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WELCOME

I want to start off by offering my condolences to colleagues at the Czech Alzheimer Society (ČALS), after the recent passing of their Chairwoman Hanka Janečková. Our thoughts are with her family, friends and colleagues.

In much happier news, our colleagues in Poland have informed us that the Polish Government has confirmed that it is developing an interdisciplinary strategy on dementia. We congratulate them on this great progress!

Moving on to our Annual Conference, organised together with Alzheimer Schweiz Suisse Svizzera and Alzheimer Genève, I am delighted to announce that the call for abstracts this year has attracted a record number of submissions, with 575 abstracts received! These are currently being reviewed and notifications will be sent to all applicants during June.

We recently launched the 2024 edition of our Anti-Stigma Award, together with the Alzheimer Europe Foundation. The Award will recognise a European journalist for an article, news story or documentary which has contributed to combating stigma and promoting a positive image of dementia and people living with dementia. The call is closing on 15 June, so please apply now!

Speaking of imminent deadlines, the EU elections are just around the corner, taking place between 6 and 9 June. We are pleased with the progress on our campaign in the run-up to the elections and hope that our hard work will contribute to making dementia a priority issue for European decision-makers. We have been campaigning on three fronts to reach this goal: The Helsinki Manifesto, which currently has 74 endorsements; a public Call to Action, with over 6,600 signatories so far; and the Dementia Pledge 2024, which candidates standing for election in the European Parliament (EP) can sign, pledging to prioritise dementia and to join the European Alzheimer’s Alliance (EAA), upon election. The first two branches of the campaign will continue until December, but the Pledge will end with the elections, so we urge candidates to please sign now! When current MEPs sign the Pledge, they immediately join the EAA and I am delighted to welcome 17 new members this month alone!

Lastly, I want to highlight some important publications released this month: A Czech version of our guide to help raise awareness of issues around sex, gender and sexuality in dementia was translated by ČALS and their colleagues at Freya - Institute of Sexuality and Relationships. It was fantastic to collaborate on this and we thank everyone involved, for their hard work!

The findings from the PRODEMOS study were published in the Lancet Healthy Longevity and I was delighted to be one of the co-authors, together with my colleague Cindy Birck. I would also like to congratulate the authors of an INTERDEM taskforce paper on inequalities in dementia across Europe, published in the journal Geriatric Psychiatry. Co-authors on this paper include Ana Diaz and Dianne Gove from Alzheimer Europe. And finally, Ana Diaz was also a co-author on a paper on "Social activities in multidomain dementia prevention interventions: insights from practice and a blueprint for the future", published in the journal Frontiers in Psychiatry, together with researchers from the EU-FINGERS, Lethe and Multi-MeMo projects. Congratulations to all!

Jean Georges, Executive Director

Alzheimer Europe Board

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

Alzheimer Europe Staff

Executive Director: Jean Georges; Conference Coordinator: Gwladys Guillory; Executive Assistant: Tara Klassen; Events Coordinator: Cristina Pencea; Finance Officer: Stefanie Peulen; Director for Communications and Policy: Kate Boor Ellis; Policy Officer: Owen Miller; Communications Assistant: Grazia Tomasini; Director for Research: Angela Bradshaw; Project Communications Officer: Christophe Bintener; Project Officer: Cindy Birck; Project Officer: Lukas Duffner; Director for Public Involvement and Ethics: Dianne Gove; Public Involvement Lead: Ana Diaz; Public Involvement Officers: Sarah Campill, Daphné Lamirel and Soraya Moradi-Bachiller.

IN MEMORIAM

19 APRIL

Chairwoman of Czech Alzheimer Society Hanka Janečková has passed away



On 19 April, Hanka Janečková, chairwoman of the Czech Alzheimer Society (ČALS) Board of directors, died after a serious illness, at the age of 74. Ms Janečková was behind the founding of the ČALS civic association more than 25 years ago and was the first chairwoman of the board after its transformation into a benevolent association in 2014.

Hanka was not only important to ČALS through her work on the Board of directors, but she was also a member of the Dragonfly audit team and helped bring successful foreign trends to the Czech Republic. Thanks to her, the association got to know Jitka Zgola, and her work with reminiscence techniques led to the establishment of the Reminiscence Centre in Prague. Not only did she enrich their courses with comprehensive lectures, but she was also a popular head of the Department of Social Work at the Evangelical Theological Faculty of Charles University. She played an important role in Diakonia CCE and in the community of sociologists of medicine.

Hanka Janečková leaves behind a great legacy of work, but what is equally important is that she was a very kind and empathetic person, who knew the importance of listening to others. She was a great mother to her children and a loving grandmother to her grandchildren. Her passing is a great loss for everybody, not only for our colleagues at the Czech Alzheimer Society. Our sincerest condolences to her family, friends and colleagues.

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SPOTLIGHT ON EUROPEAN ELECTIONS

7 MAY

Entire EU elections candidate list of French political party Les Écologistes - EELV signs Dementia Pledge 2024, promising to make dementia a policy priority at EU level!

We are delighted to announce that, thanks to the hard work of our member France Alzheimer, the entire list of the French political party Les Écologistes - EELV (Europe Ecology – The Greens) has signed our Dementia Pledge 2024, which forms part of our EU elections campaign. Marie Toussaint MEP signed the Pledge on behalf of her entire list of EELV candidates, bringing 81 new signatures to the Dementia Pledge. Alzheimer Europe would like to express its gratitude to Ms Toussaint and all the EELV candidates for supporting the Pledge and for putting dementia firmly on their agenda as a policy priority.

The **Dementia Pledge 2024** is a commitment which all candidates standing for election in the European Parliament 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. The current total of pledgees stands at **161**, including the 81 EELV signatories. We invite other candidates (and party lists!) to sign the Pledge, today! 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>



 @AlzheimerEurope 	 @alzheimereurope 
 @alzheimer-europe 	 @AlzheimerEurope 
 AlzheimerEurope 	

31 MAY

With just a few days until the European elections, Alzheimer Europe calls on all candidates to please sign the Dementia Pledge 2024!



Sign the European Dementia Pledge 2024

#DementiaPledge2024

I pledge that, upon my election to the European Parliament, I will:

1. Join the European Alzheimer's Alliance

2. Support the campaign of Alzheimer Europe and its member organisations to make dementia a European priority, with specific actions in the following four key areas:

- Ensuring dedicated EU funding for dementia-focused research across all disciplines, commensurate with the societal and economic cost associated with dementia
- Responding to the scale of dementia as a health challenge by prioritising the condition as part of the next health programme of the EU
- Acknowledging dementia as a disability, affording people with dementia the rights guaranteed under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
- Undertaking focused work at an EU level to provide greater support and protections for carers

On 31 May, with the European Parliament elections just around the corner (they will run between 6 and 9 June 2024), as part of its European Election Campaign 2024, aiming to make dementia a priority issue for decision-makers at a European level, Alzheimer Europe urges Members of the European Parliament (MEPs) who are standing for re-election, as well as all MEP candidates, to sign the [Dementia Pledge 2024](#).

World Health Organization (WHO) figures 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. By 2025, 9.1 million people will be living with dementia in the European Union, rising to 14.3 million in 2050. Dementia must be shown greater attention by European decision-makers!

The **Dementia Pledge 2024** is 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. There is very little time left, so we urge candidates to **please sign now**.

Sirpa Pietikäinen MEP (Finland) commented:

"It is vital that MEPs take action to upgrade attention to neuro-degenerative diseases and to prioritise dementia at the EU level. We need to ensure that the European Parliament's positions are heard and that we are raising awareness and addressing the challenges that people with dementia face. We also need to hold the Commission accountable when it is necessary. This is an area where we can create meaningful and positive change and truly address the challenges that patients and their families face. It is our responsibility to create policies that create a better EU and better everyday life in every Member State for people with dementia, so that everyone can live their lives the way they want to. I therefore strongly encourage all candidates standing in the European Parliament elections to sign the Dementia Pledge 2024 and work with Alzheimer Europe and national Alzheimer's associations to ensure that dementia is prioritised in the coming term."

Jean Georges, Executive Director of Alzheimer Europe, said:

"With the number of people living with dementia expected to substantially increase in the coming years, as well as the considerable societal costs associated, it is time for European decision-makers to prioritise dementia and dedicate the resources needed to address it across the domains of health, research, disability rights and support for informal carers. We invite all MEP candidates to sign the Dementia Pledge 2024!"

You can see who has signed the Dementia Pledge 2024, here: <https://bit.ly/DementiaPledge2024>

You can download the Pledge form, here: <https://bit.ly/DementiaPledge2024form>

Candidates can also pledge on social media (Twitter/X, Facebook and LinkedIn, by stating their support and using the hashtag [#DementiaPledge2024](#)

31 MAY

We are delighted with the progress of our European Election Campaign 2024, with the June elections just around the corner. Please continue to show your support!

As at end of May 2024, we are truly delighted with the progress of our EU elections campaign so far. The European Parliament elections are a mere few days away, running from 6 to 9 June, and our work in the run-up to these elections, aiming to make dementia a priority issue for decision-makers at a European level, is proving to be a success. We have been campaigning on three fronts:

- **The Helsinki Manifesto**
- **A public Call to Action**
- **The Dementia Pledge 2024**



The first two branches of the campaign will continue after the elections are over, up until our planned "Dementia Day" at the European Parliament, on 10 December 2024 (more to follow on this, later. Watch this space!). The **Dementia Pledge 2024** campaign, however, is aimed at Members of the European Parliament (MEPs) who are standing for re-election, as well as all MEP candidates. This will, therefore, end with the close of the June elections. Following these elections, we will re-establish the "European Alzheimer's Alliance", a multinational and cross-party group of MEPs with an interest in dementia and who support Alzheimer Europe's work and that of our national member(s) in their country.

