Welcome

It has been a great month for collaboration for Alzheimer Europe and we signed two new memoranda of understanding; one with the European Association of Service Providers for Persons with Disabilities to create a more inclusive society for people with dementia and disabilities and a second with the European Academy of Neurology on a new project on the burden of sleep-wake disorders.

Alzheimer Europe was also delighted to learn that its membership to the European Medicines’ Agency’s Patients’ and Consumers’ Working Party has been successfully renewed for a new three-year mandate (2022-2025) with my colleagues Angela Bradshaw and Cindy Birck our designated representatives.

On the topic of inclusion, we were happy to learn that the European Parliament’s Constitutional Affairs Committee adopted a resolution proposing reforms to EU Electoral Law, to guarantee the right to vote for all EU citizens, regardless of legal capacity, and requiring Member States to improve accessibility for elections.

Similarly, we continued our own work to ensure we put people with dementia front and centre in our activities and we hosted an online session of our Alzheimer’s Association Academy series, titled “giving a voice to people with dementia in national Alzheimer’s associations”. These sessions are an excellent opportunity for us and our members to share knowledge, experience and best practices, together with the members of our European Working Group of People with Dementia (EWGPWD). We heard about great examples of involvement from our members in Belgium, the Netherlands and the UK.

Speaking of impact, it was great to see our members in Slovenia and Jersey making important progress on policy change. In Slovenia, President Borut Pahor received representatives of Alzheimer Slovenia, who want to establish a council for dementia management, to which the President has agreed. Meanwhile, in Jersey, a briefing was held for members of the States of Jersey government, to garner support for a dementia strategy. The session, organised by Dementia Jersey, included a talk by Chris Roberts, Chairperson of the EWGPWD, and his wife Jayne Goodrick, who shared their lived experience. Jersey’s Government has since committed to a strategy and invited Dementia Jersey to lead on this.

On a less positive note, Biogen announced that it was withdrawing its marketing authorisation application for aducanumab for the treatment of early Alzheimer’s disease, based on the feedback that there was insufficient scientific evidence for the European Medicines Agency (EMA) to support it. With the last approval of an Alzheimer’s medicine by the EMA dating back to 2002, the wait for better treatments for people living in Europe affected by Alzheimer’s disease continues.

In closing, I would like to remind you of the imminent abstract submissions deadline of 15 May, for our 32nd Annual Conference, taking place in Bucharest in October.

Jean Georges
Executive Director
UKRAINE UPDATES AND SUPPORT

4 April: WHO Europe holds briefing for Non-State Actors on activities in Ukraine

On 4 April 2022, WHO Europe held an online briefing to update Non-State Actors (NSAs) on the latest developments regarding its activities in response to the ongoing situation in Ukraine, as well as to share information between those present regarding their respective activities and to answer any questions and concerns they may have.

WHO speakers at the meeting were Robb Butler, Executive Director of the Regional Director’s Office (who also moderated the meeting), Hans Kluge, WHO Regional Director for Europe, Oleg Storozenko, Emergency Partnerships Lead, Jarno Habicht, WHO representative in Ukraine, Cristiana Salvi, Regional Adviser, Risk Communication and Community Engagement and Pierre Roca, Resource Mobilisation focal point.

As soon as the war in Ukraine began, the World Health Organization (WHO) activated contingency plans, repurposed staff and projects, and shifted its focus to meet emergency needs, in order to support Ukraine’s health system and workers. The WHO works closely with Ukraine’s Ministry of Health and authorities to identify gaps and needs in the country’s health system and to respond as swiftly as possible. It has opened an operations hub in Rzeszów in Poland, developed a pipeline of trauma supplies to most Ukrainian cities, and sent hundreds of metric tonnes of medical equipment across the border, to health facilities throughout Ukraine.

Aside from these activities, the WHO has produced and shared a number of resources to help ensure ongoing access to health care for the people of Ukraine. Resources, information and calls for donations shared at the meeting, both by the WHO and by participating NSAs, include:

- Information on the WHO Emergency appeal for Ukraine and neighbouring countries
- WHO Regional Office for Europe publishes related content on its website including weekly Situation reports
- The WHO Foundation has initiated a call for donations
- There is also a need for Medical supply donations (who.int)
- Information on Mental Health and Psychosocial Support Humanitarian response in Ukraine and neighbouring countries
- Mental Health Europe has a new web page gathering resources for some of the significant mental health challenges being faced by people fleeing Ukraine, as well as those remaining or unable to leave the country, especially children and young people, and those supporting them
- The Age and Disability Technical Working Group has lists of institutional settings that are in great need of basic services as well as specific medical requirements
- The European Disability Forum’s tools and resources to ensure inclusive emergency response

One of the concerns voiced at the meeting came from the European Disability Forum (EDF) representative Gordon Rattray, who asked whether people with disabilities, who may find it more difficult to access support and care, were receiving the necessary attention and whether full inclusion was being achieved. WHO representatives assured him that, while there is not yet enough available data on the exact proportion of people with disabilities caught up in this crisis and on how they are able to access care and support, medical evacuation and trauma rehabilitation has a big focus on people with disabilities and on older people.

Kate Boor Ellis, Communications Officer at Alzheimer Europe attended this briefing, together with more than 60 other representatives from NSAs.

11 April: International Diabetes Federation Europe "Connect Solidarity" web platform brings together information and support for people affected by the situation in Ukraine

The International Diabetes Federation Europe (IDF Europe) has launched a new webpage to promote initiatives of other organisations around support for people with diabetes (and related conditions such as dementia) during the ongoing war in Ukraine.

IDF Europe developed the online platform, "Connect Solidarity", to gather information to help Ukrainians living with diabetes understand what support they can get in the country they are in, and how to get it. It also highlights the fundraising initiatives endorsed and organised by IDF Europe. The new webpage with additional resources from other organisations is published on this platform and will continue to be updated regularly with new information and resources.

This resources webpage includes Alzheimer Europe’s online resources page to support people with dementia and carers, during the ongoing war in Ukraine. You can find the Connect Solidarity platform here: https://www.connectsolidarity.eu/

You can also find "additional resources" page on the platform, here: https://www.connectsolidarity.eu/additional-resources/

You can find Alzheimer Europe’s online resources page to support people with dementia and carers, during the ongoing war in Ukraine, here: https://www.alzheimer-europe.org/resources/ukraine-resources
28 April: European Patients’ Forum highlights importance of meeting medical needs of people with chronic diseases as part of Ukraine humanitarian assistance

The European Patients’ Forum has published a statement on its website, concerning the war in Ukraine: “The European Patients’ Forum stands in solidarity with the people in Ukraine, who are facing an aggressive military invasion in violation of international law since 24 February 2022.

We are appalled at the human suffering and loss of life caused by the war, and our thoughts are with the Ukrainian people. As a European patient organisation, we are particularly concerned about the situation of people living with chronic diseases, who are vulnerable to disruptions in healthcare services, medical treatment and medicines caused by war. Patients with chronic diseases, especially those with multiple conditions and severe illness, are less likely to have the means to flee the conflict and access humanitarian aid.

EPF calls on the international community to address the medical needs of people living with chronic diseases as part of general humanitarian assistance and relief efforts both in Ukraine and the neighbouring countries welcoming those patients. Maintaining and, if disrupted restoring, access to healthcare, including medicines and medical equipment should be a high priority on all agendas.

EPF will work with its members to understand the needs and challenges to support policy decision makers to address those needs.

We want to express our unwavering support to the Ukrainian people, as well as our hope for a peaceful normalization of the current situation.”


6 April: Access videos and poster presentations from 31st Alzheimer Europe Conference for free!

If you were unable to participate in the virtual 31st Alzheimer Europe Conference #31AEC at the end of last year, you can now access some of our on-demand content from the event, free of charge.

Videos of plenary and parallel presentations, as well as quick oral presentations are now available online. Posters are also available on our Flickr account. All details can be found on our webpage: https://www.alzheimer-europe.org/conferences/past-conferences/2021-online/videos-31aec

You can also watch the videos in three specially-created playlists, on Alzheimer Europe's YouTube channel:

Quick oral presentations, 125 videos: https://www.youtube.com/playlist?list=PLPGQHI1WQVNSocnhThS5YTjxo009wEz

Plenaries, 9 videos: https://www.youtube.com/playlist?list=PLPGQHI1WQLxP_Z3mweZbWL3Im4g9It

ALZHEIMER EUROPE

4 April: Alzheimer Europe to contribute to European Academy of Neurology project on burden of sleep-wake disorders

Alzheimer Europe will be contributing to a project of the European Academy of Neurology (EAN), on the burden of sleep-wake disorders and has signed a memorandum of understanding on this collaboration. Other partners in the project include: European Federation of Neurological Associations, European Psychiatric Association, European Paediatric Neurology Society, European Sleep Research Society, plus an independent expert on pulmonology / Scientific Communication.

