in Brain Health: from the engagement in research for drug development, to the engagement in policy making, in in health technologies assessment, in co-designing healthcare plans and interventions, in shared decision making about therapy and in self-management and treatment adherence."

Orla Galvin, Executive Director of EFNA then presented a call to action, issued by the three host organisations, Alzheimer Europe, EFNA and GAMIAN-Europe, highlighting the need for improved patient involvement in brain health in Europe. It states that in order to safeguard the future of brain health for patients, it is imperative that all stakeholders ensure the priorities, needs and expertise of those living with brain disorders are considered and included. It calls on all stakeholders to be accountable for patient involvement and shared decision making; specifically, on national and EU governing bodies to develop and, where developed, to implement policies to ensure early and meaningful engagement and involvement of patients to:

- Promote a human rights based approach in all policies and research affecting people living with brain health conditions.
- Prioritise patient needs in research agenda setting.
- Review funding proposals for research.
- Access, review and report on access to diagnosis, therapeutic intervention and care pathways.
- Support access to and design of clinical trials, and the design and use of patient reported outcome measures.
- Support approval processes for therapeutic interventions.
- Contribute, with industry, to patient-centric design in research, development and commercialisation.
- Optimise data sharing for patients and society.

You can read the full call to action, here: https://www.alzheimer-europe.org/policy/positions/patient-involvement-brain-health-call-action
Following Dr Galvin’s presentation, there was the first of two roundtable discussions, "What matters most to patients? Involving patients in research prioritisation". The session was moderated by Nigel Olisa, Executive Director of GAMIAN Europe, who introduced patient advocate Helen Rochford-Brennan first, to give the patient perspective. Helen Rochford-Brennan focused on the importance of ensuring meaningful non-tokenistic involvement, stating "If we do not have input in decisions it is not patient involvement. Patient involvement is not a tick box exercise." She also noted that "Public Involvement is very important for people with dementia because it makes us visible and reduces stigma. Involvement in research has given me hope and a sense of purpose." Finally, she reminded researchers that public involvement participants do not exist merely to endorse their existing opinions, but rather should be partners in research, who are truly listened to and whose opinions impact outcomes.

The three panellists in this roundtable were Georg Starke, École Polytechnique Fédérale de Lausanne, Stefan Schreck, DG SANTÉ, European Commission and Frédéric Destrebecq, European Brain Council, Brussels. Each gave his perspective on the topic, with Dr Starke emphasising that “medical research on neurotechnology and brain health should prioritize patients' needs to uphold its Hippocratic ideal: to work for the benefit of the sick, to cure them or at least ameliorate their condition.” There was ample opportunity for some lively and interesting discussion in the Q&A session, before the webinar moved to its second and final roundtable session, titled "Improving the way we involve patients in brain health", moderated by Jean Georges, Executive Director of Alzheimer Europe.

The patient perspective was delivered, this time, by Erik van der Eycken and panellists included Nathalie Bere, Patient Engagement, European Medicines Agency (EMA), who noted that "the insightful experiences and perspectives of patients living with a particular condition are a vital element within medicines development, assessment and approval. Ensuring that patients views are systematically captured, in a meaningful way, will ultimately result in more patient-relevant outcomes." Up next, were panellists MEP Alex Agius Saliba and Monica di Luca, Former President of the Federation of European Neuroscience Societies (FENS). Monica di Luca shared details of the European Brain Research Area (EBRA) project and pointed out that the project “clearly highlighted that public patient engagement requires increased attention. It is the role of the scientific community to engage with civil society since the first steps of research projects’ development and to educate the next generation of neuroscientists in this direction.” Jean Georges thanked the panellists and patient representative and moderated the short Q&A session. The event was then closed by Joke Jaarsma. The video of the Brain Health webinar can be viewed here:

https://www.youtube.com/watch?v=9sdkPaYeeE

13-14 May: European Working Group of People with Dementia meets face to face for the first time in over two years

On 13-14 May, the members of the European Working Group of People with Dementia (EWGPWD) and their supporters met in Luxembourg and worked on several projects within the framework of Public Involvement. It was a hectic but very productive two days during which the group worked on a number of different topics and projects including the use of technology by people with dementia during the pandemic, augmented reality, social robots in care homes, artificial intelligence-based dementia risk prediction tools and respectful communication. Ana Diaz, Project Officer and Dianne Gove, Director for Projects moderated the various debates, together with Simone Felding from DISTINCT/German Center for Neurodegenerative Diseases (DZNE) who is doing a short secondment with Alzheimer Europe. Angela Bradshaw, Project Officer and Jean Georges, Executive Director of Alzheimer Europe also joined for a few sessions. Chris Roberts, Chairperson of the EWGPWD, moderated the session on the EWGPWD symposium for the 32nd Alzheimer Europe Conference (#32AEC).

The group voted for the Chairperson for the next term of office of the EWGPWD. Chris Roberts was re-elected as Chairperson and we look forward to his continued leadership of the EWGPWD from October 2022 onwards.

15 May: Call for abstracts for the 32nd Alzheimer Europe Conference is closed

The call for abstracts is now closed for the 32nd Alzheimer Europe Conference (#32AEC), which will take place in Bucharest, Romania, under the banner “Building Bridges”. We are pleased to have received almost 270 abstracts, all of which are now being reviewed by the Scientific Committee. All submitting authors will be informed of the Committee's decision in mid-June.

Registrations remain open with the Early Bird reduced fees, available until 15 July so book your place today!
On 17 May 2022, Alzheimer Europe held an online session of its popular Alzheimer’s Association Academy series, bringing together representatives of its member organisations, European Working Group of People with Dementia (EWGPWD) and pharmaceutical companies. The topic for this session, which was moderated by Iva Holmerová, Chairperson of Alzheimer Europe, was “Dementia as a disability.”

Helen Rochford-Brennan, who is a member of the EWGPWD, as well as the Irish Dementia Working Group, began the session with some introductory remarks about the importance of taking a human rights-based approach to dementia. She noted that talking about dementia as a disability can be controversial and that some people do not want dementia to be recognised as a disability. It is therefore important, she stressed, that when we talk about dementia as a disability, it is about ensuring that the human rights of all people with dementia are respected - and recognising dementia as a disability can help with this. Under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) dementia counts as a disability because it can cause long-term physical and sensory impairments, she noted. Framing dementia in terms of a disability is quite a new approach, she stated, insisting that it is a positive step and has helped lead to a great shift in public awareness, thanks to advocacy groups. “Our voices are powerful”, she said, “and if we are recognised as having a disability, we have more hope.” People with disabilities, including people with dementia, have the same legal rights as everybody else, but unfortunately, she said, many people with dementia are not aware of their rights or cannot access them. It is our duty, as advocates, to help them become aware of their rights and to understand their implications, she concluded.

Following these opening words, Dianne Gove, Director for Projects, Alzheimer Europe, gave a presentation on the implications of recognising dementia as a disability, for the fields of ethics, policy and practice. She began by stating that Alzheimer Europe has long recognised that impairments linked to dementia can lead to disabilities and that the work the organisation is doing in this area is building on work previously carried out by its ethics working group and the EWGPWD, the result of which was a 2017 discussion paper on the possible implications for ethics, policy and practice of recognising dementia as a disability:


Her presentation explored what it means to recognise dementia as a disability, noting various models of disability, including the moral/spiritual model, the medical model, and the social model. The World Health Organization (WHO) describes disability as neither purely medical nor purely social and Dianne Gove also highlighted that there has now been more of a move towards taking a human rights-based approach to dementia. She also reminded delegates that it is not the fact of having dementia that means one has a disability, it is the experience of having certain impairments that lead to society disabling the person, through its actions, through language and stigma. She then then moved focus, to examine the implications of recognising dementia as a disability and highlighted that recognising dementia as a disability may have personal, social, ethical and policy implications. Regarding ethical implications, she noted that recognising dementia as a disability requires us to reflect on and find the right balance between ethical principles, values, related concepts and approaches. Echoing Helen Rochford-Brennan’s words, she said that if/ when people with dementia experience disability, they should have the same rights as those afforded to other people with disabilities and that this includes the right to expect reasonable accommodations to be made i.e. equity, not just equality. Recognition of dementia as a disability can be beneficial in ensuring these rights and obligations are indeed the same, she said. In the final part of her presentation, Dianne touched on some of the difficulties encountered by people with dementia whose disability may be “hidden”. The presentation concluded with a set of recommendations:

- Recognise that people with dementia do not constitute a single, unified group of people, do not all experience disability in the same way and do not all have the same goals; be sensitive to and respect people’s preferences regarding the use of the labels (e.g. ‘disability’ and ‘disabled’).
- Respect the right of every person with dementia to accept or refuse, partially or fully, disability as part of their identity.
- Avoid making it necessary for people to state that they have dementia or disability to access any support or care they may need; Aim to offer support and consideration in response to a specified, apparent or suspected need.
- Raise awareness about disability and dementia amongst the general public, policy makers, service providers and health and social care professionals. Challenge stereotypes.
• Focus on rights, equity, empowerment and inclusion.

