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WELCOME



I am delighted to kick things off with some updates on our European Election Campaign 2024, which has been running since mid-January. The support for all three branches of the campaign (the Helsinki Manifesto, a public Call to Action, and the

Dementia Pledge) has noticeably increased this month, particularly with regards to the Dementia Pledge, in no small part thanks to the reception we held at the European Parliament (EP) in Brussels, where we invited MEPs to join us and show their support by signing the Pledge. By signing, candidates pledge their support in prioritising dementia in the areas of health, research, disability policy and informal carers and commit to joining the European Alzheimer's Alliance (EAA), upon election. Ten MEPs attended our EP reception and signed the Pledge and we subsequently received a number of other signed pledges, totalling 39 as at end of March. We hope to receive many more over the next two months.

The Helsinki Manifesto has also gained support this month, with a total of 60 organisations now endorsing it, while our public Call to Action, which demands that European decision-makers prioritise dementia as a policy issue and implement the actions of the Helsinki Manifesto, now has more than 2,600 signatories! I urge you to sign the Call to Action, today, via our website.

We were pleased to see that the European People's Party (EPP) Manifesto for the EP elections 2024 contains a commitment to develop a European dementia plan. This commitment aligns with our long-standing call for the development and implementation of a European dementia strategy, and reflects one of the key calls from our Helsinki Manifesto. I hope that other European parties will include similar commitments in their manifestos.

Alongside our EP reception in Brussels, we held a series of other meetings, with Alzheimer Europe and its member associations' EU election campaigning activities featuring heavily on the agenda. These included a Board meeting, a company roundtable, a public affairs meetings and a meeting of the European Working Group of People with Dementia (EWGPWD). Two new members of the team, Public Involvement Officer Sarah Campill and Project Officer Lukas Duffner, both of whom joined at the start of March, were able to join us for these meetings and met our Board, members, sponsors and the members of the EWGPWD. We are excited to work with both of them!

I am excited to share the news that, following the recent launch of our position paper on anti-amyloid therapies for Alzheimer's disease, the paper, together with an accompanying call to action, was published as a special article in the February 2024 edition of the Journal of Prevention of Alzheimer's Disease (JPAD). I am also pleased to announce that we have published the 44th edition of our Dementia in Europe magazine, which contains many important updates on European and national policy developments in the dementia field.

I trust you will enjoy reading both our magazine and of course this newsletter!

Jean Georges
Executive Director

SPOTLIGHT ON EUROPEAN ELECTIONS

19 MARCH

We are delighted that ten MEPs attended our reception at the European Parliament in support of the Dementia Pledge 2024 campaign!

Alzheimer Europe recently launched its **European Elections Campaign 2024**. As part of this campaign, we invited MEPs to join us on 19 March 2024, between 18.00 and 19.30, in the Members' Salon in the European Parliament, at an event hosted by MEPs Milan Brglez (Slovenia), Deirdre Clune (Ireland), Tilly Metz (Luxembourg) and Sirpa Pietikäinen (Finland). This event was held in the run up to the European Parliament elections in June, to highlight why dementia must be prioritised. Jean Georges, Executive Director, Alzheimer Europe welcomed around 80 guests to the event, including MEPs, representatives from national members associations, members of the European Working Group of People with Dementia, and Alzheimer Europe Board and staff members. He outlined the priorities of the **Helsinki Manifesto**, inviting MEPs to sign the Dementia Pledge. He also welcomed our three host MEPs in attendance, Milan Brglez, Deirdre Clune and Tilly Metz to address the room, sharing their perspectives on the importance of the campaign and of prioritising dementia both at national and EU level.



During the reception, there was an opportunity for MEPs in attendance to sign a large-scale version of **Alzheimer Europe's Dementia Pledge 2024**. Additionally, MEPs had the opportunity to meet representatives of our national member associations, people living with dementia and carers of people with dementia, to hear first-hand their priorities and how policymakers can help prioritise dementia.

If you are an MEP standing for re-election and you were unable to attend, you can pledge your support:

- either by announcing your support on Twitter(X)/Facebook/LinkedIn using the hashtag #DementiaPledge2024
- or by signing and returning the **Dementia Pledge 2024 form** to us by email.

If you sign the pledge, Alzheimer Europe will add your name to a **dedicated campaign section on our website** and will publicise your support on our social media channels.

Should you have any questions about the Pledge or the Reception, please do not hesitate to contact us, via: info@alzheimer-europe.org

Many thanks to the ten MEPs who signed the Pledge during our European Parliament reception:

- Barry Andrews MEP (Ireland)
- Petras Auštrevičius MEP (Lithuania)
- Dominique Bilde MEP (France)
- Milan Brglez MEP (Slovenia)
- Deirdre Clune MEP (Ireland)
- Marie Dauchy MEP (France)
- José Gusmão MEP (Portugal)
- Stelios Kypouropoulos MEP (Greece)
- Tilly Metz MEP (Luxembourg)
- Matjaž Nemeč MEP (Slovenia).

Thanks, also, to Sirpa Pietikäinen MEP, Chairperson of the European Alzheimer's Alliance (EAA) who, despite not being able to attend in person, has already signed the Pledge and whose office was instrumental in organising this event. Finally, we are pleased to welcome three new members of the EAA, following their support of the Dementia Pledge 2024, and we look forward to working with them to ensure dementia is a policy priority:

- Petras Auštrevičius MEP (Lithuania)
- Marie Dauchy MEP (France)
- Stelios Kypouropoulos MEP (Greece).

31 MARCH

Great progress made so far on our European Election Campaign 2024 - We urge others to support our Call to Action, Dementia Pledge and Helsinki Manifesto!



In advance of the European Parliament elections between 6 and 9 June 2024, we are running a European Election Campaign 2024, aiming to make dementia a priority issue for decision-makers at a European level. The campaign highlights World Health Organization (WHO) figures which show that dementia is the third leading cause of mortality in Europe and the seventh globally, with a societal cost in Europe estimated to be EUR 392 billion in 2019. Additionally, we point out that by 2025, 9.1 million people will be living with dementia in the European Union, rising to 14.3 million in 2050. We are therefore pushing for the condition to be shown greater attention by European decision-makers.

Our campaign has three distinct elements aimed at different audiences, demanding dementia be prioritised as a policy issue:

The **Helsinki Manifesto** provides an outline of the current situation in relation to dementia across Europe, detailing specific demands for the European Commission Institutions and national governments. The Manifesto will be the basis of Alzheimer Europe's campaign work in the coming years. European and national organisations are invited to endorse the Manifesto. So far, the Manifesto has attracted the support of 60 organisations, including the following nine which endorsed it during the month of March:

- ADIS project
- AENMA Centro de día terapéutico
- AFA Fuengirola - Mijas Costa
- Alzheimer Liga Vlaanderen
- ConFEAFA
- eBRAIN-Health project
- European Ageing Network
- Fundación Pasqual Maragall
- PRIME project

We urge national and European organisations, projects and other groups wishing to endorse our Helsinki Manifesto to get in touch: info@alzheimer-europe.org or to find out more, via our website: <https://bit.ly/AEHelsinkiManifesto>

Our public **Call to Action** demands that European decision-makers prioritise dementia as a policy issue and implement the actions of the Helsinki Manifesto. We are delighted to have already got **more than 2,600 signatories!** You can sign the Call to Action, today, via our website: <https://bit.ly/AECallToAction2024>

The **Dementia Pledge 2024** is a commitment which candidates standing for the European Parliament elections are invited to sign, pledging their support in prioritising dementia in the areas of health, research, disability policy and informal carers and pledging to join the European Alzheimer's Alliance, upon election. All candidates standing in the European Parliament elections are encouraged to sign the pledge. As at 31 March 2024, 39 candidates have signed up to the Pledge. Of this number, 28 are incumbent MEPs, 12 of whom are new members of the European Alzheimer's Alliance. The Pledge campaign will run until 9 June 2024, when the European elections will conclude. The list of signatories currently signed up to the Dementia Pledge 2024 can be viewed here: <https://bit.ly/DementiaPledge2024>

ALZHEIMER EUROPE

22 FEBRUARY

Alzheimer Europe hosts online Alzheimer's Association Academy on modifiable risk factors for dementia



On 22 February, we hosted our second Alzheimer's Association Academy meeting of the year. These online capacity-building workshops bring together representatives of national Alzheimer's associations with members of the European Working Group of People with Dementia and European Dementia Carers Working Group, to learn about the latest advances in dementia research, policy, care and treatment from experts in those fields. The Academy meeting, which was moderated by Jean Georges, (Executive Director, Alzheimer Europe) was focused on the topic of modifiable risk factors for dementia and welcomed 58 participants from over 20 countries.

Sebastian Köhler, professor of Neuroepidemiology at the University of Maastricht was first to present, discussing the links between hearing loss, cognitive decline and dementia both in diagnosis and as a modifiable risk factor. He discussed the current research on the topic, concluding that hearing loss is gaining increased attention as a risk factor for cognitive decline and dementia with consistency in literature and general consensus amongst experts, but that evidence regarding hearing aid usage benefits remains inconsistent. Hearing loss as a modifiable risk factor continues to be researched and studies so far do not distinguish between the types of hearing loss (hearing loss versus impaired auditory analysis due to brain atrophies). It was also noted that the studies available did not investigate whether hearing loss leads to cognitive impairment or whether it is secondary to cognitive impairment.

Dr Neus Falgàs from the Hospital Clínic de Barcelona then spoke about sleep disturbances in Alzheimer's disease (AD) and the ADIS project. She explained the importance of sleep for brain health and outlined the sleep alterations that occur in people with AD, noting that these are frequent and that they start from the early stage of AD. They also have a negative impact on the person and their family, becoming one of the main reasons for hospitalisation. Sleep disturbances are also common in Lewy body dementia (LBD) and follow a similar pattern to those in AD. Dr Falgàs also noted that therapeutic

and preventative strategies are limited and have secondary effects.

She noted that patient education should focus on developing a regular schedule of sleep, ideally following the circadian rhythm (sleeping at night and being awake during the day), adding that pharmacological sleep aids should be limited in use. Sleep apnoea was mentioned as a vascular risk factor that lowers resilience to stress and negatively impacts neural regeneration.

Nicola Veronese, Gerontologist and professor at University of Palermo, Italy then gave a talk on physical activity for the prevention and management of mild cognitive impairment (MCI) and dementia. He presented a study which demonstrated that the positive effect of exercise was comparable to that of donepezil and explained how the European Geriatric Medicine Society (EuGMS) plans to develop specific guidelines with the involvement of several European scientific and patient societies. The study found that physical activity should be promoted for primary prevention of AD. For MCI, mind-body interventions (tai chi or yoga) were shown to have a small positive effect in global cognition. Exercise in patients with MCI and AD has global positive effects and will help to decrease the rate of disability, he said. He shared the positive physiological effects of physical activity on memory, noting that it decreases stress, improves neuroplasticity and maintains hippocampal volume (which is negatively affected by social isolation). He recommended 30 minutes (minimum) of physical activity, at least two to three times per week, noting that getting patients involved in group physical activity could also help to combat social isolation.