This new EAN study, on the topic of sleep-wake disorders, was initially inspired by the European Brain Council's "Value of Treatment" projects. This research intends not only to systematically assess the scientific literature on this topic but also to explore the socio-economic consequences of insomnia and daytime sleepiness, taking into consideration a patient-centred perspective.

Sleep-wake disorders are prevalent phenomena that significantly affect individuals’ health, their social relationships, educational and professional performance, and quality of life. Although common in the general population, they tend to be regularly underdiagnosed; treatment is frequently not evidence-based; self-treatment is an issue. Moreover, sleep-wake disorders might constitute the first signs of a latent brain disorder. Iva Holmerová, Chairperson, will represent Alzheimer Europe in project meetings and discussions.

You can find out more about the project and its objectives, here: https://www.ean.org/research/projects/sleep-wake-disorders
Parallel sessions and special symposia, 31 videos: https://www.youtube.com/playlist?list=PLO-PgQHI1WQUxye22yXTe2d4-AvyJDj

The programme book and abstract book from #31AEC can also be found on our website: https://www.alzheimer-europe.org/conferences/past-conferences/2021-online/programme-and-abstracts

6 April: Registrations are open for the 32nd Alzheimer Europe Conference #32AEC!

On 26 April 2022, Alzheimer Europe held an online session of its popular Alzheimer’s Association Academy (AAA) series, bringing together representatives of its member organisations, European Working Group of People with Dementia (EWGPWD), pharmaceutical companies and researchers. The topic for this session, which was chaired by Dianne Gove (Director for Projects at Alzheimer Europe) was "giving a voice to people with dementia". Chris Roberts, Chair of the EWGPWD, kicked off the session with some introductory remarks, explaining the importance of giving people with dementia a voice and calling on organisations to create safe spaces that allow people with dementia to express their views, concerns and beliefs.

The first speaker was Anne-Rita Øksengård from Nasjonalforeningen in Norway, who provided an overview of their experiences of interacting and engaging with people with dementia and their relatives during the COVID-19 pandemic. Anne-Rita explained how the organisation adapted to the COVID-19 restrictions, holding meetings online rather than face-to-face, and providing support using digital tools and telephone helplines. She outlined the results of their 2021 report on how the pandemic affected the lives of people with dementia, which was based on a survey of over 1,200 people and highlighted the negative consequences of daycare centre closures and nursing home visiting restrictions. Anne-Rita highlighted shortcomings in systems developed by municipal authorities to manage infection control, and a lack of adequately-trained staff. Lessons learned included the need for pathways and guides to support authorities and facilities to maintain person-centred care, with mechanisms for addressing complaints and additional training and upskilling for staff.

The second presentation was delivered by Keith Oliver and James Erskine, representing the Three Nations Working Group (3NWG) of the Alzheimer’s Society (UK). Keith is a member of the 3NWG Steering Group while James is employed by the Alzheimer’s Society to support the 3NWG, which involves people from Wales, England and Northern Ireland, and was co-founded by Keith Oliver, Chris Roberts and Hilary Doxford. Keith and James spoke about the activities of the 3NWG during the COVID-19 pandemic, explaining how the group has met online regularly via zoom, hosting webinars and informal coffee chats.
for people with dementia, informal caregivers and family members. Keith highlighted that over 45 fortnightly webinars have been hosted since the start of the pandemic, addressing a broad range of topics including faith, dementia diagnosis, creative activities, learning disabilities and gardening, among others. These webinars are made accessible via the 3NWG website and have been viewed almost 73,000 times to date. Information, materials and invitations to participate in research or voluntary activities are also disseminated via the 3NWG newsletter. James explained his role as a supporter for the administrative and technical aspects of 3NWG activities, and emphasised the value of obtaining and acting on feedback from the broader community of people with dementia and caregivers, to tailor 3NWG activities and identify new webinar topics.

Next, Olivier Constant and Laura Weyns of the Flanders Centre of Expertise on Dementia and Alzheimer Liga Vlaanderen (Belgium) delivered a presentation entitled "Staying socially active during the pandemic: the experience of the Flemish Working Group of People with Dementia." Olivier started by outlining the vision for the Flemish Working Group, which is to "forget dementia, remember the person", acknowledging the value of people with dementia as experts by experience, and the important contributions they can make to policy, research and care. He highlighted their 2019 manifesto, entitled "hand in hand"; a charter for people with dementia that calls for greater inclusion, involvement, opportunities and respect. Over the last two years, the Working Group have continued to meet online and share their stories despite the challenges caused by the pandemic; Olivier delivered a poem written by Working Group member Antonio La Paglia, explaining his worries and fears at the start of COVID-19 lockdown in 2020. Laura continued the presentation by outlining their recent work on physical and social activity, which can be very beneficial for people with dementia. This involved the development of a second manifesto (called "step by step") and the creation of information cards, banners, videos and other materials. Laura also explained how they have developed e-learning programmes and dementia assistance cards, also participating in a television programme called "Restaurant Misverstand", where the entire staff have young onset dementia. This programme, which has recently been renewed for another season, has helped increase awareness and understanding of dementia. Olivier drew the presentation to a close by explaining how the Flanders Working Group had contributed to the new Flanders Dementia Strategy, and how important it is to advocate for creating spaces for people with dementia at the heart of a caring and warm community.

The final presentation was delivered by Anne de Boer from Alzheimer Nederland (The Netherlands) who spoke about the organisation’s online consultation methods to identify views, experiences and priorities of people with dementia and their caregivers. Together with Marco Blom (Scientific Director of Alzheimer Nederland), Anne described their online panel for people with dementia, caregivers, dementia healthcare professionals and volunteers, which provides a platform for these individuals to contribute to surveys and other activities. The panel includes almost 40 people with dementia, over 1800 caregivers, 210 healthcare professionals and 3,500 volunteers from the Alzheimer Nederland local associations, providing their expertise by experience and insights. Anne explained how this online panel allows Alzheimer Nederland to support dementia research and provides a platform for people affected by dementia to express their views. Giving some examples of surveys on the panel (on housing, and on the Dutch Compulsory Mental Healthcare Act) she spoke about the importance of respecting confidentiality and ensuring the platform is intuitive and easy to use, with short questionnaires that aren’t too burdensome to complete. The presentations were followed by an interactive Q&A discussion, during which questions from the audience were addressed by the panel.

28 April: Alzheimer Europe renews its membership of European Medicines’ Agency Patients' and Consumers' Working Party for the term 2022 to 2025

On 28 April 2022, the European Medicines’ Agency (EMA) notified Alzheimer Europe that its membership to the Patients’ and Consumers’ Working Party (PCWP) had been successfully renewed.

The PCWP provides a platform for exchange of information and discussion of issues of common interest between the EMA and patients and consumers. Established in 2006, it has enabled the Agency to build upon its existing interactions with patients and consumers. It provides recommendations to the EMA and its human scientific committees on all matters of interest in relation to medicines.

Find out more about the PCWP and about the process of becoming a member as outlined in its mandate, on the working party’s webpage: https://www.ema.europa.eu/en/committees/working-parties-other-groups/chmp/patients-consumers-working-party

Alzheimer Europe has nominated Angela Bradshaw, Project Officer as its member of the PCWP and Cindy Birck, Project Officer as its alternate.

28 April: Alzheimer Europe signs Memorandum of Understanding with European Association of Service Providers for Persons with Disabilities

On 28 April 2022, Alzheimer Europe and the European Association of Service Providers for Persons with Disabilities (EASPD) signed a Memorandum of Understanding, to provide
the basis for future collaboration. Both Alzheimer Europe and the EASPD share many common goals with respect to improving the understanding of illness and disabilities so as to help create a more inclusive, fulfilling, and accepting society for people with dementia and disabilities.

29 April: Call for abstracts for the 32nd Alzheimer Europe Conference closing soon!

The call for abstracts for the 32nd Alzheimer Europe Conference #32AEC, “Building Bridges”, which will take place in Bucharest, Romania, from 17 to 19 October 2022, will soon close. The deadline for submissions is 15 May 2022. This event will be mainly in-person but will include some broadcast elements such as plenary sessions, and other carefully selected parallel sessions and symposia to allow those still unable to travel to participate from the comfort of their home or office. Alzheimer Europe is calling for abstracts for oral and poster presentations on the following subjects:

- (Inter)National dementia strategies
- Arts and culture
- Brain health and dementia prevention
- Carer training and support
- COVID-19 and dementia
- Cross border dementia initiatives
- Dementia-friendly initiatives
- Gender, sex and sexuality in dementia
- Home care and support
- Intellectual disability and dementia
- Minority ethnic groups
- Needs and experiences of people with dementia
- Non-Alzheimer’s dementias
- Psychosocial interventions
- Residential care
- Technology
- Timely diagnosis
- Young onset dementia.