As at end of May, 195 MEPs and candidates have signed up to our Dementia Pledge. You can see who has signed the Dementia Pledge 2024, here: <https://bit.ly/DementiaPledge2024>

You can download the Pledge form, here: <https://bit.ly/DementiaPledge2024form>

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 74 organisations, projects and entities including the following seven which endorsed it during the month of May:

- AFA Parla, Spain
- Alzheimerfonden, Sweden
- ARAD (Associazione Ricerca Assistenza Demenze) APS ETS, Italy
- Asociación de Familiares de personas con Alzheimer y otras demencias de Barcelona, Spain
- Federació d'Associacions de Familiars d'Alzheimer, Spain
- HOMEDEM project
- SPF Seniorenerna, Spain

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 attracted **more than 6,600 signatories!**

You can sign the Call to Action, today, via our website: <https://bit.ly/AECallToAction2024>

ALZHEIMER EUROPE

30 APRIL

Alzheimer Europe presents Luxembourg HealthTech Cluster webinar on "Collaborating for patient-centric healthtech solutions"



On 30 April 2024, the Luxembourg HealthTech Cluster managed by Luxinnovation organised a webinar illustrating the benefits for healthtech companies of cooperating with associations and patient groups. It provided companies and researchers with practical guidance to setting up meaningful collaborations and real-world examples. Experts from Alzheimer Europe provided a comprehensive overview of collaborative strategies and engagement methodologies essential for creating innovation in healthcare and developing solutions for the unmet needs of patients and their careers.

Angela Bradshaw, Director for Research at Alzheimer Europe, elucidated the role of the organisation in fostering collaborations across Europe. Drawing from her experience in EU-funded projects such as AI-MIND, EPND, Neuronet, and VirtualBrainCloud, she highlighted Alzheimer Europe's commitment to advancing research and innovation in Alzheimer's disease (AD). She outlined the ecosystems of patient organisations in Europe, and the engagement of Alzheimer Europe at national and EU levels. Through debates, research projects, and flagship events like its annual conference, Alzheimer Europe networks with relevant stakeholder in order to keep the research for AD and other neurodegenerative diseases on the agenda of politicians.

Complementing Dr Bradshaw's insights, Ana Diaz, Public Involvement Lead at Alzheimer Europe, explored the concept of Public Involvement in research. Dr Diaz articulated Alzheimer Europe's approach to empowering patients and caregivers to become active participants in the research processes. With examples from EU projects like EU-Fingers and the Multi-Memo project, she highlighted how patients and carers can provide invaluable insights and advice to researchers, working together to develop solutions that better meet their needs and can improve their quality of life.

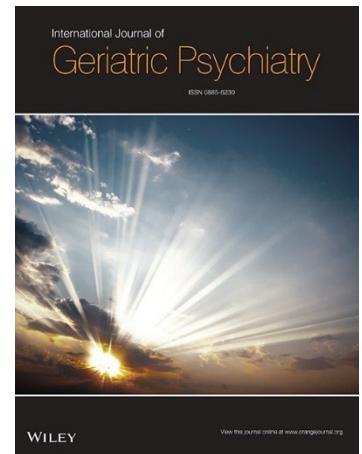
The webinar ended with a Q&A session moderated by Francesca Borrelli, Senior Advisor – European R&D and Innovation Support at Luxinnovation, during which attendees had the opportunity to engage directly with the speakers and discuss potential collaborations between healthtech solution providers and associations such as Alzheimer Europe.

8 MAY

Article "The landscape of inequalities in dementia across Europe: First insights from the INTERDEM taskforce" published in Geriatric Psychiatry and co-authored by Alzheimer Europe

A new article called "The landscape of inequalities in dementia across Europe: First insights from the INTERDEM taskforce" has been published in the May 2023 issues of the journal Geriatric Psychiatry. Alzheimer Europe is pleased to have been involved in this paper, with both Dianne Gove, Director for Public Involvement and Ethics, and Ana Diaz, Public Involvement Lead, being co-authors. Article link:

<https://onlinelibrary.wiley.com/doi/10.1002/gps.6096>



15 MAY

Record number of abstracts submitted for 34th Alzheimer Europe Conference!

Alzheimer Europe, Alzheimer Schweiz Suisse Svizzera and Alzheimer Genève would like to thank everyone who submitted abstracts for the 34th Alzheimer Europe Conference (#34AEC), taking place from 8-10 October 2024, in Geneva, Switzerland. A record number of 575 abstracts was received this year, which are currently being reviewed by our Scientific Committee and notifications will be sent to all applicants during June. The detailed



programme for the conference will also be made available to view on our website, during June.

We would also like to remind you that you can take advantage of our special early bird registration fees until 15 July 2024 to attend in Geneva.

Find out more about registration fees:

<https://www.alzheimer-europe.org/conferences/2024-geneva/registration-fees>

Click here to register:

<https://www.alzheimer-europe.org/conferences/2024-geneva/online-conference-registration>

31 MAY

Closing date for Anti-Stigma Award is just a few days away. Journalists, please apply now!

For the 2024 edition of their Anti-Stigma Award, Alzheimer Europe and the Alzheimer Europe Foundation will recognise a European journalist for an article, news story or documentary which has contributed to combating stigma and promoting a positive image of dementia and people living with dementia. Following the great success of this initiative over the past two years, they announced the launch of the 2024 edition back in mid-April, with a deadline for submissions of 15 June. The deadline is now just a few days away, so we urge journalists to submit their articles, videos or documentaries, right away, to avoid missing this great opportunity!

The award is open to journalists established in a **member country of Alzheimer Europe** for articles, news stories or documentaries which were produced and published in the past three years (2021-2024). Applications can be made by journalists themselves or by a nominating national Alzheimer's association. In those cases, the written consent of the nominated journalist needs to be sought. The award can be for stories covered by print media, radio or TV programmes or in social media channels.

The 2024 award will consist of a cash prize of EUR 5,000 for first place, a cash prize of EUR 2,500 for second place and a cash prize of EUR 1,250 for third place, each of which will be



accompanied by a trophy. The winning journalists will be announced during a special award ceremony as part of the European Parliament Dementia Day, on 10 December 2024, in Brussels.

Applicants may be short listed and asked to present their article, news story or documentary to the members of the Award Committee at an online meeting on 15 July. Travel and accommodation costs for the top three journalists will be covered by Alzheimer Europe, to attend the award ceremony in Brussels on 10 December.

More information can be found at: <https://www.alzheimer-europe.org/our-work/anti-stigma-award/anti-stigma-award-2024>

The application form can be downloaded via: https://www.alzheimer-europe.org/sites/default/files/2024-04/anti-stigma_award_-_application_form.docx

Interested journalists or national Alzheimer's associations wishing to nominate a particular journalist, should send in the completed application form by the deadline of **15 June 2024**.

AE NETWORKING

2 MAY	Soraya participated in a consultation with the ADIS Young Adults Advisory Board (ADIS YA-AB)
3 MAY	(Luxembourg, Luxembourg), representatives of the Vlaamse Alzheimer Liga paid a visit to the Alzheimer Europe office
6 MAY	Daphné, Dianne and Sarah participated in a meeting of the eBRAIN-Health Public and Patient Advisory Group
8 MAY	(Luxembourg, Luxembourg), Jean attended a meeting of the Luxembourg Fondation Alzheimer
9 MAY	(Praha, Czechia) Alzheimer Europe Board member Martina Mátlová (Czech Alzheimer Society) attended a meeting of The Government Council for Older Persons and Population Ageing
11-12 MAY	(Ljubljana, Slovenia), Daphné attended the European Disability Forum Annual General Assembly
13-15 MAY	Angela participated in the General Assembly meeting for the PRIME project
13-14 MAY	(Milan, Italy), Owen presented at the HOMEDEM training week
14 MAY	Ana, Cindy and Sarah participated in a meeting of the Multi-MeMo Advisory Board
16 MAY	Owen attended the Patient Think Tank meeting organised by EFPIA
16-17 MAY	Cindy attended the Euro-PAD scientific symposium (Amsterdam, Netherlands)
21 MAY	Angela recorded a video panel session for presentation at the Annual Meeting of Health Technology Assessment International
21 MAY	(Praha, Czechia) Martina Mátlová introduced the new Czech version of Alzheimer Europe's guidelines on "Sex, Gender and Sexuality" at the conference "Sexuality doesn't age"
22-24 MAY	(Brussels, Belgium), Daphné attended the CPDP (Computers, Privacy and Data Protection)-AI conference
24 MAY	Dianne and Soraya met with members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) to discuss the Joint Plenary Session at the upcoming Alzheimer Europe Conference
24 MAY	Jean attended the Extraordinary General Meeting of the European Patients' Forum
27 MAY	(Vechta, Germany) Chris held a virtual guest lecture about Alzheimer Europe's conference and campaigning activities at the University of Vechta
28 MAY	Alzheimer Europe organised an Alzheimer's Association Academy on "Partnering in research projects as patient organisations"
29 MAY	Daphné, Dianne and Sarah participated in a meeting of the Prominent Public Involvement Board
29 MAY-1 JUNE	(Vienna, Austria), Gwladys attended the ICCA Business Workshop European Venues Sector 2024



ean congress Helsinki 2024
 10th Congress of the European Academy of Neurology
 June 29 – July 2

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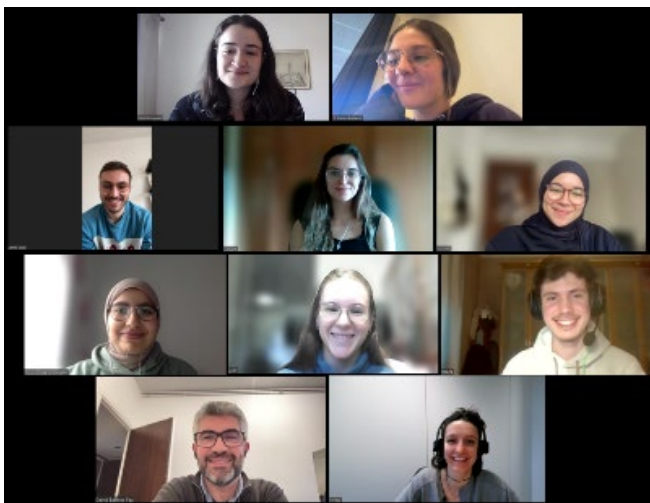
Become a member of the EAN and save on Congress fees!
 Apply before: 31 May

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EU PROJECTS

29 APRIL-2 MAY

Members of the ADIS Young Adults Advisory Board gather online to discuss successful ageing and stigma around Alzheimer's disease



On 29 April, 30 April and 2 May, the members of the ADIS Young Adults Advisory Board (ADIS YA-AB) met online in three sessions that were also attended by David Bartrés-Faz (Universidad de Barcelona), and facilitated by Soraya Moradi-Bachiller (Public Involvement Officer at Alzheimer Europe).