Jeroen Bruinsma, Assistant Professor at the University of Maastricht discussed his work in the LETHE project with regards to lifestyle-related behaviour change for dementia risk reduction. He described the project's research on preventive interventions of diet, exercise, cognitive training, monitoring vascular risks through sleep, social activity, relaxation, limiting or avoiding alcohol and cigarettes with a digital twin app based on the FINGER protocol. This app can be used on a smartphone and Fitbit watch, and it provides recommendations based on the FINGER protocol. Adherence is being monitored, following up with motivational messages and the data gleaned so far shows that dementia risk is considered abstract, leading to ambivalence towards changing behaviours. It also showed "all-or-nothing" thinking about lifestyle change, with people feeling that change had to be radical, resulting in a lack of tangible goal setting. Negative self-image and behavioural control, particularly where previous attempts had failed, reduced the willingness to make further attempts at lifestyle change. Jeroen Bruinsma acknowledged that lifestyle change for dementia risk reduction is complex, requiring more communication of risks, raising awareness and knowledge and the

need to support participants. Personal contact and support is key to engagement, he stressed.

During a panel discussion, the speakers agreed that it is necessary to look at both individual interventions as well as public health initiatives, with the goal of making policy and environmental changes that will benefit people and encourage healthier living. They also acknowledged the fact that making changes at a national level is slow and often complicated to achieve. On an individual level, people should be encouraged to do what they find fun and feel that they can achieve. The speakers reiterated the need to present people with all of the options for lifestyle modification, giving as much choice and autonomy as possible to help people decrease their risk or slow progression.

1 MARCH

Alzheimer Europe welcomes two new colleagues



Alzheimer Europe is pleased to welcome two new colleagues, who joined the team on 1 March 2024, Sarah Campill and Lukas Duffner.

Sarah (she/her/hers) joined Alzheimer Europe’s Public involvement and Ethics team in the role of Public Involvement Officer. She holds a MSc in Gerontology from the Friedrich-Alexander-University Erlangen-Nuremberg (Germany) and has a background in Psychology (BSc) as well as Science of Education (BA). Some of her prior work experiences include managing activities for people with dementia within different residential aged care facilities. At Alzheimer Europe, she primarily contributes towards EU-funded projects in relation to Public Involvement, such as AD-RIDDLE, MULTI-MeMo, and PREDICTOM.

Lukas (pictured, right) joined Alzheimer Europe as Project Officer. Previous to his start, he was finishing up his PhD at the research line “dementia prevention and risk reduction” of the Alzheimer Centre Limburg (Maastricht University), which focused on the role of a cognitively and socially active lifestyle

for healthy cognitive and brain ageing. Within Alzheimer Europe, Lukas is involved in several projects including AD-RIDDLE, AI4HOPE and Gates Ventures. You can see a list of all our staff at: <https://www.alzheimer-europe.org/about-us/who-we-are/staff>

6 MARCH

Our Position Paper on anti-amyloid therapies is published in the JPAD journal

In January, we launched a new position paper on anti-amyloid therapies for Alzheimer’s disease, calling for concrete actions to ensure safe, timely and equitable access to these innovative medicines, for all people with early AD who could benefit from treatment.



The position paper, together with an accompanying call to action, has just been published as a special article in the February edition of the Journal of Prevention of Alzheimer’s Disease (JPAD).

Anti-amyloid drugs represent a new hope for many people with AD, with the potential to slow the progressive, clinical decline associated with the disease. However, the benefits and risks of initiating treatment are multifaceted and complex, as are the findings from high-profile clinical trials such as CLARITY-AD and TRAILBLAZER-AD. Together with eligibility and safety concerns, access to anti-amyloid drugs is also major challenge - dependent on a timely and accurate diagnosis of early AD, with biomarker confirmation of AD pathology. Inadequate resourcing of European healthcare systems excludes many from accessing a timely diagnosis, patient-centred support, care and treatments.

The Alzheimer Europe position was developed following engagement with its national members and the European Working Group of People with Dementia (EWGPWD). Together, we identified three priority areas to support equitable access to anti-amyloid therapies: effective communication of risks and benefits; an accurate, timely diagnosis; and healthcare systems preparedness. The JPAD paper also lists concrete, enabling actions for industry, regulators, payers, healthcare systems and governments. These include the adoption of realistic, sustainable pricing policies for anti-amyloid therapies; clear reimbursement frameworks that do not impact the coverage of existing interventions for people with dementia; as well as investment in infrastructures and workforce for diagnosis and treatment. Importantly, we call for continued investment in the development of diagnostics and treatments for other causes and stages of dementia, as well as support and

care services that can help people live well with dementia at all stages. To read the position paper and call to action, published as an Open Access article in JPAD, visit: <https://link.springer.com/article/10.14283/jpad.2024.37>

To read the French translation of the Alzheimer Europe position paper and call to action, published by France Alzheimer, visit:

<https://www.francealzheimer.org/traitements-anti-amyloides-contre-la-maladie-dalzheimer-la-position-dalzheimer-europe/>

7 MARCH

Alzheimer Europe presents the 44th edition of Dementia in Europe magazine



It is with great pleasure that we introduce the 44th edition of our Dementia in Europe magazine, which contains many important updates on European and national policy developments in the dementia field.

We open the Alzheimer Europe section with a report on our most recent European Parliament lunch debate, held in December 2023 and focusing on a new edition of

our European Dementia Monitor as well as on our 2024 EU Elections Campaign. We would like to thank Deirdre Clune MEP (Ireland), Vice-Chairperson of the European Alzheimer's Alliance, for hosting this important event. Our next article takes a closer look at the content of the European Dementia Monitor 2023. We then have a series of articles about four new publications from Alzheimer Europe: Our 2023 Yearbook on the topic of legal capacity and supported decision-making, our new guide on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) review process, and two new position papers – one on disclosing dementia risk and one on anti-amyloid therapies for Alzheimer's disease. The penultimate article in this section focuses on a recent collaborative event for Public Involvement in European brain health research, held in Luxembourg and involving six European research projects that joined together in a series of consultations, whilst the final article looks back at the newly-closed EU-FINGERS project, a collaborative initiative developing tools to conduct new clinical studies for the prevention of Alzheimer's disease and dementia.

In the Policy section, we start with important news from Slovenia, which has just published its second National dementia strategy. Minister of Health, Valentina Prevolnik Rupel, outlines more details about the new strategy, and President of Spominčica, Štefanija L. Zlobec, shares the association's re-

sponse to the strategy. Up next, we share details of our campaign work in the run up to the European Parliament elections 2024, aiming for dementia to be prioritised as a policy matter at a European level. Building on previous advocacy work, the campaign has been developed with three distinct elements: The Helsinki Manifesto; A Public Call to Action, and the Dementia Pledge 2024. Going back to the national level, we speak to Dr Mairéad Bracken-Scally and Dr Seán O'Dowd from the Irish Health Service Executive to find out more about the publication of the Model of Care for Dementia in Ireland in 2023, and then to Jacqueline Hoogendam and Sara Elkiki from the Dutch Government, to learn about the country's recent international conference which took place under the banner "Defeating Dementia". Closing off the policy section, we asked Yongjie Yon, Technical Officer on Ageing and Health at the World Health Organization (WHO) to tell our readers about the Regional Summit for Policy Innovation on Healthy Ageing in Lisbon, Portugal, co-organised by WHO Europe and the Directorate General of Health of Portugal.

Our third and final section, Dementia in Society, starts off with a personal account of living with dementia, written by Barry Northedge, Scottish member of the European Dementia Carers Working Group, who shares his wife Margaret's story both before and after diagnosis. We then find out about the "ABOARD" project in the Netherlands, the halfway point of which was marked by the "ABOARD Midterm Meeting" in late 2023. Project leader Wiesje van der Flier from Alzheimer Center Amsterdam shares the achievements so far and we also hear from some of the project's early stage researchers about their involvement. The film "Waltzing Matilda" is the subject of the third article in this section. Directed by Czech screenwriter, renowned documentary and theatre director and author of several TV dramas, Petr Slavík and produced by his wife Nataša Slavíková, the film is an intimate family drama about bailiff Karel Jaroš, his mother the former choir singer Matilda, and Karel's teenage son Pavel. We interviewed producer Nataša Slavíková about the reasons for making the film and to learn more about the characters and the message. We end this section and indeed the magazine with a look at a new book emerging from Scotland, called "Challenging Assumptions Around Dementia". The book seeks to challenge preconceived ideas about dementia and its co-authors are six people living with dementia and six who support or have supported someone with the condition. Their work was brought together by research psychologist Dr Rosalie Ashworth, so Alzheimer Europe asked Dr Ashworth and two of the book's co-authors, David Ross and Agnes Houston, to tell us more.

The Dementia in Europe magazine can be downloaded, here: <https://bit.ly/DementiaInEurope44>

19 MARCH

Alzheimer Europe organises a Company Round Table meeting in Brussels

On 19 March, Alzheimer Europe (AE) hosted a Company Round Table meeting in Brussels. The meeting was a hybrid event, with many participants attending in person and some joining remotely. It was attended by company representatives from Biogen, Bristol Myers Squibb, Eli Lilly, EFPIA, Essity, GE Healthcare, Grifols, Novo Nordisk, Nutricia, Prothena, Roche, members of the AE staff and members of the AE Board. During the meeting, four speakers provided updates on recent policy and research developments.

First, Cindy Birck, AE Project Officer, gave an update on our Clinical Trials Watch, an online database providing accessible and up-to-date information on clinical trials that are investigating drugs for Alzheimer’s disease and/or dementia. Next, Owen Miller, AE Project Officer, shared some updates on EU policy developments, European Parliament elections and AE European Parliament election campaign. Alexandra Tamas, Director for Public Affairs at EFPIA, gave then a talk on the EU Pharmaceutical Legislation and provided an update on the discussions at the European Parliament and Member States. Finally, Jean Georges, AE Executive Director, informed participants about Alzheimer Europe’s activities in 2024 including projects and the upcoming annual conference to be held from 8 to 10 October in Geneva, Switzerland, under the motto "New horizons – Innovating for dementia". We would like to thank our sponsors and members for participating in this meeting and we look forward to welcoming them to the next Company Round Table meeting in June in Luxembourg.