As in previous years, we hope that #32AEC will be a great networking opportunity, bringing together people with dementia, their carers and supporters, volunteers and staff of Alzheimer associations, policymakers, health and social care professionals, researchers, academics and industry representatives from across Europe and beyond. Registrations are open, with an Early Bird fee available until 15 July:

https://www.alzheimer-europe.org/conferences/2022-bucharest/online-conference-registration

Submit your abstract before 15 May, via:

https://www.alzheimer-europe.org/conferences/2022-bucharest/abstract-submission

Alzheimer Europe networking

On 1 April, Jean, Cindy and Dianne attended the AMYPAD project symposium “Perspectives on biomarker testing for AD in people without dementia”.

On 4 April, the Alzheimer Europe Board met.

On 4 April, Kate attended a WHO Europe briefing for Non-State Actors, on activities in Ukraine.

On 4 April, Ana, Dianne and Ange participated in an EPN project meeting on stakeholder involvement.

On 6 April, Cindy and Ana attended the EU-FINGERS and LETHE projects’ joint educational event.

On 6 April, Dianne and Ana participated in a meeting of the European Working Group of People with Dementia.

On 6 April, Owen attended a meeting of the European Commission’s High Level Group on the future of social protection.

On 7 April, Chris and Kate attended an European Parliament meeting on Communications Aspects for Civil Society Organisations.

On 7 April, Ana and Dianne participated in the RADAR-AD Patient Advisory Board meeting.

On 7 April, Ana, Dianne and Ange organised a planning meeting with Eodyne for the TVB_Cloud project.

On 8 April, Dianne had a meeting with Nicole Huige from Essity to discuss ongoing work on continence care.

On 10 and 11 March, Ana and Dianne attended the RADAR-AD project Annual General Meeting.

On 12 April, Gwladys took part in a discussion on Request for Proposal Process organised by Conferli.

On 12 April, Dianne and Ana organised a consultation with people with mild cognitive impairment (MCI) and subjective cognitive decline (SCD) for the AI-MIND project.

On 14 April, Owen attended a European Disability Forum webinar on the war in Ukraine and the coordination of needs for people with disabilities.

On 15 April, Ange took part in an EPN project meeting on cohort onboarding.

On 19 April, Jean met with representatives of the Davos Alzheimer’s Collaborative.

On 19 April, Jean and Owen attended a meeting with the European Federation of Neurological Associations and GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks-Europe) to coordinate on a brain health Call to Action.

On 20 April, Jean attended the Pattern-cog Executive Management Board.
On 20 April, Cindy attended the quarterly AI-Mind Executive Board Meeting.

On 21 April, Ange participated in a meeting on dissemination organised by the PRIME project

On 22 April, Jean, Owen and Ange organised a call with Gates Ventures on data sharing.

On 22 and 23 April, Chris participated in a Web Video Hackathon for students, researchers and science communicators organised by the Fast Forward Science contest in cooperation with the FNR - Luxembourg National Research Fund.

On 23 April, Jean attended the Annual General Meeting of the European Patients’ Forum.

On 25 April, Gwladys participated in a round table discussion on sustainable destinations and events organised by Business Events Luxembourg.

On 26 April, Cindy and Chris participated in a webinar on how to disseminate successfully EU-funded project results - Expert Insights organised by EMDESK in cooperation with Europa Media Trainings.

On 26 April, Alzheimer Europe organised an Alzheimer’s Association Academy on “Giving a voice to people with dementia in national Alzheimer’s associations”.

On 26 April, Dianne attended the MIND network meeting.

On 26 April, (Brussels, Belgium), Chris attended the Future of Science Communication Conference 2.0.

On 27 April, Kate, Chris and Owen participated in a Communications Strategy meeting for Patient involvement in Brain Health: Safeguarding the future of Brain Health for patients.

On 28 April (Brussels, Belgium), Ana attended the 2022 JPND / JPco-fuND2 Midterm Symposium for Supported Projects.

On 28 and 29 April Jean attended the online meeting of the European Alzheimer’s Disease Consortium.

On 29 April, Ange took part in a meeting of the European Medicines’ Agency’s Advisory Group on Raw Data.

On 29 April, Dianne and Ange conducted the first interviews with clinicians for the AI-MIND project.

**EU PROJECTS**

6 April: Members of the EU-FINGERS and LETHE Advisory Boards participate in an informative event

On 6 April, members of the EU-FINGERS and LETHE Advisory Boards participated in a joint informative event on the topic of nutrition and exercise. The event was co-hosted by Alzheimer Europe (AE) and Karolinska Institutet (KI).

A first speech was provided by Charlotta Thunborg (KI), who talked about physical activity, exercise training and strength training and daily activities that could be regarded as low to moderate physical activity. She also discussed the latest research results and gave some suggestion on how to decrease sedentary time. Secondly, Jenni Lehtisalo, from the Finnish Institute for Health and Welfare (THL), covered key aspects of supporting brain health with diet, focusing on practical food choices. She discussed both individual foods and dietary patterns and also some aspects related to healthy aging beyond brain health. This was followed by a very interactive Questions and Answers session between Jenni Lehtisalo, Charlotta Thunborg and members of the Advisory Boards. The discussions were co-facilitated by Ana Diaz (AE) and Anna Rosenberg (KI). Project Officers Cindy Birck and Ana Diaz participated in the event.

7 April: AMYPAD paper publishes a state-of-the-art review on the quantification of amyloid PET

The Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) project has published a new paper in the European Journal of Nuclear Medicine and Molecular Imaging, entitled “Quantification of amyloid PET for future clinical use: a state-of-the-art review”. In this article, methods for quantification of static amyloid PET scans are summarised and compared along with a discussion of the overall utility of amyloid PET quantification in routine clinical practice, observational research, and clinical trials.

Congratulations to the authors! The paper can be read here: [https://doi.org/10.1007/s00259-022-05784-y](https://doi.org/10.1007/s00259-022-05784-y)

7 April: EPAD launches its first national follow-on study

On 7 April, the first study participant for the EPAD Scotland study was seen at the University of Edinburgh in the UK. The EPAD Scotland study is the first follow-on study to the large pan-European EPAD Longitudinal Cohort Study (LCS) which finished study visits in 2020. The European Prevention of Alzheimer’s Dementia (EPAD) LCS was a pan-European study with an aim to identify
the very earliest signs of Alzheimer’s disease years before any clinical symptoms manifest. As part of the EPAD LCS, over 2,000 participants were screened and a wide range of cognitive, clinical, neuroimaging and biomarker data collected. All the EPAD LCS data is open access and available through data access request.

Since the end of the overall Innovative Medicine’s Initiative funding of EPAD LCS, there are follow-on studies to the EPAD LCS being set up locally within each host country in order to continue collecting longitudinal data on early risk factor for dementia. EPAD LCS continues to be one of the largest cohorts of participants in the pre-dementia stages and will be further enhanced with local follow-on studies inviting the same participants back to continue building up longitudinal data over many years. The EPAD Scotland study is the first national initiative to have started study recruitment. The primary investigator for the EPAD Scotland study is Prof Craig Ritchie and the study is funded by the Alzheimer’s Disease Discovery Fund.

25 April: Neuronet project publishes 10th Newsletter – showcasing the achievements of IMI’s neurodegeneration research programme

On 25 April, Neuronet (a three-year coordination and support action that began in 2019) published its 10th Newsletter.

The aim of the Neuronet project was to set up an efficient platform to boost synergy and collaboration across the Innovative Medicines Initiative (IMI) projects of the Neurodegenerative Disorders (ND) portfolio, assisting in identifying gaps, multiplying its impact, enhancing its visibility and facilitating dovetailing with related initiatives in Europe and worldwide. Read the newsletter here: https://bit.ly/Neuronet_Newsletter-10

28 April: JPND-funded projects meet at the 2022 Midterm Symposium

On 28 April, the JPND/JPco-fuND2 Midterm Symposium took place in Brussels. During the event, representatives of projects funded by the EU Joint Programme – Neurodegenerative Disease Research (JPND) over the last few years were able to present their work and achievements. Among others, two of the projects in which Alzheimer Europe is participating, EU-FINGERS and ADAIR took part in the event.

