

# ALZHEIMER EUROPE NEWSLETTER

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## WELCOME



This month, we were delighted and proud to launch a joint publication with NHS England, on intercultural dementia care for health and care professionals. This is great recognition of our work on intercultural dementia care and of our 2020 guide on this topic, which served as the foundation of the new guide for NHS England.

Staying in the United Kingdom, I would like to congratulate our colleagues in Scotland, where a new ten-year dementia strategy has been published. It was developed through engagement with people across Scotland, including people with lived experience, and commits to tackling stigma as a priority. We were also pleased to hear that a dementia strategy on managing dementia until 2030 has been backed by the parliamentary health and labour committees in Slovenia.

Echoing the focus in the new Scottish strategy, on combatting stigma and upholding rights, during the 5<sup>th</sup> European Parliament of Persons with Disabilities, at the European Parliament in Brussels, the Chair of the European Working Group of People with Dementia, Chris Roberts, had the opportunity to speak during the session "Fighting for our Rights – combating inequality, social exclusion and poverty", highlighting the importance of more funding for services and support for people with dementia and for national dementia plans.

On the research front, the Multi-MeMo (shorter and longer-term mechanisms of multimodal interventions to prevent dementia) project has been launched. It is

funded by the EU Joint Programme – Neurodegenerative Disease Research and Alzheimer Europe is one of six partners.

In global research news, Eli Lilly announced positive top-line results from the phase III TRAILBLAZER-ALZ2 trial of donanemab for the treatment of early symptomatic Alzheimer's disease. We look forward to hearing more at the Alzheimer's Association International Conference in July.

Regarding our own upcoming conference, in Helsinki from 16 to 18 October, we would like to thank everyone who submitted abstracts. A record number of 539 abstracts was received, which have all now been reviewed and responses sent. The detailed programme is now available on our website. As part of the conference programme, we will again be recognising an outstanding initiative aimed at combating stigma and promoting a positive image of dementia and people living with dementia. The 2023 award will consist of a cash prize of EUR 5,000 and a trophy which will be presented in Helsinki. The deadline for applications is fast approaching, so please make sure you submit yours before 15 June!

In closing, it is a relief to note that the World Health Organization (WHO) has declared that COVID-19 is no longer a Public Health Emergency of International Concern. As a result of this statement, Alzheimer Europe has decided to discontinue its website page with national and European COVID-19 resources.

Wishing you all an excellent month ahead!

**Jean Georges**  
**Executive Director**

Help us give a voice to people with dementia

Donate



## ALZHEIMER EUROPE

### 1 May: TouchNEUROLOGY interviews Alzheimer Europe on its Dementia in Europe Yearbook 2022 on Employment and Related Social Protection for People with Dementia and Their Carers

In an expert interview with touchNEUROLOGY, Alzheimer Europe Policy Officer Owen Miller discusses the Dementia in Europe Yearbook 2022: Employment and Related Social Protection for People with Dementia and their Carers. The Yearbook is a report that provides an overview of the challenges and opportunities that people with dementia and their caregivers face in Europe, and is based on a survey of national Alzheimer associations from 30 European countries, providing insights into the employment status of people with dementia, their access to social protection, and the support available to their caregivers.

It also highlights the significant barriers to employment that people with dementia and their caregivers face and the lack of adequate social protection and support for these groups. The report concludes with recommendations for policymakers, employers and civil society organizations to address these challenges and promote greater social inclusion for people with dementia and their caregivers. Read the touchNEUROLOGY expert interview, here:

<https://touchneurology.com/alzheimers-disease-dementia/journal-articles/dementia-in-europe-yearbook-2022-employment-and-related-social-protection-for-people-with-dementia-and-their-carers/>

TouchNEUROLOGY is an independent information resource supporting physicians, clinicians and industry professionals in continuously developing their knowledge, effectiveness and productivity, via free-to-access content in multimedia formats.

It produces concise and balanced peer-reviewed, free-to-access articles, carefully selected video and podcasts on a variety of salient topics which are designed for busy physicians and HCPs seeking the latest developments in their field.

Its journal touchREVIEWS in Neurology is a peer-reviewed, free-to-access, bi-annual journal that aims to provide insightful and topical articles relevant to the day-to-day practice of physicians in the field of neurology and provides practical advice relevant to the clinical setting on the diagnosis and treatment of neurological conditions.

### 15 May: NHS England releases new resources on intercultural dementia care including a joint guide with Alzheimer Europe

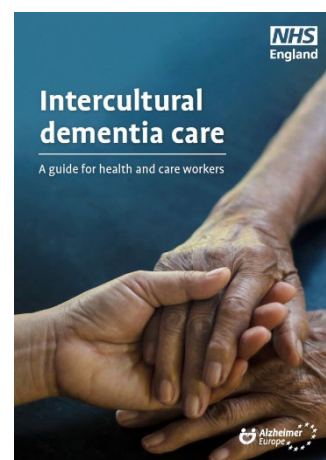
The number of people living with dementia from an ethnic minority background is expected to double by 2026 in England. Currently, people from ethnic minority communities often face delays in dementia diagnosis, barriers to services and there is insufficient culturally competent dementia care available. Working in partnership with Alzheimer Europe and the Royal College of Psychiatry, NHS England (NHSE) has published [new guidance](#), and launched a new [free e-learning module](#) aiming to improve care for people living with dementia from an ethnic minority background.

NHSE hopes these new resources will help raise awareness of the challenges people from ethnic minority communities face when accessing dementia care and help narrow the health inequalities gap. The launch coincides with Dementia Action Week 2023, taking place from 15 to 23 May.

This new set of resources includes:

- The new NHSE and Alzheimer Europe guide on intercultural dementia care - for health and care professionals: <https://www.alzheimer-europe.org/sites/default/files/2023-05/intercultural-dementia-care-guide.pdf>
- A new NHSE and Royal College of Psychiatrists (RCPsych) e-learning module – for health and care professionals: [https://elearninghub.rcpsych.ac.uk/products/NHSE\\_Dementia](https://elearninghub.rcpsych.ac.uk/products/NHSE_Dementia)
- Two new culturally competent activity booklets for use in care settings; one tailored for South Asian communities and one tailored to Black Caribbean/African communities - for health and care professionals
- A new leaflet designed for ethnic minority communities – for Voluntary, Community and Social Enterprise (VCSE) and faith organisations.

These will be of interest, mainly, to dementia health and care professionals, VCSE organisations supporting people from



ethnic minority communities and to people living with dementia/caring for someone with dementia from an ethnic minority background.

Jean Georges, Executive Director, Alzheimer Europe said:

"Alzheimer Europe is delighted and proud to have partnered with NHS England on this new resource. This is great recognition of our work on intercultural dementia care and of our 2020 guide on this topic, which served as the foundation of the new guide for NHS England. It is great that the NHS feels this is such an important guide and that they will be using it to help improve care in England, for people living with dementia from an ethnic minority background."

## 25 May: Apply for Alzheimer Europe's 2023 Anti-Stigma Award before 15 June



Last month, Alzheimer Europe and the Alzheimer Europe Foundation announced that, following the success of their first Anti-Stigma Award in 2022, they would again be recognising an outstanding initiative aimed at combating stigma and promoting a positive image of dementia and people living with dementia. The 2023 award will consist of a cash prize of EUR 5,000 and a trophy which will be presented during the Alzheimer Europe Conference in Helsinki, on 17 October 2023. The deadline for applications is fast approaching, so please make sure you submit yours before 15 June!

The award is open to individuals and organisations established in a [member country of Alzheimer Europe](#) for initiatives and projects which have been developed and/or implemented in the past three years (2020-2023). The award can be for projects, campaigns, films/videos or publications/books which aim to address the stigma attached to dementia. It will be for initiatives and projects rather than for individuals or associations.

The 2023 call is focusing on initiatives and campaigns addressing the stigma experienced by people with dementia and their carers from specific groups:

- Minority ethnic groups
- LGBTQ+ community
- People with intellectual disability and/or Down syndrome
- Socio-economically disadvantaged groups.

Interested organisations and individuals should send in information on their initiative via the enclosed application form by the deadline of **15 June 2023**. Applicants may be short listed and asked to present their initiative to the members of the Award Committee at a virtual meeting on 10 July. The winner of the award will be announced at the Alzheimer Europe Conference in Helsinki (17 October) and the travel and accommodation costs for the shortlisted initiatives will be covered by Alzheimer Europe. Find out more:

<https://www.alzheimer-europe.org/our-work/anti-stigma-award/anti-stigma-award-2023>

Download the application form: [https://www.alzheimer-europe.org/sites/default/files/2023-03/ae\\_anti-stigma\\_award\\_-\\_application\\_form\\_0.pdf](https://www.alzheimer-europe.org/sites/default/files/2023-03/ae_anti-stigma_award_-_application_form_0.pdf)

Alzheimer Europe gratefully acknowledges the support of the sponsors of the Alzheimer Europe Anti-Stigma Award: Alzheimer Europe Foundation, Lilly and Roche.

## 31 May: 33<sup>rd</sup> Alzheimer Europe Conference agenda available online and new bursaries also available for early stage researchers!



Alzheimer Europe and Muistiliitto (Alzheimer Society of Finland) would like to thank everyone who submitted abstracts for the 33<sup>rd</sup> Alzheimer Europe Conference (#33AEC), taking place from 16 to 18 October 2023, in Helsinki, Finland. A record number of 539 abstracts was received this year, which have all now been reviewed by our Scientific Committee and notifications have been sent to all applicants.

The detailed programme for the conference is available to view on our website:

<https://www.alzheimer-europe.org/conferences/2023-helsinki/detailed-programme>

Exciting news, also, for early stage researchers wishing to attend this event, as the Alzheimer Europe Foundation will collaborate with the INTERDEM Academy to award ten bursaries of EUR 1,000 for early stage researchers wishing to



attend and present at the Alzheimer Europe Conference. We are looking for “Dementia researchers of the future” willing to share their work and research on “Innovative approaches to dementia” with a quick oral presentation of five minutes during the conference. The bursaries are open to researchers coming from European countries whose gross national income (GNI) per inhabitant is less than 90% of the European Union average. The following countries will be eligible: Armenia, Bulgaria, Croatia, Cyprus, Czech Republic, Estonia, Greece, Hungary, Latvia, Lithuania, Malta, North Macedonia, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Turkey and Ukraine. Please apply for these bursaries by sending in your abstract and a short bio by 30 June 2023 via the abstract submission portal <https://www.alzheimer-europe.org/conferences/2023-helsinki/online-abstract-submission-form> under the topic “Dementia researchers of the future – Innovative approaches to dementia”.

Finally, we remind you that you can take advantage of our special early bird registration fees until 30 June 2023 to attend in-person in Helsinki or virtually. Register now, to avoid missing this opportunity:

<https://www.alzheimer-europe.org/conferences/2023-helsinki/online-conference-registration>



**Follow us on Twitter**

### ***Sponsor of the month***

Alzheimer Europe would like to express its gratitude to a new sponsor for its 2023 activities.

Read more about sponsorship opportunities here:

<https://www.alzheimer-europe.org/about-us/governance/finances/2023-sponsorship-opportunities>

**GRIFOLS**

## **ALZHEIMER EUROPE NETWORKING**

On 2 May, the Alzheimer Europe Conference Committee had its meeting.

On 2 May, Jean attended the FAST (Finding Alzheimer’s Solutions Together) Council.