The final talk was given by Marine Uldry, Human Rights Officer at the European Disability Forum (EDF) and focused on UNCRPD reports as opportunities to improve the lives of people with disabilities and dementia. In March 2022, the United Nations (UN) Committee on the Rights of Persons with Disabilities started its second evaluation of the protection of disability rights by the European Union (EU) - an important moment for the disability movement in Europe. The presentation walked delegates through this process, as well as EDF’s response. Marine Uldry shared what organisations can do to ensure the voices of those they represent are listened to, with regards applying the UNCRPD in countries across Europe. She explained what CRPD reporting is and to whom the reporting is done. All States that have ratified the UNCRPD are reviewed by the UN Committee on the Rights of Persons with Disabilities. Civil society, she said, and especially disability organisations representing people with any type of disabilities can (and should, she stressed) take part in the process, because a country’s report may not reflect the situation in that country in the same way that people with disabilities see it. It may be inaccurate and may lack information, for example concerning dementia. It is hugely important, therefore, to engage with the Committee and ensure they have the right information, and that they see it from the angle of the person with the disability. There are different opportunities to engage and information can either be in written format (called an “alternative report”, submitted together as a disability coalition and/or as individual organisations), or it can also be delivered orally, during the Committee’s two annual sessions in Geneva (including via video conference). EDF’s alternative reports give information to the CRPD Committee about how the EU implements the Convention. Its first alternative report was prepared for the first review of the EU in 2015. In February 2022, working closely with its members, including Alzheimer Europe, EDF submitted its alternative report for the second evaluation of the EU, with a suggested list of questions. This second alternative report identified 17 main concerns, three of which are specific to people with dementia. Regarding next steps, the EU will have 12 months to respond and once the Committee receives a reply, it will schedule the “constructive dialogue” and adoption of Concluding Observations (probably in 2024). The EDF will engage in the second part of the process by preparing an updated report and participating in meetings with the Committee.

Delegates were strongly encouraged to check the UN website to see if their own country had sent its report. Marine Uldry also referred to an EDF guide on engagement in the work of the CRPD Committee:

https://www.edf-eph.org/publications/crpd-guide/

There was ample time for lively discussion and questions to the speakers, after which Iva Holmerová closed the session. The next Academy session is scheduled to take place online, on 12 July 2022.

30 May: “Tea and blether” digital get together with the Scottish Dementia Working Group

On 30 May, members of the Scottish Dementia Working Group (SDWG) and of the European Working Group of People with Dementia (EWGPWD) held a “tea and blether” (tea and chat) digital get together as part of Scotland’s Dementia Awareness Week. For details, please see:

https://www.alzscot.org/tea-blether-2022

The meeting was chaired by Margaret McCallion (member of both working groups) who presented the main priorities of the SDWG for 2022. Jim Pearson briefly joined to say hello and welcome the members of the EWGPWD and Wendy Rankin and Vicki Cahill provided support. From the EWGPWD, Chris Roberts (Chair) and Kevin Quaid (Vice Chair) presented some of the work of the EWGPWD and referred to their experiences as members of this and other national groups. Members of both groups also shared their personal experiences on diagnosis, post-diagnostic support and stigma. Dianne Gove and Ana Diaz participated in the meeting on behalf of Alzheimer Europe.
Alzheimer Europe networking

On 2 May, Ana attended a RADAR-AD Steering Committee meeting.

On 3 May, Jean attended an OECD/EBRains meeting “Towards the new European Brain Initiative. Delivering on the promise of actionable brain health data”.

On 3 May, Jean participated in the management group meeting of the dementia panel of the European Academy of Neurology.

On 4 and 5 May, Cindy and Dianne attended the Al-Mind General Assembly Meeting (Rome, Italy).

On 4 and 5 May, Jean attended a meeting of the WHO Pan-European Mental Health Coalition and contributed to the work package discussion on mental health of older adults.

From 9-12 May (Nicosia, Cyprus), Chris attended the AG Leventis Foundation conference on prevention on Alzheimer’s disease & cognitive decline with diet lifestyle starting.

On 9 and 10 May, Jean attended the Finding Alzheimer’s Solution Together (FAST) Council.

On 11 May, Ana and Dianne participated in the LETHE Advisory Board meeting.

On 11 May, Jean had a meeting with representatives of the RECAGE project.

On 12 May, Alzheimer Europe co-organised a symposium “Patient involvement in brain health: safeguarding the future of brain health for patients” together with EFNA, the European Federation of Neurological Associations and GAMIAN Europe.

On 12 May, Angela participated in an advisory board meeting organised by TauRx.

On 12 May, Dianne participated in the DARE (Disability Advocacy Research in Europe) meeting.

On 13 May, Jean met with a representative of LuMind IDSC Foundation to discuss collaboration on dementia and intellectual disabilities.

On 13 May, Angela participated in a meeting on the GDPR and informed consent organised by the LETHE project.

On 13 and 14 May (Luxembourg, Luxembourg), Dianne and Ana participated in the meeting of the European Working Group of People with Dementia.

On 16 May, Angela joined a Human Brain Project training session on brain data governance.

On 16 May (Copenhagen, Denmark), Dianne attended the kick-off meeting of the TIMING project.

On 16 May, Owen joined a European Commission civil society dialogue on access to essential services.

On 17 May, Ana attended the DISTINCT Supervisory Board meeting.

On 17 May (Luxembourg, Luxembourg), Gwladys attended an event with the Suisse Convention Bureau.

On 17 May, Alzheimer Europe organised an Alzheimer’s Association Academy meeting on “Dementia as a disability”.

On 17 May, Jean gave a presentation on the advocacy and public involvement activities of Alzheimer Europe, at the DISTINCT Summer School.

On 17 May, Cindy and Angela attended a webinar on healthcare systems preparedness, by the Davos Alzheimer’s Collaborative.

On 18 May, Jean attended the Ethics Committee of the Luxembourg Alzheimer’s Association.

On 18 and 19 May, Ana and Dianne attended the WHO Informal Consultation with People Living with Noncommunicable Diseases and Mental Health Conditions in the European Region.

On 19 May, Dianne participated in the DG MOVE online “Consequences of road traffic offenses and medical fitness” consultation on the revision of EU Directive on driving licences.

On 20 May (Bucharest, Romania), Gwladys met with representatives of the Marriott Hotel to discuss the preparations of the 32nd Alzheimer Europe Conference.

On 20 May, Cindy attended a webinar during the International Clinical Trials Day about the Patient’s Perspective, organised by the European Centre for Clinical Research Training.

On 25 May, Angela participated in a meeting of the Neuronet Regulatory and HTA Working Group.

On 25 May, Owen attended a World Health Assembly side event launching ADI’s Plan to Impact report.

On 30 May, Jean attended the General Assembly meeting of the ADAIR project.

On 30 May, Angela attended the General Assembly meeting of the VirtualBrainCloud project.

On 30 May, Dianne and Ana participated in the “International Tea & Blether” meeting hosted by the Scottish Dementia Working Group and European Working Group of People with Dementia.

On 31 May, Owen attended the European Academy of Neurology (EAN) Brain Health Summit.
EU PROJECTS

15 April: PRODEMOS announces end of recruitment in its main study

The members of the Prevention of Dementia using Mobile phone Applications (PRODEMOS) project announced the completion of the enrolment of research participants in its main study.

The PRODEMOS study is a randomised controlled trial investigating the effect of the use of a coach-supported, interactive mHealth platform facilitating self-management of dementia risk factors in people in the UK and China. The first participant was recruited in the UK in January 2021. Participants are 55-75 years, are of low socio-economic status (UK) or from the general population (China), have ≥ 2 dementia risk factors, and use a smartphone. PRODEMOS is a hybrid implementation-efficacy study. The main effectiveness outcome is change in dementia risk, measured with the CAIDE (Cardiovascular Risk Factors, Aging, and Incidence of Dementia) dementia risk score. Improvement of individual risk factors and cost-effectiveness will also be evaluated. Implementation outcomes include acceptability, adoption, feasibility, and sustainability of the intervention.

The recruitment in the main PRODEMOS study was formally ended in April and the study succeeded in recruiting 600 participants in UK and 884 participants in China. The trial will run until April 2023 and the results will be published in an international peer-reviewed journal. The final aim of the PRODEMOS project is to implement the flexible, fully adaptable mHealth platform in a culturally appropriate form, in a range of healthcare settings across the globe. Further information on the PRODEMOS project can be found here:

https://www.prodomos-project.eu/

28 April: ABOARD project hosts consortium meeting in Utrecht

On 28 April 2022, over 70 project members gathered in Utrecht (Netherlands) for the ABOARD project Spring meeting. There was a good atmosphere, lots of inspiration, and it was great to share what has been achieved so far.

The day was filled with inspiring group discussions in breakout rooms, a sunny guided city tour to foster networking, in-depth updates of each of the work packages, and valuable input from the end users. The cherry on top was a panel discussion chaired by Henk J. Smid (Chairman, Foundation LSH, Health~Holland and former director of ZonMw) about “the Alzheimer patient journey of the future”.

ABOARD-representatives from healthcare, health insurance, digital health, pharma, big data, education and patient organisations conducted an animated discussion, with lively input from the other project members in the audience. A wide range of perspectives and opinions was brought to the table, yet all shared the common vision that future prevention strategies, consisting of personalised combinations of lifestyle interventions and medication, will lead to the ability to stop Alzheimer’s before dementia had started. Alzheimer Europe Director Jean Georges is a member of the project’s Advisory Board.