In all sessions, a Public Involvement (PI) representative was present and was invited to provide feedback or ask questions from the perspective of members of the public/people affected by the disease. Kevin Quaid (Chair of the Irish Dementia Working Group and Vice-Chair of the European Working Group of People with Dementia), Carmel Geoghegan (supporter of a member of the EWGPWD and PI advocate for the voices of patients and the wider community) and Ana Diaz (Project Officer at Alzheimer Europe) participated as panel members in several of the sessions.

The ADAIR and EU-FINGERS project provided presentations and a poster, which were very well received.

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:

AMYPAD – grant agreement 115952
EPAD – grant agreement 115736
LETHE – grant agreement 101017405
NEURONET – grant agreement 821513
EU DEVELOPMENTS
1 April: European Parliament committee publishes resolution on election reform

The European Parliament’s Constitutional Affairs Committee (AFCO) has adopted a resolution proposing reforms to the EU Electoral Law, which would guarantee the right to vote for all EU citizens, regardless of their legal capacity, as well as require Member States to improve accessibility for European elections. The AFCO adopted compromise amendments for the resolution, as well as recitals and articles of a Council regulation laying down the new electoral law.

Article four states that: “Every Union citizen from 16 years of age, including persons with disabilities regardless of their legal capacity, shall have the right to vote in elections to the European Parliament”, whilst article six obliges Member States to ensure that people living in closed residential settings are able to exercise their right to vote.

Article seven includes provisions on accessibility, mandating that appropriate arrangements are in place to allow persons with disabilities to vote, whilst allowing them to be able to choose a person to support them in casting their vote. The legislative initiative together with the draft resolution will be subject to a Plenary vote of the European Parliament. It must then be adopted unanimously by the Council and receive the approval of all Member States in accordance with their respective constitutional requirements. Further details can be found at: https://www.europarl.europa.eu/news/en/press-room/20220328IPR26315/eu-elections-meps-want-transnational-lists-and-all-countries-to-vote-on-9-may
12 April: European Disability Forum launches accessibility discrimination database

Supported with resources from the European Commission and the European Railway Awards, the European Disability Forum (EDF) has launched an Accessibility Discrimination Database, focused on transport.

Despite legislation introduced by the European Union and Member States legislatures in recent years to challenge discrimination in transport faced by persons with disabilities, they often still face difficulties in practice across all types of transport.

Individuals can submit examples of discrimination they have faced when using different forms of transport to the database – this can be done anonymously if preferred.

EDF will not directly contact transport companies, national authorities or other bodies to resolve the issue. Rather, the examples will be aggregated and used as part of EDF’s policy work, as it campaigns for Member States to adopt and implement laws and policies that will hopefully prevent such situations from happening in the future.

More information, and how to submit examples to the database, can be found at: https://accessibility.edfeph.org/

20 April: European Doctors issue statement on medicine prices

The Standing Committee of European Doctors (CPME) has issued a statement warning that the concept of value should not be used to justify high medicines prices in Europe.

CPME notes that new medicines frequently enter the market at unaffordable prices, which poses a challenge for the sustainability of health budgets and affects doctors’ and patients’ ability to choose the appropriate treatment.

The statement highlights that pharmaceutical companies previously justified high medicine prices as being necessary to cover research and development costs and to compensate for the associated risks. However, it notes the recent shift towards basing medicine prices on their perceived value to society and health systems.

It is further explained that a multidimensional approach to characteristics in value-based pricing models should consider medicine efficacy and safety outcomes, improvement in patient quality of life and quality of evidence, as well as economic evaluation. This should also consider wider societal perspectives to assess the costs and benefits of a medicine.

However, it noted that the pharmaceutical industry places a disproportionate weight on economic aspects, as they argue that the value of a medicine is equal to the cost saving for society.

The statement concludes by advocating for pharmaceutical pricing which prioritises patient’s rights and ethical provisions, in addition to considering solidarity in care determined by need, with cost efficiency as a final consideration. Furthermore, it is noted that transparency on net medicine prices and research and development costs is indispensable for competition and a balanced market. The full article published by CPME can be read at: https://www.cpme.eu/news/how-the-pharmaceutical-industry-misuses-the-concept-of-value-to-justify-high-medicine-prices

POLICY WATCH

12 April: World Health Organization (WHO) launches QualityRights training on mental health

The World Health Organization (WHO) has launched a QualityRights e-training initiative, aiming to improve the quality of care in mental health and related services, as well as promoting the rights of people with psychosocial, intellectual and cognitive disabilities. The QualityRights e-training is available in 11 languages and covers a range of different aspects, including:

- Taking care of one’s own mental health
- Supporting friends, family and colleagues with their mental health
- Tackling stigma, discrimination, abuse and coercion in mental health services
- Taking action in support of transformation of mental health services towards a person-centred, rights-based recovery approach.

The training has been developed for a wide variety of groups, including people involved in making decisions about mental health care provision, those who provide mental health care and psychosocial support, and people who have received or are receiving support for their mental health. The QualityRights e-training can be accessed at: https://www.who.int/teams/mental-health-and-substance-use/policy-law-rights/qr-e-training
13 April: Spominčica’s proposal for the establishment of a dementia management council is accepted by the President of the Republic of Slovenia

On 13 April 2022, the President of the Republic of Slovenia Borut Pahor received representatives of Spominčica - Alzheimer Slovenia, Štefanija Lukič Zlobec and Zvezdan Pirtošek. Ms Zlobec and Prof. Dr Pirtošek presented an initiative for the establishment of a council for dementia management to the President, which would be under the patronage of the President. The Council would work under his auspices and bring together experts in the field of dementia to develop common positions and recommendations to try to influence decision-makers and raise public awareness of the growing problem of dementia.

The President accepted the initiative and the interlocutors agreed to prepare everything necessary for the establishment of this new Council, in the coming weeks.

Štefanija Lukič Zlobec, thanked President Borut Pahor for his many years of constant support to Spominčica and for his care for people affected by dementia.

The President confirmed that he was aware that dementia was a growing social and health problem. In the past, the President has supported the National Plan for Dementia and was the honorary sponsor of the Alzheimer Europe Conference, when it was held in Ljubljana in 2015.

In 2018, the President of the Republic awarded Zvezdan Pirtošek for his exceptional in-depth, highly professional and philanthropic work in the field of dementia and Štefanija Lukič Zlobec for exceptional self-sacrificing work with patients and their relatives, within Spominčica.

20 April: UN committee published list of questions for EU review

The UN Committee on the Rights of Persons with Disabilities (UNCRPD), has adopted its list of issues prior to reporting on the European Union. The document lists questions to which the EU must reply within 12 months and which will serve as basis of the second evaluation of the EU’s compliance with the Convention (the first evaluation having taken place in 2015). The questions span across all articles of the Convention and includes themes such as:

- Accessibility
- Freedom of movement
- Use of EU funds
- Access to health
- Education and employment
- Data collection.

Following the submission of the EU’s response to the Committee, it will schedule an interactive dialogue with the EU and adopt recommendations (expected sometime in 2024). The full list of issues prior to reporting can be accessed at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fIC%2fEU%2fQPR%2f2-3&Lang=en

27 April: Dementia Jersey briefing for members of States of Jersey government leads to a commitment to create a dementia strategy

Dementia Jersey held a virtual briefing (via Teams) for members of the States of Jersey government. The purpose was to create a burning platform for a dementia strategy in Jersey, to get support from politicians and government officials.

Unfortunately, writes CEO Claudine Snape, Jersey finds itself behind most of Europe, when it comes to prioritising dementia. There has sadly been little political support for a dementia strategy in Jersey, to face the speculation over the location and cost of a new hospital (GBP 800 million, equivalent to approximately EUR 950 million) and other local priorities.

The briefing was split into three short parts:

- an introduction from Claudine Snape about dementia
- a talk from Chris Roberts, Chairperson of the European Working Group of People with Dementia and his wife and supporter Jayne Goodrick, about their lived experience
- and a talk from the CEO of Family Nursing and Home Care (FNHC) about the different factors needed to ‘age well’, followed by a Q&A.

Ms Snape used the Jersey Government’s disease projections report and highlighted that with an ageing population on the island, dementia is forecast to be the fastest rising health condition in the over 65s within the next generation. "Chris and Jayne were inspirational speakers and showed how, with the right practical approaches and problem-solving mentality they overcame the barriers Chris’s dementia put in the way", said Ms Snape. She continued: “And Rosemarie from FNHC tied in dementia to a general ‘ageing well’ agenda which
enabled us to call our briefing ‘Improving health outcomes for Jersey’s ageing population, through the lens of Dementia.’"