On 2 May, Angela participated in a workshop with the EPND Research Community Experts' Group.

On 4 May, Jean met with a representative of Novo Nordisk.

On 10 May, Jean and Owen attended the Stakeholders Dialogue on the pharmaceutical package organised by the European Commission.

On 10 May (Luxembourg, Luxembourg), Jean met with a representative of the Dementia Discovery Fund.

On 10-12 May (Budapest, Hungary), Angela participated in the General Assembly meeting for the PRIME project.

On 11 May, Jean met with a representative of Dementia Australia.

On 11 May, Jean met with representatives of the INTERDEM Academy.

On 11 May, Jean, Dianne, Ange and Chris attended the kick-off meeting of the PROMINENT project.

On 15 May, Kate met with Leicia Feare, Head of Communications - Health Inequalities Improvement, NHS England, to discuss the launch of new resources on intercultural dementia care, including a joint guide with Alzheimer Europe.

On 15-16 May (Amsterdam, Netherlands) Dianne and Ana participated in the RADAR-AD consortium meeting and Public Event.

On 17 May, Ana and Cindy participated in the EU-FINGERS Advisory Board meetings.

On 17 May, Angela participated in a meeting of the EPND External Stakeholder Advisory Board.

On 19 May, Ana participated in the LETHE Advisory Board meeting.

On 22 May, Jean met with a representative of Alnylam.

On 22 May (Brussels, Belgium), Dianne attended the GA of the EDF.

On 23 May (Brussels, Belgium), Dianne and Daphne attended the 5<sup>th</sup> European Parliament of Persons with Disabilities.

On 24-25 May (London, UK), Cindy attended the Euro-PAD neuroimaging symposium.

On 24 May, Owen attended the EFPIA Patient Think Tank.

On 25 May, Owen attended a the EU4Health Civil Society Alliance meeting.

On 25 May, Angela and Jean met with members of the EMA Patients and Consumers' Working Party.

On 26 May, Angela, Daphne and Jean attended the eBRAIN-Health General Assembly meeting.

On 30 May, Angela participated in a meeting of the PROMINENT steering committee.

On 30 May, Ana and Cindy attended the Multi-MeMo kick-off meeting.

On 30 May, Dianne and Daphné participated in an online consultation with the eBRAIN-Health Public and Patient Advisory Group.



## EU PROJECTS

### 3 May: LETHE project enrolls 40 Participants for feasibility trial recruitment



The LETHE project, a four-year project focused on providing personalized prediction and intervention models for the early detection and reduction of risk factors causing dementia using Artificial Intelligence and distributed machine learning,

has successfully enrolled 40 study participants in its feasibility trial recruitment.

The project aims to establish digital biomarkers for early detection of risk factors based on unobtrusive ICT-based passive and active monitoring, leading to an ICT-based preventive lifestyle intervention through individualized profiling, personalized recommendations, feedback, and support. The LETHE solution is being tested in the feasibility study to validate the achieved improvements. The milestone achieved in recruitment is a significant accomplishment for the LETHE team, who expressed gratitude to all those who applied and joined them. Find out more about the project:

[www.lethe-project.eu](http://www.lethe-project.eu)

### 10-12 May: PRIME project convenes a general assembly meeting in Budapest

The Horizon 2020-funded PRIME project aims to connect the dots between diseases such as diabetes, obsessive-compulsive disorder (OCD), and Alzheimer's disease, identifying shared mechanisms and disease drivers. Between 10-12 May, the PRIME consortium met in Budapest, discussing the latest findings of the project and planning the next steps to achieve the objectives of this ambitious and wide-ranging research project.

PRIME brings together a wide range of disciplines and stakeholder groups, including laboratory scientists, clinical researchers, metabolic disease specialists and experts working in non-governmental organisations. Together, they are investigating whether altered insulin signalling could connect brain-based diseases, such as Alzheimer's and autism, with somatic diseases like type 2 diabetes and obesity. PRIME involves partners from 17 institutions across Europe, and is



coordinated by Professor Barbara Franke, of Radboud University Medical Center (RUMC).

Although insulin is most commonly linked to diabetes - thanks to its role in regulating how we process sugar - it also has effects on our blood vessels and brain cells, potentially impacting the development of neuropsychiatric disorders and neurodegenerative diseases. In PRIME, scientists are analysing the role of insulin in these diseases using a wide range of laboratory, preclinical and clinical research methods. The first day of the PRIME General Assembly focused on the clinical end of the research spectrum. Willemijn Jansen (University of Maastricht) presented a recent meta-analysis investigating the association between diabetes measures and Alzheimer's disease biomarkers, and Valérie Bertaina-Anglade (Biotrial) provided an update on the PRIME clinical study, which is collecting data and samples from people with Romano-Ward Syndrome.

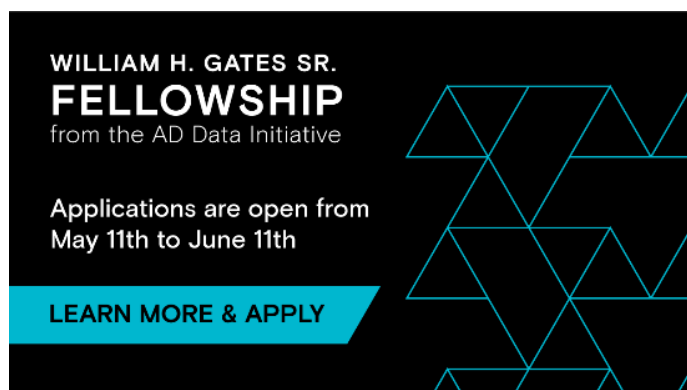
PRIME is also using advanced analytics to probe existing clinical datasets. Nina Roth Morta (RUMC) and Hyun Ruisch (Drug Target ID) presented their work on identifying potential disease mechanisms at the genetic and genomic level, and Olha Shkaravska (Machine2Learn) outlined how she is analysing data from the UK Biobank and PREDIMED-Plus studies to identify risk factors for cognitive decline in type 2 diabetes. Clinical partners from the Mannheim-based Central Institute for Mental Health explained how they are reviewing clinical guidelines on brain and somatic diseases from over 15 countries, including the UK, Germany and France among others. Rounding off the first day of the General Assembly, dissemination partners from the European Brain Council and RUMC (Jeanette Mostert) led a lively discussion on how to communicate PRIME to different stakeholders, outlining plans for a policy event in 2024 and detailing the ongoing webinar series.

Day two of the PRIME General Assembly brought the audience back to the laboratory. Partners from the Instituto Superiore di

Sanita (Rome), University College Dublin (Ireland) and Johann Wolfgang Goethe Universität (Germany) shared updates on their studies looking at mechanism validation and refinement in preclinical models of disease. This research uses established models of diabetes and Alzheimer's disease to study the presence of neuropsychiatric traits, and whether existing and potential drugs could be useful treatments. Partners from Heidelberg University (Germany) and Semmelweis University (Hungary), explained how they are using neurons derived from connective tissue cells donated by patients with diabetes to refine and validate disease mechanisms, identifying targets and molecules that overlap with the preclinical and clinical PRIME studies. A final session of the General Assembly was focused on patient involvement in research, and how patient organisations can contribute to projects such as PRIME. Angela Bradshaw (Alzheimer Europe) and Sabine Dupont (International Diabetes Federation – Europe) introduced their respective organisations and explained how they contribute to research projects, providing examples and learnings on public involvement. Finally, Janita Bralten, who co-coordinates PRIME, drew the meeting to a close, thanking attendees for their valuable input and contributions. Discover the PRIME project, here:

<https://prime-study.eu/>

## 11 May: Alzheimer's Disease Data Initiative launches William H. Gates Sr Fellowship to accelerate AD research



The Alzheimer's Disease Data Initiative (ADDI) was launched in 2020, with the goal of enabling new discoveries and innovations to advance research on Alzheimer's disease (AD) and dementias. The AD Workbench is a cornerstone of ADDI, providing a cloud-based environment for discovering and sharing data from clinical research studies. On 11 May, ADDI launched a new funding initiative for early- and mid-career researchers: the William H. Gates Sr. Fellowship programme.

The William H. Gates Sr. Fellowship was named after the father of Bill Gates, who passed away from AD in 2020. To honour his legacy of advocacy and philanthropy, the William H. Gates Sr. Fellowship will support scientists with a background in machine learning, statistics, or other data science methods, to address important AD research questions by analysing human or human-derived data on the AD Workbench. Up to five Fellows will be funded in the inaugural, 2023 cohort, receiving up to

USD100,000 over two years to support their research. Fellows will also receive support for conference presentations, publications and mentorship.

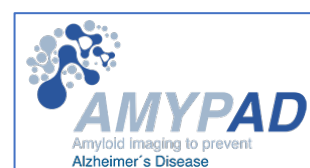
Prospective Fellows are invited to submit their application materials by 11 June, to include a short CV, personal statement and concise research outline. Researchers from a diverse range of cultural, geographical and technical backgrounds are encouraged to apply.

Further information on Fellowship eligibility criteria, benefits, and application materials are available on the ADDI website:

<https://www.alzheimersdata.org/fellows/apply>

## 12 May: The primary manuscript of the AMYPAD Diagnostic Study is out

The AMYPAD Diagnostic and Patient Management Study (DPMS) was designed as a prospective, multicentre, randomised clinical trial and is the largest European study



assessing the clinical effect of amyloid PET in memory clinic patients. It aims to fill the current evidence gap by providing strong evidence on the clinical utility and cost-effectiveness of amyloid PET. A total of 840 patients from 8 European memory clinics have participated in this study.

In a new paper published in JAMA Neurology, researchers investigated whether participants allocated to undergo amyloid PET early in their diagnostic workup received an etiological diagnosis with very high diagnostic confidence after 3 months more frequently than those who had not undergone amyloid PET yet. Moreover, they also assessed whether early amyloid PET is associated with more frequent changes in diagnosis, diagnostic confidence, and treatment plan. Finally, they examined the real-world use and clinical effect of unrestricted amyloid PET imaging in a free-choice group.

The study showed that access to this diagnostic test resulted in an etiological diagnosis with very high certainty in 40% of patients, within three months of initial clinic visit. This corresponds to a percentage of 3.5 times higher than those who had not undergone amyloid PET. Moreover, amyloid PET changed the initial diagnosis in 44% of cases, compared to only 11% in the group without amyloid PET.

You can read the paper [here](#).

## 15-16 May: RADAR-AD final consortium meeting and public event (Amsterdam, the Netherlands)

On 15 May, Ana and Dianne attended the final RADAR-AD consortium meeting in Amsterdam. The research partners discussed preliminary findings, the possible implications of those findings in relation to existing tests for functioning, planned publications and the management of data sets. The RADAR-AD public final event was held the following day. The event was chaired by the project leads Dag Aarsland (Kings' College London) and Gayle Wittenberg (Janssen). Members of



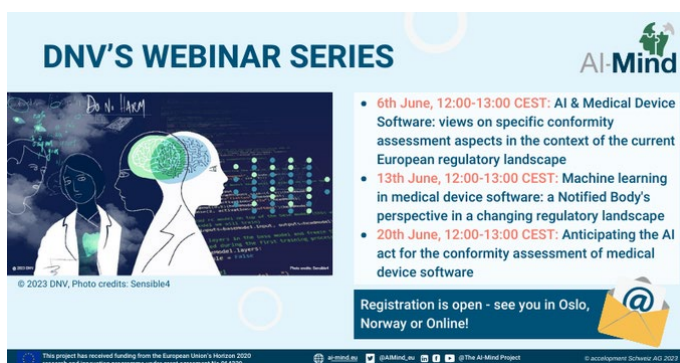


the RADAR-AD Patient Advisory Board actively participated in the event. In the morning, Dianne Gove gave an overview of Public Involvement work in this project and presented the work of the PAB, and Helen Rochford-Brennan and Nélida Aguiar presented the perspectives of a person with dementia and carer about PI work in research. In the afternoon, Ana Diaz participated in a discussion panel together with Chris Roberts and Carmel Geoghegan. It was a very interesting meeting. All members of the PAB were presented with a certificate of appreciation for the work and involvement in the project.