ABOARD, short for “A personalized medicine approach for Alzheimer’s disease”, is a public-private project which aims to prepare for a future in which Alzheimer’s disease is stopped before dementia has started. Find out more about the project, here: www.aboard-project.nl

4 May: AI-Mind holds its fourth General Assembly Meeting in Rome

On 4-5 May, the H2020-funded AI-Mind project held its general assembly meeting as a hybrid event (online and in Rome, Italy). The project kicked off in March 2021 and aims to facilitate a paradigm shift in clinical practice. AI-Mind will create intelligent digital tools for screening of brain connectivity and dementia risk estimation in people affected by mild cognitive impairment. The meeting was hosted by two project partners, the Università Cattolica del Sacro Cuore (UCSC) and the Istituto di Ricovery e Cura a Carattere Scientifico San Raffaele Roma (IRCCS). Paolo Maria Rossini (IRCCS) and Americo Cicchetti
(UCSC) kicked off the meeting by welcoming more than 70 members from the AI-Mind consortium counting 15 partners. The event was an opportunity for some of the project members to meet each other in person for the first time. This was especially important as at the end of February, AI-Mind closed its first year of duration.

The welcome introduction was followed up by a “state of the play” from the project coordinator, Ira Haraldsen (Oso University Hospital, OUS), whose talk focused on the AI-Mind progress. Then, the first impressions from the AI-Mind clinical study were shared with delegates. After the first session dedicated to AI-Mind’s “state of the play”, project partners attended two scientific lectures on the definitions of Mild Cognitive Impairment by Frank Jessen (University of Cologne) and Michael Wagner (University Hospital Bonn).

Next, several sessions dedicated to the different work packages were held to discuss progress, ongoing activities, challenges and next steps to develop artificial intelligence (AI)-based tools for dementia prediction. Dianne Gove gave an update on Task 1.5 led by Alzheimer Europe, including the rapid review, the Public Involvement work/stakeholder consultation and the planned communication strategy for ethical communication of AI-based dementia risk prediction.

The first part of the second day continued with meaningful discussions on the AI-Mind study, effective communication and management aspects. This was followed by a talk on the innovation management by Jeanette Muller (accelopment Schweiz AG, accelICH). Next, the floor was given to Mathias Toft and Ainar Drews (OUS) who talked respectively about the biomarkers dynamics in pre-symptomatic Alzheimer’s disease and the limitations of artificial intelligence. Ira and Paolo then drew the meeting to a close, thanking all the participants for their active contribution to the meeting.

Director for Projects Dianne Gove and Project Officer Cindy Birck represented Alzheimer Europe at the meeting in Rome. Project Officers Ana Diaz, Christophe Bintener and Angela Bradshaw joined online. The full summary of the fourth AI-Mind General Assembly is available on the project website: https://www.ai-mind.eu/blog/closing-the-first-year-with-in-person-meeting-4th-general-assembly/

9 May: The Neuronet Coordination and Support Action releases updated Decision Tool for engagement with Regulatory and Health Technology Assessment bodies

The members of the Neuronet (Efficiently Networking European Neurodegeneration Research) programme are pleased to announce the launch of an updated version of their Decision Tool to support engagement with Regulatory and Health Technology Assessment (HTA) bodies. The Decision Tool now provides a clickable overview of the processes and procedures for HTA and regulatory interactions at different stages of the development pipeline. This will help ensure that the outputs being developed by projects are relevant for regulatory and HTA settings, where applicable.

Neuronet is a Coordination and Support Action aiming to support and better integrate projects of the Innovative Medicines Initiative’s (IMI) neurodegeneration (ND) research portfolio. One of Neuronet’s workstreams aims to develop tools and services to support IMI ND projects in areas where unmet needs have been identified, which include the need for further support for interactions with HTA and regulatory agencies.

Representatives of the Neuronet project partner, NICE (UK National Institute for Health and Care Excellence) have performed a general update of the Decision Tool that is going live on 9 May. This involved updating the signposting information and text to include any changes to organisations and processes and providing case studies from projects within the Neuronet portfolio that have been through HTA or regulatory processes and procedures. Additional signposting information on relevant agencies, organisations, tools and projects was also incorporated.

The Decision Tool can be accessed through the Neuronet Knowledge Base, here: https://kb.imi-neuronet.org/

“The timing of engagement with regulators and which procedures to follow are important considerations to maximize the value of feedback received for research strategies. Neuronet’s interactive tool can help in making such fit-for-purpose decisions”, Dr Lennert Steukers, Neuronet Project Leader and Associate Director, Clinical Scientist, Janssen Pharmaceutica NV, a member of the Neuronet Project. Contact info@imi-neuronet.org for further information.

11 May: AMYPAD announces end of recruitment in the Prognostic and Natural History Study

On 11 May, the members of the Amyloid Imaging to Prevent Alzheimer’s Disease (AMYPAD) project announced the completion of the enrolment of research participants in its Prognostic and Natural History Study (PNHS).

The PNHS study is an open-label, prospective and multi-centre cohort study aiming to understand the role of amyloid PET imaging in the earliest stages of Alzheimer’s disease (AD). The first participant was recruited in Amsterdam, The Netherlands, in October 2018.

The study has been established to collect amyloid PET scans in a large-scale population in the early stages of AD. The study recruited participants from various European parent cohorts of similar characteristics. The main and original parent cohort was the European Prevention of Alzheimer’s Dementia (EPAD) due to the inherent collaborative framework between the two projects. In addition to EPAD, there were 9 other Parent Cohorts actively recruiting into AMYPAD. These are: EMIF-AD (60+ and 90+), ALFA+, FACEHBI, FPACK, UCL 2010-412, Microbiota, AMYPAD DPMS (VUMC) and H70.
On 30 April the recruitment was formally ended and the study succeeded in recruiting 1320 participants. As of 11 May 2022, the number of prospective scans collected within AMYPAD PNHS is 1361 (1144 baseline and 217 follow-up). The non EPAD Parent Cohorts also shared their historical data and therewith the total numbers of scans in AMYPAD PNHS is ~2600. Of course these are not the final numbers as sites are allowed to continue scanning (and collect additional data if applicable). In May and/or June sites will perform their final scans and the Last Patient Out date is the 30th of June 2022. At this moment, seven sites are finished with the scanning of participants (UEDIN, Tayside, CHUT, Nantes, Paris la Pitié, UZ Leuven and Fundació ACE) and the focus will be on the close out of the sites.

17 May: ADDI calls on experts to join the NeuroToolKit Data Hackathon

On 17 May, the Alzheimer’s Disease Data Initiative (ADDI) has opened registrations for its upcoming Data Hackathon to be held from July 1-17, 2022.

The ADDI NeuroToolKit (NTK) Data Hackathon will be a virtual event, bringing together researchers, biostatisticians, data scientists, and clinicians to investigate the potential clinical utility of different biomarkers in Alzheimer’s disease.

In self-selected teams of two to four people, participants will be using the new NTK app, developed by Roche in partnership with leading academic collaborators, and work with datasets from the EPAD project by utilizing ADDI resources. Participants will also be able to collaborate with other participants in the new ADDI online community.

Specifically, teams will:
- Perform exploratory data analysis
- Execute standardized descriptive analysis
- Conduct standardized hypothesis-related analysis
- Create their own standardized analysis
- Share and validate the customization analysis in different datasets.

Interested in participating? Space is limited and registration will close on June 24, 2022 (or when spaces are full).

https://www.alzheimersdata.org/hackathon

11 and 20 May: LETHE project publishes article on AI-Based Predictive Modelling of the Onset and Progression of Dementia & outlines how it will use Federated Learning with Dynamic Model Exchange

On 11, respectively 20 May, collaborators from the four-year LETHE project (A personalized prediction and intervention model for early detection and reduction of risk factors causing dementia, based on AI and distributed Machine Learning) published two articles. The first is entitled “Federated Learning with Dynamic Model Exchange”, explaining how Federated Learning will be used in the project. The second is goes under the title “AI-Based Predictive Modelling of the Onset and Progression of Dementia” and was published in the “Smart Cities” open access journal.

Understanding the complex and multifactorial causes of dementia is still an unmet goal in dementia research. The collection of behaviour and medical data is therefore a key part of the LETHE project and requirement for personalised and smart interventions. The LETHE project aims to leverage large multidimensional data about individual behaviours, lifestyle, health, and digital biomarkers on a previously unprecedented scale. The second article provides an introduction to the project and the challenges it aims to address.

You can access the open access publications via these links:

https://doi.org/10.3390/electronics11101530
https://doi.org/10.3390/smartcities5020036

24 May: AI-Mind passes the mark of 300 research participants for its clinical study

The AI-Mind consortium recently reached a significant milestone with the recruitment of the 300th research participant in its clinical study.

This clinical study is a key part of the AI-Mind project and will help develop and validate artificial intelligence (AI)-based tools to predict who is likely to develop dementia. The AI-Mind Connector will identify dysfunctional brain networks in an automated manner, and the AI-Mind Predictor will assess
dementia risk using data from the Connector, enriched with information collected through advanced cognitive tests, and genetic biomarkers.

Out of a total of 1,000 expected participants with mild cognitive impairment (MCI), aged between 60 and 80 years, 319 research participants (as of 24 May 2022) have already been recruited in five European clinical centres:

- Complutense University of Madrid (UCM, Madrid, Spain)
- Helsinki University Hospital (HUS, Helsinki, Finland)
- Oslo University Hospital (OUS, Oslo, Norway)
- The Catholic University of Sacred Heart (UCSC, Roma, Italy)
- San Raffaele Roma (IRCCS, Roma, Italy).