13 local politicians attended, including all but one of Jersey’s party leaders, which was an excellent result. Politicians who attended have been followed up with a request for support for the dementia strategy and wider initiatives to support Jersey’s ageing population.

The Government has now committed to a dementia strategy and has invited Dementia Jersey to write it and the organisation is currently negotiating a partnership agreement to take this forward.

**SCIENCE WATCH**

**25 March: TouchNEUROLOGY discusses potential role of inflammation in Alzheimer’s disease with Professor Jeffrey Cummings**

Alzheimer’s disease (AD) is the most common form of dementia, and causes a progressive decline in memory, language, executive and visuospatial function and behaviour. For many years, there have been only four approved medications to improve cognition in patients with AD, but these only address the symptoms, and do not affect the course of the underlying disease. TouchNEUROLOGY interviewed Professor Jeffrey Cummings, regarding the role of inflammation in AD and about the upcoming GREEN MEMORY study, a global randomised clinical trial investigating the use of GV-971 (sodium oligomannate) for the treatment of AD.

Jeffrey Cummings is the director of the Chambers-Grundy Center for Transformative Neuroscience. He was a founding director of the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas and served as director of the Mary S. Easton Center for Alzheimer’s Disease Research and the Deane F. Johnson Center for Neurotherapeutics, at the University of California, Los Angeles. He is a world-renowned AD researcher and leader of clinical trials, with expertise in neuropsychiatric assessment, clinical trials, developing new therapies for brain diseases and the interface of neuroscience and society.

You can view the full interview, here:

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**28 March: Prothena Corporation announces FDA clearance of investigational new drug application for PRX012 for the treatment of AD**

On 28 March, Prothena Corporation, a late-stage clinical company with a robust pipeline of novel investigational therapeutics built on protein dysregulation expertise, announced that the US Food and Drug Administration (FDA) has cleared the investigational new drug application for PRX012, a potential best-in-class anti-amyloid beta (Aβ) antibody in development for the treatment of Alzheimer’s disease (AD).

Prothena has initiated the Phase I single ascending dose study to investigate the safety, tolerability, immunogenicity and pharmacokinetics of PRX012 in both healthy volunteers and people with AD. In this Phase I single ascending dose study, participants will be randomised to receive a single subcutaneous injection of either PRX012 or placebo. The company expects to initiate the Phase I multiple ascending dose study by end 2022.

In preclinical studies, data have shown that PRX012 binds to beta amyloid plaques and oligomers with high avidity, enabling effective levels of Aβ plaque occupancy at relatively lower dose ranges, which are optimal for subcutaneous delivery. Additional preclinical data demonstrated clearance of both pyroglutamate modified and unmodified Aβ plaque in brain tissue at concentrations of PRX012 estimated to be clinically achievable in the central nervous system with subcutaneous delivery.

PRX012-a-Subcutaneous-Anti-Amyloid-Beta-Antibody-Under-
Investigation-for-the-Treatment-of-Alzheimers-Disease/default.aspx

**1 April: Researchers discover novel protein aggregates that accumulate in the brain during aging**

Accumulation of protein aggregates in the brain is a hallmark of several neurodegenerative diseases. In Alzheimer’s disease (AD), clumps of amyloid-beta and tangled tau proteins build up in regions of the brain that help to control memory. In back-to-back studies recently published in the Nature journal, researchers identify a novel protein aggregate in aging brains, composed of fibrils of a protein called TMEM106b.

In separate articles published in the same issue of Nature, two teams of researchers led by David Eisenberg at UCLA (USA),
Sjors Scheres and Michel Goedert at the University of Cambridge (UK) use similar cryo-electron microscopy techniques to probe the composition of protein aggregates from the brains of people of different ages, and with different types of neurodegenerative diseases. Studying samples donated by people who died of frontotemporal lobar degeneration, David Eisenberg and colleagues found filaments of TMEM106b, which has known genetic ties to frontotemporal dementia (FTD). Similarly, the Cambridge team identified TMEM106b aggregates in brain samples from 22 people with different types of neurodegenerative disease, including FTD, familial AD, dementia with Lewy bodies and multiple system atrophy.

Both research teams observed a range of different TMEM106b structures and folds, adopting different shapes in the brain, although no clear pattern or association between types of structure and disease was observed. Sjors Scheres and Michel Goedert found that TMEM106b aggregates were much more prevalent in the brains of older individuals aged over 70 years, suggesting that accumulation of this protein aggregate may be age-dependent. Further research is required to understand the pathological significance of these aggregates, and how they are linked to the genetic mutations in TMEM106b that are found in dementias such as FTD.


2 April: Amylyx Pharmaceuticals presents safety results from its PEGASUS clinical trial for AD

On 2 April, Amylyx Pharmaceuticals, a clinical-stage pharmaceutical company developing a novel therapeutic for Amyotrophic Lateral Sclerosis, Alzheimer’s disease (AD) and other neurodegenerative diseases, announced the presentation of safety results from its Phase II PEGASUS trial at the American Academy of Neurology Annual Meeting.

The PEGASUS Phase II trial was a 24-week randomised, double-blind, multi-site and placebo-controlled study evaluating the safety and tolerability of AMX0035 in people with late mild cognitive impairment or early dementia due to AD. AMX0035 is a combination of existing compounds designed to prevent neuroinflammation and nerve cell death.

Findings showed that AMX0035 was safe and well tolerated. The majority of treatment-emergent adverse events associated with AMX0035 were gastrointestinal with no new safety signals identified.


4 April: Researchers find 42 new genes associated with Alzheimer’s disease

On 4 April, a large group of international scientists published findings on the largest genetic study of Alzheimer’s disease (AD) to date in the journal Nature Genetics.

In this project carried out in research centres in eight partner countries including the UK, US, Australia and across Europe, researchers analysed the genome of over 100,000 people with AD and 600,000 cognitively healthy people. In total, the new international study identified 75 genes that were associated with an increased risk of developing AD, 33 of which were already known such as genes implicating hallmark proteins called amyloid and tau. An additional 42 genes that had not previously been linked to the condition have been found.

A number of the newly discovered genes are linked to pathways for disease development, immune system and inflammation. The new findings provide compelling evidence to support a role for inflammation and the immune system in the disease. The findings show for the first time that a specific biological signalling pathway involving TNF-alpha, a protein with an important role in inflammation and the immune system, is implicated in AD. Additionally, findings confirmed the involvement of innate immunity and microglial activation in AD.

Researchers found that a handful of the new genes may cause the dysfunction of microglia, immune cells in the brain that are responsible for eliminating toxic substances.

“This study more than doubles the number of identified genes influencing risk for the more common form of Alzheimer’s disease. It provides exciting new targets for therapeutic intervention and advances our ability to develop algorithms to predict who will develop Alzheimer’s in later life”, said Dr Rebecca Sims, Senior Research Fellow at Cardiff University and UK Dementia Research Institute Co-investigator and co-leader of the study.

https://www.nature.com/articles/s41588-022-01024-z

5 April: Sage Therapeutics reports preliminary results from its LUMINARY Phase 2 clinical trial for AD

On 5 April, Sage Therapeutics, a biopharmaceutical company leading the way to create a world with better brain health, presented findings from its LUMINARY Phase II clinical trial in a talk at the American Academy of Neurology’s 74th Annual Meeting, held in Seattle.
The LUMINARY study is an open-label study evaluating the safety, tolerability and efficacy of SAGE-718 in people with mild cognitive impairment (MCI) and mild dementia due to Alzheimer’s disease. 26 participants, aged 50 to 80 years old, received an oral tablet of SAGE-718 once daily during two weeks. The study’s primary goal was to determine the treatment’s safety. In the trial, SAGE-718 was found to be well-tolerated with no serious adverse events. Various tests were used to assess multiple domains of cognitive performance in participants. At Day 14, improvements were observed from the study’s start on multiple tests of executive functioning, namely Digit Symbol Substitution, Multitasking, One Touch Stockings, Spatial Working Memory, and 2-Back tests. In addition, improvements were observed in tests of learning and memory, namely Pattern Recognition Memory and Verbal Recognition Memory tests. The company also reported a statistically significant increase of 2.3 points over a month from the study’s start in the Montreal Cognitive Assessment (MoCA).


7 April: US Medicare limits coverage of aducanumab for AD

On 7 April, the Centers for Medicare and Medicaid Services (CMS) has released its finalised national coverage decision on aducanumab and future monoclonal antibodies directed against amyloid that are approved by the US Food and Drug Administration (FDA) for the treatment of Alzheimer’s disease (AD).