Read the full report on the RADAR-AD website:

<https://www.radar-ad.org/newsroom/radar-ad-consortium-celebrates-4-years-research-and-achievements-close-out-project-meeting>

## 22 May: AI-Mind and DNV organise jointly a series of hybrid webinars



**DNV'S WEBINAR SERIES**

AI-Mind

- 6th June, 12:00-13:00 CEST: AI & Medical Device Software: views on specific conformity assessment aspects in the context of the current European regulatory landscape
- 13th June, 12:00-13:00 CEST: Machine learning in medical device software: a Notified Body's perspective in a changing regulatory landscape
- 20th June, 12:00-13:00 CEST: Anticipating the AI act for the conformity assessment of medical device software

Registration is open - see you in Oslo, Norway or Online!

© 2023 DNV, Photo credits: Sensible4

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 746220

AI-Mind, AI-Mind, AI-Mind, AI-Mind, AI-Mind, AI-Mind, AI-Mind, AI-Mind, AI-Mind, AI-Mind

Det Norske Veritas® (DNV) is co-organising with the AI-Mind consortium, of which DNV is a partner, hybrid webinar series on Artificial Intelligence (AI), medical devices, Regulation (EU) 2017/745 on Medical Devices (MDR) and the upcoming AI Act (AIA). The webinars aim to highlight some relevant aspects of the conformity requirements for medical device software which use AI.

The webinar series is tailored to a diverse group of stakeholders with a shared interest in the intersection of AI and healthcare. This includes AI-Mind members and stakeholders and other relevant stakeholders who are researching and using AI in healthcare including clinicians, researchers, lawyers, hospital management and IT support.

Three webinars will be delivered by medical device software expert, Dr Frédéric Courivaud from DNV's Healthcare Research Programme. Save the dates:

- Tuesday June 6 (12-13h CET) "AI & Medical Device Software" (i.e. views on specific conformity assessment aspects in the context of the current European regulatory landscape)
- Tuesday June 13 (12-13h CET) "Machine Learning in medical device software" (i.e. a Notified Body's perspective in a changing regulatory landscape)
- Tuesday June 20 (12-13h CET) "Anticipating the AIA for the conformity assessment of medical device Software" (i.e. interplay between, MDR and the upcoming AI Act regarding the conformity management of AI medical software).

You can find more information about the European Artificial Intelligence Act and the DNV webinars on the AI-Mind website:

<https://www.ai-mind.eu/blog/european-artificial-intelligence-act-and-webinar-series-from-dnv/>

## 24 May: The Euro-PAD initiative holds a neuroimaging symposium in London



On 24 and 25 May, the new Euro-PAD initiative held a neuroimaging symposium in London (UK). The Euro-PAD initiative is a continuation of the AMYPAD pan-European collaborative framework, including several cohorts such as EPAD, AMYPAD, ALFA+, Prevent-AD and Microbiota.

Frederik Barkhof, AMYPAD project coordinator, kicked off the meeting with a warm welcome to all delegates. The opening session was then followed by an overview presentation of the Euro-PAD initiative and its goals.

The event brought together more than 60 on-site participants. The meeting agenda included over 40 scientific talks by academic researchers including many early career researchers, who covered neuroimaging topics such as on fluid and imaging biomarkers, advanced magnetic resonance imaging, PET quantification and disease progression, imaging and genetic risk, Tau PET imaging and disease modelling, and centiloid quantification.

Throughout the two days, all delegates were engaged in lively discussions and the symposium offered a place for presenting results and developing research questions aimed at cross-modality analyses to further our understanding of the natural history of Alzheimer's disease. The meeting demonstrated continuous academic collaborations as a key legacy of both EPAD and AMYPAD projects.

AE Project Officer Cindy Birck attended the meeting and presented an overview of the communication activities performed in both EPAD and AMYPAD projects. In these projects, AE led and coordinated external communication and dissemination activities, by addressing liaison with external stakeholders including the wider dementia community and general public.

### 30 May: Multi-MeMo project holds its virtual kick-off meeting



On 30 May, the Multi-MeMo project hosted its kick-off meeting online. Multi-MeMo stands for “Shorter and longer-term mechanisms of multimodal interventions to prevent dementia” and is funded by the EU Joint Programme – Neurodegenerative Disease Research (JPND) in collaboration between national funders and the European Union. The project involves six partners, including Alzheimer Europe (AE), and several external collaborators. The project will run for three years and is coordinated by Associate Professor Alina Solomon from University of Eastern Finland (UEF).

The kick-off meeting provided partners with the opportunity to introduce their organisations and involvement in the project as well as opportunities for cross work package collaboration. The project is looking at multimodal interventions for the prevention of dementia. The consortium synergises and builds upon innovative preclinical models and clinical trials to produce crucial knowledge for developing enhanced, mechanistically multimodal lifestyle intervention models with built-in

compatibility for combination with new Alzheimer’s disease drugs.

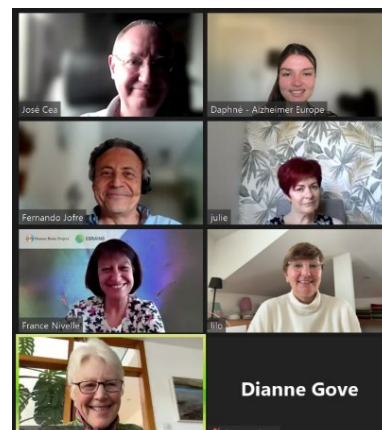
AE Project Officers Ana Diaz and Cindy Birck attended the meeting and presented on AE’s main involvements:

- Leading on the Patient and Public Involvement activities (PPI) with the establishment of Advisory Board who will be composed of people affected by Alzheimer’s disease across the continuum.
- Leading on the communication and dissemination activities.

After a discussion session between attendees, Alina Solomon closed the Multi-MeMo kick-off meeting by thanking all partners and wishing them continued success and effective collaborations over the next three years.

### 30 May: The eBRAIN-Health Public and Patient Advisory Group members gather online for their third consultation about the project!

On 30 May, members of the eBRAIN-Health Public and Patient Advisory Group, Lilo (Germany), José (Spain), Fernando (Spain), Eileen (UK) and Julie (UK), met online for their third consultation about the project. The meeting was facilitated by Daphné Lamirel (Project Officer) and also attended by Dianne Gove (Director for Projects) and France Nivelles (from eBRAINS). The discussions centred around addressing the critical challenge of effective public communication. The group provided valuable perspectives and ideas regarding how researchers should go about communicating about the eBRAIN-Health project to the general public in a way that is accessible and does not promote fear or false hopes. Members gave recommendations surrounding the use types of pictures, videos and diagrams. The consultation also explored the public figures and other experts that the public tends to trust when it comes to information about healthcare research.



### 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, Innovative Medicines Initiative 2, and the Innovative Health Initiative 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

**eBRAIN-Health** – grant agreement 101058516



LETHE – grant agreement 101017405  
Prime – grant agreement 847879

RADAR-AD – grant agreement 806999



**Multi-Memo** - The Multi-Memo project is supported by the Luxembourg National Research Fund (INTER/JPND22/17107181/Multi-Memo) under the aegis of the EU Joint Programme - Neurodegenerative Disease Research (JPND) - [www.jpnd.eu](http://www.jpnd.eu)

## Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at **87**, representing **26** out of 27 Member States of the European Union and seven 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). **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:** Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France:** François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie 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); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland:** Barry Andrews (Renew Europe); Deirdre Clune (EPP); 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 (EPP); Brando Benifei (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:** Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP). **Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP). **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 (Renew Europe); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estaràs Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens/EFA); Ernest Urtasun (Greens/EFA). **Sweden:** Peter Lundgren (ECR).

## EU DEVELOPMENTS

### 22-26 May: European Public Health Association (EUPHA) hosts European Public Health Week 2023 with 224 events organised across 40 European countries

The European Public Health Week (EUPHW) aims to raise awareness about public health and promote collaboration among the public health community in Europe. It is an annual initiative that began in 2019 and keeps on growing. The fifth EUPHW took place under the banner "Public health: Global issues, local actions", between 22 and 26 May 2023.

The event launched with an opening webinar on 22 May, discussing vital global issues in public health and showcasing

initiatives by EUPHA members from around Europe, trying to tackle those issues with local actions. During the opening event, speakers included Prof. Ilona Kickbusch (Global Health Centre at the Graduate Institute of International and Development Studies in Geneva), Prof. Andrzej Fal (Polish Society of Public Health), Dr Maria Gabriela Barbaglia Navarro (Spanish Public Health Society), Prof. Christos Lionis (University of Crete), Dr Isabel de la Mata (European Commission DG SANTE), Dr Caroline Bollars (The WHO Representation Office to the European Union), Dr Iveta Nagyova (EUPHA President) and Dr Marieke Verschuuren (EUPHA Executive Director). The



recording of the opening webinar is available here:  
<https://vimeo.com/829409465?share=copy>

The programme for the week consisted of a different dedicated topic for each day:

- Monday 22 May - Mental health for all
- Tuesday 23 May: Diversity in health
- Wednesday 24 May: Access to care
- Thursday 25 May: Prevention and control of chronic diseases
- Friday 26 May: Global health emergencies and response.

The European Public Health Week (EUPHW) is an initiative by the European Public Health Association (EUPHA) supported by the WHO Regional Office for Europe and co-funded by the European Union. Key messages from the event have been gathered together in this document:

<https://eupha.org/repository/EUPHW/EUPHW2023/Key%20messages%20EUPHW%202023.pdf>

### **23 May 2023: 5<sup>th</sup> European Parliament of Persons with Disabilities gathers 600 advocates to discuss 'an inclusive future for persons with disabilities in the EU'**



The "5<sup>th</sup> European Parliament of Persons with Disabilities" took place on 23 May at the hemicycle of the European Parliament in Brussels. This event brought together 600 disability advocates from across the European Union to discuss the role of the EU in advancing

Disability Rights.

Alzheimer Europe was represented by the Chair of the European Working Group of People with Dementia, Chris Roberts and Vice-Chair, Kevin Quaid. Their supporters Jayne and Helena, and Dianne Gove (Director for Projects) and Daphné Lamirel (Project Officer) also participated in the meeting.

During the event, the European Disability Forum's (EDF) Manifesto on the 2024 European Elections was adopted, which serves as a roadmap for their campaign in the upcoming year. The Manifesto puts forward key demands for the next legislative term to ensure the protection of the rights of persons with disabilities.