Moreover, this achievement was recently followed by more positive news shared by Prof. Camillo Marra from UCSC at the Alzheimer Europe General Assembly that took place in Rome. With the first participant included in January 2022 there is a positive trend of increasing interest in the study and the numbers of recruited participants.

People interested in the study can learn more about it from dedicated sections on the AI-Mind website, as well as watch an explanatory video developed to inform potential participants about the AI-Mind study procedures.

With the goal to distinguish people at risk and not at risk of dementia in a group of mild cognitive impairment subjects, the AI-based platform with both tools, AI-Mind Connector and AI-Mind Predictor, will be tested and validated in the above European clinical centres.

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
- **EPAD** – grant agreement 115736
- **LETHE** – grant agreement 101017405
- **NEURONET** – grant agreement 821513
- **PRODEMOS** – grant agreement 779238

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 91, 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:** Claudia Gamon (Renew Europe); 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 Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D). **Czech Republic:** Tomáš Zdechovský (EPP). **Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe); **Finland:** Alvina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Mia Petra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France:** François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffrey Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). **Greece:** Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraiki (EPP); Ellissavet Vozemberg (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland:** Barry Andrews (ALDE); Deirdre Clune (NI); Ciarán Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke ’Ming’ Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Grace O’Sullivan (Greens/EFA). **Italy:** Isabella Adinolfi (NI); Brando Benifei (S&D); Pierfrancesco Majorino (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:** Vilija Blinkeviciute (S&D). **Luxembourg:** Marc Angel (S&D); Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Isabel Wiseler-Lima (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D).
Netherlands: Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). Poland: Elżbieta Łukacijewska (EPP); Jan Olbrycht (EPP). Portugal: Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D). Romania: Cristian-Silviu Busoi (EPP); Marian-Jean Marinescu (EPP). Slovakia: Ivan Stefanec (EPP). Slovenia: Franc Bogovič (EPP); Milan Brglez (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP). Spain: Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtasun (Greens/EFA); Elzbieta Lukacijewska (EPP); Jytte Guteland (S&D); Peter Lundgren (ECR).

**EU DEVELOPMENTS**

1 May: European Ombudsman publishes findings into EU funding and disability rights

The European Ombudsman has published the findings of its own initiative inquiry, recommending that the European Commission implement measures to improve how it monitors whether EU Structural and Investment Funds (ESI) are being used to promote the right of persons with disabilities and elderly people to independent living.

Rules governing the ESI funds state that they should be implemented in a way that promotes the transition from institutional to family- and community-based care. During the own-initiative inquiry, 18 ombudsmen from around Europe as well as civil society organisations provided input and expertise.

The proposed measures include providing clearer guidance both to Member States and Commission staff on the need to promote deinstitutionalisation, as well as the need to set out indicators defining the process of deinstitutionalisation.

The findings also recommended that the Commission encourage Member States to make it easier for organisations representing persons with disabilities to participate in monitoring committees, and that it should pursue enforcement of the rules more proactively.

The Ombudsman urged the Commission to also carefully monitor how funds from the Recovery and Resilience are spent in relation to persons with disabilities and older people. The full findings can be read at: https://www.ombudsman.europa.eu/en/news-document/en/155398

3 May: European Commission launches European Health Data Space proposal

The European Commission has launched the European Health Data Space (EHDS), as part of its work on the European Health Union. The EHDS aims to empower people to control and utilise their health data in their home country or in other Member States. In addition, will create a consistent framework for the use of health data for research, innovation, policymaking and regulatory activities, while ensuring compliance with the EU’s data protection standards. From the patient and healthcare perspective, the EHDS will:

- Ensure that patients will have access to their data in electronic form, which will be able to be shared with other health professionals in and across Member States
- Require Member States to ensure that patient summaries, ePrescriptions, images and image reports, laboratory results, discharge reports are issued and accepted in a common European format
- Mandate interoperability and security as requirements, with manufacturers of electronic health record systems needing to certify compliance
- Require Member States to appoint digital health authorities.

In relation to the use of health data for research, innovation and policymaking:

- The EHDS creates a legal framework for the use of health data for research, innovation, public health, policy-making and regulatory purposes
- Access to such data by researchers, companies or institutions will require a permit from a health data access body, to be set up in all Member States. Health data access bodies will be connected to the new decentralised EU-infrastructure for secondary use, which will be established up to support cross-border projects.

The proposal put forward by the European Commission will now be discussed by the Council and the European Parliament. Further details on the EHDS can be found at: https://ec.europa.eu/commission/presscorner/detail/en/ip_22_2711

16 May: European Disability Forum publishes human rights report

The European Disability Forum (EDF) has published the sixth edition of its Human Rights Report, which this year focuses on the rights of persons with disabilities to participate in the political process across Europe.

The report explores legal and practical barriers preventing persons with disabilities from exercising the same political rights as other EU citizens, as well as highlighting their effects, such as the underrepresentation in politics of persons with disabilities.
The report concludes by providing recommendations for both EU policy makers and national governments, as well as EU-level and national political parties. Additionally, it provides data and tools to reduce inequalities and ensure accessible elections at the national and EU level.

Recommendations in the report include:

- Guaranteeing the right to vote and stand for election, regardless of legal capacity status
- Maximising accessibility to the proceedings, facilities and materials of elections
- Providing reasonable accommodation so that persons with disabilities can vote independently and secretly
- Ensuring the free choice of assistance
- Cooperating with disability organisations to assess and define how to solve the legal and practical barriers that prevent persons with disabilities from participating in elections, both as voters and candidates.

The full report is available at: https://www.edf-feph.org/content/uploads/2022/05/edf_hr_report_issue_6_2022_compressed.pdf

17 May: European Commission publishes EU4Health consultation

The European Commission has published a targeted consultation to seek the opinions of stakeholders about current and future EU health priorities and strategic orientations of the EU4Health programme, as well as the key health needs which should be addressed in its annual Work Programmes.

The consultation targets the European health community including organisations representing patients, civil society, and other parties active in public health and social issues. Additionally, healthcare professionals and healthcare providers, researchers, academics and experts networks, as well as Member States’ health authorities, are invited to submit their views.

The consultation will inform the priorities and strategic orientation of the 2023 annual work programme, as well as the health needs which will be addressed. The consultation will run from 17 May until 27 June 2022, and is available at: https://ec.europa.eu/eusurvey/runner/2023EU4HealthSurvey

19 May: European Disability Forum publishes position paper on disability card

The European Disability Forum (EDF) has published a position paper on the development and implementation of a European Disability Card.

In its Strategy on the Rights of Persons with Disabilities 2021-2030 (ESRPD), the European Commission indicated that it would issue a proposal for a European Disability Card by 2023. One year on from the launch of the ESRPD, EDF has issued the position paper, noting that many key questions have yet to be answered.

The position paper makes a number of recommendations, proposing the European Disability Card should:

- Be based on binding EU legislation, i.e. a Regulation or a Directive
- Allow for mutual recognition of one’s disability status
- Cover a maximum of different areas beyond culture, leisure, and sport. It should by default also cover national, regional, and local public transport, education in the framework of EU Mobility Programmes, facilitate employment in the transition phase to access the national disability benefit system when moving abroad, as well as commercial benefits.
- Be accompanied by an EU-level website and online database available in all EU languages
- Be accompanied by an EU funding instrument that ensures continuity and a lasting legacy beyond the initial launch
- Be accompanied with a communication and awareness raising campaign to ensure the biggest possible impact
- Not be combined physically with the European Parking Card but they should be kept separately.

The position paper is available at: https://www.edf-feph.org/publications/edf-position-on-the-european-disability-card-2022/

16-20 May: During European Public Health Week 2022 EUPHA and partners urge governments to provide strong leadership to “build back better”

The fourth edition of the European Public Health Week (EUPHW) was organised from 16-20 May 2022. Institutions and individuals across 32 countries organised a total of 235 events in 21 different languages. European Public Health Week is an initiative of the European Public Health Association (EUPHA), co-funded by the European Commission and with the support of the World Health Organization (WHO) – Regional Office for Europe. The event aimed to highlight the importance of improving health throughout the life course of all people living in Europe, particularly in light of the global COVID-19 pandemic. Each of the five days covered a different topic area:

- the first day discussed “A healthy and health literate youth”
- the second day addressed vaccination as key prevention strategy
• the third day focused on climate change and its impact on health
• the fourth day shone a light on mental health services and the long-term effects of adversities throughout the life course
• the fifth and final day addressed: “Building resilient health systems”.

Read more about this event, here:

POLICY WATCH

17 May: Davos Alzheimer’s Collaborative Calls for Five Key Actions to Strengthen Health System Readiness

On 17 May, the Davos Alzheimer’s Collaborative (DAC) hosted a webinar on “Driving early detection across aging societies”. The webinar was organised as part of its Learning Laboratory series, a forum for representatives across national public health organisations, policy, research, and industry, from different resource settings, to share learnings from Alzheimer’s research initiatives aimed at common operational challenges in healthcare system preparedness. George Vradenburg, Chairman of DAC, launched the webinar by welcoming the audience and speakers, highlighting the value of platforms such as the Learning Laboratory, which bring together stakeholders to engage and learn from shared projects, and take action in their jurisdictions. The keynote speaker was Dr Antonio Arauz of the Mexican National Institute of Neurology and Neurosurgery. He gave an overview of the prevalence and risk factors for dementia in Mexico, explaining how clinicians and social services are working together to implement the Mexican dementia plan and improve diagnosis rates and post-diagnostic support. The first section of the webinar was focused on incorporating digital technologies into clinical practice, and challenges encountered along the way in different countries and resource settings.