During the first part of the consultations, members of the ADIS YA-AB talked about successful ageing and the reasons why they think some people grow older while maintaining their cognitive abilities optimally. It was also discussed what and how young adults could learn from older adults who aged successfully. The second part of the consultation was focused on the stigma around Alzheimer's disease, which, in young adults, was mostly associated with disinformation and misunderstanding about neurodegenerative diseases and people who have them. Members of the ADIS YA-AB provided insightful feedback during these consultations, which are part of a series of meetings that will help shape a brain health campaign for young adults.

6 MAY

The eBRAIN-Health Public and Patient Advisory Group meets online for a consultation

On 6 May, the members of the eBRAIN-Health Public and Patient Advisory Group met online. They were joined by Daphné Lamirel (Public Involvement Officer at Alzheimer Europe), Dianne Gove (Director for Public Involvement and Ethics at Alzheimer Europe), Sarah Campill (Public Involvement Officer at



Alzheimer Europe) and Klaudia Kwiatkowska (Research Associate at the Department of Innovation and Digitalisation in Law at the University of Vienna).

The meeting kicked off with a presentation by Daphné about the recently agreed-upon proposal of the European Health Data Space (EHDS). The EHDS is a proposal from the European Union to create a system through which information/data about people's health can be accessed more easily, by patients/ individuals, different types of health practitioners (e.g. GPs, specialist doctors) and researchers/organisations conducting research across all countries in the European Union. Klaudia and Daphné then facilitated a consultation, where members were invited to provide their views on this new proposal. In particular, they discussed issues related to the opt-out system of the EHDS. Drawing from examples of other opt-in and opt-out systems (e.g. the EU GDPR or organ donation in the UK), they provided their opinions on the advantages and drawbacks of such a system. Discussions also focused on the types of data that might be shared and accessed via the EHDS for research purposes. Lastly, members gave their views on the exception to the EHDS proposed legislation. The latter specifies that individuals may not be able to opt-out from primary and secondary use of data under the EHDS where the data is used for purposes 'of the public interest', among others.

The conversations were very engaging, with all members contributing actively and sharing their diverse opinions and experiences. The feedback will be used in the context of Public Involvement activities in the eBRAIN-Health project, and to inform the legal and ethics work carried out by Alzheimer Europe and the University of Vienna on the EHDS.

13-15 MAY

PRIME consortium holds its fifth General Assembly



On 13-15 May 2024, the PRIME consortium reconvened for the 5th General Assembly (GA) meeting in the beautiful city of Bologna (Italy). PRIME, an EU-funded research project, aims to unravel the insulin-dependent mechanisms that underly both somatic conditions (i.e. type 2 diabetes, obesity, metabolic syndrome) and brain disorders (i.e. Alzheimer's disease, obsessive-compulsive disorder, autism spectrum disorders). Until now, very little attention has been paid to the role of insulin signalling in brain disorders, and the overlap (or 'multimorbidity') with somatic conditions. Therefore, through PRIME, the aim is to develop tools for improved diagnosis, clinical care and prevention of insulin-related lifespan multimorbidity.

During the GA meeting, the latest research findings were discussed, and early career scientists were given opportunities to present their projects. The participants also enjoyed exploring the charms of Bologna. Additionally, an insightful keynote lecture was provided by Prof. Leszek Czupryniak on GLP-1 drugs, such as Ozempic. He elaborated on how these innovative drugs might enhance cognition and brain function in Alzheimer's disease, though further research is needed in this area. The consortium was also delighted to listen to talks from its project partners Alzheimer Europe, IDF Europe, and ADHD Europe about how to improve communication between researchers and individuals with lived experience. As always, communication is key! PRIME is very grateful to have these initiatives on board and appreciates the constant exchange. It was wonderful for the members to reconnect and discuss the latest research results on insulin and brain disorders, in person. The time in Bologna was indeed inspiring and enriching. As the consortium enters the final seven months of the project, it is committed to diligently compiling collected data and connecting the dots.

Angela Bradshaw represented Alzheimer Europe at the PRIME GA.

Read more about PRIME on the project website: <https://prime-study.eu/>

Follow PRIME on Social Media: X (former Twitter) and LinkedIn

14 MAY

Members of the Multi-MeMo Advisory Board meet online



Shorter- and longer-term mechanisms of multimodal interventions to prevent dementia

Multi-MeMo (“Shorter- and longer-term mechanisms of multimodal interventions to prevent dementia”) is a European funded project that focuses on brain health in older people, overall, and tailored, multidomain interventions (i.e., targeting multiple risk factors simultaneously) for the risk-reduction of cognitive impairment and dementia, in particular.

On 14 May, the first online meeting of the Multi-MeMo Advisory Board took place. The Advisory Board is composed of members of the public, with and without cognitive impairment, from seven European countries. Nine of the 13 members of the Advisory Board participated in the meeting. They discussed two main topics related to multidomain interventions: (1) the intensity of multidomain interventions, and (2) the adherence of participants to the interventions. The meeting was facilitated by Ana Diaz (Alzheimer Europe) and the group discussions were co-facilitated by Mariagnese Barbera (University of Eastern Finland), Laura Forcano (Hospital del Mar Medical Research Institute) and Marissa Zwan (Vrije Universiteit Amsterdam).

During the interactive and lively meeting, the groups examined in detail the terminology and connected concepts of various interventions’ intensity, adherence, barriers, and facilitators. They also shared personal insights into the needs of participants before, during, and after joining a multidomain intervention programme. All the feedback provided to the research partners was very valuable and relevant for carrying out and planning current and future research projects within the Multi-MeMo consortium.

For further information about Multi-MeMo, please visit the project’s website: <https://www.multi-memo.eu/>

15 MAY

Recently-launched REBALANCE project will explore potential of focused ultrasound in Alzheimer’s treatment



Alzheimer’s disease, characterised by progressive memory loss and cognitive decline, presents significant challenges to medical researchers worldwide. A new project entitled “REBALANCE - Mechanisms of focused ultrasound-mediated brain

cleaning coupled with enhanced mechanosensation”, explores a novel approach using focused ultrasound that hopefully could help people with Alzheimer’s disease (AD).

Focused ultrasound (FUS) is a non-invasive technology that uses targeted sound waves to influence brain tissue. This method has the ability to temporarily open the blood-brain barrier (BBB), a protective layer of cells that guards the brain against harmful substances while allowing essential nutrients to pass through. When FUS is applied, sound waves gently vibrate the cells that make up the BBB. This vibration temporarily loosens the junctions between these cells, allowing openings to let molecules through, such as certain medications. This can be particularly useful in brain diseases. Temporarily opening the BBB can also enhance the removal of beta-amyloid plaques, proteins strongly associated with AD. In addition, FUS may induce beneficial neuromodulation or altered nerve activity, which will be explored in the REBALANCE project.

In the REBALANCE project, researchers are exploring the synergy between the mechanical stimulation provided by FUS and targeted pharmacotherapy. A particular focus is on Piezo1 receptors, which play a crucial role in brain cells’ ability to detect and respond to mechanical stimuli. The goal of the project is to understand how FUS and FUS combined with Piezo1 drugs work together and take promising results from preclinical research to early-phase human studies.

The project carefully considers ethical aspects to address any concerns from various perspectives, including the translation of the data and results of preclinical research to early-phase human studies. Therefore, the project also conducts focus groups and interviews not only with basic scientists or clinicians but also with people living with dementia and their supporters.

One of the project partners is the University of Latvia and the university is also collaborating with Alzheimer Europe and the Alzheimer Society of Finland. Alzheimer Europe’s role is to provide input on and assist in organising qualitative research focus groups with people with dementia and carers. Both organisations also contribute to discussions about public involvement in preclinical and clinical research in the context of dementia as well as on ethical issues.

The project’s first consortium meeting was held in early April 2024, in Riga, Latvia. Alzheimer Europe was represented at the meeting by Public Involvement Officer Daphné Lamirel and Chair of the European Dementia Carers Working Group Sonata Mačiulskytė.

16 MAY

Findings from the PRODEMOS study have been published in Lancet Healthy Longevity

THE LANCET
Healthy Longevity



On 16 May, the Prevention of Dementia using Mobile phone Applications (PRODEMOS) project has published a new paper in the journal The Lancet Healthy Longevity, entitled "Prevention of dementia using mobile phone applications (PRODEMOS): a multinational, randomised, controlled effectiveness-implementation trial". This paper describes the design, procedures and outcomes of the PRODEMOS study, which aimed to reduce dementia risk factors in underserved populations at high-risk using a coach-supported mobile health (mHealth) intervention.

In collaboration with the target population, the project's team developed a coach-supported mHealth intervention to reduce dementia risk. They used interviews, focus groups and think-out-loud sessions throughout the intervention development. They hypothesised that a coach-supported mHealth intervention would reduce dementia risk factors in older people at increased risk of dementia from low socioeconomic status populations in the UK and from the general population in Greater Beijing, China, and that this can be successfully implemented. 1488 people were randomly assigned to the PRODEMOS study. Results showed that a coach-supported mHealth intervention aimed at self-management of lifestyle-related dementia risk factors can lead to a reduction of dementia risk as assessed with the CAIDE risk score in participants aged 55–75 years from low-socioeconomic-status populations in the UK and the general population in China. Coverage response rates were low in the UK and fair in China, but in those who participated, perceived appropriateness, acceptability, and feasibility were good, and overall engagement of participants and fidelity among coaches appeared satisfactory. Whether this will translate into the prevention of dementia is unknown and requires a large and long study. Implementation in these target populations appeared feasible, but reaching the populations remains a major challenge.