These demands include: ensuring the right to vote and stand as candidates in Europe elections, establishing strong services focused on disability rights in EU institutions, creating a new European agency for accessibility, adopting an EU-wide Disability Card for mutual recognition of disability status,

enacting stronger legislation to protect the rights of disabled passengers, establishing a Disability Employment and Skills Guarantee, providing further protection for women and girls with disabilities, supporting Ukrainians with disabilities, guaranteeing the availability and affordability of assistive technologies, and ensuring the EU Budget supports independent living and disability inclusion in the Green and Digital transition.

In relation to the Manifesto, Yannis Vardakastanis, the President of the EDF, emphasised that persons with disabilities aspire to be full citizens of the European Union and called on EU institutions to ensure their participation in the democratic process and the shaping of policies.

Following the adoption of the Manifesto, discussions centred around three main themes: free movement and full participation of persons with disabilities; inequality, social exclusion and poverty; and disability-inclusive resilience. Various members of the European Parliament and disability advocates were invited to share their views and experiences during each session.

Chris Roberts, took the floor during the session focused on 'Fighting for our Rights – combating inequality, social exclusion and poverty'. He highlighted the importance of increased funding for services and support for people with dementia and national dementia plans, emphasising that 'we will not be forgotten or left behind' and 'nothing about us without us'.

Link to the manifesto: [EDF Manifesto on the European Elections 2024 - European Disability Forum \(edf-feph.org\)](https://edf-feph.org/EDF-Manifesto-on-the-European-Elections-2024-Europe-Disability-Forum)

### **31 May: European Commission proposes Regulation on cross border protection for vulnerable adults**

The European Commission is proposing new rules to ensure the protection of vulnerable adults in cross-border cases, and that their right to individual autonomy, including the



freedom to make their own choices, is respected when they move within the EU. Specifically, the proposals cover adults who, by reason of an impairment are unable to protect their own interests, for example, a person with Alzheimer's disease.

A proposed Regulation defines the rules that will apply within the EU, in particular to establish which court has jurisdiction, which law is applicable, under what conditions a foreign measure or foreign powers of representation should be given effect and how authorities can cooperate. It also proposes tools, such as:

- Facilitating digital communication
- Introducing a European Certificate of Representation, which will make it easier for representatives to prove their powers in another Member State

- Establishing interconnected registers that will provide information on the existence of protection in another Member State
- Promoting closer cooperation among authorities.

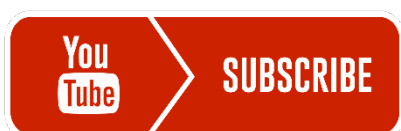
A separate proposal for a Council Decision provides for a uniform legal framework for protecting adults involving non-EU countries and obliges all Member States to become or remain parties to the 2000 Protection of Adults Convention.

The proposed Regulation must be discussed and adopted by the European Parliament and the Council, coming into force 18 months after its adoption. Member States would then have four years to make their communication channels electronic, and five years to create a register and interconnect it with registers of other Member States.

For the proposed Council Decision, Member States that are not yet party to the HCCH 2000 Protection of Adults Convention would have two years to comply with the Council Decision and join the Convention.

Further information is available at:

[https://ec.europa.eu/commission/presscorner/detail/e%20n/ip\\_23\\_2955](https://ec.europa.eu/commission/presscorner/detail/e%20n/ip_23_2955)



## POLICY WATCH

**4 April: A new Irish report by The Alzheimer Society of Ireland and Family Carers Ireland highlights the financial challenges faced by family carers of people with dementia**



On 4 April 2023, The Alzheimer Society of Ireland launched "The Cost of Living While Caring: A brief report on the financial situation of family carers of people with dementia in Ireland", in collaboration with Family Carers Ireland. The report highlights significant financial challenges faced by family carers of people with dementia. Over 180,000 people in Ireland are or have been carers for a family member or partner with dementia, with many more providing support and care in other ways.

The Cost of Living While Caring report highlights the financial challenges faced by 129 family carers of people with dementia and is based on anonymised dementia-specific data collected by Family Carers Ireland as part of The State of Caring 2022 report. The Irish health and social care system depends on family carers who provide the lion's share of care to people with dementia. The value of this work to the State is estimated to be in the region of EUR 804 million *per annum*.

The report provides a picture of the costs of caring in Ireland in 2022 for family carers of people living with dementia:

- 55% of carers said they have difficulty making ends meet. Notably, 12% of family carers state they have great difficulty making ends meet
- 17.8% of family carers stated that they were cutting back on household essentials
- 22.5% have cut back on seeing friends and family
- In some cases, financial difficulties were so impactful that people had fallen into arrears with mortgage payments (4.7%) and utility bills (5.4%).

The ASI is calling on the Irish Government to introduce a range of measures to provide financial support for family carers who are struggling in the midst of the current cost of living crisis.

To read the report in full, please visit:

<https://alzheimer.ie/creating-change/awareness-raising/current-campaigns/>

**6 April: Proposed Slovenian strategy on dementia is backed by parliamentary health and labour committees**

On 6 April, in Ljubljana, Slovenia, a strategy on managing dementia in Slovenia until 2030 was presented to the parliamentary health and labour committees. The strategy, which envisages the setting up of a national centre for dementia, was backed by committee members, who expressed hope it will be endorsed by the cabinet soon.

<https://english.sta.si/3158145/strategy-on-dementia-envisages-national-dementia-centre>

**25 April: Roundtable discussion with decision-makers and experts from various fields in Montenegro, focuses on "Family accommodation as a form of care for the elderly"**

Within the framework of the project "Protecting of the right to dignified ageing and dementia preventing", Zavod Krog and NVO Impuls organised roundtable discussion (the third they have held in this context) on 25 April 2023, in the municipality of Plužine in Montenegro. The topic of the roundtable was







"Family accommodation as a form of care for the elderly" and the meeting was attended by representatives of the Municipalities of Plužine, Nikšić and Plav, representatives of centres for social work from Plav, Nikšić, Plužine, Šavnik and Berana,

Home for the Elderly Podgorica, Health Centre Plav, Nikšić and Plužine, Red Cross Nikšić and Plužine, Centre for Social and Child Protection and Health Insurance Fund Plužine.

The project, which is implemented in the north of Montenegro, is supported by the European Union, Ministry of Foreign and European Affairs of the Republic of Slovenia and the Ministry of Public Administration of Montenegro.

At the roundtable, the activities of the project were presented, which are aimed at educating and mentoring the volunteers to offer lay psychosocial support to people with dementia, their caregivers and family members. Another important activity was the mapping research of people with dementia, their families and caregivers in the north of Montenegro, and the needs and challenges they face, which is the first such survey in the country. This research, carried out as part of the project in 2022, is pioneering work that represents a big step forward in identifying people with dementia, say the organisers, noting, "We hope it can serve as the first basis for the future introduction of strategies and legislation that will benefit people with dementia and their families, enabling them access to much needed support and help for a better and dignified life and aging."

As a continuation of the constructive discussion from the second roundtable, where the participants discussed institutional care as a form of protection for the elderly, the representative of the Home for the Elderly Podgorica, Jelena Šofranac (pictured), and the representative of the Institute for Social and Child Protection, Dragana Pešić, presented the programme and manual of family accommodation as a form of care for elderly people and people with dementia. Family accommodation is an organised care programme for adults and elderly people, which is divided into several forms depending on the health status and specific characteristics of the families, and can take place with relatives or other families.

The speakers emphasised that, despite certain challenges that may arise during implementation of such a programme - related, for example, to the capacities of families and the needs of beneficiaries - family accommodation represents an important assistance programme that should be widely

available and known to all for whom such services could significantly facilitate care for the elderly and people living with dementia.

"As in our project, in which we designed and implemented the training of volunteers for practical work with people with dementia, similar trainings are also needed for families and people who decide to join the program of offering family accommodation. The aging of the population and related challenges are a broad and interdisciplinary social problem, so we must approach potential solutions in the same way, with the greatest possible involvement of civil society and volunteers as well. The family accommodation program allows people with dementia to stay in home care and familiar surroundings for as long as possible, which is a key factor in improving their quality of life", the organisers stated.

The participants at the roundtable spoke about the importance of establishing connections and cooperation of institutions and organisations that deal with the protection of the elderly at the local level, as well as emphasising the need to establish a national strategy that would regulate the field of elderly protection to ensure the long-term achievement of set goals with the involvement of all important stakeholders.

The discussion showed many common points between the participants, the desire and need for further cooperation, promotion of the topic among the general public and, above all, better promotion of the existing help and support programs available for the elderly and people with dementia. Zavod Krog and NVU Impuls are very satisfied that, within the framework of their project, through events such as this roundtable, they can connect decision-makers and experts from various fields, with the goal of establishing and improving cooperation for the greatest benefit of the elderly, people with dementia, their families and caregivers.

## 5 May: World Health Organization declares COVID-19 is no longer a Public Health Emergency of International Concern



On 5 May 2023, the World Health Organization (WHO) released a statement, declaring that COVID-19 was no longer a Public Health Emergency of International Concern (PHEIC). Discussions at the fifteenth meeting of the International Health Regulations (2005) (IHR) Emergency Committee regarding the coronavirus 2019 disease (COVID-19) pandemic, held on 4 May 2023, led to this recommendation being made to WHO Director-General Tedros Adhanom Ghebreyesus, who concurred with the advice

offered by the Emergency Committee and determined that COVID-19 is now an established and ongoing health issue which no longer constitutes a PHEIC.

The WHO and WHO/Europe stressed in their communications about this statement that, while COVID-19 may no longer be defined as a global health emergency, the removal of the highest level of alert "does not mean the danger is over" and that the emergency status could be reinstated if the situation changes. A number of Temporary Recommendations were issued by the WHO Director-General to all States Parties, to help ensure this does not happen:

- Sustain the national capacity gains and prepare for future events
- Integrate COVID-19 vaccination into life course vaccination programmes
- Bring together information from diverse respiratory pathogen surveillance data sources to allow for a comprehensive situational awareness
- Prepare for medical countermeasures to be authorized within national regulatory frameworks to ensure long-term availability and supply.
- Continue to work with communities and their leaders to achieve strong, resilient, and inclusive risk communications and community engagement (RCCE) and infodemic management programmes.
- Continue to lift COVID-19 international travel related health measures
- Continue to support research.

Read the full WHO statement and recommendations, here: [https://www.who.int/news/item/05-05-2023-statement-on-the-fifteenth-meeting-of-the-international-health-regulations-\(2005\)-emergency-committee-regarding-the-coronavirus-disease-\(covid-19\)-pandemic](https://www.who.int/news/item/05-05-2023-statement-on-the-fifteenth-meeting-of-the-international-health-regulations-(2005)-emergency-committee-regarding-the-coronavirus-disease-(covid-19)-pandemic)

As a result of this statement, Alzheimer Europe has decided discontinue its website page with national and European COVID-19 resources.

### 31 May: Scottish Government publishes 10-year national dementia strategy



The Scottish Government has published a 10-year national dementia strategy, "Everyone's Story", which was developed over a period of eight months of engagement with people across Scotland, including people with lived experience.

These include support pre- and post-diagnosis, actions to enable

more people to live well in their communities, involving people who are affected in the design and delivery of their own support, as well as access to care and support from a skilled and trauma-informed workforce when appropriate

The strategy commits to tackling stigma as a priority and will do this by developing and agreeing two-year delivery plans to ensure progress is made against the ambitions of the strategy. The first of these plans is to be published at the end of this year.