19-20 MARCH

Alzheimer Europe’s March 2024 Public Affairs meeting in Brussels brings together 21 member organisations from across Europe



On 19-20 March 2024, Alzheimer Europe (AE) was delighted to welcome representatives from 21 member organisations to our Public Affairs meeting, a forum which enables sharing of updates, experiences, challenges and good practices in policy developments and campaign activities at both a national and

European level. The meeting started on 19 March with a warm welcome from Maria do Rosário Zincke dos Reis, Chairperson of Alzheimer Europe (Portugal) and a tour de table of introductions. This was followed by presentations from AE staff and many member organisations. Topics included:

- **National Policy and Campaigning activities:** Country representatives from Portugal, France, Ireland, Poland, Lithuania and Germany shared their updates and developments, which followed with fruitful discussions, sharing and questions from participants looking at how to integrate strategies that work into their own countries and how to apply lessons learned in other countries to own strategies.
- **Expectations of the general public and experiences of people with dementia in research participation, views on data sharing and consent policies:** Angela Bradshaw (AE Director for Research) shared the scope of the Gates Ventures II project to identify key barriers and facilitators in research with people with dementia, and asked for recommendations on how the researchers can engage the national organisations in research. This prompted a great discussion amongst the participants on various barriers and facilitators that they recognise in their countries.

Continuing on this topic, Lukas Duffner (AE Project Officer) presented AE’s primary systematic literature review of studies assessing barriers and facilitators in research involving people with dementia that he worked on. He shared the three main themes that were identified, and this was followed by further discussion and idea sharing amongst the attendees on various issues affecting research participation and how to improve engagement. The following day, Jean Georges (AE Executive Director) opened the meeting and presented the topics:

- **National Policy and Campaign activities:** Member organisations from Italy, Hungary, Finland, Belgium, Greece, Turkey and Iceland presented their national policy campaign activities which was followed by questions and idea sharing.
- **2024 Yearbook on Independent Living :** Owen Miller (AE Policy Officer) introduced the topic and scope of the 2024 Yearbook on Independent Living and requested feedback from participants on the proposed questions. Many participants responded with their feedback and information on their country’s current situations, pointing out the need for more clear definition of terms and suggesting related topics to consider adding to the questions. This was followed by presentations from members organisations from Finland, Greece, Netherlands and the United Kingdom (England) on their country’s strategies and targets for independent living.
- **European Parliament elections - update on AE activities:** Owen Miller opened the afternoon session with an overview of AE’s election campaign and communication activities, followed by an overview of activities related to the **Helsinki Manifesto**. Chris

Bintener (AE Project Communications Officer) continued with a presentation on the **Public Call for Action** campaign and communication activities. Kate Boor Ellis (AE Director for Communications and Policy) then discussed the campaign and communications activities around the **Dementia Pledge 2024**, advising the member organisations how to engage their MEPs and candidates. Owen then presented the AE plan for post-election activities leading up to the European Parliament Dementia Day on 12 December 2024.

- **National Policy and campaigning activities:** Representatives from member organisations in Slovenia, France, Bulgaria, Montenegro, Netherlands, United Kingdom (England), Ukraine, Italy and North Macedonia then presented their updates, which followed with questions and idea sharing amongst the participants.

Jean Georges closed the meeting with thanks for the great engagement and contributions of participants and then gave an update on the upcoming Annual General Meeting that will take place in June in Luxembourg.

19-20 MARCH

The EWGPWD and supporters meet in Brussels



On 19 and 20 March members of the EWGPWD and their supporters gathered in Brussels. The discussions were facilitated by Public Involvement Lead, Ana Diaz. Public Involvement Officers Soraya Moradi-Bachiller, Sarah Campill and Daphné Lamirel also attended the meeting.

On the first day of the meetings, Ana introduced the new model of the EWGPWD and its implications for members' tenure within the group. She then turned to the upcoming Alzheimer Europe conference, which will be held in October in Geneva. Members discussed who would represent the EWGPWD in the plenary session and the topics they would address. Some members also expressed interest in speaking at some of the conference's plenary sessions.

Later that evening, EWGPWD members and supporters attended an event at the European Parliament alongside other representatives of Alzheimer Europe and national dementia associations. The focus of the reception was on highlighting the importance of prioritising dementia in the upcoming EU elections. Ten MEPs attended, and signed a pledge showing their commitment to the cause.

The following day's discussions centred on Alzheimer Helsinki Manifesto, which highlights recommendations for action at national and EU level to prioritise dementia in Europe. Ana Diaz presented the document and members highlighted which areas they saw as most crucial, drawing from their experiences in their countries. They also expressed their opinions on issues that may not be sufficiently addressed in the Manifesto. The meeting then focused on the next steps for campaigning on dementia in the EU elections. Attendees reflected on the key messages that should be put forward for the campaign and on effective methods to spread these messages, such as videos.

The meetings concluded with a consultation on the INTEREST project, a European Joint Programme for Neurodegenerative Disease Research (JPND)-funded project. Two researchers from this project joined the meeting: Martina Roes (DZNE, Germany) and Louise Hopper (DCU, Ireland). Members and supporters shared their experiences and opinions on the topics of social health, inequities and intersectionality. They also discussed their opinion on unmet needs as a person living with dementia or a supporter. The session was interactive, with participants offering very valuable feedback. The researchers intend to thoroughly analyse and summarise this feedback, using it as a foundation for their future work on the project. We would like to thank all members for joining the EWGPWD meetings in Brussels and for actively participating throughout.

Help us give a voice to people with dementia

[Donate](#)



AE NETWORKING

4 MARCH	The Board of the Alzheimer Europe Foundation met
5 MARCH	Ana, Cindy and Sarah attended the General Assembly Meeting of the Multi-MeMo project
FROM 5-8 MARCH	Angela attended the AD/PD conference and met with Biogen, Bristol Myers Squibb, Ely Lilly, InRAD and the AD-RIDDLE & EPND projects (Lisbon, Portugal)
7, 14 & 15 MARCH	Soraya participated in three consultations with the ADIS Young Adults Advisory Board
11 MARCH	Daphné, Dianne and Sarah participated in a consultation with the eBRAIN-Health Public and Patient Group
11-12 MARCH	Cindy attended the General Assembly Meeting of the AI-Mind project (Amsterdam, Netherlands)
14 MARCH	Angela met with representatives of Ely Lilly (Brussels, Belgium)
15 MARCH	Angela attended an IMPACT Workshop for a project proposal
18-19 MARCH	The Alzheimer Europe Board met (Brussels, Belgium)
19 MARCH	Alzheimer Europe organised a company round table meeting (Brussels, Belgium)
19 MARCH	Alzheimer Europe hosted a European Parliament reception “Making dementia a European priority” (Brussels, Belgium)
19-20 MARCH	Alzheimer Europe organised a public affairs meeting with members (Brussels, Belgium)
19-20 MARCH	Alzheimer Europe organised a meeting of the European Working Group of People with Dementia (Brussels, Belgium)
22 MARCH	Ana, Sarah and Ange participated in a consultation with the Evidera Advisory Group
25 MARCH	Alzheimer Europe convened the Organising Committee for the 34 th Alzheimer Europe Conference
26 MARCH	Jean attended the meeting of the World Dementia Council (London, United Kingdom)
26 MARCH	Jean met with Dutch Health Minister Conny Helder (London, United Kingdom)
27 MARCH	Alzheimer Europe organised a meeting of the European Group of Governmental Experts on Dementia
28 MARCH	Jean met with representatives of Bristol Myers Squibb and C2N Diagnostics

EU PROJECTS

29 FEBRUARY-1 MARCH

Kick-off meeting of JPND INTEREST Working Group takes places in Dublin



On 29 February and 1 March, over twenty members of the INTEREST (Innovations in diversity and equity in social health research in dementia) project attended a two-day hybrid meeting to kick-off their work on inequity and unmet needs in dementia care in Europe, with a special focus on social health and intersectionality. Funded by the EU Joint Programme – Neurodegenerative Disease Research (JPND), the INTEREST Working Group is led by Dr Louise Hopper (Dublin City University) and consists of international experts with interdisciplinary backgrounds. Aside from discussing the core frameworks (Social Health Framework, Intersectionality, Inequity), the meeting resulted in a refined primary question and goal of the Working Group:

“How can we collaboratively influence the research agenda in Europe so that it prioritises the investigation of multifaceted inequities leading to unmet needs among diverse populations living with dementia and their carers? We will systematically examine these issues through the lens of social health and intersectionality, with an emphasis on the specific mechanisms of policy and tailored interventions including technology.”

To drive these efforts further, the members split into several sub-groups working on:

- Reviewing (unmet) needs, led by Dr Wei Qi Koh (University of Queensland, Australia)
- Gaining a deeper understanding into effective interventions, led by Dr David Neal (Amsterdam University Medical Center, Netherlands)
- Surveying inequities across Europe, led by Adelina Comas (London School of Economics and Political Science, United Kingdom)
- Consulting the European Working Group of People with Dementia as well as European Dementia Caregiver Working Group about lived experiences, led by Dr Ana Diaz (Alzheimer Europe, Luxembourg)
- Communicating to and with audiences from academic, healthcare, policy, industry, and the public, led by Dr Sara Laureen Bartels (Maastricht University, Netherlands).

These groups will collaborate closely with the framework sub-groups, namely:

- Social Health and Intersectionality, co-led by Prof. Marjolein de Vugt (Maastricht University, Netherlands) and Prof. Martina Roes (DZNE, Germany), and
- Inequality, led by Dr Clarissa Giebel (University of Liverpool, United Kingdom).

Following this fruitful kick-off meeting, members are starting the work and will reconvene in June 2024 to discuss progress and first insights. If you are interested in receiving updates from INTEREST, please reach out to Dr Sara Laureen Bartels (sara.bartels@maastrichtuniversity.nl)

5 MARCH

Multi-MeMo hosts its first General Assembly meeting



Since May 2023, partners of the JPND-funded Multi-MeMo project have been working together, looking at multimodal interventions for the prevention of dementia. Multi-MeMo stands for “Shorter and longer-term mechanisms of multimodal interventions to prevent dementia” and is coordinated by Associate Professor Alina Solomon from University of Eastern Finland (UEF).

On 5 May, the consortium members gathered for their first General Assembly meeting in Lisbon, Portugal. Held as a hybrid event, with both in-person and online participation, the meeting was attended by representatives from all the institutions and organisations that make up the consortium, including Alzheimer Europe.

Alina Solomon, in her opening remarks, set the stage for a day of fruitful exchanges and collaboration, emphasising the importance of collective efforts in advancing research and innovation in the field of dementia prevention. During the meeting, partners presented the major developments and discussed future activities. AE Project Officer Cindy Birck, Public Involvement Officer Sarah Campill and Public Involvement Lead Ana Diaz attended the meeting.

Following the General Assembly Meeting, some project members attended the International Conference on Alzheimer’s

and Parkinson's Diseases and related neurological disorders and presented their respective work.

<https://www.multi-memo.eu/multi-memo-partners-convene-in-lisbon-for-global-communication-and-engagement/>

7 MARCH

Members of the ADIS Young Adults Advisory Board meet online to discuss different aspects of brain health campaigns for people their age



On 7, 14 and 15 March, the members of the newly set up ADIS Young Adults Advisory Board (ADIS YA-AB) gathered online. These three sessions were also attended by Jesús Rodrigo (Confederación Española de Alzheimer, CEAFA) and David Bartrés-Faz (Universidad de Barcelona), and facilitated by Soraya Moradi-Bachiller (Public Involvement Officer at Alzheimer Europe, AE).