The publication of this paper coincided with the PRODEMOS presentation at the 10th European Stroke Organisation Conference (ESOC 2024) in Basel, Switzerland by Professor Edo Richard, one of the lead authors on the study from the Radboud University Medical Center in Nijmegen. "The difference we found was small, but consistent. I think we have to be modest about the effectiveness of the mHealth intervention at this point. We do not yet know if this change in a dementia risk

score will eventually translate in a reduction in cognitive decline and dementia.", Professor Richard said. You can find the press release of the conference, including PRODEMOS (on page 7-8), here: https://eso-stroke.org/wp-content/uploads/Day_2_Clinical_Trial_Highlights_Full.pdf

Alzheimer Europe Executive Director Jean Georges and Project Officer Cindy Birck are co-authors of this paper. You can read the paper, here: [https://doi.org/10.1016/S2666-7568\(24\)00068-0](https://doi.org/10.1016/S2666-7568(24)00068-0)

17 MAY

The Euro-PAD initiative holds a scientific symposium in Amsterdam



On 16 and 17 May, the Euro-PAD initiative held a scientific symposium in Amsterdam, aimed to discuss the latest developments in neuroimaging and biomarkers for Alzheimer's disease. This year, the event began with two imaging workshops on the advancements in Positron Emission Tomography (PET) and advanced Magnetic Resonance Imaging (MRI) quantification.

The first afternoon of the symposium officially commenced with a warm welcome from Frederik Barkhof and Lyduine Collij, establishing a collaborative atmosphere for the event. Over 70 participants attended the meeting in person, highlighting the strong interest and commitment within the scientific community. The opening session featured an overview of the Euro-PAD initiative, highlighting the substantial progress made over the past year. The symposium's agenda was packed with insightful scientific sessions covering key topics such as the use of Amyloid-PET in the clinical routine and trials, advancements in disease modelling and MRI-PET analysis. Additionally, on the second day, sessions covered topics on imaging/genetics and developments in fluid biomarkers. Euro-PAD continues the pioneering efforts of the AMYPAD pan-European collaborative framework, integrating several

major cohorts including EPAD, AMYPAD, ALFA+, Prevent-AD and Microbiota. This year, new cohorts were introduced, including the T-POT study, Insight-preAD, SCIENCE and REALAD, reflecting the consortium's expanding scope. The two-day event was marked by lively discussions where delegates had the opportunity to present their latest results, share insights and explore potential collaborations.

AE Project Officer Cindy Birck attended the meeting and presented a talk on communication and dissemination. She provided an overview of consortia outreach through Alzheimer Europe, emphasising the importance of effective communication in scientific research.

20 MAY

Researchers from EU-FINGERS, Lethe and Multi-MeMo projects advocate for social activities in dementia prevention interventions



An international team of researchers highlights the importance of social activities in preventing dementia, in an article called "Social activities in multidomain dementia prevention interventions: insights from practice and a blueprint for the future", published in the journal *Frontiers in Psychiatry*, on 20 May 2024. They advocate for being clearer about what we mean by social activities, how to measure them, and use these insights in interventions.

Current research is hindered by unclear definitions and a lack of standardized measures to assess social activities, resulting in fragmented evidence about protective effects against dementia. Therefore, the authors call for questionnaires that accurately capture engagement in social activities and use them as a point of departure for intervention activities.

Randomized controlled trials, such as the FINGER trial, show that multidomain interventions—including nutrition guidance, physical exercise, cardiovascular management, and cognitive training—can reduce the risk of dementia. These interventions benefit older adults who are cognitively healthy, have mild cognitive impairment, or prodromal Alzheimer's disease.

The authors suggest that incorporating social activities into these interventions can enhance both adherence and effectiveness. Based on interviews, they conclude that participants highly value social activities that increase feelings of social support. One participant stated, "We are a good group of friends, or have become [during the intervention]. We have fun, laugh, and we do our best".

The authors also explore the potential of digital technologies, such as smartphones, Fitbits, and apps, which are increasingly used to deliver interventions. There is uncertainty about the effectiveness of these technologies in measuring or enhancing social activities. Based on a workshop hosted by Alzheimer Europe, involving individuals at risk of dementia and those with cognitive complaints or dementia, the authors recommend using simple tools that increase in-person contact and consider privacy.

In conclusion, the researchers call for more efforts to incorporate social activities into interventions to enhance cognitive health in ageing populations. They aim to (a) develop clear definitions and instructions for measuring social activities, (b) promote social engagement beyond intervention settings, for instance through community participation, and (c) ensure technology and interventions are co-created to address older adults' needs, enhancing rather than replacing in-person activities.

The authors are working in three different EU-funded projects in which Alzheimer Europe is a partner: EU-FINGERS, Lethe and Multi-MeMo. They are: Bruinsma J, Visser LNC, Abaci A, Rosenberg A, Diaz A, Hanke S, Crutzen R, Mangialasche F, Kivipelto M, Thunborg, C. One of the authors, Ana Diaz, is Public Involvement Lead at Alzheimer Europe and Alzheimer Europe is delighted to have been involved in authoring this article.

Article link:

<https://www.frontiersin.org/journals/psychiatry/articles/10.3389/fpsy.2024.1386688/full>

21 MAY

AI-Mind wins at the AIIC-awards during the XXIV AIIC national conference



The third edition of the AIIC-Awards was held during the XXIV AIIC National Conference in Rome, Italy, from 15 to 18 May 2024. The AIIC, the Italian Association of Clinical Engineers, organised the congress under the theme "Chronicity, territory, proximity: we build the digital ecosystem" at the Roma Convention Centre "LA NUVOLA".

The event attracted 2,600 attendees and featured more than 160 speakers, all focusing on the integration of healthcare services in Italy. Discussions centred on managing chronic diseases, addressing local healthcare needs and enhancing patient care proximity through a unified digital ecosystem. Innovative solutions tackling healthcare challenges, from intricate medical devices to logistical processes, were meticulously evaluated.

A highlight of the conference was the AIIC-Awards, which celebrated excellence across 11 categories with a total of 190 proposals. The AI-Mind project triumphed in the category “Methods and experiences in the Health Technology Assessment”. This recognition was particularly significant as attendees had the opportunity to vote for the best project, emphasising the collaborative spirit of the event.

On 18 May, the AI-Mind WP6 leader, Prof. Rossella di Bidino, presented the AI-Mind project during the XXIV Annual Congress of AIIC. Her presentation, titled “The EU project AI-Mind develops and validates methods for the assessment of AI-based technologies: from early HTA to a full assessment,” highlighted the project’s innovative work.

The AIIC-Awards have become a focal point for sharing experiences and nurturing innovation within healthcare, providing both physical and virtual platforms for dialogue, exploration, and collaboration. By propelling forward the most promising ideas, the Awards serve as catalysts for positive change within the healthcare landscape. For more information, please visit the AI-Mind project’s website:

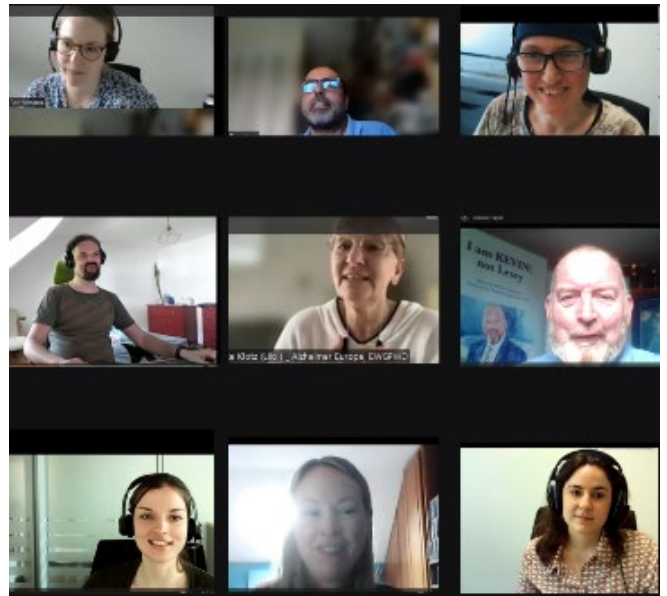
<https://www.ai-mind.eu/blog/ai-mind-wins-at-the-aiic-awards-during-the-xxiv-aiic-national-conference/>

29 MAY

The PROMINENT Public Involvement Board meets online for a consultation about the project’s clinical studies and participant facing material

On 29 May, the members of the PROMINENT Public Involvement Board (PIB) met online. They were joined by Dianne Gove (Director for Public Involvement and Ethics at Alzheimer Europe), Sarah Campill (Public Involvement Officer at Alzheimer Europe), Daphné Lamirel (Public Involvement Officer at Alzheimer Europe) and Lena Sannemann (University Hospital of Cologne).

The meeting began with a presentation by Lena about the validation study of the PROMINENT project. This study aims to test the Clinician Decision Support System (CDSS), examining, for instance, its accuracy, its impact on clinicians’ confidence, and its potential to save time and financial resources. Daphné then explained the purpose of a participant information sheet and an informed consent form in the context of clinical studies.



In smaller group discussions, facilitated by Dianne, Lena and Daphné, the members provided feedback on the participation information and informed consent form that participants of the PROMINENT validation study will receive. They discussed how to make the document more understandable, and respectful and inclusive towards people with cognitive problems and their supporters/carers. They also gave feedback on whether any crucial information was missing from the draft document.

The second half of the consultation focused on gathering input on the design of the validation study. PIB members were asked to comment on potential outcome measures for the study, including which outcomes were seen as essential and which were merely interesting. A final discussion centred on the possible combination of participant-facing materials for both the validation study and another clinical study planned in PROMINENT, weighing the pros and cons.

Overall, the conversations were highly engaging, with all members actively contributing and sharing valuable feedback on the participant-facing material and design of the PROMINENT study. This feedback will help clinical partners in PROMINENT plan the clinical studies and finalise the participant-facing material.