The strategy outlines a vision with five key points:

- Dementia is recognised in public health and in practice as disease of the brain that affects a person's whole life and those close to them
- Policy makers, support and service providers, communities and society all have an understanding of dementia, including the importance of prevention and early detection
- People living with dementia and their care partners/unpaid carers have equity of access to high quality, information and advice, evidence-based treatment, care and support when and where they need it
- The human rights of people living with dementia and their care partners are upheld throughout the duration of their illness
- People are supported by a skilled and knowledgeable workforce with access the highest quality dementia specialist education and training.

The strategy is available to download at:

<https://www.gov.scot/publications/new-dementia-strategy-scotland-everyones-story/documents/>



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## SCIENCE WATCH

### 27 April: Alzheon presents new findings from its Phase II trial for AD

Alzheon, Inc., a clinical-stage biopharmaceutical company focused on developing new medicines for neurodegenerative disorders such as Alzheimer's disease (AD), reported one-year findings from its Phase II trial assessing the safety and efficacy of daily ALZ-801 treatment for up to two years in people with early AD who have one or two copies of APOE4. Data were presented in an oral presentation at the American Academy of Neurology (AAN) Conference, held April 22-27 in Boston and virtually.

ALZ-801 is an oral small molecule that works to inhibit the formation of amyloid-beta oligomers, or toxic clumps. Interim six-month results indicated that ALZ-801 safely lowered the levels of p-tau 181, a key biomarker of neurodegeneration, and led to significant memory improvements.

A total of 75 participants completed a year of treatment, 70% of which were in the mild cognitive impairment stage and 30% of which were in the mild AD stage. One-year findings supported the interim six-month results with significant reductions in p-tau 181 levels, 41% by week 52 with significant reductions seen as early as 13 weeks. Moreover, significant

reductions in the levels of amyloid-beta were observed at the same time point. ALZ-801 was well tolerated.

The Phase II trial will finish later this year. Alzheon is also conducting a Phase III trial, APOLLOE4, to confirm the findings of the Phase II trial in people who have early AD with the high-risk APOE4/4 genotype. Alzheon presented baseline characteristics from the ongoing APOLLOE4 phase III trial at AAN. The APOLLOE4 study is expected to finish in mid-2024. The company plans to file for regulatory approval of ALZ-801 in 2024.

<https://alzheon.com/alzheon-to-present-baseline-imaging-characteristics-from-ongoing-apolloe4-phase-3-trial-of-oral-tablet-alz-801-valiltramiprosate-and-results-of-phase-2-biomarker-study-at-american-academy-of-neurology>

### **1 May: Alnylam and Regeneron report positive interim results from their Phase 1 trial of ALN-APP in patients with early-onset Alzheimer's disease**



Alnylam and Regeneron have reported positive interim results from their Phase 1 trial of ALN-APP in patients with early-onset Alzheimer's disease (AD), showing a reduction in AD biomarkers with no severe adverse events.

ALN-APP is a novel "gene silencing" therapeutic that

targets the amyloid precursor protein (APP) at an early stage of processing. Accumulation of amyloid plaques in the brain is one of the pathological hallmarks of AD, and an early event in both AD and cerebral amyloid angiopathy (CAA), which denotes the build-up of amyloid in the walls of blood vessels in the brain. The Phase 1 study of ALN-APP is a multi-centre, randomised, double-blind and placebo-controlled trial which is aiming to enrol 60 participants with early-onset AD at study sites in Canada, the Netherlands, the UK and USA. ALN-APP is delivered via intrathecal injection (injection into the spinal canal) and the interim results reported by Alnylam and Regeneron come from part A of their clinical trial, in which participants received a single dose of ALN-APP.

In a press release published earlier this month, Alnylam and Regeneron explained that ALN-APP was well-tolerated by study participants, with no severe adverse events reported to date. Participants showed a dose-dependent and rapid reduction in the levels of soluble APP in cerebrospinal fluid samples, with reductions of up to 90% compared to placebo. On average, a 70% reduction in the APP biomarkers was sustained for at least 3 months at the highest ALN-APP dose tested, indicating that the drug is effectively targeting APP. Studies are ongoing and the companies are planning to report detailed interim results at an upcoming scientific conference. Read the press release:

<https://investors.alnylam.com/press-release?id=27441>

### **3 May: Eli Lilly announces positive top-line results from the TRAILBLAZER-ALZ2 trial of donanemab**

On 3 May, Eli Lilly announced positive top-line results from the phase III TRAILBLAZER-ALZ2 trial of donanemab, an investigational amyloid plaque-targeting antibody, for the treatment of early symptomatic Alzheimer's disease (AD).

TRAILBLAZER-ALZ2 was a global phase III placebo-controlled, double-blind, parallel-group and randomised study evaluating the safety and efficacy of donanemab. TRAILBLAZER-ALZ2 enrolled 1,736 people with mild cognitive impairment due to AD or mild AD dementia, with confirmed accumulation of amyloid and tau proteins in the brain. Participants from US, Australia, Canada, Europe and Japan received either donanemab or placebo via a monthly intravenous infusion.

Top-line results revealed that the study met its primary endpoint at 18 months, showing a significant reduction of clinical decline on the global cognitive and functional scale, iADRS, by 23% for all participants receiving donanemab compared to those receiving placebo. The company highlighted that the primary analysis population, 1,182 participants with intermediate levels of tau in the brain, had a 40% reduction in clinical decline on the iADRS scale. These individuals were at an earlier stage of disease progression, relative to the 552 participants with high levels of brain tau at baseline.

Additionally, Eli Lilly announced that all key secondary endpoints were met with highly statistically significant results. Key secondary endpoints were the change from baseline at 18 months compared with placebo, in the Clinical Dementia Rating – Sum of Boxes scale (CDR-SB), Alzheimer's Disease Cooperative Study – instrumental Activities of Daily Living inventory (ADCS-iADL), and the 13-item AD Assessment Scale-cognitive subscale (ADAS-cog13). On the CDR-SB scale, a key secondary endpoint, participants receiving donanemab experienced 29% slower decline compared to placebo.

On safety, amyloid-related imaging abnormalities (ARIA) were identified as the most common side-effect of treatment, consistent with other investigational therapies in the same class. In the donanemab treatment group, brain swelling (ARIA-E) occurred in 24% of TRAILBLAZER-ALZ2 participants. Brain microbleeds (ARIA-H) occurred in 31.4% of participants receiving donanemab, compared to 13.6% of participants on placebo. The majority of ARIA cases were mild to moderate, with 1.6% of participants experiencing serious ARIA. Eli Lilly announced plans to file for approval with global regulators as quickly as possible, aiming to file for traditional approval in the US by the end of the second quarter in 2023.

Alzheimer Europe welcomes the encouraging top-line results reported today and looks forward to hearing more at the upcoming Alzheimer's Association International Conference (AAIC) in July (Amsterdam, the Netherlands). Access the Eli Lilly press release:

<https://investor.lilly.com/news-releases/news-release-details/lillys-donanemab-significantly-slowed-cognitive-and-functional>



## 10 May: Otsuka and Lundbeck receive FDA approval for brexpiprazole for agitation in AD

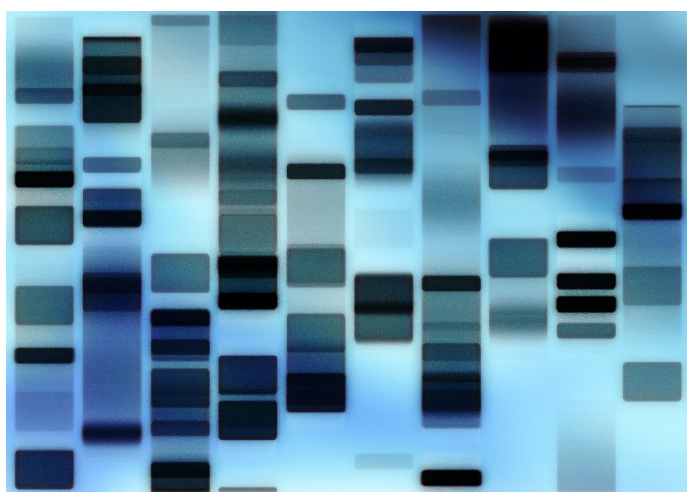
On 10 May, Otsuka Pharmaceutical and Lundbeck announced that the US Food and Drug Administration (FDA) has approved the supplemental New Drug Application (sNDA) of brexpiprazole for use in the treatment of agitation associated with dementia due to Alzheimer's disease (AD). With this approval, brexpiprazole becomes the first drug approved in the US for agitation associated with dementia due to AD. Brexpiprazole was approved in the US in 2015, as an adjunctive therapy to antidepressants in adults with major depressive disorder and as a treatment for schizophrenia in adults.

The FDA granted the application based on data from two Phase III clinical trials evaluating the safety and efficacy of brexpiprazole in people with agitation in AD. The primary endpoint across the studies was improvement from baseline in the Cohen-Mansfield Agitation Inventory (CMAI) total score while the key secondary endpoint was an improvement from baseline to week 12 in the Clinical Global Impression-Severity (CGI-S) score related to agitation.

The two randomised, double-blind and placebo-controlled fixed-dose Phase III studies showed a statistically significant treatment effect in the reduction of agitation over a 12-week treatment period. Brexpiprazole demonstrated a 31% improvement from baseline agitation symptoms compared to placebo. In addition, results showed that brexpiprazole was well-tolerated with a safety profile consistent with the known safety profile of brexpiprazole in other indications.

<https://otsuka-us.com/news/otsuka-and-lundbeck-announce-us-food-and-drug-administration-fda-approval-supplemental-new>

## 15 May: Study published in Nature Medicine identifies genetic mutation conferring resilience to inherited Alzheimer's disease



Alzheimer's disease (AD) is characterised by the accumulation of amyloid plaques in the brain, sticky clusters of proteins that damage neurons involved in memory, reasoning and other cognitive processes. In a new study published in the Nature Medicine journal, researchers show how a little-known gene

called Reelin protected against the development of Alzheimer's dementia in a man carrying the presenilin 1 E280A mutation. This finding has the potential to inform future therapies to build resilience against AD and cognitive decline.

The COLBOS study follows the world's largest known family group of people with autosomal dominant AD: an inherited, genetic form of AD that leads to the development of dementia by the age of 50, on average. The causative mutation, called *PSEN1*-E280A, leads to defective processing of amyloid proteins, and their accelerated accumulation in the brain. The man who was the subject of the Nature Medicine research carried this mutation, and had extremely elevated amounts of amyloid plaques in his brain. However, unlike his relatives who also share the *PSEN1*-E280A mutation, he lived without dementia until his early 70's. To find out why, a team of researchers led by Yakeel Quiroz (Harvard Medical School, USA) and Francisco Lopera (University of Antioquia, Colombia) carried out detailed clinical examinations and genetic analyses, identifying a promising variant in a gene called *RELN* (Reelin).

This little-known gene encodes a protein that helps control the actions and processing of tau, another biological driver of dementia and a drug target that is currently being evaluated in clinical trials. A tantalising clue from the Nature Medicine study: post-mortem evaluation of the brain showed much lower levels of tau in a small area of the brain called the entorhinal cortex. Situated in the medial temporal lobe deep within the brain, the entorhinal cortex is a central hub for communications with the hippocampus, supporting the consolidation of memories, navigation, and perception.