The panel of speakers included representatives of flagship sites for the DAC Healthcare Systems Preparedness (HSP) project, based in the US, Mexico, Scotland, south and central America, and Japan. Discussions centred around challenges in raising awareness of digital technologies and biomarkers in different patient populations and to different types of healthcare professionals; speakers highlighted that there is substantial variation in how diagnosis and post-diagnostic support is managed in different countries, with special efforts required to ensure timely and targeted involvement of these groups. The second section of the webinar was chaired by Phyllis Ferrell, who is leading the HSP project at DAC. This section was focused on how to improve cognitive assessment rates for older adults, in different countries and healthcare systems.

The speakers represented recipients of the first DAC grant for improving AD detection, which received 75 applications from 24 countries. They talked about how they would use funding to embed cognitive assessment programmes in primary care systems that are currently overstretched; develop and pilot novel diagnostic tools in the community setting, and provide training and outreach platforms to engage healthcare professionals, patients and caregivers in constructive dialogues around mental health and cognitive impairment. The Learning Laboratory webinar was closed by Dr Tarun Dua of the World Health Organisation, who congratulated DAC on identifying health systems preparedness as an important issue to tackle. She explained that community screening, management and engagement initiatives can reduce stigma for other diseases as well as for dementia, and lauded efforts to bring together stakeholders in the private and public sectors to build capacity, accelerate innovation, and address a key area of unmet clinical need.

The DAC calls on national governments, health system leaders, civil society organisations, the private sector, and other stakeholders to scale emerging lessons and innovative models for health system readiness, as we work together to transform Alzheimer’s responses around the world. Speakers at the Learning Laboratory highlighted five focus areas that are vital for progress:

• Ensure solutions are sustainable and scalable for all resource levels. To deliver impact at scale, solutions for early detection, prevention, and care must work in high-, medium-, and low-resource settings. Governments and health systems should explore how digital cognitive assessments, blood-based biomarkers, and other tools can integrate into clinical practice and democratize access by addressing common barriers, such as expense, wait times, specialist shortages, and cultural stigma.

• Drive change from both the “bottom-up” and “top-down.” Health systems can accelerate progress against Alzheimer’s by joining high-level strategies, policies, and guidelines with autonomy and choice for frontline health workers. Health system efforts should engage working groups of providers and other stakeholders on key program design decisions, then empower frontline providers as much as possible to choose what works best for their practice, their community, and those they serve.

• Coordinate new care models with existing policy initiatives. Policy, civil society, medical, and private-sector leaders should collaborate across domains to assess how new care models or efforts can best fit into or build on current Alzheimer’s policy initiatives. As novel scientific and
medical advances emerge, they should be harnessed in collaboration with national action plans, health registries, community health centres, and global research groups.

- Tailor for local cultural context. Health equity and program efficacy depend on meeting the needs, priorities, and cultures of local communities. By sharing best practices and toolkits across geographies and health systems, the global Alzheimer’s community can provide the foundation to then customize strategies to each society. This requires continuous effort, sincere relationship-building, and close attention to feedback from individuals and families.

- Prioritize innovative approaches to detection and diagnosis. Governments and research organizations should continue to invest in the development and deployment of more efficient approaches to Alzheimer’s detection, such as retinal screening, mobile clinics, and digital cognitive assessments. These emerging modalities promise to transform care pathways for earlier and more widespread risk reduction, prevention, diagnosis, and intervention, bolstering overall health system readiness.

Project Officers Angela Bradshaw and Cindy Birck represented Alzheimer Europe at the meeting.

To view a video recording of the Learning Laboratory:
https://www.youtube.com/watch?v=NHIaO6c6tNw

26 May: Alzheimer Society of Ireland launches its 2022-2024 Research Strategy

The Alzheimer Society of Ireland (ASI) has launched its 2022-2024 Research Strategy. This new strategy sets out the priorities, objectives, and actions that will guide ASI's research activities over the next two years and result from almost 300 consultations with ASI Staff, volunteers, people with dementia, family carers/supporters, and the clinical research communities.

Over the next two years, the ASI will:
- Support the development of essential research infrastructure in Ireland to assert research readiness and prepare for current and future developments in the field.
- Develop and support quality dementia research that aligns with The ASI's mission and values and is essential to our communities of people living with dementia, family carers/supporters, staff and branches. Translate and disseminate evidence-based research to promote public awareness of dementia research.
- You can read the strategy at:
https://alzheimer.ie/creating-change/research/

27 May: World Health Assembly passes neurological conditions action plan

Delegates at the 75th World Health Assembly have approved a new intersectoral global action plan on epilepsy and other neurological disorders (including stroke, migraine, dementia and meningitis) that aims to improve access to care and treatment for people living with these conditions, while preventing new cases and promoting brain health and development across the life course.

The plan was developed in response to neurological disorders being the leading cause of disability-adjusted life years and the second leading cause of death globally. During the session it was noted that despite the high global burden of neurological conditions, access to both services and support for these conditions is insufficient, especially in low- and middle-income countries.

The action plan will address the challenges and gaps in providing care and services for people with neurological disorders and ensure a comprehensive, coordinated response across sectors. Further information on the intersectional plan is available at:

SCIENCE WATCH

17 April: TouchNEUROLOGY discusses diagnosis and precision management in early Alzheimer’s disease with Dr Sharon Cohen

Dr Sharon Cohen joined touchNEUROLOGY in an interview published online on 27 April, to discuss the challenges in diagnosing Alzheimer’s disease (AD) at an early stage, the most exciting recent developments in diagnostic criteria, genetic testing, and neuroimaging techniques. Dr Cohen also talked

**3 May: BioXcel Therapeutics announces first participant dosed in its TRANQUILITY II Phase III Trial for agitation in AD**

On 3 May, BioXcel Therapeutics, a commercial-stage biopharmaceutical company utilising artificial intelligence approaches to develop transformative medicines in neuroscience and immuno- oncology, announced that the first participant has been dosed in its TRANQUILITY II study for agitation in people with Alzheimer disease (AD).

Initiated in December 2021, TRANQUILITY II and III are two pivotal Phase III trials evaluating BXCL501 for the acute treatment of agitation in people with AD. BXCL501 is an orally dissolving thin film formulation of dexmedetomidine. Each trial will enrol approximately 150 participants 65 years and older in assisted living or residential facilities and nursing homes. They will self-administer BXCL501 or placebo whenever agitation episodes occur over a three-month period. The studies will assess agitation as measured by the changes from baseline in the Positive and Negative Syndrome Scale-Excitatory Component (PEC) and Pittsburgh Agitation Scale (PAS) total scores.


**4 May: FDA issues marketing approval for new in vitro diagnostic test for Alzheimer’s disease pathology**

On 4 May, the US Food and Drug Administration (FDA) announced its approval of a first in vitro diagnostic test for early detection of amyloid proteins in the brain. Marketed by Fujirebio, the test measures the concentration of two forms of beta amyloid proteins in samples of cerebrospinal fluid (CSF), which has been shown to correlate with the amount of amyloid plaques in the brain.

A pathological hallmark of Alzheimer’s disease is the presence of sticky plaques of amyloid beta proteins in the brain, which contribute to symptoms such as memory loss and other types of cognitive impairment. Until now, the detection of these plaques in the clinic has only been possible using costly positron emission tomography (PET) scans of the brain. The new in vitro test uses specific antibodies to detect the quantities of amyloid 1-42 and amyloid 1-40 in CSF samples from lumbar punctures.

In evaluating the safety and efficacy of the test, the FDA analysed data from a clinical study of 292 participants from the Alzheimer’s Disease Neuroimaging Initiative (ADNI). Samples from these participants were screened using the new test kit, and the results were compared to PET scans of the same individuals. 97% of participants with positive PET scans also tested positive using the new in vitro test, while 84% of those with negative results using the in vitro test also had negative PET scans.

Based on these study results, the FDA authorised the use of the new in vitro test in adults with cognitive impairment aged 55 years and older, who are undergoing evaluation for suspected Alzheimer’s disease or other causes of cognitive decline. In their press release, the FDA emphasised the importance of using the new test in conjunction with other clinical evaluations, to avoid the risk of false positive results.


**5 May: Alzamend Neuro initiates its Phase Ila clinical trial with AL001 for mild to moderate AD**

On 5 May, Alzamend Neuro, an early clinical-stage biopharmaceutical company focused on developing novel products for the treatment of neurodegenerative diseases and psychiatric disorders, announced the initiation of its Phase Ila clinical trial with AL001 for the treatment of dementia related to Alzheimer’s disease (AD).

The Phase Ila study will evaluate the safety and tolerability of AL001 under multiple-dose, steady-state conditions and determine the maximum tolerated dose in people with mild to moderate AD. AL001 is a novel lithium-delivery system with the potential to deliver benefits of marketed lithium carbonate while mitigating or avoiding current toxicities associated with lithium.