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/>)
- eBRAIN-Health - grant agreement 101058516 (<https://www.ebrain-health.eu/>)
- PRIME – grant agreement 847879 (<https://prime-study.eu/>)
- PRODEMOS - grant agreement 779238 (<https://www.prodemos-project.eu/>)
- LETHE - grant agreement 101017405 (<https://www.lethe-project.eu/>)
- Prominent - grant agreement 101112145 (<https://www.ih-prominent.eu/>)



The **ADIS** 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

The **EU-FINGERS** project is supported by the Luxembourg National Research Fund (INTER/JPND/19/14012609) under the aegis of the EU Joint Programme - Neurodegenerative Disease Research (JPND) - www.jpnd.eu

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

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 Blinkeviciute (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 MAY

MEPs join European Alzheimer's Alliance



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 following MEPs to the alliance:

- Benoît Biteau (European Greens, France)
- Caterina Chinnici (EPP, Italy)
- David Cormand (European Greens, France)
- Maria Angela Danzi (NI, Italy)
- Jarosław Duda (EPP, Poland)
- Carlo Fidanza (ECR, Italy)
- Claude Gruffat (European Greens, France)
- Pär Holmgren (European Greens, Sweden)
- Chris MacManus (European Left, Ireland)
- Ana Miranda Paz (European Greens, Spain)
- Manuela Ripa (European Greens, Germany)
- Caroline Roose (European Greens, France)
- Mounir Satouri (European Greens, France)
- Massimiliano Smeriglio MEP (NI, Italy)
- Francois Thiollet (European Greens, France)
- Marie Toussaint (European Greens, France)
- Stefania Zambelli (EPP, Italy).

The EAA members can be viewed at:

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

SPONSORS OF THE MONTH

Alzheimer Europe would like to express its gratitude to two sponsors for its 2024 Annual Conference:



Read more about sponsorship opportunities here:
<https://www.alzheimer-europe.org/about-us/governance/finances/2024-sponsorship-opportunities>

Help us give a voice to people with dementia

Donate



EU DEVELOPMENTS

7 MAY

EU4Health Civil Society Alliance issues statement on EU health budget



On 7 May, the EU4Health Civil Society Alliance issued a statement outlining concerns over the midterm review of the EU Multiannual Financial Framework (MFF) which saw the EU4Health Programme have EUR 1 billion cut from its total budget.

The statement notes that EU4Health programme is key to strengthening healthcare systems, including preparing for future health threats and increasing Europe's health resilience. Additionally, it highlights that whilst some progress has been made, the programme has not fully delivered on its objectives and budget cuts further threaten its ability to do so. To address these concerns and ensure a fit-for-purpose EU4Health Programme, the signatories call on the EU institutions to:

- Learn lesson from the pandemic and keep health as a key EU priority for the next MFF (2028-2035)
- Engage with civil society organisations on the implications of the EU4Health budget cuts for 2025-2027
- Consider civil society organisations as strategic partners in the operation of the EU4Health programme and support meaningful engagement of civil society organisations, including providing sustainable funding to support their public health mission.

The full statement is available at: <https://eu4health.eu/for-a-strong-and-stable-eu4health-programme/>

15 MAY

European Disability Forum (EDF) publishes enforcement toolkit

The European Disability Forum (EDF) has launched a guide that aims to help persons with disabilities and their organisations ensure that existing legislation on disability rights is enforced and protects their rights.

The guide, "EDF's Enforcement Toolkit", provides an overview of the remedy mechanisms that can be used when a breach of rights occurs (as defined in EU legislation), clarifying which is most appropriate for each circumstance. As enforcement is a combined effort of both European and national bodies, the toolkit makes a distinction between the administrative and judicial levels. The toolkit can be downloaded at:

<https://www.edf-feph.org/publications/edfs-enforcement-toolkit/>



POLICY WATCH

1 MAY

Polish Minister confirms work on national dementia strategy



During Alzheimer Disease International's 36th Global Conference on Alzheimer's disease, Polish Deputy Minister of Health, Wojciech Konieczny, confirmed that the government is developing an interdisciplinary strategy on dementia. During the conference in Krakow, Poland, Deputy Minister Konieczny addressed delegates, highlighting the challenges associated with an ageing population and the risk of various forms of dementia. Additionally, he presented the main principles of the interdisciplinary strategy against dementia that is currently under development.

A summary of the Minister's address is available at: <https://www.gov.pl/web/zdrowie/wiceminister-zdrowia-wojciech-konieczny-bierze-udzial-w-36-tej-globalnej-konferencji-poswieconej-chorobie-alzheimer>

27 MAY

Alzheimer Scotland publishes long-term care findings



On 27 May, Alzheimer Scotland published the findings of its Commission on the Future of Long-Term Care in Scotland. The Commission identified a clear lack of strategic planning and commissioning OF long-term care, with no national or local plans for addressing the current and future

needs of people with dementia, and more specifically, people with advanced dementia.

The report sets out 16 recommendations to deliver a comprehensive and ethical commissioning strategy for long-term care, whilst also exploring a range of alternative models and approaches. Additionally, the report challenges the Scottish Government to re-think how to fund and pay for care, now and in the future.

The recommendations are intended as a roadmap to transform long-term care, with a focus on delivering fairness and equality in the system, to meet the needs of people living with dementia in Scotland. The full report is available at: <https://www.alzscot.org/news/scotland-needs-urgent-plan-for-the-future-of-long-term-care-for-people-with-dementia-long-term-care>

SCIENCE WATCH

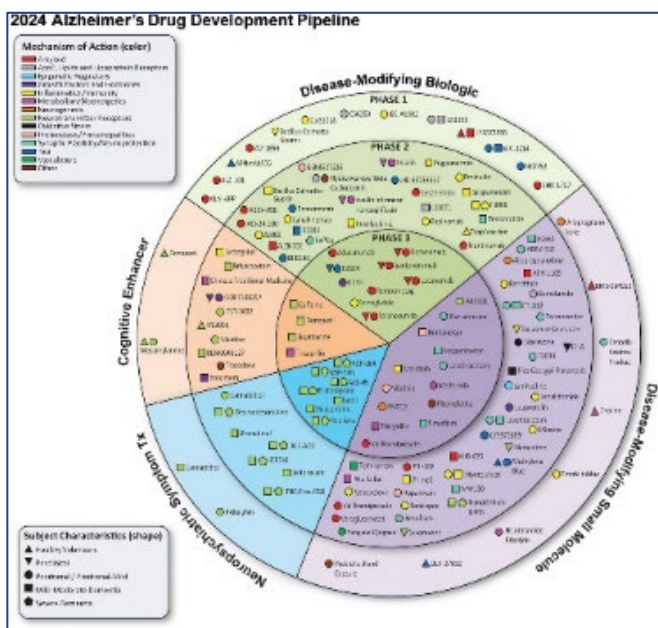
24 APRIL

The 2024 Alzheimer's disease drug development pipeline report is out

The ageing of the global population anticipated the current marked increase in people with Alzheimer's disease (AD). The 2019 Alzheimer Europe Yearbook reported that the number of people with dementia in Europe will almost double by 2050. Recent progress has been made in the development and approval of disease-modifying therapies (DMTs) and symptomatic treatments for neuropsychiatric syndromes of AD. Two DMTs, aducanumab and lecanemab, have recently been approved by the US Food and Drug Administration (FDA) and another, donanemab, is currently under review. In Europe, the European Medicine Agency (EMA) is currently reviewing lecanemab and donanemab.

On 24 April, the annual pipeline report, led by Dr Jeffrey Cummings, was published in *Alzheimer's & Dementia: Translational Research and Clinical Interventions*, a journal of the Alzheimer's Association. The goal of this report was to spot trends in clinical trial design and outcome measures and also to investigate the types of agents and biological targets that are being pursued.

Researchers used data from clinicaltrials.gov, including all current phase 1, 2 and 3 clinical drug trials for AD and Mild Cognitive Impairment, as of 1 January 2024. In this report, authors did not include trials of non-pharmacologic therapeutic approaches such as exercise trials and lifestyle interventions. In total, there were 164 trials assessing 127 drugs, 48 trials in Phase 3, 90 trials in Phase 2 and 26 trials in Phase 1. Of the 164 trials, 34% (N = 56) assess disease-modifying biological agents, 41% (N = 68) test disease-modifying small molecule drugs, 10% (N = 17) evaluate cognitive enhancing agents, and 14% (N = 23) test drugs for the treatment of neuropsychiatric symptoms. Most of the drugs in the AD drug development



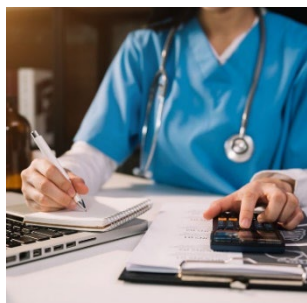
pipeline are DMTs. In total there are 96 DMTs representing 76% of drugs in clinical trials. Considered together all current trials require 51,398 participants. DMTs account of 79% of all participants required for current trials. On average, it takes 2.1 years to recruit the populations for a Phase 1 trial, 2.5 years to recruit enough participants for a Phase 2 trial, and 3.2 years for recruitment of participants for a Phase 3 trial. Authors noted that the approval of DMTs may affect recruitment if patients choose approved over experimental therapies.

Compared to the 2023 pipeline, there are fewer trials (164 vs. 187), fewer drugs (127 vs. 141), fewer new chemical entities (88 vs. 101) and a similar number of repurposed agents (39 vs. 40).

<https://doi.org/10.1002/trc2.12465>

29 APRIL

EMA authorises AriBio's Phase III clinical trial for AD



On 29 April, the biopharmaceutical company AriBio announced authorisation from the European Medicines Agency (EMA) for its POLARIS-AD Phase III clinical trial for early Alzheimer's disease (AD). This follows previous approvals by the US Food and Drug Administration (FDA) and the UK Medicines and Healthcare Products Regulatory Agency (MHRA).

The final decision from EMA was completed on 24 April allowing the trial to proceed in Czech Republic, Denmark, France, Germany, Italy, Spain and the Netherlands. The trial is expected to enrol 1,150 participants across 200 sites globally.