During the consultations, members of the ADIS YA-AB were asked what their views and opinions are about dementia prevention, dementia risk reduction, healthy lifestyle and brain health, and other different terms and expressions that could be used in a brain health campaign for people their age. There were also discussions about the barriers young people face when adopting healthy habits and what motivates (or would motivate) them to have a healthy lifestyle.

All the members participated actively and provided insightful feedback during this consultation, which is part of a series of meetings that will help shape a brain health campaign for young adults.

7 MARCH

EPND launches its extended Catalogue, enabling discovery of over 75 neurodegenerative disease studies with 240,000+ research participants



The development of effective treatments and accurate diagnostics requires biomarkers for early detection of neurodegenerative disease in individuals, for assessing treatment efficacy, and for patient stratification. Thanks to funding from the Innovative Medicines Initiative (IMI), EPND (the European Platform for Neurodegenerative Diseases) is establishing a data- and sample-sharing platform for collaborative, large-scale biomarker research. Alzheimer Europe is one of 29 public- and private sector partners in EPND, and is proud to co-lead its stakeholder engagement, public involvement and communications activities.

On 7 March, EPND launched the next iteration of its Catalogue, a first-of-its kind, open, accessible database bringing together information about clinical cohorts researching neurodegenerative diseases including Alzheimer's, Parkinson's and dementia with Lewy Bodies. The EPND Catalogue provides a single point of access for research discovery and collaboration, listing over 70 studies from 17 countries, covering 13 disease areas with 240,000+ research participants. Responding to feedback from researchers, cohorts and data scientists, updates to the EPND Catalogue enhance the visibility and discoverability of studies, offering new pathways for collaborative research and sharing of biosamples and data.

The design of the Catalogue has been updated to offer:

- improved search, filter and contact functions, with a streamlined interface that allows researchers to easily discover and connect with studies of interest.
- additional categories of information on study design, participants, datasets and biosample collections, their use/access conditions.
- a self-service, study administration dashboard allowing investigators to manage, update and edit their study listings with ease.

"This is a crucial advance in our mission to change the future of neurodegenerative diseases with new diagnostics and treatments" said Niranjana Bose, EPND Project co-Leader. "Discovery is the first step towards data and sample sharing and our expanded Catalogue is forging new paths for collaborative research, with functionalities designed to support and connect researchers and study investigators."

Explore the EPND Catalogue, here: <https://discover.epnd.org/catalogue/studies>

To learn more about EPND, visit: <https://epnd.org/>

11 MARCH

The eBRAIN-Health Public and Patient Advisory Group gathers online for an information session and consultation about the project



On 11 March, the members of the eBRAIN-Health Public and Patient Advisory Group met online for a consultation about the project. The meeting also included the presence of Public Involvement Officers Sarah Campill and Daphné Lamirel alongside Dianne Gove, Director for Public Involvement and Ethics at Alzheimer Europe.

In the first part of the meeting, Petra Ritter who leads the eBRAIN-Health project and neuroscientist Leon Stefanovski from Charité University Berlin provided an overview of ongoing work within the eBRAIN-Health project and new research findings related to the use of digital brain twins. Attendees had the opportunity to ask Petra and Leon questions.

In the second part of the meeting, Klaudia Kwiatkowska, a legal specialist from the University of Vienna who is working in eBRAIN-Health, joined the meeting. Daphné and Klaudia gave an introduction to the European Health Data Space programme. They clarified questions from the members of the advisory group and facilitated a discussion about views on the potential benefits and concerns of this new EU programme.

11-12 MARCH

AI-Mind holds its General Assembly Meeting in Amsterdam

On 11-12 March, the AI-Mind Project consortium gathered for its 8th General Assembly meeting hosted by partners from The Radboud University Medical Center (RUMC) and Oslo University Hospital (OUS) in Amsterdam, the Netherlands. The meeting held at the iconic Nemo Museum – the Studio, brought together more than 50 in-person attendees and an additional 10 joining online, representing both the AI-Mind consortium and external speakers. The #AIMindGA coincided with Brain Awareness Week, making the event an excellent opportunity to raise awareness of the importance of brain health.

The AI-Mind General Assembly commenced with a warm welcome from the local host, Dr Tim Govers (RUMC), setting the stage for two days of enriching discussions and insights into

the project's progress. The project coordinator, Dr Ira Hebold Haraldsen (OUS) provided a comprehensive overview of the project progress and highlighted the key steps to be taken to bring the AI-Mind tools to their validation in the clinical setting. On the first day, all Work Package leaders presented the major achievements and challenges that occurred within the last months, including updates from the AI-Mind study that now welcomes participants to their 4th and last visit. On the second day, the assembly featured a series of insightful lectures from external speakers followed by Q&A sessions.

Participants joining in person had also an opportunity to explore the Living Looonger exhibition at the NeMo museum and engage in the interactive displays. AE Project Officer Cindy Birck attended the meeting on behalf of Alzheimer Europe. You can read the full summary of the AI-Mind General Assembly on the project's website:

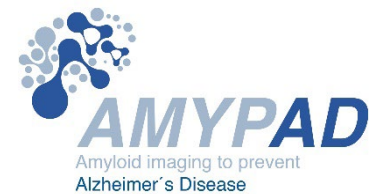
<https://www.ai-mind.eu/blog/takeaways-from-ai-minds-8th-general-assembly/>



14 MARCH

EMA issues a draft Biomarker Qualification Opinion for the use of the Centiloid quantitative methodology in clinical settings

On 14 March, the AMYPAD Consortium announced a significant milestone as the European Medicines Agency (EMA) has issued a draft Biomarker Qualification Opinion (BQO) for the use of the Centiloid quantitative methodology in clinical settings.



This achievement underscores the team's dedication to advancing Alzheimer's disease research and diagnostic capabilities. The Centiloid method enables direct quantitative comparison of amyloid-PET scans acquired with different amyloid tracers. The AMYPAD Centiloid working group worked intensively on the implementation of (Centiloid) quantification into the clinical routine, to not only support visual assessment of

challenging cases, but also prepare the field for a potential necessity which could arise from the possible approval of disease-modifying therapies in the near future. The team's efforts have been comprehensive, delving into the robustness of the Centiloid quantification method, its feasibility in detecting early A β pathology, and its ability to monitor changes over time. These findings have been consolidated into a Biomarker Qualification Opinion document, submitted to the EMA in September 2022 with the following context statement "Use of the Centiloid Quantitative Methodology for measuring brain amyloid". After a first round of reviews, the team defended their work and received a positive assessment from the EMA. The document is now available for public review on the EMA website. The deadline for comments is set to 18 April 2024. The EMA's Committee for Medicinal Products for Human Use (CHMP) considers the Centiloid Unit for the measurement of brain amyloid level as a validated measure of global amyloid

load in the brain for enrichment in clinical trials, if properly used with quality control procedures. The advantage would be potential use of different PET tracers and scanning and analysis procedures (scanning pipelines) in cross sectional settings, as non-normalised raw data for different available tracers are not comparable.

The primary sources of data presented in this BQO is amyloid measures from the two AMYPAD studies, the Diagnostic and Patient Management study (DPMS) and the Prognostic Natural History Study (PNHS). Additionally, work has been performed by members of the AMYPAD consortium on other cohorts. You can find the draft document on the EMA website: https://www.ema.europa.eu/en/documents/other/draft-qualification-opinion-centiloid-measure-amyloid-pet-quantify-brain-amyloid-deposition_en.pdf

EU project acknowledgements



A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon 2020, Horizon Europe, the Innovative Medicines Initiative 2 (IMI2) Joint Undertaking (JU), or the Innovative Health Initiative (IHI) JU. Projects funded through the IMI2 or IHI JU receive support from EU Research & Innovation programmes, as well as industry federations and other contributing partners. Please visit the project website(s) listed below for specific details on the organisations, federations and funders providing support for individual projects.

The projects in this newsletter are:

- AI-Mind - grant agreement 964220 (<https://www.ai-mind.eu/>)
- AMYPAD - grant agreement 115952 (<https://amypad.eu/>)
- eBRAIN-Health – grant agreement 101058516 (<https://www.ebrain-health.eu/>)
- EPND - grant agreement 101034344 (<https://epnd.org/>)



ADIS – This project is supported by the Luxembourg National Research Fund (INTER/JPND21/15741011/ADIS) under the aegis of the EU Joint Programme - Neurodegenerative Disease Research (JPND) - www.jpnd.eu (www.adis-project.eu)

Multi-MeMo – This 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 (<https://www.multi-memo.eu/>)



MEMBERS OF THE EUROPEAN ALZHEIMER'S ALLIANCE

Currently, the total number of MEPs in the Alliance stands at **96**, representing **26** Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance (EAA):



Austria: Claudia Gamon (Renew Europe); Monika Vana (Greens/EFA). **Belgium:** Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D). **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); Patricia Chagnon (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Marie Dauchy (I&D); Geoffroy Didier (EPP); Catherine Griset (I&D); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Jean-Lin Lacapelle (I&D); Pierre Larrourou (S&D); Eric Minardi (I&D); Nadine Morano (EPP); Philippe Olivier (I&D); 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 (NI); Ciarán Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke 'Ming' Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Grace O'Sullivan (Greens/EFA). **Italy:** Isabella Adinolfi (NI); Brando Benifei (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:** Petras Auštrevičius (Renew); Vilija Blinkevičiute (S&D); Liudas Mažylis (EPP). **Luxembourg:** Marc Angel (S&D); Charles Goerens (Renew Europe); 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:** João Albuquerque (S&D); Sara Cerdas (S&D); Maria da Graça Carvalho (EPP); 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); Klemens Grošelj (Renew Europe); Irena Joveva (Renew Europe); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA). **Sweden:** Peter Lundgren (ECR).

EUROPEAN ALZHEIMER'S ALLIANCE

27 MARCH

MEPs join European Alzheimer's Alliance



Making dementia a European policy priority



As part of Alzheimer Europe's EU Election Campaign, a number of existing Members of the European Parliament (MEPs) signed up to the Dementia Pledge 2024, joining the European Alzheimer's Alliance (EAA). Alzheimer Europe is delighted to welcome the follow MEPs to the alliance:

- João Albuquerque MEP (S&D, Portugal)
- Petras Auštrevičius MEP (Renew, Lithuania)
- Patricia Chagnon MEP (I&D, France)
- Marie Dauchy MEP (I&D, France)
- Maria da Graça Carvalho MEP (EPP, Portugal)
- Catherine Griset MEP (I&D, France)
- Jean-Lin Lacapelle MEP (I&D, France)
- Liudas Mažylis MEP (EPP, Lithuania)
- Eric Minardi MEP (I&D, France)
- Philippe Olivier MEP (I&D, France).