The company announced that the first participant with mild to moderate AD has been dosed. Up to 40 participants will complete the Phase Ila trial. Multiple ascending doses will be administered for 14 days under fasted conditions (at least 1 hour before or 4 hours after meals). The maximum tolerated dose will then be used for further studies.

**13 May: Green Valley announces early termination of Phase III drug trial, citing funding concerns and practical issues caused by the COVID-19 pandemic**

On 13 May, the Shanghai-based pharmaceutical company, Green Valley, announced the early termination of the global, multi-centre Phase III trial of their investigational drug, GV-971 (also known as Sodium Oligomannate).

Following on from approval of GV-971 by China’s National Medical Products Administration in November 2019, Green Valley had initiated a Phase III trial of the drug in April 2020, aiming to use the data from this global, multi-centre trial to complete their Investigational New Drug submission to the US Food and Drug Administration (FDA). GV-971 is a small molecule drug derived from seaweed, purported to reduce brain inflammation by acting on the gut microbiome, and is taken orally in capsule form.

At the time of Green Valley’s announcement, the Phase III Green Memory trial had screened 1,308 participants from 162 clinical centres around the world, randomising 439 participants from North America, Europe and China. In their press release announcing termination of the trial, Green Valley cited funding concerns linked to low sales during the pandemic on the one hand, coupled with accelerating recruitment rates and increasing trial costs on the other. In addition, Green Valley highlighted elevated dropout rates due to the pandemic, as well as challenges completing the regular cognitive assessments required for participant follow-up.

Green Valley are now in discussions with regulatory agencies, clinical centres, investigators and participants to minimise the negative impacts of trial termination, and will focus primarily on accelerating and expanding access to GV-971 for the Chinese market.


**15 May: It has been 20 years since the last approval of an Alzheimer’s medication in Europe**

With the last approval of an Alzheimer’s medicine by the European Medicines’ Agency (EMA) dating back to 2002, people living in Europe affected by Alzheimer’s disease have been waiting to gain access to better treatments for 20 years. Biogen recently announced that it had notified the EMA about the withdrawal of its marketing authorisation application for aducanumab for the treatment of early Alzheimer’s disease, following discussions with the Agency’s Committee for Medicinal Products for Human Use (CHMP) during which the CHMP had indicated that there was insufficient scientific evidence to support the authorisation of aducanumab, and so the wait for innovative, disease modifying treatments continues in Europe.

Alzheimer Europe continues to monitor clinical trial developments with great interest and notes the welcome announcement by Biogen about the upcoming launch of a phase IV trial of aducanumab. The organisation hopes that this trial and ongoing trials by other companies will lead to positive results and to the approval by the EMA a new treatment against Alzheimer’s disease, after two decades of disappointments.

Alzheimer Europe also calls for continued research into much-needed and anticipated treatment options, including symptomatic treatments for people in more advanced stages of the disease. In addition, the organisation remains committed to a holistic approach to Alzheimer’s disease and dementia where treatment needs to be provided alongside counselling, support and adequate care of people with dementia and their carers throughout the disease process.

**23 May: Alzheimer’s disease in people with Down syndrome has similar variability in age of onset and mortality rate as autosomal dominant forms**

Down syndrome is the most frequent genetic cause of intellectual disability, associated with multiple comorbidities, due to the presence of all or part of a third copy of chromosome 21. Although improvements in health care have remarkably increased life expectancy of people living with Down syndrome, a consequence has been the emergence of age-related diseases including Alzheimer’s disease (AD). People with Down syndrome have a high risk of developing AD dementia. In a new study published in the journal JAMA Network Open, researchers assessed whether variability in AD symptom onset in people with Down syndrome is similar to autosomal AD and assessed its association with mortality. The study combined meta-analysis with the assessment of mortality data from US death certificates (77,347 record) obtained in the past 50 years and from a longitudinal cohort study from the Down Alzheimer Barcelona Neuroimaging Initiative (DABNI), which included 889 individuals. Researchers investigated the age at onset, age at death and duration of AD dementia in Down syndrome. The estimated age of onset was found to be 53.8 years, the estimated age at death 58.4 years and the estimated disease duration 4.6 years. In addition, US mortality data revealed an increase in life expectancy in Down syndrome from a median of 1 year in 1968 to 57 years in 2019.
These findings suggest that the variability in symptom onset of AD in people with Down syndrome was comparable to those who experienced autosomal dominant AD, while mortality was also similar.

https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2792538

24 May: New research identifies FMNL2 as a potential genetic link between Alzheimer’s and vascular disease

A new study published in the Acta Neuropathologica journal has identified a potential genetic link that connects Alzheimer’s disease with cardiovascular and cerebrovascular risk factors such as hypertension, obesity and diabetes. Alzheimer’s disease, cardio-vascular and cerebrovascular disease share similar risk factors that are linked to blood vessel dysfunction, such as hypertension, obesity and diabetes. In their new study, a team of researchers led by Richard Mayeux of Columbia University (New York, USA) identified a novel gene that may connect these risk factors to Alzheimer’s disease (AD). This gene, called FMNL2 (Formin-Like protein 2), was identified via a genome-wide screen of over 12,000 participants with a history of cardiovascular or cerebrovascular disease in the WHICAP, EFIGA, NACC and ROSMAP clinical studies, representing many different ethnic backgrounds. Analyses of post-mortem brain samples donated by people with brain infarcts or AD revealed larger quantities of FMNL2 transcript in areas of the brain with AD or vascular pathology.

To understand how FMNL2 might influence the development of AD, the researchers then turned to animal models of disease. By manipulating the levels of FMNL2 in a zebrafish model, and by analysing the brains of AD mice, they found that increased FMNL2 was linked to abnormal brain blood vessels. Microscopic evaluation of brain samples revealed altered connections between astrocytes and vascular cells of the blood-brain barrier. Astrocytes help maintain the structure of the blood-brain barrier, and support the clearance of damaging proteins from the brain. Blocking FMNL2 in zebrafish led to defective clearance of toxic amyloid beta proteins from the brain, pointing to a potential biological role for FMNL2 in AD.

https://link.springer.com/article/10.1007/s00401-022-02431-6#Sec22

25 May: New research shows that seven healthy habits and lifestyle factors may reduce dementia risk

Researchers in the US have found that seven healthy habits and lifestyle factors may play a role in lowering the risk of dementia in people with the highest genetic risk. The findings were published in the journal Neurology, the medical journal of the American Academy of Neurology. The seven cardiovascular and brain health factors, known as the American Heart Association’s Life’s Simple 7, are: being active, eating better, losing weight, not smoking, maintaining a healthy blood pressure, controlling cholesterol, and reducing blood sugar.

The study looked at 8,823 European Americans and 2,738 African Americans who were followed for 30 years. People had an average age of 54 at the beginning of the study. Participants completed questionnaires to assess how well they followed the Life’s Simple 7 habits. Total scores ranged from 0 to 14, with 0 representing the unhealthiest score and 14 representing the healthiest score. Researchers also assessed their genetic risk of dementia, including whether they carried the APOE-e4 gene. The average score among Europeans and Africans was 8.3 and 6.6 respectively.

Over the 30-year study period, more than 2,200 of the participants developed Alzheimer’s disease or another form of dementia. Results showed that European people with the highest scores in the Life’s Simple 7 habits had a lower risk of dementia, including among those at high genetic risk, by the end of the study. Among Africans a similar pattern of declining dementia risk across those with higher scores on the lifestyle factors was identified. However, researchers said the smaller number of participants in this group limited the findings, so more research is needed.

https://doi.org/10.1212/WNL.0000000000200520

MEMBERS NEWS

25 April: Brain Health Scotland launches world’s first free Massive Open Online Course on brain health from a sport and exercise perspective

Brain Health Scotland is delighted to announce the launch of the world’s first free Massive Open Online Course (MOOC) on brain health from a sport & exercise perspective. The course, which went live on 25 April 2022, aims to build knowledge for anyone who plays sport, or exercises regularly, at any level, introducing
key concepts and practical tips to support brain health across the life course.
This new resource has been developed in response to direct calls from athletes asking for evidence-based information and support. The course content is delivered in an engaging and interactive format and features perspectives from former international sports stars and Olympians.
Brain Health Scotland is developed in partnership with Alzheimer Scotland and is funded by the Scottish Government. The course can be accessed at:
https://www.brainhealth.scot/sportscourse

5 May: Alzheimer Society of Ireland welcomes new CEO Andy Heffernan

The Alzheimer Society of Ireland (ASI) is very pleased to announce that Andy Heffernan has been appointed as its new CEO. Mr Heffernan has recently taken up the role, as ASI continues its work in supporting people with dementia, their family carers, and supporters in Ireland. He will bring expertise, experience, and drive to his new role. Mr Heffernan has the value set, corporate oversight and compliance experience, and the commitment to person-centred approaches to lead the ASI forward. He holds significant experience at a senior leadership level across several areas and most recently with The Society of St Vincent De Paul, where he served as National Secretary. He has previously worked in the disability and mental health sector serving as Chief Executive of St John of God Community Services. Before this, he served in the Defence Forces.
The Alzheimer Society of Ireland CEO, Andy Heffernan said: “I’m delighted to have started my role with The Alzheimer Society of Ireland and I feel so privileged to meet with our service users, staff, volunteers, and supporters across Ireland. I am really looking forward to working with everyone in the charity and continuing our work as the leading dementia- specific service provider in Ireland. The ASI works across Ireland in the heart of local communities providing dementia-specific services and supports and advocating for the rights and needs of all people living with dementia and their carers. Our vision is an Ireland where people on the journey of dementia are valued and supported. I would like to thank the ASI board, express my sincere gratitude to Siobhan O’Connor for serving as our Interim CEO and to thank former CEO Pat McLoughlin for his service to our charity. I am really looking forward to the journey ahead and working with everyone in Ireland and our counterparts in Europe and beyond. Thank you.”