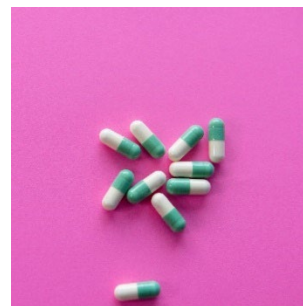
POLARIS-AD is a double-blind, randomised and placebo-controlled study evaluating the efficacy and safety of AR1001 in treatment of people with early AD with confirmed amyloid pathology. AR1001 is a small molecule that has demonstrated its potential as a therapeutic agent for AD via its polypharmacological characteristics with multiple mechanisms to ameliorate AD pathology. POLARIS-AS utilises the Clinical Dementia Rating Scale–Sum of Boxes (CDR-SB) as its primary endpoint, a measure accepted by both the FDA and EMA. Secondary endpoints include Alzheimer's Disease Assessment Scale–Cognitive Subscale 13 (ADAS-Cog 13), Geriatric Depression Scale (GDS), Amsterdam-Instrumental Activities of Daily Living Questionnaire (A-IADL), Mini-Mental Status Examination (MMSE), and changes in plasma and cerebral spinal fluid (CSF) biomarkers.

<https://www.business-wire.com/news/home/20240428705759/en>

1 MAY

New study suggests that antipsychotics are associated with a wider range of adverse outcomes than previously known

Antipsychotic use is widely prescribed to people with dementia for the treatment of behavioural and psychological symptoms (such as apathy, depression, aggression, anxiety, irritability, delirium and psychosis) despite concerns about their use. Previous studies have reported increased



risks for stroke and mortality, and although other adverse side effects have been investigated, results are more limited and less conclusive in people with dementia.

In a new study published in the British Medical Journal (BMJ), a team of researchers led by Dr Pearl L H Mok from the University of Manchester (UK) investigated the risks of multiple adverse outcomes (i.e. stroke, venous thromboembolism, myocardial infarction, heart failure, ventricular arrhythmia, fracture, pneumonia, and acute kidney injury) potentially associated with antipsychotic use in people with dementia. A total of 35,339 older adults, who were aged 50 years or over at the time of the dementia diagnosis and were not prescribed any antipsychotic in the year before their dementia diagnosis, were prescribed an antipsychotic on or after the date of their dementia diagnosis. Each of them was then matched with up to 15 randomly selected individuals with a dementia diagnosis who never became users of antipsychotics. The most prescribed antipsychotics were risperidone, quetiapine, haloperidol, and olanzapine.

Data collected showed that antipsychotic users were more likely than their matched non-users to have a history of mental

illness. Moreover, in the two years after initiation of antipsychotics, and compared with non-use, antipsychotics were associated with increased risks for all outcomes analysed, except for ventricular arrhythmia. In addition, and for almost all the outcomes, risks were highest during the first week of antipsychotic treatment.

The study findings show a wide range of adverse events in a large population of people with dementia with the use of antipsychotics. However, this is an observational study and no firm conclusions can be drawn. Further research is therefore needed and any potential benefits of antipsychotic treatment need to be weighed against risk of serious harm.

<https://www.bmj.com/content/bmj/385/bmj-2023-076268.full.pdf>

7 MAY

APOE4 homozygosity causes a distinct, genetic form of Alzheimer’s disease, according to a new study



A new study, published on 7 May in the Nature Medicine journal, has identified APOE4 homozygosity as a distinct, genetic form of Alzheimer’s disease. According to the research team, led by Juan Fortea and Victor

Montal at the Biomedical Research Institute of Sant Pau (Spain), people with two APOE4 alleles almost always develop Alzheimer’s disease brain pathology – a sign that APOE4 homozygosity should be viewed as an inherited form of Alzheimer’s disease (AD).

APOE4 has consistently been ranked as the strongest genetic risk factor for AD, with two copies boosting the odds of developing the disease up to 15-fold. There are three types of APOE genes a person can carry (APOE2, APOE3 and APOE4) with each person inheriting two copies of APOE from their biological parents. Of these, APOE4 homozygosity – which means the possession of two copies of the APOE4 gene variant – confers the highest risk of developing AD. Until now, APOE4 has been viewed as a genetic risk factor: an element of our genetic makeup that strongly predisposes carriers to AD. Based on their new study, however, the Spanish research team argue that APOE4 homozygosity should be viewed as a distinct, genetic form of AD, as 95% of people carrying two copies of APOE4 have amyloid plaques in the brain by age 65. To understand how APOE4 genotype relates to AD, Juan Fortea and his team gathered brain pathology, biomarker, and clinical data from over 13 thousand participants in clinical studies, including the US-based ADNI, OASIS and NACC studies

and the Spanish ALFA cohort. Of the 13,000 participants involved in the research, 792 carried two copies of the APOE4 gene - the first time such a large number of individuals with APOE4 homozygosity have been studied. When examining brain pathology data, amyloid-PET scans, and cerebrospinal fluid biomarkers (CSF) amyloid-beta42 and p-tau181, the research team observed that by the age of 65, nearly all APOE4 homozygotes had abnormal CSF levels of amyloid beta42. 75% showed signs of amyloid deposition in brain PET scans. By age 80, 88% of APOE4 homozygotes were positive for all biomarker tests: amyloid-PET, and CSF levels.

Next, Fortea and his team looked at clinical symptoms, to see when and how people with two copies of APOE4 started showing symptoms of cognitive impairment and dementia. On average, mild cognitive impairment started at age 71, with dementia developing around two years later. It is important to note that the age of symptom onset varied widely, ranging between 49 to 81 years. In addition, half the individuals with two copies of APOE4 lived until 85 without developing dementia, despite having signs of AD pathology (as measured by PET or fluid biomarker tests) in the brain. Nevertheless, the researchers conclude that APOE4 homozygosity represents a genetic form of AD based on a biological definition of the disease, suggesting the need for individualised prevention strategies, clinical trials and treatments for people carrying two copies of APOE4.

<https://www.nature.com/articles/s41591-024-02931-w>

10 MAY

A brain-healthy lifestyle may be related to lower dementia risk, regardless of demographic or socioeconomic differences



A new meta-analysis, recently published in the journal Alzheimer’s and Dementia, underlines the potential of a healthy lifestyle for dementia risk reduction. The international group of researchers, led by the Alzheimer Centre Limburg (Maastricht University, Netherlands), harmonised and combined infor-

mation from 21 geographically, ethnically and socio-economically diverse cohorts. Those cohorts were part of the Cohort Studies of Memory in an International Consortium (COSMIC) collaboration, representing 31,680 people from 17 countries across six continents.

The potential for risk reduction by lifestyle modification in each cohort was quantified using the group's Lifestyle for BRAin-health (LIBRA) index, which summarises the relative contribution of the following factors to dementia risk: physical activity, smoking, diet, cognitive activity, obesity, high blood pressure, high cholesterol, diabetes, depression, chronic kidney disease, coronary heart disease, and alcohol consumption. Demographic information was also collected, along with information about education and socio-economic position (inferred from income and occupation).

The authors found that a generally healthier lifestyle was associated with a lower risk for dementia in a majority of included cohorts. More specifically, a one point decrease in LIBRA scores (indicating a healthier lifestyle and ranging from -5.9 to +12.7) was associated with a 6% decrease in dementia risk. They further note that these associations remained generally stable for people with different levels of educational attainment, socio-economic status, and were also comparable between men and women.

However, though a healthier lifestyle predicted dementia risk across geographical regions, this was particularly pronounced in Asian cohorts. "Our findings underline the prospect of lifestyle modification for dementia risk reduction, which appears to be relevant on a global scale", Stephanie Van Asbroeck, lead author of the paper, explains. The full open-access article can be read here: <https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.13846>

15 MAY

Antihypertensive medication classes and risk of incident dementia in primary care patients: a longitudinal cohort study in the Netherlands



On 15 May 2024, a study on antihypertensive medication classes and risk of incident dementia in primary care patients was published in the journal *The Lancet Regional Health - Europe*. This was a longitudinal cohort study conducted in the Netherlands.

Hypertension is a modifiable risk factor for dementia affecting over 70% of individuals older than 60. Lowering dementia risk through preferential treatment with antihypertensive medication (AHM) classes that are otherwise equivalent in indication could offer a cost-effective, safe, and accessible approach to reducing dementia incidence globally, write the researchers

responsible for the study. Certain AHM-classes have been associated with lower dementia risk, potentially attributable to angiotensin-II-receptor (Ang-II) stimulating properties. Previous study results have been inconclusive, however, and the researchers thought this was possibly due to heterogeneous methodology and limited power. They therefore aimed to comprehensively investigate associations between AHM (sub-)classes and dementia risk using large-scale continuous, real-world prescription and outcome data from primary care.

They used data from three Dutch General Practice Registration Networks. Primary endpoints were clinical diagnosis of incident all-cause dementia and mortality. Using Cox regression analysis with time-dependent covariates, they compared the use of angiotensin-converting enzyme inhibitors (ACEi) to angiotensin receptor blockers (ARBs), beta blockers, calcium channel blockers (CCBs), and diuretics; and Ang-II-stimulating- to Ang-II-inhibiting AHM.

Among patients receiving AHM, ARBs, CCBs, and Ang-II-stimulating AHM were associated with lower dementia risk, without excess mortality explaining these results. Extensive subgroup and sensitivity analyses suggested that confounding by indication did not importantly influence these findings. The researchers state that dementia risk may be influenced by AHM-classes' angiotensin-II-receptor stimulating properties. An RCT comparing BP treatment with different AHM classes with dementia as outcome is warranted, they conclude.

Study link: <https://www.sciencedirect.com/science/article/pii/S2666776224000942>

20 MAY

Recent study identifies genetic variant which may protect against APOE ε4

People carrying the ε4-allele of the Apolipoprotein E gene (APOE ε4) have a significantly higher risk for developing Alzheimer's disease, as compared to non-carriers. However, some carriers remain cognitively healthy, indicating the presence of protective mechanisms against its pathological effects. In a recent study published in *Acta Neuropathologica*, a group of researchers lead by Columbia University New York (US) set out to assess genetic variants which may affect APOE ε4 in Alzheimer's disease.