The decision is ultimately that Medicare will be able to cover the cost of aducanumab only for participants enrolled in qualifying clinical trials. For drugs similar to aducanumab, the CMS said it would allow coverage if the medication receives traditional approval from the FDA under coverage with evidence development.

The FDA approved aducanumab last year under an accelerated approval pathway, based on clinical trial data showing that aducanumab could reduce amyloid plaques in the brains of people treated with the drug.


14 April: TauRx reaches new milestone for its Lucidity Phase III trial for AD

On 14 April, the company TauRx Therapeutics Ltd announced that the last participant has completed treatment in the blinded phase of its late-stage Phase III clinical trial, LUCIDITY, for the treatment of Alzheimer’s disease (AD). The company will now progress to the data cleaning and analysis phase. Topline results are expected in May.

The Lucidity trial is a randomised, double-blind and placebo-controlled study evaluating the safety and efficacy of hydromethylthionine in people with AD encompassing mild cognitive impairment due to AD. Hydromethylthionine (which TauRx refer to under the chemical abbreviation, LMTM) acts by blocking abnormal accumulation of Tau protein in the brain. LUCIDITY is the only late-stage study targeting the tau pathology of AD.

"This milestone takes us one step closer to announcing the topline results of our potentially ground-breaking Lucidity study. We’re extremely grateful to all who are progressing the trial; the study coordinators and investigators, and most importantly the patients who volunteered to take part.” said Professor Claude Wischik, Executive Chairman and Co-Founder.


19 April: Synaptogenix completes enrolment in its NIH sponsored Phase IIb trial for AD

On 19 April, Synaptogenix, a clinical-stage biopharmaceutical company developing regenerative therapeutics for neurodegenerative disorders, announced that it has completed the enrolment of participants for its ongoing Phase IIb clinical trial of Bryostatin for people with advanced and moderately severe Alzheimer's disease (AD).

The Phase 2b clinical trial is a 6-month randomised, double-blind and placebo-controlled study assessing safety, tolerability and long-term efficacy of Bryostatin in the treatment of moderately severe AD. Sponsored by the National Institutes of Health (NIH), the study has completed enrolling its target of 100 participants. Topline data from the study are expected during the fourth quarter of 2022. In addition, the company reported that the independent Data Safety Monitoring Board (DSMB) overseeing the trial has confirmed the absence of any drug-related adverse safety issues.
The two previous 3-months pilot trials demonstrated safety and significant cognitive enhancement for the participants who received Bryostatin, while the participants receiving placebo showed no significant benefit. Findings have recently been published in a peer reviewed article in the Journal of Alzheimer’s Disease.


**20 April: An accumulation of cardiovascular risk factors over time is linked to increased dementia risk, study finds**

A new study published on 20 April suggests that people who accumulate cardiovascular disease risk factors over time, at a faster pace, have an increased risk of developing Alzheimer’s disease dementia or vascular dementia, compared to people whose risk factors remain stable throughout life. Findings were published in the online issue of Neurology, the medical journal of the American Academy of Neurology.

The study followed 1,244 people with an average age of 55 who were considered healthy in terms of cardiovascular health and memory skills at the start of the study. Participants were given memory tests, health checks and completed lifestyle questionnaires every five years for up to 25 years.

People had their cardiovascular disease risk calculated using a measurement called the Framingham Risk Score which predicts a person’s 10-year risk of going on to have a cardiovascular event, such as a stroke or heart attack. It looks at factors such as age, sex, body mass index, blood pressure, smoking status and diabetes. Researchers determined who had an accelerated cardiovascular disease risk.

Of all participants, 6% developed Alzheimer’s disease and 3% vascular dementia. Results showed that cardiovascular disease risk remained stable in 22% of participants, increased moderately over time in 60% and accelerated more rapidly in 18%. Participants in the study with stable cardiovascular disease risk were less likely to go on to develop Alzheimer’s disease or vascular dementia, compared to those with an accelerated cardiovascular risk. Researchers determined that people with an accelerated cardiovascular disease risk had a three to six times greater chance of developing Alzheimer’s disease dementia and a three to four times greater risk of developing vascular dementia.

https://n.neurology.org/content/early/2022/04/20/WNL.0000000000200255

**22 April: New clinical study shows that the performance of blood tests for Alzheimer’s disease proteins varies between ethnic groups**

Blood tests that can measure biomarkers for Alzheimer’s disease (AD) offer the potential to detect proteins that accumulate in the brain during the development of AD, in a minimally-invasive way that avoids lumbar punctures and costly PET scans. These biomarkers, if proved to be accurate, could help diagnose AD and monitor disease progression. However, there is an acknowledged lack of diversity in many clinical studies on AD, with an under-representation of Black and minority ethnic groups. In a new study published in the Neurology journal on 22 April, researchers show that experimental blood tests for AD biomarkers perform differently in Black participants compared to their White counterparts.

In their study, a team of researchers led by Suzanne Schindler and John Morris of the Washington University School of Medicine (USA) used different test platforms to measure the levels of amyloid beta, tau and neurofilament light chain (NFL) biomarkers in blood plasma from 76 matched participant pairs of African American and non-Hispanic White backgrounds. The average age of participants was 68.4 years and over 90% did not have any cognitive impairment. As well as measuring biomarkers in blood samples, the researchers performed brain PET scans and analyses of cerebrospinal fluid samples, the current gold standard methods for detecting biomarkers for AD.

The study showed that a test platform that uses mass spectrometry to detect amyloid beta performed well regardless of ethnicity, accurately measuring amyloid beta proteins in blood samples from participants irrespective of ethnicity. On the other hand, blood tests using a different platform to detect tau and NFL were not as sensitive, and performed differently in Black participants. In these individuals, a model that combined blood tests for tau and NFL was only validated in approximately 30% of participants - compared to 65-76% of White participants.

https://n.neurology.org/content/early/2022/04/22/WNL.0000000000200358
22 April: Biogen announces withdrawal of marketing authorisation application for aducanumab for the treatment of Alzheimer’s disease

On 22 April 2022, Biogen announced that it had notified the European Medicines Agency (EMA) about the withdrawal of its marketing authorisation application for aducanumab for the treatment of early Alzheimer’s disease.

The agency had previously found on 16 December 2021 that the benefits of aducanumab did not outweigh its risks and had therefore recommended refusing marketing authorisation. Biogen requested a re-examination of the EMA’s decision and started discussions with the Agency’s Committee for Medicinal Products for Human Use (CHMP). In its press release issued on 22 April, Biogen highlighted that the CHMP had indicated that the “data provided thus far would not be sufficient to support a positive opinion”.

With the last approval of an Alzheimer’s medicine by the 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. It will therefore be disappointing news for them to hear that there was insufficient scientific evidence for the EMA to support the authorisation of aducanumab, and that the wait for innovative, disease modifying treatments will have to continue in Europe.

The EMA discussions and the decision by Biogen to withdraw its marketing authorisation application follow developments in the US where the Food and Drug Administration (FDA) chose to grant conditional approval for aducanumab using its “accelerated approval pathway”. This approval was based on aducanumab’s proven effect on lowering amyloid beta, a surrogate endpoint that the FDA deemed “reasonably likely” to predict a clinical benefit to patients.

In its December recommendation, the EMA recognised that aducanumab reduces amyloid beta in the brain, but stated that “the link between this effect and clinical improvement has not been established”. The agency found that the results on cognition and executive function derived from the two phase III clinical trials conducted to date were conflicting, and highlighted potential difficulties in monitoring side effects of the medicine in clinical practice. As a result, the agency concluded that the risk-benefit balance was unfavourable and decided against approval. According to the EMA, “At the time of the withdrawal, while the re-examination was ongoing, the Agency was still of the opinion that the benefits of [aducanumab] did not outweigh its risks.”

Alzheimer Europe will continue to monitor clinical trial developments with great interest and notes the welcome announcement by Biogen about the launch of a phase IV trial of aducanumab in May 2022. The organisation hopes that this trial and ongoing trials by other companies will lead to positive results and to the approval by the EMA of the first new treatment against Alzheimer’s disease in over 20 years.

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.


MEMBERS NEWS

26 April: Alzheimer Hellas supports new project "Genetic counseling in European universities: The case of neurodegenerative diseases" (GECONEU)

Alzheimer Hellas is pleased to announce a new very innovative Erasmus+ project in Higher Education (2021-1-EL01-KA220-HED-000032173) “Genetic counseling in European universities: The case of neurodegenerative diseases” (GECONEU). The GECONEU project aims to develop an online Course for University students focusing on Genetic Counseling. The main goals and central impact of this project are to support people, caregivers and society to better understand the aims of genetic testing and the usefulness of genetic counselling by involving students in an innovative learning and teaching setting.