24 May: Ireland’s “TeamUp for Dementia Research” celebrates milestone moment!
The Alzheimer Society of Ireland launched TeamUp for Dementia Research in July 2021 (in collaboration with Dementia Research Network Ireland). The service connects people with an experience of dementia with opportunities to participate in ethically approved dementia research in Ireland.
Participant recruitment has long been a familiar struggle within the research community. Prior to the launch of the TeamUp service, there was no coordinated or inclusive way for people in Ireland affected by dementia to express an interest in taking part in dementia research or indeed, to learn about actively recruiting studies. TeamUp for Dementia Research fills this gap in the research process.
TeamUp for Dementia Research recently welcomed its 150th member to the service! This milestone means that there are now over 150 people from all experiences and backgrounds participating in unique and innovative dementia research in Ireland. And the service continues to grow!
Members are supported to register to the service in an accessible manner; online, over the phone or by video call. Importantly, the new members’ research preferences are recorded, ensuring they are only offered opportunities to engage in research relevant to their interests. When a suitable project is announced, eligible members are identified using specific study parameters, invited to participate and then linked in with the research team.
To learn more about this exciting new service, visit www.teamupfordementia.ie or contact Clara on teamup@alzheimer.ie
24 May: Jenni Kulmala is the new Chairperson of the Alzheimer Society of Finland

Jenni Kulmala has started as the new Chairperson of the Alzheimer Society of Finland (Muistiliitto), after MP Merja Mäkisalo-Ropponen stepped down following a long and committed period of ten years in the role. Jenni Kulmala is a researcher in the field of ageing, currently working as a senior researcher and associate professor of gerontology. She has a long-standing background in the field of ageing research. Her research interests include dementia prevention and social inclusion of people with cognitive decline, and she has been involved in many national and international research and development projects in the field. She sees the Alzheimer Society of Finland as an innovative actor changing negative attitudes, giving a voice to people with dementia and showing the way on how to create an age- and memory-friendly Finland.

25 May: Alzheimer Bulgaria starts work on new “Smart Against Ageism” Erasmus+ project

Alzheimer Bulgaria has started working on a new Erasmus+ project for older people – “Smart Against Ageism” (SAA). Alzheimer Bulgaria is a partner in a consortium involving seven organisations in six European countries, namely: SHINE2Europe, AGE PLATFORM EUROPE, ASOCIACIJA SENJORU INICIATIVU CENTRAS, Alzheimer Bulgaria, Academy on Age-Friendly Environments in Europe BV and European Association for the Education of Adults.

The SAA project, which runs from January 2022 to June 2024, aims to contribute to better social inclusion of older adults, by developing an educational game that will introduce the users to the perspectives of older people concerned by or at risk of discrimination and segregation. It is hoped that this will in turn contribute to developing empathy, tolerance of diversity and civil society skills. Overall, encouraging people to reflect on their own negative biases towards old age and being protected from condescending attitudes and practices is the main objective of the project.

The SAA project will deliver an accessible online game to raise awareness of ageism and to help the players understand the perspectives of people experiencing ageism, to promote empathy, tolerance, respect, and civic skills. In this way, the SAA project hopes to contribute to restoring older adults’ image as full citizens and remove barriers to their social participation.

The SAA educational game will be oriented at the needs of volunteers, formal and informal carers, assistants, staff with diverse professional backgrounds (janitors, social workers, etc.), and family members of older adults. Additionally, the project will reach out to associations in the social, educational, health and care sectors, alongside research organisations and policy makers. An interactive learning platform, a high-quality learning game, and accompanying materials will be made available for informal and non-formal learning.

26 May: Alzheimer’s Association Larissa visits Monastery of Agios Antonios Agias with a group of people with dementia and carers/supporters

The Alzheimer’s Association Larissa (EENAL), together with a large group of people with dementia, carers/supporters and employees, recently visited the monastery of Agios Antonios, which is 35 km from the city of Larissa and is distinguished for its history and museum exhibits. The purpose of the visit was the “mental empowerment” of the people with dementia, through involvement in the religious events in view of the “Holy Week” (Easter). The goal was to encourage interaction between them, with their environment, and to increase socialisation.

First, the visiting group attended the pre-sanctified ceremony with religious fervour. Then, they were informed by the priest about the history of the monastery and its use in the past, as a sanatorium for the mentally ill with prayer. This provoked an interactive discussion. Questions were asked to the priest about how the patients were treated, the length of stay and the number of patients treated. Also, some of the participants recalled and told similar stories they had heard from their grandmothers.

Then, they were guided by the priest to the church museum, where they were impressed by style of the icons, the relics and books from the 14th century. The visit ended with the priest gifting a copy of the icon of St Anthony and a book with the history of the monastery to EENAL, while the president of EENAL, Eleni Nifli expressed her gratitude for the hospitality and reciprocated with gifts for the needs of the monastery. The group left full of knowledge and images, both from the monastic environment, as well as the spring landscape of the route with the blossoming almond and cherry trees.
27 April: Forget Me Nots choir presents its new song "Waltzing on borrowed time"

The Forget Me Nots choir is proud to present its latest song “Waltzing on borrowed time”, which is a climate change awareness anthem written by renowned Irish songwriter Pete St John, with harmonies and choral arrangement by the choir’s Musical Director, Norah Walsh. It includes schoolgirls from a local school and little waltzers from a local Montessori creche.

The Forget Me Nots Dementia-Inclusive Community Choir Baldoyle, North Dublin is a seniors choir and counts many people with memory loss conditions and their carers within its ranks. The choir also featured at the closing ceremony of the 31st Alzheimer Europe Conference (31AEC) in 2021.

The video of "Waltzing on borrowed time" can be viewed here: https://www.youtube.com/watch?v=x2bMPmFaRSg

5 May: Info-Zenter Demenz organises an evening of cinema and debate around the theme "Love, sexuality and dementia"

On the evening of 5 May, Info-Zenter Demenz, the national information centre on dementia in Luxembourg, organised an event in the Utopia cinema, on the topic “Love, sexuality and dementia”.

The evening began with a welcome by Corinne Cahen, Minister for Family and Integration, followed by the screening of the film "Les plus belles années d’une vie" (the best years of a life), starring Jean-Louis Tritignant and Anouk Aimée.

The screening of the film was followed by a round-table discussion with Michèle Halsdorf, head of the "Beim Goldknapp" residential and care home of the Luxembourg Alzheimer’s Association and Martine Laloux, clinical sexologist, psychotherapist and teacher at the Haute Ecole Libre de Bruxelles Ilya Prigogine.

This event took place within the framework of the "Week of affective and sexual health", organised by the national reference centre for the promotion of affective and sexual health (Cesas).

The Info-Zenter Demenz is the national information and counselling centre in Luxembourg for all questions related to the topic. The team is available Monday to Saturday and can be reached by phone +352 26 47 00 or email: mail@i-zdl.lu.

5 May: Dutch-Spanish children's book explaining dementia now available in English

Julissa Cruz is a doctor of geriatric medicine, of Dominican origin, based in the Netherlands. She wrote a children's book called "Why Does Granny Forget Things? A trip to the brain", which was published in both Dutch and Spanish in 2020, and as of May 2022 is available in English.

The story is drawn from her own experiences with her mother’s cognitive difficulties and how these affected her young niece. Dr Cruz therefore wanted to present some of the realities of dementia in a fun and easy-to-understand way, to help her nieces and nephews, as well as other children, to understand what might be happening to an older family member with dementia.

The story is illustrated by Gustavo Desimone and is complemented by an educational guide for parents and guardians, where dementia is defined in a more formal and professional way, together with information about its impact worldwide.

Find out more about the book and how to obtain it, here: https://en.julissacruz.com/libro

9 May: New podcast "Sleep, Cognition & Dementia, ISTAART Research Perspectives" features Helen Rochford-Brennan, member of the European Working Group of People with Dementia

Is there a connection between sleep, memory, and dementia? This is the question addressed in a new podcast called “Sleep, Cognition & Dementia, ISTAART Research Perspectives”. This is a complex issue, as different types of dementia are associated with different sleep problems, so there is much research being done in this area. Whether poor sleep causes or exacerbates dementia, is being looked at and then the separate but related issue of dementia contributing to poor sleep. It is clear that more research is needed to understand this relationship; in particular research that observes large groups of affected people for very long periods of time.
In a new ISTAART Research Perspectives Special podcast, published online on 9 May 2022, Fernando Peres and Dr Clara Dominguez Vivero get two perspectives on a research topic, from the researcher and the person who lives with the disease, Epidemiologist and Sleep Research expert Dr Yue Leng from the University of California, San Francisco and Helen Rochford-Brennan, a member of the European Working Group of People with Dementia (EWGPWD) who has been living with dementia for a number of years and transformed her life to advocate for improved awareness of dementia and human rights for people with dementia. Find out more about the podcast and see a full transcript, here: [www.dementiaresearcher.nihr.ac.uk/podcast](https://www.dementiaresearcher.nihr.ac.uk/podcast)

For information, ISTAART membership is now free for students!