For this, they conducted whole genome sequencing (a method in which information about an individual's entire genome is being collected) in a large group of people from the US. Doing so, they were specifically interested in those genetic variations only present in cognitively healthy APOE ε4 carriers. Of 510 such variants, two genes (fibronectin 1/FN1 and collagen type VI alpha 2 chain/COL6A2) were especially highly represented. FN1 encodes a protein bearing the same name, which supports cell functioning and is also found in the blood-brain barrier.

In a second analysis step using another group of APOE ε4 carriers, the researchers found that carriage of a certain variant of FN1 (rs140926439) was associated with 71% lower odds of developing Alzheimer's disease and a later disease onset by 3.37 years, on average. In further analyses using zebrafish models, deletion of an equivalent to the FN1 gene gave rise to beneficial neuronal processes, such as less gliosis (change in glial cells in reaction to disease or injury to the central nervous system).

While fibronectin generally supports functioning of cells, too much of it could impair the clearance of toxic proteins, and thus add to the pathogenic effect of APOE ε4. A variation in the FN1-gene, resulting in less FN1 deposition may, in turn, be protective against such pathogenic processes. The full open-access article can be read here: <https://link.springer.com/article/10.1007/s00401-024-02721-1>

22 MAY

Recent Finnish register study explores criminal behaviour in alcohol-related dementia and Wernicke-Korsakoff syndrome



A recent paper by Anniina Palm and colleagues studied alcohol-related brain disorders like Wernicke-Korsakoff syndrome and alcohol-related dementia. Despite the data

that shows a strong link between alcohol and crime, almost no research exists on the criminal behaviour of people living with these conditions. Therefore, this study aimed to gain further insights into the complex relationship between alcohol-related cognitive impairments, i.e. Wernicke-Korsakoff syndrome and alcohol-related dementia, and criminality.

The included data focused on people diagnosed with Wernicke-Korsakoff syndrome (n=1149) or alcohol-related dementia (n=2432) in Finland between the years 1998 and 2015. The data on diagnoses, mortality, and type of committed crimes were obtained from Finnish nationwide registers and compared to the general population in Finland. The crime rates were looked up before and after diagnosis.

35.6% of people with Wernicke-Korsakoff syndrome and 23.6% of people with alcohol-related dementia committed crimes (e.g. property offences, traffic offences, violent crimes). In both cases after diagnosis, the crime rates decreased significantly. The crime rates declined linearly in the four years before and after diagnosis, with a marked reduction post-diagnosis.

The study was published in the journal *European Archives of Psychiatry and Clinical Neuroscience*. To learn more about the paper, follow the link: <https://pubmed.ncbi.nlm.nih.gov/38613687/>

28 MAY

New study investigates the gender-specific differences in the relationship between social activity and dementia risk



Poor social health has been identified as a potentially modifiable risk factor for dementia. Yet little research has been conducted to examine how the link between social activities and dementia might vary between men and women.

A new study by Htet Lin Htun and colleagues, published in May 2024 in the *Journal of Gerontology*, focused on analysing the relationship between different types of social activities and dementia risk, and looked specifically at how this relationship may be different based on people's gender. The study involved Australians who lived in the community and were 70 or older. A total of 9,936 participants were enrolled in the study and were followed up over time. They were asked to complete questionnaires about the social activities they engaged in. Data about dementia diagnosis was also gathered. The association between social activities and dementia was analysed over a median period of 6.4 years and adjusted for the effects of age, education, baseline global cognition and depression. The study results revealed some gender-specific results. In particular, for men, interpersonal social support (in this case, having nine or more relatives that they felt close enough to call for help) was associated with a reduced risk of developing dementia. For women, providing care for a person with an illness or a disability was associated with decreased dementia risk. Surprisingly and unlike men, women with five friends or more whom they felt comfortable discussing private matters were more likely to develop dementia (compared to having two friends or less). No other significant association between social activities and dementia risk was found.

The authors comment that these findings may be partially explained by existing gender roles and societal expectations. In particular, men may often get more support from relatives due to their traditional roles as 'providers and protectors'. Women, on the other hand, are expected to maintain wide social networks and engage in informal caring duties. Balancing multiple

social roles could lead to increased stress and less meaningful relationships for women.

The researchers also found that many social activities previously linked to dementia no longer showed a significant connection to dementia risk when adjusting for the factors that the study took into account. It is postulated that this might be because most of the study participants were socially active, with

only a very small fraction experiencing social isolation or loneliness.

[Social Activities and Risk of Dementia in Community-Dwelling Older People: Gender-Specific Findings From a Prospective Cohort Study - PMC \(nih.gov\)](#)

MEMBERS' NEWS

2 MAY

The Alzheimer Society of Ireland marks 30 years of national fundraiser



On 2 May, The Alzheimer Society of Ireland's (The ASI's) Alzheimer's Tea Day saw communities across Ireland come together to celebrate 30 years of raising vital funds and awareness for those affected

by dementia. ASI staff, board, volunteers, advocates, supporters and service users raised a cup of kindness in support of the 64,000 people living with the condition in Ireland and their family carers. The fundraising campaign garnered significant national and local media coverage, including a live broadcast from The ASI's Day Care Centre in Kildangan, County Kildare. On 9 May, the All-Party Oireachtas Group on dementia marked Tea Day at the Irish Parliament to raise awareness for The ASI. The event was attended by TDs (Members of the Irish Parliament), Senators and representatives from The Alzheimer Society of Ireland, members of The Irish Dementia Working Group and The Dementia Carers Campaign Network. It was an excellent opportunity to bring the lived experience of dementia to political representatives and continue The ASI's work to build understanding of dementia in the political system. Funds raised through Alzheimer's Tea Day will support critical services like the Alzheimer's National Helpline, day care, home care, family carer training, social clubs and Alzheimer cafés.

10 MAY

The Alzheimer Society of Ireland wins at Irish Healthcare Centre 2024 Awards



On 10 May, The Alzheimer Society of Ireland's (The ASI) 'Creating a Dementia Inclusive Generation' programme won the Healthcare Initiative Student Programme Award at the Irish Healthcare Centre Awards. The awards celebrate and recognise the incredible work, dedication and achievements in Irish healthcare. The ASI was shortlisted in the categories of best use of information technology (for two initiatives), day care centre of the year, and student programme, with the 'Creating a Dementia Inclusive Generation' programme winning in the latter category.

The ASI congratulates its Community engagement team – which works tirelessly to deliver this programme – on this remarkable achievement. The 'Creating a Dementia Inclusive Generation' transition year programme aims to educate teenagers about dementia and remove its stigma; it is delivered to schools across Ireland. The ASI created this programme in collaboration with the Dementia Services Information and Development Centre.

The ASI congratulates the winner and nominees and highlights that the organisation's operations, community engagement, and external learning and development teams do exceptional work. The recognition across multiple categories highlights the dedication and commitment of The ASI in providing exceptional care and support for people living with dementia and their families.

13 MAY

Alzheimer's Care Armenia founder Jane Mahakian receives prestigious Armenian American Medical Society President's Leadership Award



American-Armenian gerontologist and founder of Alzheimer's Care Armenia, Dr Jane Mahakian has been awarded the 2024 Armenian American Medical Society (AAMS) President's Leadership Award. This prestigious recognition is a testament to her unwavering dedication and commitment to advancing healthcare in Armenia. Dr Mahakian has been at the

forefront of developing ground-breaking Alzheimer's disease programmes and services in Armenia and has made significant contributions to the field.

Her hard work and commitment have not gone unnoticed, as she was also awarded the City of Glendale Mayor's Commendation and Certificate of Recognition from the California State Senate. Alzheimer's Care Armenia is beyond proud of Dr Mahakian and her achievements, and looks forward to seeing her continue to make a positive impact in Armenia for people with Alzheimer's and their families.

22 MAY

Czech Alzheimer Society and Freya translate Alzheimer Europe guide aimed at raising awareness of issues around sex, gender and sexuality in dementia



A Czech language version of Alzheimer Europe's guide to help raise awareness of issues around sex, gender and sexuality in dementia was published on 22 May 2024, translated by our Czech member association Česká alzheimerovská společnost (Czech Alzheimer Society) and their colleagues at Freya, z. s. - Institut sexuality a vztahů (Freya - Institute of Sexuality

and Relationships).

The original English language version, *Sex, Gender and Sexuality in the Context of Dementia: A guide to raise awareness amongst health and social care workers* was written by Alzheimer Europe in 2022 (published in January 2023) and is based on the ethics report *Sex, gender and sexuality in the context of dementia: a discussion paper*, published by Alzheimer Europe in December 2021.

The guide is about the experience and wellbeing of men, women and non-binary people with dementia who are living alone or with a partner and who may or may not be sexually active. We draw attention to inequality, discrimination and lack of sensitivity towards their needs and wishes, both from other people and through structures and procedures within society, also towards their families, carers and in some cases health and social care workers. The guide is not limited to the experience of LGBTQ+ people but their experience is often qualitatively different to that of non-LGBTQ+ people and they encounter several issues that others do not, hence the frequent reference to this group in the guide.

The new Czech version of the guide can be downloaded from the Alzheimer Europe website, at:

https://www.alzheimer-europe.org/sites/default/files/2024-05/cz_sex_gender_report_final.pdf

25 MAY

The Alzheimer Society of Ireland's Bessboro Day Centre launches first-of-its-kind Activity Lodge and celebrates the 30th anniversary of Tea Day

On 25 May, The Alzheimer Society of Ireland's (The ASI's) Bessboro Day Centre in County Cork officially opened its Activity Lodge. The first-of-its-kind in Ireland, the Activity Lodge will help clients who have been diagnosed with young onset dementia (under 65 years) and those in the early stage of their dementia journey, providing an opportunity to meet socially and engage in community activities tailored to their interests and with their peers. The Activity Lodge is focused on its garden to help users reconnect with the natural world.