The EAA members can be viewed at:

<https://www.alzheimer-europe.org/policy/european-alzheimers-alliance/members>

EU DEVELOPMENTS

6 MARCH

European People's Party manifesto contains European dementia plan commitment



On 6 March, at its Congress in Bucharest, Romania, the European People's Party (EPP) adopted its Manifesto for the European Parliament elections 2024. The "Our Europe, a safe and good home for the people"

document contains a commitment to develop a European dementia plan.

Under section 3.5 "Our Europe improves people's lives through innovation in health", the Manifesto states:

"While ensuring the full implementation of the Beating Cancer Plan, we want to take the next step and develop a European plan to address Alzheimer's disease, dementia, and Parkinson's disease."

This commitment aligns to a long-standing call of Alzheimer Europe for the development and implementation of a European dementia strategy, and reflects one of the **key calls from our Helsinki Manifesto**.

The full EPP manifesto is available at: https://www.epp2024.eu/_files/ugd/8e086a_1f2f80e365d34cd386bd2343fa427c99.pdf

13 MARCH

European Parliament adopts position on European Cross Border Associations legislation

On 13 March, the European Parliament adopted its report on the Directive on a European Cross-Border Associations (ECBA), responding to the proposal published by the Commission in September 2023.



The legislation proposes allowing (non-profit) associations to operate on a cross-border basis in an equivalent way to that of multinational organisations, affording them a European legal form and EU-wide protection. Some amendments made to the Commission's original text include:

- A declaration on respecting the EU values as indicated in art. 2 TEU which have been integrated into the text.
- Provision is made for the consultation of stakeholders and NGOs in the implementation of the directive.

The Council of the European Union is yet to adopt its position on the file.

Further information on the ECBA is available at: [https://oeil.secure.europarl.europa.eu/oeil/popups/ficheprocedure.do?reference=2023/0315\(COD\)&l=en](https://oeil.secure.europarl.europa.eu/oeil/popups/ficheprocedure.do?reference=2023/0315(COD)&l=en)

13 MARCH

European Parliament passes AI Act

On 13 March, the European Parliament, following the completion of trilogue negotiations, passed the Artificial Intelligence (AI) Act. The Act sets out:

- The safeguards on general purpose AI
- Limits on the use of biometric identification systems by law enforcement
- Bans on social scoring and AI used to manipulate or exploit user vulnerabilities
- The right of consumers to launch complaints and receive meaningful explanations.

The regulation is still subject to a final lawyer-linguist check and is expected to be finally adopted before the end of the legislative session. It still needs to be formally endorsed by the Council. It will enter into force twenty days after its publication in the official Journal, and be fully applicable 24 months after its entry into force, except for:

- Bans on prohibited practises (six months after the entry into force)
- Codes of practise (nine months after entry into force)
- General-purpose AI rules including governance (12 months after entry into force)
- Obligations for high-risk systems (36 months after entry into force).

The full text of the AI Act is available at: https://www.europarl.europa.eu/doceo/document/TA-9-2024-0138_EN.html

15 MARCH

Political agreement reached on European Health Data Space

On 15 March, the Council of the EU and the European Parliament reached a provisional agreement on the European Health Data Space (EHDS).

The proposed regulation for the EHDS aims to improve individuals' access to, and control over, their personal electronic health data, while also enabling certain data to be reused for public interest, policy support, and scientific research purposes. Key points of new agreement include:

- Opt-out: Member States can allow patients to opt-out on the use of their health data being accessed, whether by a healthcare professional (primary use) or for further use (secondary use, always under strict conditions), except for purposes of public interest, policy making, statistics and research purposes in the public interest
- Restricted information: if patients choose to restrict information, healthcare professionals will only be able to access restricted health data in situations of vital interest
- Sensitive data: member states may put in place stricter measures governing access to certain kinds of sensitive data, such as genetic data, for research purposes.

The agreement must now be formally signed off by the Parliament and the Council. The compromise text is available at: <https://www.consilium.europa.eu/media/70909/st07553-en24.pdf>



POLICY WATCH

1 FEBRUARY

TAP-dementia - a large-scale collaboration to improve diagnosis of dementia as part of the Dutch National Dementia Strategy - hosts consortium meeting in Rotterdam



TAP-dementia is a Dutch consortium, which is part of the Dutch National Dementia Strategy. TAP-dementia stands for Timely, Accurate and Personalized diagnosis of dementia. Researchers collaborate to improve the diagnosis of Alzheimer's disease and other types of dementia. On 1 February 2024, re-

searchers from the TAP dementia consortium met for their annual consortium meeting. This edition was organised by the Rotterdam researchers at Erasmus MC.

The day started with a Junior Meeting, organised by work package leads Inez Ramakers (neuropsychologist, University of Maastricht) and Evelien Lemstra (neurologist, Amsterdam UMC). They shared their experiences and knowledge about dementia diagnosis and why it can be complicated. There was particular attention for diagnoses other than Alzheimer's, such as frontotemporal dementia and dementia with Lewy bodies. Also, they illustrated how in many patients, there is actually not one diagnosis, but mixed pathology. For example, Alzheimer's and vascular pathology. Getting a firmer grasp on mixed pathology is one of the main themes of TAP-dementia. During a network lunch there was ample opportunity for active dialogue and to catch up with each other on a more personal level. Professor Daniel Alexanders from UCL (London, UK), who is also a member of the TAP-dementia Scientific Advisory Board, then delivered a keynote lecture. He provided an over-

view of the research performed at his lab, on modelling of different disease pathways within dementia based on brain scans.

During the afternoon, project leads of the five TAP projects gave updates with regard to where they stand after the first year, and what the plans are for the years to come. And because science and arts are an excellent match, the day ended with a visit to Art Hall Rotterdam, where a fully Artificial Intelligence (AI) based exhibition formed a clear link with the AI work being done in the context of TAP-dementia. The overall conclusion of this meeting was that TAP-dementia is well on its way and that the cooperation between the (junior) researchers is phenomenal.

6 MARCH

Support for people with dementia in Montenegro continues with creation of new EU-funded project "Navigating Life with Dementia"



"Navigating Life with Dementia: A Project for People with Dementia or at Risk of Dementia and their Families," funded by the European Union and the Government of Montenegro, will focus on creating socially inclusive communities by providing relevant social services to families and communities addressing the needs of older persons with

dementia or at risk and the needs of their families and caregivers, and by providing psycho-social support to people with dementia and their families in northern Montenegro. **Institute Circle** from Slovenia, in partnership with the **NGO Impuls** from Montenegro, and eight Montenegrin municipalities will continue their joint work in the field of dementia in 2024 and 2025. Montenegro, a country with 621,873 inhabitants, has 16.02% of people aged over 65, with dementia being the leading cause of disability and dependency among older people worldwide.

Montenegro follows the broader European trend that the number of people with dementia will nearly double by 2050. The key factor in this change appears to be a significant increase in the number of people aged over 70, especially those over 85. A study was conducted to identify the most urgent issues in this area. Data obtained from the first mapping by the Institute Circle and the NGO Impuls in 2022 on early dementia detection are one of the first attempts in Montenegro to collect and provide relevant information on this issue, as official statistics do not exist. An analysis of the legislative and strategic framework in Montenegro showed that there is no law specifically regulating the protection and support of persons with dementia. This target group is mentioned in documents related to the protection of the elderly and persons with disabilities. The provision of integrated social services and/or specialised support services and programmes for persons with dementia and their families has so far not found its place in either documents or practice.

Led by experience and best practices, initial first research, public awareness-raising, volunteer training, and capacity-building in the local government sector over the past two years of working with people with dementia and their families, they have decided to continue with improved accessibility and effectiveness of social services in eight municipalities, to address the needs of people with dementia and their families/caregivers; raising awareness among older persons and their families/caregivers about dementia; and improving quality of life through the use of counselling services and psycho-social support for older persons with dementia and their families/caregivers.

Nikšić, Plav, Gusinje, Berane, Plužine, Šavnik, Andrijevisa, and Petnjica are becoming municipalities that care for their locals and will raise the level of services and recognition of the dementia issue to a much higher level in the next period.

The associate partners in this project are the municipalities of Nikšić, Berane and Plav, the Center for Social Work Berane, Andrijevisa, and Petnjica, as well as the Red Cross Nikšić.



SCIENCE WATCH

19 FEBRUARY

UK spousal caregivers of people with dementia who experience increase in health conditions over time also experience increase in stress and social network reductions



A new study by Serena Sabatini et al. based on longitudinal findings from the IDEAL programme, looked deeper into the effects of caregiving on the health of spousal caregivers of people living with dementia. Their aim was to dive deeper into the relationship between the development of health conditions with person characteristics (age, education, sex), levels of stress, positive care experiences of caregiving, hours of care per day, and social network size among the caregivers of people with dementia over time.

The variables were administered at three timepoints, using self-report scales. Health conditions were assessed using the Charlson Comorbidity Index, which includes conditions such as cerebrovascular diseases, dementia, diabetes, and cancer. To analyse the data, a mixed-method approach was adapted. The pool of participants comprised 977 people from London, UK. All of them were spousal caregivers.

Compared to their non-caregiving peers, the number of health conditions presented by the spousal caregivers of people living with dementia didn't vary noticeably. On average, the caregivers presented 1.5 health conditions, with a general increase of 2.1 conditions over the course of two years. Although care partners reported relatively low levels of stress, those with more health conditions experienced greater stress at baseline. Spousal caregivers of higher age, with a lower educational background, who spent more time daily caring for their partners, showed an increased risk of developing more health conditions over time.

<https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-024-04707-w>

29 FEBRUARY

Spatial navigation may predict Alzheimer's disease decades before onset



People at risk for Alzheimer's disease (AD) may show impaired spatial ability long before the onset of cognitive symptoms, a UK study shows. Researchers from the University of Cambridge and University College London assessed visuospatial ability in 100 people participating in the PREVENT dementia cohort study with a familial history of AD. In particular, participants were asked to navigate through a virtual environment using virtual reality goggles. Importantly, they were on average 25 years younger than the usual age of onset of AD.

The researchers found that participants showed selective impairment on this spatial navigation task without an accompanying impairment on cognitive tests. These findings have been interpreted in support of the notion that poor spatial navigation may be a very early marker of AD, showing long before the onset of cognitive symptoms. In support of this, the researchers note that spatial navigation relies on those brain areas first to be affected by AD (the entorhinal cortex). Identifying such potential early symptoms is relevant for directing intervention efforts, they write.

<https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.13733>

4 MARCH

Varoglutamstat fails to meet primary and secondary clinical endpoints in Phase 2b study

On 4 March, the Germany-based pharmaceutical company Vivoryon Therapeutics announced results from its Phase 2b study evaluating Varoglutamstat for the treatment of early Alzheimer’s disease (AD).

The VIVIAD Phase 2b study was designed to evaluate the safety, tolerability and efficacy of Varoglutamstat in 259 European participants with mild cognitive impairment and mild AD (collectively referred to as “early AD”). Varoglutamstat is an enzyme inhibitor developed to target the enzyme glutamyl cyclase, which catalyses the formation of a particularly neurotoxic variant of Amyloid-beta (N3pE).