This project will provide the opportunity to take all the factors of an appropriate training course to society into account by involving the families of people with neurodegenerative disorders in the development of the learning and teaching outcomes, consequently improving their visibility and enhancing their level of knowledge. It is coordinated by Aristotle University of Thessaloniki (Greece) and supported by five more partners, including the Panhellenic Institute of Neurodegenerative diseases (Greece), Ruprecht-Karls University of Heidelberg (Germany), Fundació Clinic per a la Recerca Biomèdica (Spain), Vrije Universiteit Brussel (Brussels) and Izmir Ekonomi Universitesi (Turkey).
Alzheimer Hellas will support this project by offering genetic counselling services to caregivers and using the project materials. For more information, you can visit the website: http://www.genecounsel.eu/

Alzheimer’s Society Annual Conference
17 May 2022
Registration open
Sponsored by Rothesay

LIVING WITH DEMENTIA

21 April: Chris Roberts, Chairperson of European Working Group of People with Dementia shares his experience of addressing States of Jersey elected Members at Dementia Jersey event

We, myself and my wife Jayne, were contacted through Alzheimer Europe by Claudine Snape, the CEO of Dementia Jersey to ask if we would be able to speak at a virtual event they had been organising titled "Improving health outcomes for Jersey’s ageing population, through the lens of dementia" for the States of Jersey elected Members (their equivalent of members of Parliament), they were expecting between 15-25 members to attend the event.

The ask was a ten-minute speech from the perspective of a person with dementia and their carer/supporter; just the job for us! The focus of our talk was about the impact dementia has had on our family, the adjustments and adaptations we have made together to overcome the barriers that dementia puts in front of us by putting "cognitive ramps" (our solutions) in place, and also reflecting on what type of community and local health support has been helpful.

We decided to just have an informal chat with each other (Jayne and I) on screen, in front of the participants, as this format suits us at the moment because of my progression during the COVID-19 Lockdown (another story, maybe).

We wanted to help the politicians understand what it is like to have and live with dementia, to try and explain what the families themselves can do plus what the community around them can do to improve their quality of life and support them better to live with dementia. We also spoke about the need for person-centred care, social prescribing, care-coordinators/supporters, having the correct, relevant support and respite in place for families, plus the benefits of cognitive stimulation and exercise.

We had very positive feedback, which is always nice, thanking us for a memorable talk and saying that many of the politicians who joined us were talking about some of our examples of changes and solutions we had put in place, saying it really struck a chord with them. One of them said that we had completely opened her eyes to the reality of dementia and wanted to extend thanks to us both for speaking.

Claudine Snape, CEO, Dementia Jersey, said: “I was able to draw on what you said to support my points, which was incredibly helpful and linked well with the political asks we were making to support the development of more dementia-friendly environments and a dementia strategy on the island”. In summary, our time was very well spent!
4 April: British Psychological Society gives lifetime achievement award to INTERDEM founder Esme Moniz-Cook

The British Psychological Society (BPS) Practice Board awards celebrate BPS members who have been instrumental in using psychological science to improve the lives of people living with dementia, Northern Ireland prisoners, women housed in mental healthcare services and to help tackle illegal poaching in Africa. This year, the Lifetime Achievement Award was given to Professor Esme Moniz-Cook (Psychology, Ageing and Dementia Care, University of Hull). Prof. Moniz-Cook has worked with people, families, care staff and communities in all areas of dementia care in Hull. She pioneered the establishment of Memory Clinics that have delivered timely diagnosis and support to people with dementia and their families. Her research transformed thinking about “challenging behaviour” in dementia and she has developed many new services to support people with dementia and their carers at home and in care homes. Prof. Moniz-Cook also founded INTERDEM, a pan-European network for psychosocial research in dementia care.


On 23 and 24 March, the World Joint Artificial Intelligence Network Challenge (WJC) was broadcasted by the Dutch Embassy in Sweden live on YouTube. The main purpose of the WJC is to form the international learning community who are the developing e-health products and services for people with memory problems or dementia, informal carers and family, informal carers, healthcare professionals, healthcare institutions, government and healthcare insurers, which:

- Increase self-reliance and quality of life of people with memory problems or dementia and informal carers
- Extend the time that people with memory problems or memory problems or dementia can live in one’s own living environment
- Support informal carers, family, and healthcare professionals
- Reduce costs within healthcare promoting affordable healthcare, with the same number of FTE’s serving more clients.

The WJC 2022 is a public competition for developed or prototyped technical products and services based on Artificial Intelligence. It concerns products that support the quality of life and self-reliance of people with memory problems or dementia and their informal carers and that will support professionals and informal carers in providing optimal care. The programme on both days was chaired by Hans Arnold and moderated by Thomas Arnold.

On 23 March, the WJC programme included a series of presentations including an opening by Charles Scerri (Vice-Chairperson of the Board of Alzheimer Europe), followed by two presentations. After that, the three finalists presented their prototypes in the form of pitches. Which were followed by questions by the audience. The three prototypes presented were:

- CeCe: A platform with a wearable tracker (patient) and a companion behaviour noting app (caregiver) aimed at collecting information that can be provided to doctors and care professionals for treatment decisions.
• myAVOS: A healthcare platform for cognitive screening, patient monitoring and to provide interventions through a mobile application.
• DeepVibes: A phone application aimed at stimulating and recording conversations between family members and people with dementia. It applies Artificial Intelligence to monitor disease progression.

On the second day of the competition three speakers and three selected pitchers of products gave their presentations via Zoom. The three products presented were:
• ReACT: A phone application that gathers several functions where users can store photographs, audio memories, videos and organise these in albums, so that users can share memories and important events with friends and family.
• Inspired: A phone application to support reminiscence where users can store photographs, audio memories, videos and organise these in albums, so that users can share memories and important events with friends and family.
• GenusCare: An always on smart frame device that connects, monitors users and alerts relatives when users are inactive.

Both a member of Alzheimer Europe staff and three members of the European Working Group of People with Dementia participated as reviewers in the WJC. Marco Blom (Honorary Treasurer of the Board of Alzheimer Europe) was part of the JAIN Expert Committee. On 6 April, the award ceremony of the WJC took place. The ceremony started with a roundtable discussion involving two experts in the field (Franka Meiland and Wijnand IJsselsteijn), Jos De Groot from the Dutch Ministry of Economic Affairs & Climate Policy, Roland Driece, Director of International Affairs of the Ministry of Health of the Netherlands as well as the finalists moderated by Thomas Arnold. This was followed by a speech by Conny Helder, who is Dutch Minister for Long-term Care and Sport. After that, Conny Helder announced the WJC winners: The prototype winner of the 2022 WJC is DeepVibes: https://deepvibes.ai
The product winner of the 2022 WJC is Genus Care: https://genus.care
The three events can be viewed on the JAIN YouTube channel: https://www.youtube.com/channel/UCTgNRCH86XAlFzv9kYezWBg

8 April: Film "remember me" aims to raise awareness of frontotemporal dementia (FTD)

"Remember me“ is a film production aiming to raise awareness of frontotemporal dementia (FTD) and drum up support for people affected by FTD.

The story of the film revolves around a couple, Elina and Max, who are expecting their first child and for whom is full of hope and possibilities. When rising opera star Elina’s behaviour begins to change dramatically and she starts to act strangely, Max, a junior doctor, must fight his self-doubt to try to salvage the family unit.

Lukas Olszewski, a doctor, as well as an actor, writer and filmmaker from Leipzig, Germany is heading up this new film project, which needs financial support to move forwards. 20 percent of all donations will go to Deutsche Alzheimer Gesellschaft e.V.
Here is the link for donations: https://gofund.me/36003243

25 April: International Alzheimer’s Research Society and University College London survey turns a spotlight on early career researcher life and challenges

The Alzheimer’s Association International Society to Advance Alzheimer’s Research and Treatment (ISTAART) Professional Interest Area to Elevate Early Career Researchers (PEERS) and University College London (UCL) have published compelling, and sometimes worrisome, new survey results. Listening to Early Career Dementia Researchers Report has unearthed both encouraging and cautionary new insights related to life as an early career dementia researcher.

The voluntary survey was completed by more than 500 early career researchers (ECRs) from 42 countries, with the UK and US providing 34% of responses, working across all fields of dementia research and discovery, including lab-based research, clinicians and those working in care and qualitative research. Two thirds of those completing the survey were women, and 22% considered themselves as holding an identify which is underrepresented at their institution.