Minister of State for Mental Health and Older People, Mary Butler, T.D. (Member of the Irish Parliament) officially opened the Activity Lodge at The ASI's Bessboro Day Centre in front of esteemed guests including public representatives, day centre users, their families and carers, community groups who have supported the development of the Activity Lodge and the wider community.

The event was also the culmination of a month-long celebration of the 30th anniversary of Alzheimer’s Tea Day which saw over 800 Tea Day events take place across Ireland. The official opening of the Activity Lodge aired on Virgin Media News, Ireland’s national independent television news service.

28 MAY

Spominčica Alzheimer Slovenija won the 2024 award of the City of Ljubljana



Spominčica Alzheimer Slovenija won the 2024 award at the ceremonial event of the City Council of the Municipality of Ljubljana, where the highest awards were presented.

Štefanija L. Zlobec, president of Spominčica, received the award of the City of Ljubljana and, on this occasion, she said that the award represents recognition for the many years of dedicated work performed by Spominčica. She expressed her sincere gratitude for the support and cooperation of the City of Ljubljana in creating a friendly environment for all citizens, including people with dementia and their family members and carers.



LIVING WITH DEMENTIA

21 May: Lieselotte Klotz and Johannes Förner write "Together for the Future: Patient Representatives at the Perspective Forum of the German Future Prize"



At the suggestion of the German Centers for Health Research (DZG), I, Lieselotte Klotz (member of the DZNE Patient Advisory Board, member of the "Living with Dementia" Advisory Board DAIZG, and member of the European Working Group of People with Dementia - EWGPWD, Alzheimer Europe), together with Johannes Förner (member of the DKFZ Patient Advisory Board and member of the DZG-wide Working Group on Patient Involvement), were sent by the Federal President's Office as knowledgeable patient representatives to the Perspective Forum as part of the German Future Prize. The event, themed "AI in Medicine - Opportunities and Challenges," took place on 19 March 2024, from 10 a.m. to 3:45 p.m. at the House of Bavarian Economy in Munich.

The aim of the event was particularly to foster exchange and networking among the nominees and laureates from the healthcare sector of the German Future Prize with young people – students, apprentices, nursing students, as well as alumni of Youth Research and other representatives from academic and economic life. The event was moderated by Yve Fehring (ZDF), who also hosted the award ceremony for the German Future Prize 2023.

The German Future Prize annually honours outstanding technical, engineering, or scientific innovations, as well as software and algorithm-based innovations, which, in addition to scientific achievement, are characterised by the market viability of the products, their potential to create jobs, and their contribution to societal transformation. Information about the Future Prize and previous

laureates can be found on the German Future Prize homepage: <https://www.deutscher-zukunftspreis.de/en>. The invitation from the Federal President's Office emphasises the importance of collaboration between patient representatives and researchers, medical professionals, pharmaceutical industry representatives, government officials, policymakers, and healthcare professionals such as nurses, therapists, and social workers.

Our participation offered a unique opportunity to bring patients' perspectives into the debate about innovative technologies in medical research and to represent the voice of those affected in this important forum. The significance of this exchange and networking is immense. Through collaboration, new insights can be gained, barriers overcome, and innovative solutions developed together. As an introduction to the topic, Prof. Fabian Theis from the Helmholtz Munich Computational Health Center presented his research approach on the use of AI in data-based medicine. The panel discussion "AI in Healthcare – Opportunities and Challenges" brought together laureates and experts to discuss various aspects of AI in research, medicine, and care. In the afternoon, all participants met in working groups to actively work together on diverse topics and projects. The results of these working groups clearly highlighted that AI presents different opportunities and challenges for each of the target groups (users, patients, and researchers) that must be considered.

Lieselotte Klotz commented:

"The PerspectiveForum radiated an incredible spirit! Hope and enthusiasm were the core feelings, but also incomprehension as to why AI is so underutilised and underused in healthcare. MRI (Magnetic Resonance Imaging), for example, plays an important role in therapy with Lecanemab. We see the low-field MRI platform developed by Prof. Dr Uder, Dr Grodzki, and Dr Biber as a key innovation in medical imaging. This new technology offers a cost-effective, accessible, and reliable alternative to conventional MRI technology. Concrete benefits include improved early detection, person-centred treatment of dementia diseases, reduction of physical strain through fewer incorrect diagnoses, and improved therapy and treatment concepts. This gives hope for a better future for those affected and their loved ones."

Johannes Förner commented:

"Active patient involvement advances our healthcare system and leads to better outcomes for patients, just as the progressive use of AI does. AI means both the further development of previously successful medical technology and the expansion of this technology with new, ground-breaking approaches. The benefits are clear: newer, better, faster, and more accurate diagnostic and therapeutic options, as well as relieving medical professionals from routine tasks, allowing for a more intense focus on patients with personalised approaches in diagnosis and therapy."

Our conclusion: The participation of patient representatives at the Perspective Forum of the German Future Prize is another important step towards more participation, inclusion, and a better future in healthcare. A heartfelt "thank you" to the organisers and the patron of this very important event!

<https://www.dzd-ev.de/en/latest/news/news/article/gemeinsam-fuer-die-zukunft-patientenvertretende-beim-perspektivforum-des-deutschen-zukunftspreises/index.html>

NEW PUBLICATIONS AND RESOURCES

2 MAY

touchNEUROLOGY offers free-to-access educational resources for healthcare professionals to sustain their professional development and improve clinical practice and patient outcomes

If you are a healthcare professional wishing to sustain your professional development and improve clinical practice and patient outcomes, you may be interested in touchNEUROLOGY's free-to-access educational resources. Sign up and benefit from:

- 1,000+ topical and insightful peer reviewed journal articles
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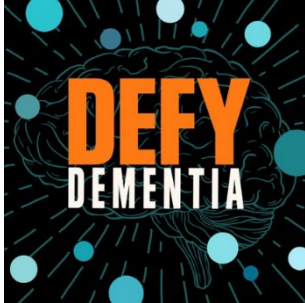
Find out more and access these resources via:

<https://touchneurology.com/your-free-10-minutes-at-a-time-medical-education/>



6 MAY

Defy Dementia podcast is for anyone interested in brain health



Defy Dementia is a podcast series dedicated to helping listeners reduce their dementia risk. Join the presenters on an exploration of dementia risk, as they interview experts and hear inspiring stories from people with lived experience. They also share practical advice to help "optimise the ageing journey".

Defy Dementia is hosted by Jay Ingram (Canadian author and broadcaster) and Dr Allison Sekuler (President and Chief Scientist, Baycrest Academy for Research and Education, and the Centre for Aging + Brain Health Innovation).

Tune in and subscribe via: <https://pod.co/defy-dementia>

8 MAY

New German-language manual published to help assess capacity of people with dementia to give consent

On 8 May, a German-language manual to help assess capacity of people with dementia to give consent was published by Kohlhammer Verlag. The manual, written by researchers at

Ruhr-Universität Bochum provides practice-oriented advice to help carers, supporters and healthcare professionals to support people with dementia to make therapy decisions and assess their ability to consent. The manual accompanies the guideline "Consent of people with dementia to medical measures" and makes the recommendations from the guideline applicable to practice. For the first time, the internationally recognised instruments for assessing the ability to give consent, MacCAT-T and MacCAT-CR, are also included in a complete German translation.

The manual is available here: <https://shop.kohlhammer.de/entscheidungsassistenz-und-einwilligungsfahigkeit-bei-demenz-38716.html#147=19>

The guideline here: <https://shop.kohlhammer.de/einwilligung-von-menschen-mit-demenz-in-medizinische-massnahmen-37897.html#147=19>

And here for free as a PDF: <https://register.awmf.org/de/leitlinien/detail/108-001>



AE CALENDAR 2024

DATE	MEETING	AE REPRESENTATIVE
3-4 June	35 th Alzheimer Europe Conference site inspection (Bologna, Italy)	Gwladys
3-4 June	AD-RIDDLE kick off meeting (Stockholm, Sweden)	Ana, Ange, Lukas and Sarah
4-5 June	ADIS General Assembly meeting (Regensburg, Germany)	Chris and Soraya
5-6 June	AI4Hope General Assembly meeting	Daphné and Lukas
6 June	Lethe Advisory Board	Ana
9-11 June	GoALS workshop on therapies for AD (Paris, France)	Ange
12 June	OECD (Organisation for Economic Co-operation and Development) Workshop on long-term care	Jean
12 June	Farewell to some members of the European Working Group of People with Dementia (EWGPWD)	Ana, Daphné, Dianne, Sarah and Soraya
13 June	WHO Non-State Actor Engagement Plan	Owen

17 June	Alzheimer Europe Board meeting (Luxembourg, Luxembourg)	AE Board and staff
18 June	Company round table meeting (Luxembourg, Luxembourg)	AE Board, members, sponsors and staff
18 June	Alzheimer Europe Annual General Meeting (Luxembourg, Luxembourg)	AE Board, members and staff
18 June	Information meeting with Lilly (Luxembourg, Luxembourg)	AE Board, members and staff
18-19 June	Consultations with the European Dementia Carers Working Group (EDCWG) (Luxembourg, Luxembourg)	Ana, Daphné, Dianne, Sarah and Soraya
19 June	Alzheimer Europe Public Affairs Meeting	AE members and staff
26 June	Consultation with the ADIS Advisory Board (Luxembourg, Luxembourg)	Ana and Soraya
27-28 June	34 th Alzheimer Europe Conference site inspection (Geneva, Switzerland)	Cristina, Gwladys and Jean

CONFERENCES 2024

DATE	MEETING	PLACE
6-7 June	Care, communication and biomedical challenges, https://www.neurocare.si/programme2/	Ljubljana, Slovenia
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, https://www.alzheimer-europe.org/	Geneva, Switzerland
29 October – 1 November	17 th Clinical Trials on Alzheimer's Disease (CTAD), https://www.ctad-alzheimer.com/	Madrid, Spain

34th Alzheimer Europe Conference

New horizons – Innovating for dementia

Geneva, Switzerland

8 - 10 October 2024 #34AEC

www.alzheimer-europe.org/conferences