Top-line results showed that the VIVIAD Phase 2 study failed to reach its primary endpoint and did not show significant difference in change over time on cognition. Additionally, the study did not meet key secondary clinical endpoints.

In general, Varoglutamstat was well-tolerated and showed few adverse events. Vivoryon Therapeutics is conducting further analysis of other (exploratory) cognitive and biomarker endpoints. The full press release can be accessed here: <https://www.vivoryon.com/vivoryon-therapeutics-n-v-provides-update-on-viviad-phase-2b-study-of-varoglutamstat-in-early-alzheimers-disease>

5-9 MARCH

18th International AD/PD conference draws over 4,700 participants, sharing the latest scientific advances in diagnosis and treatment



The 2024 edition of the International Conference on Alzheimer’s Disease and Parkinson’s Disease (AD/PD) took place between 5-9 March, at the Congress Center in Lisbon. With a strong focus on clinical and biomedical science, AD/PD hosted over 600 presentations across six parallel sessions, welcoming more than 4,700 on-site participants. Our Director

for Research, Angela Bradshaw, attended AD/PD, and reported back on some of the scientific advances presented at the conference.

The AD/PD programme was packed with updates on disease mechanisms, diagnostics and therapeutics, on highly prevalent diseases such as AD and PD, as well as rarer conditions like dementia with Lewy Bodies, multiple system atrophy, and Huntington’s disease. While many sessions were focused on a single disease area, AD/PD also hosted sessions that combined updates from different disease areas – a great opportunity to learn about shared and distinct experiences and perspectives. As a case in point, the conference started with a fireside chat between Michael J. Fox, Ronald Lauder, Philip Scheltens and Henrietta Nielsen, bringing together PD advocacy, AD philanthropy, neurology and fundamental research. Biomarkers, which are measurable indicators of processes happening inside the body, were a prominent feature of the AD/PD programme. With 14 sessions on the topic, no stone was left unturned: presentations covered a huge breadth of disease areas, technologies, and applications, from digital speech data to cerebrospinal fluid biomarkers. Presentations on biomarkers such as p-tau217 showed that we are inching ever closer to having validated, blood-based biomarkers that can inform the diagnosis and management of early AD. There are also promising developments for non-Alzheimer’s dementias, with interesting presentations on alpha-synuclein assays for early detection and risk prediction for dementia with Lewy bodies (DLB) and studies on the TDP-43 biomarker in frontotemporal dementia and ALS. However, leading experts acknowledged that technologies and tests still need to be validated in the community setting, with clear clinical guidelines allowing doctors to choose the right test to reliably detect different types of dementia in people from different ethnic backgrounds who may have additional conditions such as kidney disease or diabetes.

On therapeutics, the majority of presentations focused on Phase 1 or Phase 2 early-stage clinical trials, or on subgroup analyses of results from blockbuster Phase 3 trials for anti-amyloid drugs lecanemab and donanemab. Roche presented new findings from their Brainshuttle AD study, a Phase 1b/2a clinical trial investigating ascending doses of trontinemab. Trontinemab combines a section of Roche’s anti-amyloid antibody, gantenerumab, with a transferrin-based “brain shuttle” that transports the drug across the blood-brain barrier. In their presentation, Roche researchers showed that treatment of trontinemab at the highest dose (3.6mg/kg) led to a rapid depletion of amyloid in the brain, with a majority of participants below the amyloid positivity threshold after 12 weeks of treatment. Although participant numbers were very small, the early safety signals appear positive.

Dementia risk reduction and brain health also featured in the AD/PD programme. A session on “prediction and prevention of cognitive decline” brought together researchers from the WorldWide FINGER programme, sharing new findings on the

impact of diabetes and inflammation on cognitive decline. Cognitive reserve, a concept that describes how certain people are less susceptible to age- or disease-related brain changes, was shown to mitigate the risk of dementia – potentially influenced by genetic variants. As this emerging research field progresses, it will be interesting to learn how people can build cognitive resilience across the lifecourse, and which interventions can most effectively prevent dementia in a personalised way. To view highlights of the 2024 AD/PD conference, visit their YouTube channel here:

<https://www.youtube.com/@adpdnetwork4142/videos>

Read the Alzforum coverage of AD/PD:

<https://www.alzforum.org/news/conference-coverage/adpdtm-2024-advances-science-therapy>

11 MARCH

FDA issues a revised draft guidance for drug development in early AD

On 11 March, the Food and Drug Administration (FDA) announced the availability of a revised draft guidance for industry entitled “Early Alzheimer’s Disease: Developing Drugs for Treatment.”

This newly proposed draft guidance is a revision of the prior draft issued on February 16, 2018. This guidance document is being distributed for comment purposes only. The final version is intended to assist sponsors in the clinical development of drugs for the treatment of the stages of sporadic Alzheimer’s disease (AD) that occur before the onset of overt dementia. These stages are collectively referred to as “early AD” in this guidance; however, it is recognised that AD occurs on a continuum and patients in the last stage of early AD (i.e., late Stage 3) and patients with AD in the earliest stages of overt dementia (i.e., early Stage 4) may not differ significantly in clinical presentation. This document provides an overview on the FDA current thinking on diagnostic criteria and clinical staging of AD to inform enrolment in clinical trials and the selection of appropriate endpoints in clinical trials.

This latest version of the FDA’s draft guidance introduced a new subsection dedicated specifically to surrogate endpoints and accelerated approval. FDA states in the document that there has been an effort to incorporate in clinical trials the use of biomarkers reflecting underlying AD pathophysiological changes and the enrolment of people with AD at earlier stages of the disease.

“Clinical trials showing an effect on a surrogate endpoint that is determined to be reasonably likely to predict clinical benefit can be the basis for accelerated approval, including for drugs intended for the treatment of AD. For example, in certain cir-

cumstances, FDA has considered a reduction of the brain amyloid beta burden, as assessed by positron emission tomography, to be a surrogate endpoint that is reasonably likely to predict clinical benefit.”

<https://www.fda.gov/regulatory-information/search-fda-guidance-documents/early-alzheimers-disease-developing-drugs-treatment>

22 MARCH

Lecanemab deliberations regarding the Marketing Authorisation Application in the EU have been rescheduled due to procedural reasons

On 22 March, Eisai announced that the Oral Explanation scheduled on 19th March at the Committee for Medicinal Products for Human Use (CHMP) for lecanemab, which is currently under review by the European Medicines Agency (EMA), did not take place. The company noted that this decision is entirely related to procedural reasons at the EMA and is not related to the marketing authorisation application (MAA) for lecanemab itself. It is a consequence of a 14th March legal ruling by the Court of Justice of the EU on the organisation of EMA’s Scientific Advisory Groups (SAGs) attendance. The judgement has implications on EMA’s policy on the handling of competing interests of experts, in relation to SAG members. For this reason, the EMA has decided to annul advice it received from its neurology SAG meeting for lecanemab held on 11 March. The EMA will schedule a new SAG meeting for lecanemab. The timing for the new meeting has not been determined yet.

The SAG is convened at the request of the CHMP of the EMA to provide independent advice on scientific or technical matters relating to products under evaluation by the CHMP, or on other scientific issues relevant to the work of the CHMP.

Lecanemab, which is marketed by Eisai and Biogen under the Leqembi® brand name, is an antibody that targets plaques of amyloid-beta proteins that accumulate in the brain during the development of Alzheimer’s disease (AD). Lecanemab was approved for the treatment of early AD by the US Food and Drug Administration in July 2023. Lecanemab is also approved in China and Japan. Approval was based on positive results from the CLARITY-AD clinical trial, which showed a 27% reduction in clinical decline for participants receiving lecanemab. Eisai announced the submission of a marketing authorisation application (MAA) for Lecanemab to the EMA on 11 January 2023.

<https://www.eisai.com/news/2024/news202417.html>

MEMBERS' NEWS

8 FEBRUARY

Province of Liège becomes first "Dementia Friendly Province" in Belgium



On 8 February 2024, the Province of Liège became the first Dementia-Friendly Province in Belgium, making official a partnership that has existed for many years, with the Belgian Ligue Alzheimer. The "Ami Démence" network, already available to towns and municipalities, has

now been extended to the Provinces of Belgium, and Liège is the first to sign the "Province Amie Démence" charter. Belgium's government structure involves different levels of power, and the Provinces have specific characteristics that towns and cities do not. The aim is therefore to obtain greater support in terms of awareness-raising, information, prevention and promotion, so as "not to forget those who forget".

21-24 FEBRUARY

Romanian Alzheimer Society organises National Alzheimer Conference in Bucharest



Between February 21-24, the 14th edition of the National Alzheimer Conference took place in Bucharest, in a hybrid format, organised by Prof. Dr Catalina Tudose, president of the Romanian Alzheimer Society (pictured, left).

The purpose of the conference was to bring together the educational programmes addressed to medical specialists, psychologists and nurses, continuing the tradition of conferences dedicated to this field, by holding plenary sessions, symposia, workshops and e-posters, from the fields of clinical neuroscience, neuroimaging, genetics, results of the most recent significant research, the presentation of the results of projects in

the field carried out in Romania, new therapies and therapeutic strategies, legislative aspects regarding the rights and protection of elderly people with neurocognitive disorders.

The theme of this year's conference referred to prevention, diagnosis in the preclinical stage and current treatments. In this sense, debates took place regarding the secondary prevention of Alzheimer's disease, which aims to prevent the onset of cognitive deficits (either MCI or dementia) in people who do not have neurocognitive disorders, but who are at risk of developing the disease in the future. There were discussions about preventive interventions from international studies carried out in the last 3-4 years and whose conclusions prove that cognitive performance can be stimulated through lifestyle interventions and the reduction of vascular risk. Ten years after the launch of the National Strategy and Plan for Dementia, the Romanian Alzheimer Society continues to draw the attention of public opinion and government authorities to the suffering and needs of patients with neurocognitive disorders and their carers. In this year's edition, the Romanian Alzheimer Society tried to highlight how the government strategies in Romania, but also private actions, improved the quality of life and the quality of care given to the elderly and showed the importance of health policies regarding the adoption of a National Dementia Plan.

12 MARCH

The Alzheimer Society of Ireland launches 30 years of Tea Day



On 12 March, The Alzheimer Society of Ireland (The ASI) launched the 30th anniversary of Tea Day and is calling on the nation to raise a cup of kindness and help make a difference to people living with dementia in Ireland and their family carers on 2 May.

ASI staff, ambassadors, advocates and supporters gathered at the Radisson, in South Dublin, to celebrate the 30th anniversary of Tea Day, The ASI's biggest fundraising campaign. The ASI is pleased to welcome back actors Bryan Murray and Una

Crawford O'Brien as ambassadors for Alzheimer's Tea Day. Funds raised through Alzheimer's Tea Day support critical services like the organisation's National Helpline, Daycare programmes, home care, family carers training, social clubs, and Alzheimer's cafes.