To understand how Reelin might be exerting its protective effects, Prof. Quiroz and colleagues used animal models and laboratory research tools to study its impact on brain cells, and on biological processes such as tau phosphorylation. These studies revealed that Reelin can influence the phosphorylation of tau proteins, limiting their ability to form tangles that prompt cognitive decline. Reelin also binds to receptors for a protein called APOE, and its competition for access to these receptors may also help protect the brain from AD. Further studies are now ongoing to refine this new disease mechanism, and pinpoint options for targeted drug development. Read the Nature editorial about this research:

<https://www.nature.com/articles/d41586-023-01610-z>

## MEMBERS' NEWS

### 28 April: Alzheimer Larissa organises week-long action called "All together a hug"

The Hellenic Alzheimer's Association of Larissa participated in the action "All together a hug", from 22 to 28 April 2023, with a kiosk in the central square of the city, following the invitation of the Prefecture of Thessaly and of the Pharmaceutical Association. The aim of this action was to promote volunteerism, social contribution and solidarity through the provision of free services by the participating organisations.



“how much love”, a painting and a chorokinetic workshop took place. The Department of Pharmacy Assistants of the public IVT were informed about the 10 points of recognising Alzheimer's disease, the reduction of the disease risk factors and the prevention steps. An interactive discussion with the students followed and an interest in volunteering was expressed. 1,500 information leaflets were distributed, 20 carers enrolled for psychoeducation, 80 older people enrolled for mental - physical empowerment and 52 people joined for training in the Digital School.

On 28 April, at the end of the action, President of the association Eleni Nifli, along with members of the Board and volunteers, offered pots of marigolds to Pinakas Vasileios, President of the Prefecture of Thessaly, Koutsoukis Thanos, President of the Pharmaceutical Association of Larissa, Kyropoulos Theodoros, Director of social policy of the municipality of Larissa, the 14 presidents of the city's voluntary organisations and to journalists Giourmetakis Andreas and Apostolopoulou Sasa. The flowers came from the Alzheimer's Association Garden, in a sign of love and mental empowerment through their care.

### 3 May: Alzheimer Scotland Centre for Policy and Practice hosts 10-year celebration event



Members of the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) were delighted to attend the 10-year celebration of the Alzheimer Scotland Centre for Policy and Practice (ASCPP) at the University of the West of Scotland's Paisley campus on 22 March 2023. It was a wonderful opportunity to recall a decade of achievements; to hear from the Centre's staff, students and partners, both from home and around the world; and to look to the future.

Since opening in 2013, the Centre has been at the forefront of driving forward research-informed dementia education; driving

up standards in hospital dementia care; and championing innovative dementia research and practice.

Lived experience has been central to the work of the ASCPP over the last 10 years and the involvement of SDWG and NDCAN members has been key to the success of initiatives such as the Dementia Champions Programme, which has prepared over 1,100 Dementia Champions committed to improving the care and experience of dementia patients in the area where they work.

Through their partnership with the Centre, SDWG and NDCAN members have contributed to research and supported students both as advisors and co-researchers. They have worked with members of the Centre to develop research ideas and have helped to ensure the research carried out by ASCPP students is useful and makes a meaningful difference.

SDWG and NDCAN members value their partnership with the ASCPP and said that it has been a privilege to have been with the Centre every step of the way over the last 10 years. They also said that it was an honour for each Group to receive 'Inspiring People' awards in recognition of their collaboration with the Centre and contribution to all that has been achieved over the decade. “We look forward to the next 10 years as our partnership goes from strength to strength!”

### 3 May: Scottish Dementia Working group member Stuart Dougall attends National Dementia Learning and Sharing Network meeting and shares his experience of having dementia

Alzheimer Scotland's two active voice groups, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN), exist to raise awareness of dementia and to allow the voices of those with lived experience to be heard.



The National Dementia Learning Network was created for Dementia Champions, Dementia Specialist Improvement Leads, Dementia Ambassadors and other health and social care professionals interested in learning more about dementia. The aim is to provide learning opportunities, to network, and to share ideas and projects. They meet regularly and their recent meeting in March was attended by over 100 people. It is vital that people working with people with dementia hear directly from the experts themselves, the people with lived experience.

At their March meeting they were joined by SDWG member Stuart Dougall, who gave an invaluable presentation to the network members on what it's like to have a dementia. He spoke about early symptoms, getting a diagnosis, the challenges faced and about how to overcome those challenges and live well with dementia. Stuart Dougall has younger onset Alzheimer's disease and joined the group in 2022 to help others who find themselves in a similar situation.



“Our active voice groups want all those who work with people with dementia to have a better understanding of dementia and be empowered to work in partnership at all points from diagnosis”, said the SDWG, noting that Stuart Dougall’s contribution would, without doubt, help those who attended to build a richer picture of the experience of people living with dementia and ultimately gain a better understanding of how to offer support.

### **3-4 May: The Alzheimer Society of Ireland Celebrates Tea Day 2023**



On 3 May 2023, the All-Party Oireachtas Group on Dementia hosted an Alzheimer’s Tea Day in Leinster House at the Irish Government Buildings in Co. Dublin to raise awareness for The Alzheimer Society of Ireland (The ASI). The event was attended by members of the All-Party Oireachtas Group on Dementia, Oireachtas members and representatives from The Alzheimer Society of Ireland, members of The Irish Dementia Working Group (IDWG) and The Dementia Carers Campaign Network (DCCN). Alzheimer’s Tea Day ambassadors Bryan Murray and Una Crawford O’Brien were also in attendance. Bryan lives with Alzheimer’s Disease and is a member of the IDWG.

Alzheimer’s Tea Day, on 4 May, saw communities across Ireland host Tea parties to help raise vital funds and awareness for families affected by dementia in Ireland. The ASI marked its biggest fundraising campaign of the year with a National event in Dublin and parties in many of its day care centres across Ireland. ASI staff, board, volunteers, advocates, supporters and service users all came together for a cuppa and a chat to support the 64,000 people living with dementia in Ireland and their family carers.

Funds raised will support vital services, such as The ASI’s National Helpline, Dementia Advisers, Family Carer Training, Care, and Support Groups.

*Pictured: ASI CEO Andy Heffernan and advocates with Chair of the All-Party Oireachtas Group on Dementia, Senator Fiona O’Loughlin and Minister of State for Mental Health and Older People Mary Butler TD*

### **8-9 May: Queen Silvia of Sweden is guest of honour at Nordic dementia associations’ meeting in Stockholm hosted by Demensförbundet**



Representatives from the dementia associations in Norway, Finland, Iceland, Denmark, Faroe Islands, Åland Islands and Sweden meet annually to exchange experiences and network. The Dementia Association in Sweden was the host this year and invited the other organisations to Stockholm on 8 and 9 May. The theme for this year’s conference was younger people with dementia. Among other things, the participants got to listen to experiences from people with a dementia diagnosis. They also got to listen to what it is like to be a relative of someone with dementia, as a partner or as a child.

The organisations shared their work with the aim of spreading good examples and each country held a presentation, all of which was very much appreciated by the participants. They all saw common areas in their countries that need improvement, for example, directly ensuring support after a dementia diagnosis for the person with the diagnosis as well as for their relatives, and the importance of offering knowledge and support to maintain a good quality of life based on the research from the “FINGER study”. Another reflection that was significant in all the participating countries was the importance of a meaningful everyday life for younger people with dementia when their professional life is over.

H.M. Queen Silvia (pictured) was a guest of honour on the second day of the conference. The Swedish Queen has her own experience of being a relative to someone with dementia and has a strong commitment to this cause. In her speech, she declared the importance of knowledge about living with dementia and of the importance of the work being done the participating organisations and others like them.

The Nordic meeting will be followed up by a digital meeting in autumn 2023, for continued collaboration within different projects, with the aim to expand and deepen our Nordic cooperation further.

The Nordic meeting will be held in Iceland next year.



## 25 May: Irish Dementia Working Group meets to consult on Pre-Budget Submission



Each year, The Alzheimer Society of Ireland (The ASI) submits a Pre-Budget Submission (PBS) to the Irish Government for funding for vital dementia supports. Extensive research is undertaken

before the PBS takes place, and focus groups and meetings are held with relevant stakeholders. Members of the Irish Dementia Working Group (IDWG) - based in Southern Ireland - recently gathered in County Cork to consult about The ASI's PBS 2024.

Members discussed their current and future needs, and what supports they may need now and in the future. They discussed what needed to change in Ireland and what was important to them. The information gathered during this consultation is invaluable to The ASI, as it represents the voice of those living with dementia in Ireland and informs The ASI of what is required in Ireland currently.

*Pictured: Members of The Alzheimer Society of Ireland team with members of the Irish Dementia Working Group*

## 25 May: The Alzheimer Society of Ireland's Dementia Research Advisory Team takes part in Research Review Workshop



A key objective of The Alzheimer Society of Ireland's (The ASI) Research Strategy 2022 – 2024 is the continued development of its Person & Public Involvement (PPI) initiative, the

Dementia Research Advisory Team (DRAT). In addition to delivering novel and authentic opportunities for research leadership for members of the DRAT, their research work must be underpinned by robust, strategic training.

With the launch of The ASI's Dementia Research Award earlier this year and the ongoing commitment to fully integrating PPI into all aspects of its research activities, it was evident that the members of the DRAT would play a vital role in assessing the Phase 1 applications.

Led by The ASI's Research Team and with the support of Independent observer Dr Sarah Delaney with Health Research Charities Ireland, the DRAT recently took part in a Research Review workshop, where they learned the purpose of peer

review, why it is necessary to declare conflicts of interest and the critical role public reviewers play in ensuring projects are relevant and important to people affected by dementia.

The members broke up into pre-assigned groups (each with a mix of people living with dementia and family caregivers) to apply their learnings to the review and scoring of the Phase 1 applications. Building the confidence and capacity of the DRAT members (and PPI contributors at large) through the development of transferable skills ensures their work as collaborators and co-researchers is meaningful in the first instance and also offers the individual opportunities to experience self-fulfilment and empowerment in their co-research engagements.

## 25 May: Alzheimer Athens inaugurates three new day care centres with mobile units for dementia in Greece

The new units located- two in the region of Attica and one in the city of Arta are funded by the National Recovery and Resilience Plan Greece 2.0. They are fully staffed with specialised health professionals

(neurologists, psychiatrists, psychologists, social workers, nurses, speech therapists, physiotherapists and administrative personnel).

Services provided are Memory Clinics, non-pharmacological interventions (cognitive training, physical exercise, speech therapy, occupational therapy, art therapies, and other alternative psychosocial interventions). All the above services are delivered in groups or individually and are also available online. In addition, they provide education, support and counselling to caregivers and training for health professionals.

Mobile Units provide medical, psychosocial and counselling services to people with dementia and caregivers who are unable to move from their place of residence due to either severe health problems or living in remote areas. In collaboration with local public health and social services, they promote early diagnosis of dementia, rehabilitation services and dementia awareness campaigns for local people.

The new day centres and Mobile Units have been fully operational since late March 2023 and provide services to an increasing number of people with dementia and caregivers. All services are provided free of charge. The Greek Dementia Helpline 1102 is fully cooperating with the new units and has contributed a great deal to making them known to the public.



Alzheimer Athens, after 20 years of struggle and tireless efforts to mobilise the Greek Government and to establish institutions and services for dementia throughout the country, now runs nine day care centres and four Mobile Units in total, all over Greece, thus taking a big step closer to the full implementation of the Greek National Plan for Dementia and Alzheimer Disease.