For information on the Alzheimer’s Association International Society to Advance Alzheimer’s Research and Treatment (ISTAART) visit: [www.alz.org/istaart](https://www.alz.org/istaart)

### 17 May: Krembil Brain Institute launches new podcast with first episode asking "What's it going to take to cure Alzheimer’s?"

The Krembil Brain Institute (KBI) in Canada is pleased to announce that its new KBI podcast, "Your Complex Brain", has officially launched. The podcast aims to cover the mysteries, myths and cutting-edge science around the brain and brain diseases, such as Alzheimer’s disease, Parkinson’s, stroke, concussion, epilepsy, mental health and brain cancer. Researchers and clinicians, as well as patients and members of their health care teams will be featured.

The first episode “What is it going to take to cure Alzheimer’s?” features KBI neurologist and medicinal chemist Dr Donald Weaver, and the daughter of one of Dr Weaver’s patients, whose mother is currently living with Alzheimer’s dementia.

Here is a link to the Your Complex Brain podcast: [https://apple.co/3KlpMna](https://apple.co/3KlpMna)

### 25 May: Alzheimer’s Disease International publishes monitoring report

Alzheimer’s Disease International (ADI) has published its “From Plan to Impact” report providing an overview of the implementation of the World Health Organization’s (WHO) “Global action plan on the public health response to dementia”. This report monitors the stages of creation and implementation of national dementia plans, as well as providing examples of from around the world related to the seven action areas of the WHO’s action plan.

Some of the key points of the ADI report include:

- Only 39 WHO member states have developed national dementia plans, despite all 194 member states committing to developing such policies in 2017
- 35 new plans are needed annually to reach the WHO target of 146 plans (75% of member states) by 2025
- The number of people living with is expected to rise to 139 million in 2050, according to most recent WHO figures
- The global contribution of informal carers for people living with dementia is worth 133 billion unpaid hours each year (about eight hours a day per carer)
- Older people with dementia continue to be vulnerable to COVID-19 two years on, while many, including carers, have experienced increased isolation as a result of pandemic management policies.

The full report is available at: [https://www.alzint.org/resource/from-plan-to-impact-v/](https://www.alzint.org/resource/from-plan-to-impact-v/)

### EDUCATION

### 31 May: Have experience in design and development of electronic tracking devices for use in dementia care? You are invited to take part in a qualitative interview study!

The Centre for Biomedical Ethics and Law at KU Leuven would like to invite persons with experience in the design and development of electronic tracking devices for use in dementia care to participate in a qualitative interview study. The study aims to gain understanding in what developers’ perceptions are of the ethical issues surrounding the design, development, and use of electronic tracking devices in dementia care. Interviews are anonymous, last approximately 1 hour, and are conducted over an online video meeting. Interested? Please email Jared Howes at jaredmichael.howes@kuleuven.be

### 31 May: Want to learn more about Living Labs methodologies and infrastructures for health and wellbeing research studies? Join the “VITALISE Summer School” for free!

Interested in learning more about Living Labs methodologies and infrastructures for health and wellbeing research studies? You can do it in “VITALISE Summer School”. The training is completely free and will take place on 6 and 7 July, in Athens, Greece. You will be able to acquire new knowledge from professionals with extensive experience in this field.

If you participate, you will have access to VITALISE ICT tools and e-infrastructure to collaborate in scientific research with other Living Labs recognised by the European Network of Living Labs.

Closing date for applications is 6 June 2022!

You can find more information about the call in the attached documents and on our website: [https://vitalise-project.eu/vitalise-summer-school-2022/](https://vitalise-project.eu/vitalise-summer-school-2022/)
### AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tbody>
<tr>
<td>1-2 June</td>
<td>EMA Patients and Consumers Working Party meeting</td>
<td>Angela</td>
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<tr>
<td>3 June</td>
<td>NordSTAR workshop on @Trustworthiness@Sustainability: What about AI?</td>
<td>Dianne</td>
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<tr>
<td>3 June</td>
<td>European Commission NCD initiative</td>
<td>Owen</td>
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<tr>
<td>7 June</td>
<td>Alzheimer’s Disease International (ADI) Board (London, UK)</td>
<td>Jean</td>
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<tr>
<td>7 June</td>
<td>AMYPAD Sustainability Workshop (London, UK)</td>
<td>Cindy</td>
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<tr>
<td>7 June</td>
<td>Global dementia steering committee meeting on shared decision making</td>
<td>Dianne</td>
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<tr>
<td>8 June</td>
<td>Pattern-Cog kick-off meeting</td>
<td>Cindy</td>
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<tr>
<td>8 June</td>
<td>ADI Council Meeting (London, UK)</td>
<td>Jean</td>
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<tr>
<td>8 June</td>
<td>EFPIA Patient Think Tank</td>
<td>Owen</td>
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<tr>
<td>9 June</td>
<td>European Disability Forum (EDF) ENGO meeting</td>
<td>Owen</td>
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<tr>
<td>9-10 June</td>
<td>Meeting with Prothena (London, UK) and ADI Annual Conference (London, UK)</td>
<td>Jean</td>
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<tr>
<td>10 June</td>
<td>NovoNordisk symposium “Elevating the Patient Voice in Research and Development” (London, UK)</td>
<td>Jean</td>
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<td>Date</td>
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<tr>
<td>13 June</td>
<td>Alzheimer Europe Board (Brussels, Belgium)</td>
<td>AE Board and staff</td>
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<tr>
<td>13 June</td>
<td>NeuroCohort review meeting</td>
<td>Angela</td>
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<tr>
<td>14 June</td>
<td>Alzheimer Europe Company Round Table Meeting (Brussels, Belgium)</td>
<td>AE Board, sponsors and staff</td>
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<tr>
<td>14 June</td>
<td>Alzheimer Europe European Parliament Lunch Debate (Brussels, Belgium)</td>
<td>AE members, supporters, sponsors and staff</td>
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<tr>
<td>14-15 June</td>
<td>Meeting of the European Working Group of People with Dementia</td>
<td>Dianne and Ana</td>
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<tr>
<td>22 June</td>
<td>EU Non-communicable diseases initiative launch</td>
<td>Owen</td>
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<tr>
<td>23 June</td>
<td>Sustainability Workshop for the EPND project</td>
<td>Angela</td>
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<tr>
<td>23 June</td>
<td>EC civil society dialogue on European Social Fund Plus Action Plan</td>
<td>Owen</td>
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<tr>
<td>24 June</td>
<td>DataSavesLives session at the EPF Congress (Brussels, Belgium)</td>
<td>Angela</td>
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<tr>
<td>25 June</td>
<td>Dementia Panel of European Academy of Neurology (EAN) (Vienna, Austria)</td>
<td>Jean</td>
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<tr>
<td>25-26 June</td>
<td>European Disability Forum (EDF) Annual General Assembly (Athens, Greece)</td>
<td>Dianne</td>
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<tr>
<td>25-28 June</td>
<td>European Academy of Neurology (EAN) Conference (Vienna, Austria)</td>
<td>Jean</td>
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**CONFERENCES 2022**

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<tr>
<th>Date</th>
<th>Meeting</th>
<th>Format/ Place</th>
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<tbody>
<tr>
<td>1-3 June</td>
<td>XII Biennial Conference – Barcelona Pittsburgh, <a href="https://www.fundacioace.com/bcnpit/">https://www.fundacioace.com/bcnpit/</a></td>
<td>Barcelona &amp; online</td>
</tr>
<tr>
<td>7-9 June</td>
<td>7th World Conference on Adult Capacity, <a href="https://wcac2022.org/">https://wcac2022.org/</a></td>
<td>Edinburgh, Scotland</td>
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<tr>
<td>8-10 June</td>
<td>30th European Social Services Conference, <a href="https://essc-eu.org/">https://essc-eu.org/</a></td>
<td>Hamburg, Germany</td>
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<tr>
<td>25-28 June</td>
<td>8th EAN Congress, <a href="https://www.ean.org/congress2022">https://www.ean.org/congress2022</a></td>
<td>Vienna, Austria</td>
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<tr>
<td>20-22 September</td>
<td>Dementia Lab Conference - The residue of design, <a href="https://www.dementialabconference.com/">https://www.dementialabconference.com/</a></td>
<td>Leuven, Belgium</td>
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<tr>
<td>17-19 October</td>
<td>32nd Alzheimer Europe Conference “Building bridges”,</td>
<td>Bucharest, Romania</td>
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<td></td>
<td><a href="https://www.alzheimer-europe.org/Conferences/2022-Bucharest">https://www.alzheimer-europe.org/Conferences/2022-Bucharest</a></td>
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<tr>
<td>29 November-2 December</td>
<td>Clinical Trials on Alzheimer’s Disease (CTAD 2022), <a href="http://www.ctad-alzheimer.com">www.ctad-alzheimer.com</a></td>
<td>San Francisco, USA</td>
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32nd Alzheimer Europe Conference
Building bridges
Bucharest, Romania
17 to 19 October 2022

www.alzheimer-europe.org/conferences  #32AEC