Speaking ahead of the launch, Mairéad Dillon, Head of Fundraising at The ASI, said: "Whether you host an event, attend one, or simply donate, every action brings us closer to a future where no one faces dementia alone. Together, let's raise a cup of kindness and make the 30th anniversary of Alzheimer's Tea Day the most successful yet."

The 30th anniversary is a significant milestone, with an estimated 30 people being diagnosed with dementia in Ireland every day. For more information about Alzheimer's Tea Day, visit teaday.ie

13 MARCH

A number of events focusing on Alzheimer's disease were organised in Poland to mark European Brain Day



On 13 March, at the Rzeszów branch of the National Health Fund in Poland, Zygmunt Wierzynski, president of Alzheimer Polska (Alzheimer Poland), and Danuta Gatlik from the Podkarpackie Alzheimer's Association answered questions

posed by people attending an event marking Brain Day. Alzheimer Poland's member associations were also actively engaged in disseminating information on dementia and to celebrate Brain Day, two member organisations hosted brain health conferences.

On 16 March, the "Tu i Teraz" (Here and Now) Foundation based in Nowy Sącz, organised a conference called "The Sącz Brain Day" which focused on therapeutic activities aiming at prolonging the physical and mental well-being of persons living with dementia. There was also an exhibition of paintings by persons affected by dementia, as well as some art and music therapy workshops.

On 18 March, the Łódź Alzheimer's Association together with DOZ Foundation organised their conference called "Healthy Brain" for the inhabitants of Łódź, especially for seniors. The conference media was under the patronage of "Senior Voice". Elżbieta Łacina the president of DOZ Foundation said: "We should all connect with people suffering from various dementia diseases and their caregivers", while Maja Maciaszczyk, psychologist, head of the Łódź Alzheimer Association gave a lecture on the topic "Good memory, how to take care of it?"

All the events attracted a large number of people interested in issues related to Alzheimer's disease. These events were held under the patronage of Alzheimer Poland.

19-20 MARCH

Alzheimer Larissa organises events to mark "caregiver day"

On 19 March, the volunteers and employees of Alzheimer Larissa (EENAL) held an entertaining event in order to improve caregivers' mental wellbeing. The president of EENAL, Eleni Kampoura-Nifli, welcomed the caregivers, listened to their concerns and informed



them about the rights of patients and their family members as well as the new legislative regulations promoted by the Greek Ministry of Health. Afterwards, psychologist Maria Manta presented them with techniques for relieving psychological burden and improving mood.

The event was followed by music of varied content, to match the multicultural background of the caregivers. The musical sounds were light Greek and traditional corresponding to the culture of all countries. The participants enjoyed the evening and the delicious food prepared by the volunteers.

On 20 March, a second event for caregivers began: Storytelling day. It included a digital reading of the satirical poems of George Souris: "My painting" and "Tebelia". The poetry reading was met with positive emotions and laughter from the caregivers, and encouraged them to tell anecdotes and humorous stories. The events had a positive impact in that the caregivers who attended accepted that they need to adopt self-care, respite, respite care, accept help and adopt activities that can take them out of the cycle of "toxic" emotions.

26 MARCH

The Panhellenic Federation of Alzheimer's Disease and Related Disorders has a new Board

The Panhellenic Federation of Alzheimer's Disease and Related Disorders is a non-profit organisation that was founded in 2007 and consists of 53 linked Associations of Alzheimer's disease all over Greece. The main objectives of the Panhellenic Federation are the coordination and cooperation of companies/members in terms of social contribution and the awareness of the patients affected by dementia and their caregivers' needs.



The next goals of the Panhellenic Federation are:

- To create structures, services and conditions that improve the quality of life of patients and their carers
- To promote research
- To provide education and training for all stakeholders
- To provide useful information and advice on problems related to dementia
- To prevent the marginalisation of people affected by dementia.

As from the start of 2024, the Panhellenic Federation has a new Board structure:

President : M. Tsolaki

Vice-Presidents: I. Kortsidaki; M. Tzanakaki-Melissari

Secretary General: S. Tsilikis

Treasurer: D. Rallis

Members: D. Moraitou, D. Theodoropoulos, Aik. Nomidou, Chr.Vouxaras, G. Papantoniou, V. Kampourlazos, P. Potouridis, V. Pattakou-Parasiri, M. Gkioka, El. Poptsi.



LIVING WITH DEMENTIA

16 MARCH

Zornitsa Karagiozova, member of the European Dementia Carers Working Group, is delighted to share details of a new pilot group for people with dementia in Bulgaria



In December 2023, in Sofia - the capital of Bulgaria, the first pilot group for people in the early stages of dementia was launched. It was formed on the initiative and with the overall support of the civil association, Alzheimer Bulgaria. The group is of a closed type and consists of four participants, admitted to the group after presenting the necessary medical documentation and doing an interview.

The group meets every week, with the frequency of the meetings being tailored to the needs and attitudes of the people in it. The therapeutic process is led by certified systemic therapists. The theme of each gathering is related to the life, memories and current daily life of its participants, which creates a

warm and friendly atmosphere of sharing between them. Small items related to the traditions and holidays of the Bulgarian people are also made. With the active participation of the members of the group, its name was also chosen - "Friends of Memory". A logo is also being developed.

To help counter the social isolation that can occur for people with dementia, the participants create a trusting relationship and communicate with each other. They are empathetic to the problems of the others, they support each other and approach the particularities of their illness with understanding. Good social contact may help to preserve some of their thinking skills and delay cognitive decline later in their life.

Unfortunately, there is no active day care centre for people with dementia in Sofia. Therefore, the existence and functioning of the group for people in the early stages of dementia is a huge step forward in caring for them and understanding their needs to build a safe and friendly environment where they can have mental and emotional engagement, to the best of their ability. Alzheimer Bulgaria is working hard to create and launch a second group of the same type.

20 MARCH

Trevor Salomon, Vice-Chairperson of the European Dementia Carers Working Group writes "Behind one of the world's most famous doors - 10 Downing Street"

On Thursday 7 March I took a call from Alzheimer's Society asking me if I'd like to be present at a reception at 10 Downing Street. I didn't even bother to look at my calendar. I said yes immediately without even knowing what I was being invited to attend.

In due course, I received a formal invitation from Number 10 informing me of the event which was to recognise the ongoing widespread efforts to tackle dementia, alleviate its negative impact, and to discuss how the Dame Barbara Windsor Dementia Mission will support patient and carer needs. The Dame Barbara Windsor Dementia Mission was launched in 2021 by the then Prime Minister, Boris Johnson, in memory of the "EastEnders" and "Carry On" legend who died of Alzheimer's disease in 2020.

Eventually, I was sent a communication advising me what time to arrive, which ID I should bring, etc. Before I knew it, the days had flown by and I found myself in the queue on Wednesday 20 March, waiting to access the building.

After passing through very tight police security and an airport-style scanner, I then walked straight into Number 10. No photographs were allowed to be taken prior to entering the building but I was told it would be fine to take them once I'd exited.

Mobile phones and smart watches had to be left in the vestibule area and then I was directed to the stairway to the second floor, passing all the pictures and drawings of the prime ministers who had served the country. There was this instant feeling of being surrounded by history.

There were 150/200 guests in a beautiful large room, with representatives from charities, research organisations, the National Health Service, Government as well as carers and people living with dementia. The Secretary of State for Health and Social Care, Victoria Atkins, hosted the event which was to launch the Government's commitment to phase two funding of the Dame Barbara Windsor Mission. I must admit, I thought there would be at least some mention of social care and social care funding but, disappointingly, nothing.

Following the speakers, canapés and drinks were served, whilst people mingled and networked. I spent a couple of minutes talking to Scott Mitchell, Dame Barbara's husband, who it was announced has been appointed People's Champion of the National Mission to beat dementia. He is the most delightful and humble man and a true champion of the cause.

Overall, I was in the building for about an hour and a half. Probably a once-in-a-lifetime, amazing and privileged experience, and a fantastic one at that!



21 MARCH

Chris Ellermaa, member of the European Dementia Carers Working Group and Board member of NGO Living with Dementia in Estonia, writes about new memory cafés in her country



NGO Elu Dementsusega (NGO Living with Dementia), representing people living with dementia and their carers in Estonia, has launched a series of "memory cafés". The first café took place in November 2023 and the second one was held on 21 March. These cafés aim to give an opportunity to people living with dementia and their carers to meet, share experiences, and contribute to the development of dementia awareness and acceptance in society.

During the first memory café, we talked about the history of cafés in Estonia and talked to invited journalists about dementia-friendly language. The topic of the March café was "Protection of interests for people with dementia and their loved ones: what, why and how?". The guest speaker, a public relations and lobbying expert spoke in more detail about conceptualising protecting interests and lobbying activities, and the achievement of goals by influencing decisions and regulations. We learned that it is important to have a strong network and a good understanding of policy-making for effective advocacy. Early intervention and building networks and relationships in advance are key. Listening skills to gather information and argumentation to represent one's views are also important.

The strongest resources of an NGO, in the protection of interests, are its members and the time they contribute. There is power in cooperation, and it is the foundation for setting goals and building a network to realise them.

We aim to have a memory café at least once per quarter, with relevant and interesting topics and well-respected guests. NGO Living with Dementia is grateful that I, as a Board member, was invited to the morning radio programme *Vikerhommik* by Estonian Public Broadcasting to talk about life with dementia. This helps the organisation to reach the public, increase awareness and support people living with dementia.

21 MARCH

Scottish Dementia Working Group and National Dementia Carers Action Network members share their experiences of visiting the Centre for Discovery Brain Sciences at Edinburgh University



The Scottish Dementia Working Group (SDWG) and National Dementia Carers Action Network (NDCAN) are proud partners in research, supporting purposeful dementia related research by bringing their personal experiences to help shape and inform the aims and objectives of research projects; volunteering as research participants; and being kept informed of activity within the dementia research world. Members have established a strong relationship with the Centre for Discovery Brain Sciences at Edinburgh University, meeting with its deputy-director Professor Tara Spire-Jones and students to discuss the work of the Centre and touring the facility to see, first-hand, the work that is taking place there.

During February, six SDWG and NDCAN members had the pleasure of visiting the Centre, the second such visit in just a few months. From hearing about "living" tissue brain research and fruit fly brain research; to trying out some of the state-of-

the-art microscopes and learning about the ethics and protocols applied in the Centre – the members have shared their thoughts on the fascinating and inspiring visit.

Committed people doing inspiring work

"I feel so privileged to have been part of the tour of the Brain Health Lab in Edinburgh University. The first impressions from our meeting with Tara, Claire and their students and listening to everyone's enthusiasm while giving very brief summaries of their work was inspiring. Their commitment to research into Dementia was heart-warming and they understood the importance for their generation to find answers, effective treatments and perhaps a cure for generations to come. The lab tour itself was fascinating. Hearing about their strict ethical collection and use of small pieces of "living" brain tissue from brain tumour operations, as well as post-mortem tissue was inspiring.