## **25 May: “Let’s Talk About...Dementia” conference takes place in Glasgow with lived experience being shared by people with dementia and by dementia carers**



Members from the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) were pleased to participate in a one-day conference in Glasgow on 27 March, entitled ‘Let’s Talk About ... Dementia’. The event was aimed at professionals working in health and social care settings and anyone involved in working with older

people with dementia and their families. The conference was designed to provide fresh knowledge updates; a better understanding; and practical strategies and ideas to support the care of people with dementia.

The conference offered a packed programme with contributions from, amongst others, a Dementia Nurse Lead Specialist; a Senior Dementia Consultant; a Consultant in Dental Public Health; and an Advanced Practice Care Home Dietitian. The audience heard about dementia and delirium; was told about the importance of good oral health for people living with dementia; was provided with information on eating well when living with dementia; received insights and advice for communicating effectively with people with dementia; and got tips on matters including sight and hearing loss and dementia.

Margaret McCallion (pictured), SDWG, and Marion Ritchie, NDCAN, brought the conference to a close by offering personal perspectives of ‘What I Wish You Knew About Dementia and Me’. Margaret spoke about her dementia journey from pre-diagnosis to now; she highlighted her experience of being told to give up work even before receiving her final diagnosis, and of the challenges she faced navigating an alien and impersonal benefits system through the Department of Work & Pensions.

Margaret advocated for the importance of person-centred support and spoke about how, from her initial contact with Alzheimer Scotland through to her current membership of the SDWG and European Working Group of People with Dementia (EWGPWD) she has regained her sense of self-worth. Margaret closed by reminding the audience that she was more than just someone living with dementia, and encouraged the audience to ‘always see the person as a person’.

Marion spoke about grief from the point of view of a carer and highlighted that what is often diagnosed as depression can in reality be guilt and grief – what starts as anticipatory grief can become complicated grief if not recognised and treated. She spoke about her experience and journey as a carer and highlighted the grief cycle and the emotions and feelings that can repeat and return. The audience heard that grief is a complex process which needs more research and acknowledgement and Marion called for better support and understanding for those living with a dementia diagnosis and their families. Marion closed by welcoming opportunities, such as those provided by the conference, for professionals looking after people with dementia in hospitals and care homes to learn and train, and called for similar opportunities for carers looking after a loved one at home.

The SDWG also hosted an information stand throughout the day which provided an opportunity for Marion, Margaret and NDCAN member, Maureen Huggins, to engage on a one-to-one basis with care professionals from across Scotland, and to promote the work of and provide information from the SDWG, NDCAN and Alzheimer Scotland.

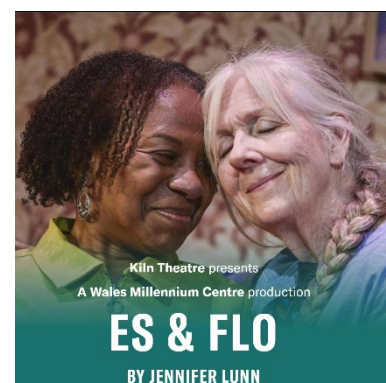
## **DEMENTIA IN SOCIETY**

### **15 May: Play "Es & Flo" celebrates the love of an older lesbian relationship and gives some insight into difficulties faced by same-sex couples when one needs to access dementia care**

Jennifer Lunn’s award-winning play, directed by Susie McKenna, celebrates the love of an older lesbian relationship, while giving the audience an insight into some of the difficulties faced by same-sex couples seeking care, when one of them is diagnosed with dementia.

Plot: Es and Flo fell fiercely in love in the 80s. They’ve been secretly living as lovers ever since. But as Es becomes more forgetful due to the onset of dementia, an unexpected carer arrives. When the outside world comes crashing in, Flo must battle to hold onto the woman she loves and protect the life they’ve built together.

The play is coloured with memories of the Greenham Common Women’s Peace Camp – where Es and Flo first met as activists. It champions women coming together to fight for what’s right and the healing power of chosen family. It will be on at the Kiln Theatre in London, from 5 to 24 June 2023: <https://kilntheatre.com/whats-on/es-flo/>





## LIVING WITH DEMENTIA

**26 April: Zornica Karagiozova, member of the European Dementia Carers Working Group, attended the first meeting of AIDA project in Bulgaria together with her father and shares their thoughts on it**



On April 26 2023, the AIDA project held its introductory meeting in the city of Sofia, Bulgaria. I participated in it as a carer, together with my father Ivan Karagyozov, who is in the first stages of Alzheimer's dementia.

"Initially, I will give some brief information about the project itself. At the beginning of 2022, the Alzheimer Bulgaria association started working on the AIDA project, financed under the Erasmus+ programme, which is implemented in partnership with organisations from Italy, Greece, Slovenia, Ireland and Denmark. The two-year project aims to create synergy between three areas: care, art and culture, technology - aimed at improving the lives of people with dementia and their carers. The associated partner to this project is the National Polytechnic Museum in Sofia where all the sessions will be held. I would also like to share my father's point of view and feelings regarding yesterday's introductory meeting."

"The introductory meeting with the AIDA project team impressed me with the warm and friendly attitude of Irina, Kalina and Maya. During the presentation of information about the project and the interviews they did, they tried very hard to make us feel free and comfortable. Also, they had chosen a very

suitable location for the meeting because regardless of the person's age, when you are in a museum, you can always see or learn something interesting and new."

"We, the people with dementia, as well as our carers, felt the attention of everyone we met today. They moved chairs in front of each of the exhibits we visited today, so that we could feel comfortable and focus our full attention on listening to the information about them. I would also like to express my gratitude to the staff at the museum who gave us special attention. Starting with getting around, because there was a person in a wheelchair; through to the fact that they tried to speak slowly, loudly, clearly and briefly; and ending with the fact that the exhibits we looked at were selected according to the professions we practiced or to our interests and hobbies. Today's afternoon brought me the excitement and satisfaction of meeting the new and interesting things that were arranged for us. I am excited about our next meeting and I am looking forward to it."

**18 May: "Expect nothing, but also expect the unexpected", writes Trevor Salomon, Vice-Chairperson of the European Dementia Carers Working Group**

In January I received a surprise email advising me I was one of three finalists shortlisted for an Alzheimer's Society Dementia Hero Award in the Campaigning and Influencing category.

It meant I was invited to the awards ceremony lunch at the end of April, attended by nearly 200 guests, celebrated professionals, community groups and members of the public. I confess I felt very humbled just to be one of the potential winners across the 11 award categories which recognise and celebrate the involvement and participation of people affected by dementia in activities and projects across England, Wales and Northern Island.

It never actually occurred to me that I might win so when my name was called out it was truly something I was not expecting. Overall it was an absolute privilege to be amongst so many people who have put something back into helping those with dementia. I also felt very proud to have been recognised by a lived experience group which had been involved not only in the judging but also at key stages of the Awards, from planning to speaking about their experiences at the ceremony.

I was asked during a television interview a few days later if I had shared the news of my award with my wife, Yvonne. I wish I had been able to but sadly this was never going to be possible. She lives in a care home, unable to speak or process what is being said to her due to her advanced Alzheimer's.





<https://www.alzheimers.org.uk/dementia-professionals/conferences-and-events/dementia-hero-awards>

A couple of weeks after the awards – on 18 May to be specific – I found myself in a room full of 350 people (and a further 150 online) at another event organised by Alzheimer's Society: this time their Annual Conference, the theme of which was making dementia a priority locally. But instead of being in the audience or attending as a guest, I was on stage acting as host for the day. The planning for such a major event takes place over very many months and it was in fact intended that I, as a carer, would co-host the event with someone living with dementia just as we had done the previous year. So well was our double act received in 2022 that we were invited back to repeat our performance. Unfortunately my co-host was taken ill on the day and was unable to participate. I only found out when I appeared for breakfast just two hours before start time.

Luckily in my professional career as a marketing director not only did I manage and host many events but I was very familiar with last minute mishaps and changes and to always expect the unexpected. The Conference was a huge success, absolutely not due to me I hasten to add, but because of the excellent, informative and inspirational speakers.

I really did miss my co-host but as they say, the show must go on.

<https://www.alzheimers.org.uk/dementia-professionals/conferences-and-events/annual-conference>

## 24 May: Chris Ellermäa, member of the European Dementia Carers Working Group and Board member of NGO Life with Dementia in Estonia, writes about activities taking place in her country



May was a very active month in Estonia for the NGO Life with Dementia (NGO LwD). Being a board member of the NGO LwD I had the honour of representing patients and their carers in the panel discussion dedicated to the care reform coming into effect on 1 July. The care reform means that the state will aid people in paying for care. Until now, nursing home fees have been fully paid for by the service user, but as from 1 July 2023, the fee will be divided between the person using the service and the local government.

The panel discussion was part of an educational day about the reform, organised by the [Estonian Social Work Association](#) (ESWA). Preparing for the discussion, we created a questionnaire among our NGO members, friends and community to get a better understanding about people's expectations and questions related to the reform. Based on the answers, I also wrote an [opinion article](#) for the Estonian Public Broadcasting portal. Some of the proposals related to the care reform that were put to the panel of the ESWA day and appeared in the article were:

- A clear and easy-to-find guide to the websites of local governments, for people looking for care home services
- A care home service fee calculator that helps calculate the financial contribution of all parties to be created and shared on the Social Insurance Board webpage.

Some other more general suggestions were:

- Let us see the person behind the disability and disease, in order to reduce labelling. Let us always use the expression "person with dementia"
- Let us see a home behind the institutional care service, because it is the last home for many people and not just a "service" where we place people needing 24-hour care.

I also had an opportunity to talk about dementia and what every individual can do for prevention, on a [TV show called Studio](#).

The Dementia Competence Centre (DKK) in Estonia has an initiative to give dementia-friendly "labels" to care homes. These dementia-friendly labels are provided at the request of the care home, followed by a detailed interview and on-site visit. In May, I had the chance to be a member of the evaluation group visiting a care home interested in obtaining the dementia-friendly label. It was a really interesting and eye-opening exercise!

I am also happy to report that our NGO was (s)elected to be a member of a donation platform called "I love to help", where everyone can make one-time or recurrent donations. Our dream is to re-establish [memory cafes](#) for people living with dementia. Make your donation today!

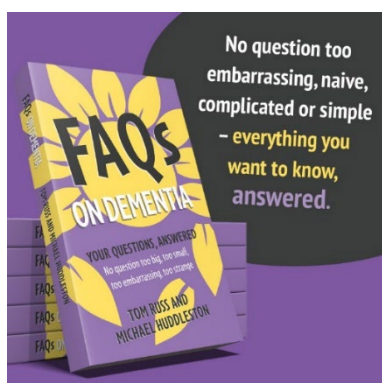
Last but not least, today, 24 May, my colleague from the NGO Board and are opening the [KUMU documentary event "Dear Memories"](#). The documentary is about Thomas Hoepker, who is one of the most important living photographers worldwide. And who has been diagnosed with Alzheimer's disease.



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## NEW PUBLICATIONS AND RESOURCES

**27 April: New book "FAQs on Dementia" aims to give readers definitive expert responses to their many and varied questions on dementia**



Will my partner stop loving me now they have dementia?

Does my mother have to go into a home now?

Is dementia a terminal illness?