77% of early career dementia researchers are happy in their current role, but 84% agree or strongly agree that “the short-term nature of research contracts and funding is a barrier to making advancements and discoveries in dementia research.” Only 25% believe dementia research is sufficiently funded.

The survey highlights that there are many ECRs who are passionate about their work and happy in the field. At the same time, many are considering leaving, and there are significant barriers to remaining within the field. The main barriers to career progression are seen as funding (74%), job availability and security (60%) and work-life balance (54%). When asked if they were thinking of leaving dementia research, 52% responded yes / maybe.

The survey included over 160 questions covering everything from thoughts on careers, health, workplace, discrimination, conferences, and the impact of the pandemic. Of particular
concern is the finding that 43% of researchers have experienced mental health issues, affecting their effectiveness at work (74%), confidence (69%) and motivation (66%).

Another significant finding comes on the issue of discrimination. The survey found that 51% of people thought that issues relating to sexism were improving. However, when considering ageism, racism, religion / faith, homophobia, and ableism, the majority are uncertain or feel the issues remain unchanged or have got worse.

Further analysis of the results is being conducted, and the ISTAART PEERS Group is now working to provide much-needed support as identified by the initial responses. The group is working with partners to (a) highlight the survey results, and (b) deliver improvements with the goal of attracting and retaining more ECRs to choose dementia as their area of focus.

It is clear from the results that survey respondents would like to see:

- increased funding, particularly in areas where there are career bottlenecks, such as Fellowships / Postdoctoral Positions, and in countries where dementia research is not prioritised
- improved job security and longer contracts
- changes to research culture with more training, personal support and mentoring
- additional concerted efforts to address discrimination.

Download the full report, and read about the authors and their work, on the Dementia Researcher website:

www.dementiaresearcher.nihr.ac.uk/survey

NEW PUBLICATIONS AND RESOURCES

31 March: Deaf Dementia Research Project comes to a close and publishes its findings

The research summarised in the report, "Deaf people with dementia and care homes in Scotland" was trying to find out how to improve care homes for Deaf people with dementia from the point of view of Deaf people and from the point of view of care home providers. All data were collected by Deaf researchers in BSL (British Sign Language) through interviews and focus groups. BSL/English interpreters were available for hearing people working at care homes. The study was carried out remotely, via teleconferencing, due to the COVID-19 pandemic and related restrictions. The report exists in three formats, including a full report, an executive summary and a video executive summary in BSL. These reports can be found on the BDA (British Deaf Association) website:

https://bda.org.uk/dementiaresearch/

8 April: ERASMUS+ EU project Embracing Dementia (EDEN) has developed two main deliverables

The Embracing Dementia (EDEN) Project, which is an EU project supported by the ERASMUS+ programme, has developed two main deliverables: the EDEN platform and the Community Collaboration Concept.

The EDEN platform is a collection of materials that support relatives to cope with the great challenge and work they carry out when they take care of their loved ones that live with dementia. The material is divided into 4 categories, which showed to be the most relevant for the relatives, namely:

- to be able to cope with the future
- to feel supported and collaborate with others
- to be socially included
- to understand and cope with dementia.

The Community Collaboration Concept is a process model that supports local communities to become dementia-friendly and dementia-inclusive. The model is a co-creation model, building on design principles. By applying the Community Collaboration Concept, local communities will be able to:

- co-design and co-create, together with all relevant community stakeholders, the best possible local solutions to embrace dementia
- offer the best care for people living with dementia
- recognise and appreciate the relatives and volunteers, who are a very important factor in the development of sustainable solutions.

Visit the EDEN website: www.embracingdementia.eu
19 April: New book “Dementia & Society” highlights the need to take collective responsibility to ensure a better future for people with dementia

Dementia is increasingly being recognised as a public health priority and poses one of the largest challenges we face as a society. At the same time, there is a growing awareness that the quest for a cure for Alzheimer’s disease and other causes of dementia needs to be complemented by efforts to improve the lives of people with dementia. To gain a better understanding of dementia and of how to organise dementia care, there is a need to bring together insights from many different disciplines.

A new book, "Dementia & Society", aims to fill this knowledge gap, by providing an integrated view on dementia resulting from extensive discussions between world experts from different fields, including medicine, social psychology, nursing, economics and literary studies. Working towards a development of integrative policies focused on social inclusion and quality of life, Dementia & Society reminds the reader that a better future for people with dementia is a collective responsibility.

The book is co-edited by Rose-Marie Droes, Amsterdam University Medical Centre, together with Mathieu Vandenbulcke and Erik Schokkaert from KU Leuven University, Belgium. Find out more and order the book, via:

http://www.cambridge.org/9781108843508
## AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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</thead>
<tbody>
<tr>
<td>2 May</td>
<td>RADAR-AD project Steering Committee meeting</td>
<td>Ana and Dianne</td>
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<tr>
<td>3 May</td>
<td>EFNA/GAMIAN catch up on Brain Health Call to Action</td>
<td>Owen and Jean</td>
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<tr>
<td>3 May</td>
<td>Dementia Panel of European Academy of Neurology</td>
<td>Jean</td>
</tr>
<tr>
<td>4-5 May</td>
<td>AI-Mind project General Assembly meeting (Rome, Italy and online)</td>
<td>Cindy, Dianne, Ange, Ana</td>
</tr>
<tr>
<td>4-5 May</td>
<td>WHO Pan-European Mental Health Coalition</td>
<td>Jean</td>
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<tr>
<td>9 May</td>
<td>NeuroCohort Taskforce meeting</td>
<td>Ange</td>
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<tr>
<td>9-10 May</td>
<td>Finding Alzheimer’s Solutions Together (FAST) Council</td>
<td>Jean</td>
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<tr>
<td>10-11 May</td>
<td>“Engage 2022!” communications event organised by Poppulo</td>
<td>Kate</td>
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<tr>
<td>10-12 May</td>
<td>Conference on the Prevention of Alzheimer’s Disease/ Cognitive Decline</td>
<td>Chris</td>
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<tr>
<td>11 May</td>
<td>Meeting of the Lethe project Advisory Board</td>
<td>Ana and Dianne</td>
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<tr>
<td>12 May</td>
<td>DARE project final training event (Brussels, Belgium)</td>
<td>Dianne</td>
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<tr>
<td>12 May</td>
<td>Brain Health Call to Action event with EFNA/GAMIAN</td>
<td>Owen and Jean</td>
</tr>
<tr>
<td>13-14 May</td>
<td>Meeting of European Working Group of People with Dementia (Luxembourg)</td>
<td>Dianne, Ana and Ange</td>
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<tr>
<td>15-16 May</td>
<td>TIMING project kick-off meeting (Copenhagen, Denmark)</td>
<td>Dianne</td>
</tr>
<tr>
<td>16 May</td>
<td>European Commission ESPR Action Plan meeting</td>
<td>Owen</td>
</tr>
<tr>
<td>17 May</td>
<td>Meeting of the Davos Alzheimer’s Collaborative Learning Laboratory</td>
<td>Cindy and Ange</td>
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<tr>
<td>17 May</td>
<td>Alzheimer’s Association Academy “Dementia as a disability”</td>
<td>AE members, sponsors and staff</td>
</tr>
<tr>
<td>17 May</td>
<td>DISTINCT project Summer School</td>
<td>Iva and Jean</td>
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<tr>
<td>19 May</td>
<td>EPAD project communications call with the Alzheimer’s Disease Data Initiative</td>
<td>Cindy</td>
</tr>
<tr>
<td>19-20 May</td>
<td>32nd Alzheimer Europe Conference site inspection (Bucharest, Romania)</td>
<td>Jean and Gwladys</td>
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<tr>
<td>30 May</td>
<td>ADAIR project meeting</td>
<td>Jean</td>
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<tr>
<td>30 May</td>
<td>VirtualBrainCloud project General Assembly meeting</td>
<td>Jean</td>
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<tr>
<td>31 May</td>
<td>European Academy of Neurology Brain Health Summit</td>
<td>Owen</td>
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</tbody>
</table>
# CONFERENCES 2022

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Format/ Place</th>
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</thead>
<tbody>
<tr>
<td>12 May</td>
<td>Patient involvement in Brain Health: Safeguarding the future of Brain Health for patients, <a href="https://brainhealth.heysummit.com/">https://brainhealth.heysummit.com/</a></td>
<td>Online</td>
</tr>
<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>
</tr>
<tr>
<td>9-11 June</td>
<td>35th Global Conference of Alzheimer’s Disease International, <a href="https://adiconference.org/">https://adiconference.org/</a></td>
<td>London &amp; online</td>
</tr>
<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>
</tr>
<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>
</tr>
<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