It was just incredible to be told how much they could do with absolutely tiny pieces of brain tissue the size of a crumb, and thin slices which could be layered into even thinner slices then combined again. The different kinds of microscopes being used for different kinds of tests was really interesting too. Kris and other students working with tiny fruit fly brains to research, analyse and report on their findings were so enthusiastic about the comparisons with the human brain. Creating tiny "hybrid" flies from embryos was like something out of science fiction! They are all using state of the art technology so expertly - I was just overwhelmed with their knowledge and skills, and their ability to explain all about their work in lay terms that we could all understand and appreciate."

Marion Ritchie, NDCAN

Mind boggling research

"The experience and welcome from everyone at the lab was something very special from start to finish and thoroughly deserving of thanks and appreciation. We started off the visit in the kitchen-lounge area for tea and coffee and general introductions, with everyone, researchers and Active Voice members, giving a little background about themselves. Professor Tara Spire-Jones was there, described her work, the research being done there, and she also baked some incredible cookies that I will remember as simply delicious. She is Wonder Woman personified! Then we toured the labs dressed in white lab coats... brought back memories of Beaker from the Muppet Show. The range and depth of the research is mind-boggling and that's besides the fact that my mind is already boggled. The machinery is so very expensive, sophisticated and specialised and lucky us got to peer into microscopes, see slides and learn about the exciting progress that's being made.

The tiny size of the tissue samples and fruit flies was a surprise and then being shown how they are handled and used to progress the research made a big impression, as did the cataloguing and care taken with the samples. Everything is so wee. It's like dicing a pin head. For me, learning about the collection and usage of the access tissue donated by folk having a brain tumour removed was very special. That and the respectful approach and delicate handling shown by the researchers in all aspects of what they do is amazing. Thank you all for the warm welcome and wonderful afternoon."

Rynagh Flynn, SDWG

Dissecting the brain of a fruit fly is mind blowing!

"I was invited along to Edinburgh University to see around the brain laboratory by Professor Tara Spires-Jones. We met lots of post graduate students, each assigned different roles in brain research. It was fascinating to hear their enthusiasm and admire their intelligence at such young ages. They were especially inspired listening to the experiences of people with dementia. We were shown around each laboratory by the lab manager Jane Tulloch and Kris who explained, in plain English, what we were viewing via microscopes. We learned about using live brain tissue from post-operative patients, incubating it and nourishing it to survive for 28 days. This allowed scientists to view the live electrical and chemical exchanges on specialist equipment. We learned about the life cycle of fruit flies and how this aids learning on diseases such as Alzheimer's. Dissecting the brain of a fruit fly is mind blowing!

What was very noticeable to me was the constraints of the old building that the staff are working in with curtains for darkness. Dementia is the leading cause of death in Scotland, but we are not looking after our brilliant genius scientists. It was apparent that they desperately need funding. The expensive equipment is squeezed into spaces not purpose built for it. Scotland has the ability to be at the forefront of research. It feels as though we are so close to a breakthrough, but we must look after our researchers better."

Elaine Deehan, NDCAN

And a final word...

They are all stars!

"It was so generous of the staff and researchers to give us the time to get to know the specifics of each of what they were working on. Also, to be reassured about the stringent protocols in place due the understandable ethics of humans, as well as animals of whatever form. I thoroughly enjoyed the trip - it was just truly phenomenal to see and hear what all the young researchers are working on and then be able to ask questions. It is tremendous to think young researchers are carrying forward the great research of the past. Oh to be a millionaire or billionaire to support all the great work of Alzheimer's Scotland, Brain Health, Brain Sciences, UWS ASCPP. - They are all stars!"

Margaret McCallion, SDWG (and Vice-Chairperson of the European Working Group of People with Dementia, EWGPWD).

DEMENTIA IN SOCIETY

18 MARCH

PROMISE Youth Association for P4 Medicine in Croatia introduces the project "Remember Me - Enriching the Lives of People with Dementia"

The PROMISE Youth Association for P4 Medicine, in collaboration with the Neuroscience Student Section of the Faculty of Medicine, University of Zagreb, the Neurobiology Section of the Biology Students Association (BIUS), Hipok.art Association, and CROMSIC Split, has started an initiative to address dementia, through volunteering in nursing homes, educating families, and raising awareness about dementia in the broader community. This interdisciplinary project involves students of biomedical disciplines and young people currently active in

Zagreb and Split, where a significant need for volunteer assistance in working with patients has been identified through various informational programs and workshops.

The idea stemmed from the recognition of the growing problem of dementia in society, lack of education, stigmatisation of patients, and a lack of activities and interactions with dementia patients in nursing homes. Implementation began with organising training sessions for interested participants, where they had the opportunity to attend



lectures by university professors, doctors, caregivers, and professionals who thoroughly prepared volunteers for working with residents. After passing the knowledge exams, an enthusiastic group of willing and warm-hearted individuals was formed, laying the foundation to try to create a generation of selfless and empathetic adolescents with the aim of establishing a better system for the elderly and shaping a society with heightened awareness of dementia.

Recently, numerous educational and creative activities have been successfully conducted in many nursing homes, bringing smiles to the residents' faces and enriching their daily routines. Based on exceptional interest and support from nursing homes, positive reactions from patients, and the motivation of volunteers, the prerequisite for establishing a sustainable systematic education programme for high school students, university students, families of patients, and the wider public has been met.

At the first volunteer training sessions held at the Clinical Hospital Center in Zagreb, the Croatian Institute for Brain Research, and the Faculty of Medicine in Split, over 40 participants from various educational backgrounds such as medicine, biology, biotechnology, rehabilitation, and speech therapy took part. They learned about working with, caring for, and interacting with people living with dementia, as well as gaining general knowledge about dementia, by expert and experienced lecturers.

As many as 10 nursing homes have joined this innovative project, where 70 workshops have been held so far, including painting and drawing, clay modelling, dance, as well as simpler activities like walks in nearby parks and poetry reading. Volunteers also monitor the effects of workshops on the cog-

nitive state of the residents using the Montreal Cognitive Assessment Score (MOCA), and the project hopes to publish a scientific paper on the impact of creative workshops on dementia, if viable results are obtained. The project is also preparing educational sessions for high school students to acquaint them with the risks of developing dementia, treatment and diagnostic options, and most importantly - prevention of its development. There is also a public health action planned on the main square in Zagreb, where project volunteers will administer the MOCA test to passers-by for early signs of dementia, with the hope of raising more awareness. This would conclude the volunteer term for the first winter generation of students and help prepare the ground for a new generation of volunteers who will operate during the summer semester.

The PROMISE Youth Association for P4 Medicine is a group of students and young people in biomedical fields who have completed the Erasmus+ program "PROMISE - Personalized Medicine Inquiry-Based Education". After gaining knowledge about the possibilities of personalised, participatory, preventive, and predictive (P4) medicine, they decided to continue acting in that spirit, seeking to modernise current concepts in medical approaches and science. In just over two years of operation, they have demonstrated this, through several major projects such as the international and award-winning Brain-Gut Axis conference, the initiative for tumour patients From Personalized Testing to Targeted Treatment (FT3), the Cell Biology and Art Class Omnibus (CACAO), workshops and lectures on P4 medicine concepts, and currently we are focusing most of our resources on the volunteer project Remember Me. More information about the project can be found on the Association's website: <https://sjetimese.carrd.co/> or you can email: promiseyouthassociation@gmail.com

AE CALENDAR 2024

DATE	MEETING	AE REPRESENTATIVE
2 April	Miriade Supervisory Board	Jean
8 April	European Health Data Space (EHDS) Stakeholder Group meeting	Angela
8-10 April	REBALANCE Ethics Meeting (Riga, Latvia)	Daphné
9-10 April	LETHE project consortium meeting (Helsinki, Finland)	Ana and Chris
10 April	JAIN Challenge meeting with the European Dementia Carers Working Group	Sarah and Soraya
10 April	WW Fingers Network Meeting	Jean
11-12 April	Evento Awards (Helsinki, Finland)	Gwladys
11-12 April	Genetically Determined Alzheimer Disease Cross-fertilization between Down Syndrome & Autosomal Dominant Alzheimer Disease (DSAD ~ ADAD) conference	Angela
12 April	European Working Group of People with Dementia meeting about EU election campaign	Ana, Daphné, Dianne, Owen, Sarah and Soraya
15 April	JAIN Challenge meeting with the EWGPWD	Sarah and Soraya
16 April	European Parliament 'Unconditional' screening event (Brussels, Belgium)	Daphné and Sarah
16 April	36 th Alzheimer Europe Conference Organising Committee	Cristina, Gwladys and Jean
17 April	Pattern-Cog consultation with the European Dementia Carers Working Group	Ana, Daphné, Dianne, Sarah and Soraya
18 April	EU4Health Civil Society Alliance	Owen
22-23 April	PANEUCARE project kick-off meeting (Bonn, Germany)	Soraya
23 April	European Innovation Council Info & Networking day (Esch-sur-Alzette, Luxembourg)	Angela and Cindy
24 April	Alzheimer's Disease International Council Meeting	Jean
24-26 April	Alzheimer's Disease International Conference (Krakow, Poland)	Ana, Gwladys and Jean
25-26 April	European AD Consortium (EADC) Meeting (Brussels, Belgium)	Angela
29 and 30 April	Consultations with the ADIS Young Adults Advisory Board	Soraya

CONFERENCES 2024

DATE	MEETING	PLACE
11-12 April	Genetically Determined Alzheimer Disease Cross-fertilization between Down Syndrome & Autosomal Dominant Alzheimer Disease (DSAD ~ ADAD), https://dsad-adad.com/	Barcelona, Spain
24-26 April	36 th Global conference of ADI - Dementia: Insights. Innovations. Inspirations, https://adiconference.org/	Krakow, Poland and online
14 May	Alzheimer's Society Annual Conference, Making dementia a priority for all, https://www.alzheimers.org.uk/dementia-professionals/conferences-and-events/annual-conference	London, United Kingdom
28 July-1 August	AAIC 2024 – A global forum to advance dementia science, https://aaic.alz.org/	Philadelphia, USA and online
18-20 September	20 th EuGMS Congress - "From Healthy Ageing to Complex Needs in Older Adults", https://eugms2024.com/	Valencia, Spain
25-27 September	IPA 2024 International Congress - Crossing Oceans and Connecting People to Improve Mental Health for Older Adults, https://www.ipa-online.org/events/2024-international-congress	Buenos Aires, Argentina
8-10 October	34 th Alzheimer Europe Conference – New horizons – Innovating for dementia	Geneva, Switzerland
29 October – 1 November	17 th Clinical Trials on Alzheimer's Disease (CTAD), https://www.ctad-alzheimer.com/	Madrid, Spain



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34th Alzheimer Europe Conference

New horizons – Innovating for dementia

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www.alzheimer-europe.org/conferences