A short but powerful, practical guide to understanding the nature, and impact, of dementia,

called "FAQs on Dementia" has been written by Tom Russ and Michael Huddleston and published by Sheldon Press. The guide aims to answer these and many more frequently-asked questions (FAQs) about dementia. Readers will find definitive, expert responses and no question is too simple, too embarrassing, too rude or too offbeat to be included. Each question is sourced from the dementia community – either from people living with dementia, or their family members and friends, so its insights are based on lived experience.

Dr Tom Russ trained in medicine and psychiatry in Scotland (Edinburgh and The Highlands) and England (London) and completed his PhD in dementia epidemiology at the University of Edinburgh. He is a consultant psychiatrist in NHS Lothian, Network Champion of the NRS Neuroprogressive and Dementia Network, and Director of the Alzheimer Scotland Dementia Research Centre at the University of Edinburgh.

Michael Huddleston is Alzheimer Scotland's Dementia Advisor for Mid and East Lothian. He provides advice and information for people living with dementia and their families, and works closely with local Health and Social Care Partnerships to influence and shape dementia and carer-specific strategies and to accommodate the needs and views of people with lived experience.

**10 May: World Health Organization publishes meaningful engagement guide**

The World Health Organization (WHO) has published a framework for meaningful engagement of people living with noncommunicable diseases, mental health and neurological conditions.

The objective of the framework is to support WHO and Members States to meaningfully involve people living with non-communicable diseases (NCDs), mental health and neurological conditions, to co-create and enhance related policies, programmes and services.

In addition, it aims to contribute to existing understanding, knowledge and actions on meaningful engagement and participatory approaches. Furthermore, the framework provides practical guidance and actions for transitioning from intention to action.

The guide is aimed at people working at WHO and in Member States, with the WHO committing to advocate for, and provide technical assistance to implement the framework at its three levels (headquarters, regional and country offices), whilst also supporting Member States in implementation at national level.

An online event took place on 11 May 2023 to launch the framework with speeches from some of the people with lived experience who had contributed to the co-creation process and representatives from WHO, Member States and other non-State actors. Chris Roberts (Chair of the EWGPWD) and Ana Diaz (AE project officer) attended this event.

The framework is available at:

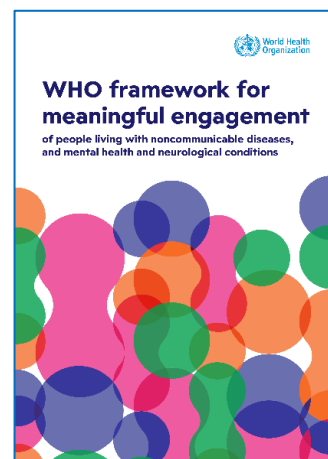
<https://www.who.int/publications/i/item/9789240073074>

**24 May: Alzheimer's Disease International publishes dementia plans report**

Alzheimer's Disease International (ADI) has published a report tracking the creation and implementation of national dementia plans globally. The report examines the development of plans against the targets set out in the World Health Organization's (WHO) Global Action Plan (GAP) on the Public Health Response to Dementia 2017-2025.

Some of key findings within the report include:

- The number of plans implemented by Member States has remained unchanged since 2022 at 39. As of May 2023, 46 countries or territories (including non-Member States) had NDPs
- 54 new plans are needed annually to reach the WHO target of 146 plans (75% of Member States) by 2025
- Data collection and harmonisation is becoming increasingly important as global projects seek to understand the life-course factors that impact dementia
- In the absence of national dementia plans or where dementia diagnosis and care pathways are unclear, it is often the civil society or non-governmental organisations

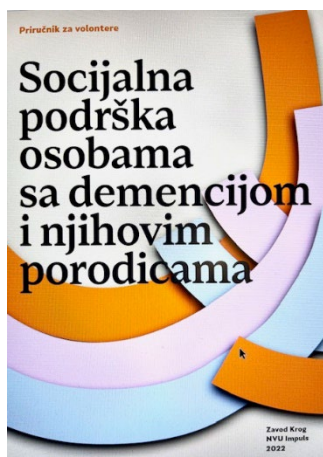


that develop innovative projects or services to plug key gaps.

The fully report is available at:

<https://www.alzint.org/resource/from-plan-to-impact-vi/>

## **26 May: "Protecting the right to dignified ageing and dementia prevention" project publishes manual for volunteers to help enable the durability and longevity of the programme**



Institute Circle from Slovenia in cooperation with partner NVU Impuls from Montenegro are implementing the project "Protecting the right to dignified ageing and dementia prevention", which is supported by the European Union, the Ministry of Foreign and European Affairs of the Republic of Slovenia and the Ministry of Public Administration of Montenegro. The project aims for the empowerment of volunteers to

offer lay psychosocial support to people with dementia, their families and caregivers, as well as towards building a sustainable mentoring programme that would enable further education and guidance of future volunteers as well.

Volunteerism is a powerful tool that has a long history and is based on the idea that the global starts with the local, which is especially important in today's fast-changing world. The right to care and support in the home community is extremely important for people with dementia. Caring for people with dementia can be a big challenge for their families and loved ones, which was also shown in the first mapping research of the needs of people with dementia, which was carried out in Montenegro as part of the project. With the programme of training and mentoring of volunteers, the project wanted to address the needs of the beneficiaries as effectively and directly as possible, and within this framework, a Manual for volunteers was created, which aims to enable the durability and longevity of the programme even in the future.

The e-manual contains important information about dementia with an emphasis on practical knowledge, including methods and techniques of working with people with dementia, specific activities and ways of communicating in a respectful, friendly, and sensitive manner. All this enables volunteers to renew and expand their knowledge and competences for direct work and help to people with dementia and their relatives. The e-manual also addresses volunteerism as such and emphasises the important role that volunteers can play in working with people with dementia and especially with their families and caregivers, who are often overlooked due to the lack of systemic support.

Based on the results of this research, which showed that the concept of dementia in Montenegro is very poorly understood, and at the same time, that there are no systemic strategies that would include people with dementia as a subgroup of the elderly and thereby enable appropriate additional support, it is important to create programmes that also give the wider community the opportunity to get educated and offer lay psychosocial help. With this goal in mind, the project also designed the relevant materials, which are easily accessible on its websites.

Humans are social beings, together we are always stronger, which is why this project prioritises well-being, connecting and empowering communities for cooperation, finding collective solutions and mutual help. Through promotion and awareness, they want their programmes and materials to be as widely accessible as possible for practical benefit and sustainable use in the future.



### **Contact Alzheimer Europe:**

Alzheimer Europe: 14, rue Dicks (L-1417), Luxembourg; [info@alzheimer-europe.org](mailto:info@alzheimer-europe.org); [www.alzheimer-europe.org](http://www.alzheimer-europe.org)

### **Alzheimer Europe Board:**

Chairperson: Maria do Rosário Zincke Dos Reis (Portugal); Vice-Chairperson: Charles Scerri (Malta); Honorary Secretary: Mario Possenti (Italy); Honorary Treasurer: Marco Blom (Netherlands). Members: Stefanie Becker (Switzerland), René Friederici (Luxembourg), Lorène Gilly (France), Andy Heffernan (Ireland), Martina Mátllová (Czech Republic), Mary-Frances Morris (United Kingdom), Chris Roberts, Chairperson of the European Working Group of People with Dementia (United Kingdom), Katariina Suonu (Finland), Jochen René Thyrian (Germany).

### **Alzheimer Europe Staff:**

Executive Director: Jean Georges; Communications Officer: Kate Boor Ellis; Conference and Event Coordinator: Gwladys Guillory; Director for Projects: Dianne Gove; Project Communications Officer: Christophe Bintener; Project Officers: Cindy Birck, Angela Bradshaw, Ana Diaz; Daphné Lamirel, Soraya Moradi-Bachiller; Policy Officer: Owen Miller; Finance Officer: Stefanie Peulen; Administrative Assistants: Cristina Pencea, Grazia Tomasini.



## AE CALENDAR 2023

Date	Meeting	AE representative
<b>1 June</b>	World-Wide FINGERS Network Meeting	Cindy
<b>2 June</b>	PRODEMOS Annual General Meeting (Amsterdam, Netherlands)	Cindy and Jean
<b>5 June</b>	Alzheimer Europe Bard (Brussels, Belgium)	AE Board and staff
<b>6 June</b>	Alzheimer Europe Company Round Table (Brussels, Belgium)	AE Board, members, sponsors and staff
<b>6 June</b>	European Parliament lunch debate (Brussels, Belgium)	AE members and European and national policy representatives
<b>6-7 June</b>	Alzheimer Europe Public Affairs Meeting (Brussels, Belgium)	AE members and staff
<b>6-7 June</b>	European Group of Governmental Experts on Dementia (Brussels, Belgium)	National health ministry official and AE staff
<b>6-7 June</b>	European Working Group of People with Dementia (Brussels, Belgium)	AE staff
<b>6-7 June</b>	EWGPWD Meetings (Brussels, Belgium)	Dianne, Ana, Soraya, Daphné, Owen and Ange
<b>8 June</b>	Swiss business dinner (Luxembourg)	Gwladys and Cristina
<b>13 June</b>	Council meeting of Alzheimer's Disease International	Jean
<b>17 June</b>	Meeting with Alzheimer Polska (Warsaw, Poland)	Jean
<b>19 June</b>	Astellas workshop on multimorbidities	Jean
<b>20 June</b>	ADIS Advisory Board meeting	Soraya and Ana
<b>22 June</b>	Meeting of the European Dementia Carers Working Group	AE staff
<b>27-28 June</b>	Meetings of the EMA Patients' and Consumers' Working Party	Angela

## CONFERENCES 2023

Date	Meeting	Place
<b>14-16 June</b>	31 <sup>st</sup> European Social Services Conference: Advancing Social Services The role of technology in promoting autonomy and inclusion, <a href="https://essc-eu.org">European Social Services Conference (essc-eu.org)</a>	Malmö, Sweden
<b>21 June</b>	Webinar on "Preventing Dementia – a challenge for health professionals", organised by Alzheimer Portugal with the support of the company PPD <a href="https://alzheimerportugal.org/programa-preventingdementia/">https://alzheimerportugal.org/programa-preventingdementia/</a>	Online
<b>29 June-2 July</b>	2023 IPA International Congress on "Better Mental Health for Older People", <a href="https://www.ipa-online.org/2023">https://www.ipa-online.org/2023</a>	Lisbon, Portugal
<b>1-4 July</b>	9 <sup>th</sup> EAN Congress - Budapest 2023: Neurology Beyond the Big Data, <a href="http://www.ean.org">www.ean.org</a>	Budapest, Hungary
<b>15-19 October</b>	WCN 2023 - The XXVI World Congress of Neurology, <a href="https://wcn-neurology.com/">https://wcn-neurology.com/</a>	Montreal, Canada
<b>16-18 October</b>	33 <sup>rd</sup> Alzheimer Europe Conference, "New opportunities in dementia care, policy and research", <a href="http://www.alzheimer-europe.org/conference">www.alzheimer-europe.org/conference</a> Helsinki, Finland	Helsinki, Finland

# 33<sup>rd</sup> Alzheimer Europe Conference

New opportunities in dementia  
care, policy and research

Helsinki, Finland

16 - 18 October 2023 #33AEC

[www.alzheimer-europe.org/conferences](http://www.alzheimer-europe.org/conferences)

