Alzheimer Europe

Newsletter
FEBRUARY 2025

## HIGHLIGHTS

## CONTENTS

# WELCOME

I am delighted to start off by welcoming three new members to the European Alzheimer's Alliance (EAA) this month, Michal Szczerba MEP (EPP, Poland), Vlad Vasile-Voiculescu MEP (Renew Europe, Romania) and Tomislav Sokol MEP (EPP, Croatia). The EAA is a non-exclusive, multinational and cross-party group of Members of the European Parliament (MEPs), which is now 86 members-strong and provides vital support in ensuring dementia is a policy priority at the European level.

Staying with policy but widening the net to the global level, we were pleased that the Executive Board of the World Health Organization (WHO) has adopted a recommendation to extend the Global Action Plan on the Public Health Response to Dementia 2017-2025, which would see it continue until 2031. The 78th World Health Assembly (WHA), at which the final decision will be made, will be held in May, so watch this space for further details.

Another important announcement came from the European Medicines Agency (EMA), which has reaffirmed its positive opinion on lecanemab, after discussions at the February Committee for Medicinal Products for Human Use (CHMP) meeting. The European Commission had asked the CHMP to consider updating its opinion, following new information on the safety of lecanemab, but after the February CHMP meeting the Agency announced that no updates would be required to its opinion. With this in mind, the Commission will now resume the decision-making process for lecanemab, Biogen and Eisai's anti-amyloid immunotherapy for early Alzheimer's disease.

In dementia research, obtaining informed consent presents unique challenges, in part due to participants' cognitive impairments and fluctuating decision-making capacities. Much of the literature on this topic has previously centred on the perspectives of researchers and healthcare professionals, with less focus on individuals with lived experience of dementia. Alzheimer Europe is pleased to have published a perspectives article in the Frontiers in Dementia journal, addressing this gap.

I am also pleased to announce two more publications from Alzheimer Europe: The 47th edition of our Dementia in Europe magazine has been launched, with many interesting developments from across Europe in relation to policy, research, culture, advocacy and dementia care. I hope you enjoy this new edition of our magazine and its special supplement as well, focusing on the 34th Alzheimer Europe Conference (34AEC) in Geneva. If you were at the conference, we hope you enjoy looking back at some of the highlights from the event and if you were unable to join us in Geneva, we hope that this publication gives you a real flavour of our Annual Conference and encourages you to join us in Bologna (Italy) from 6 to 8 October, for this year's edition, taking place under the banner "Connecting science and communities: The future of dementia care". As a reminder, the Call for Abstracts is open until 30 April and our Early Bird registrations close at the end of June.

**Jean Georges**, Executive Director

# ALZHEIMER EUROPE

### 4 FEBRUARY:

## Alzheimer Europe perspective in Frontiers in Dementia addresses informed consent in dementia research

In dementia research, obtaining informed consent presents unique challenges, in part due to participants' cognitive impairments and fluctuating decision-making capacities. Much of the literature on this important topic has centred on the perspectives of researchers and healthcare professionals, with less focus on individuals with lived experience of dementia (people living with or at risk of dementia; and their carers or supporters).

On 4 February, Alzheimer Europe published a perspectives article in the Frontiers in Dementia journal, addressing this gap by highlighting the views of people with dementia and carers regarding informed consent, drawn from its Public Involvement activities. Led by Ana Diaz (Public Involvement Lead) this article builds upon previous consultations with the European Working Group of People with Dementia (EWGPWD), as well as discussions from a face-to-face meeting about informed consent forms and processes for the ADIS and EPND projects. The EWGPWD was established by Alzheimer Europe in 2012, and is currently composed of 14 people with dementia from different European countries and with different types of dementia, nominated by a national Alzheimer Association for a term of office of three years.

The article highlights several barriers and facilitators in the informed consent process. People with lived experience of dementia underlined the necessity for consent materials to be understandable, advocating for clear and straightforward language. Beyond clarity, the discussions underscored the importance of respect and autonomy, ensuring that the values and interests of individuals with dementia remain central throughout the research process. The paper also touches upon emerging challenges in dementia research, such as the ethical considerations surrounding artificial intelligence and data sharing (or the secondary use of data). The authors argue that continuous involvement of people with lived experience is crucial in shaping consent practices to navigate these challenges. Read the open access article: https://www.frontiersin.org/journals/dementia/articles/10.3389/frdem.2025.1536762/full

### 12 FEBRUARY:

## We hope you enjoy our special new publication looking back at the 34th Alzheimer Europe Conference in Geneva!

We are delighted to announce a special publication about the 34th Alzheimer Europe Conference (34AEC) which took place from 8 to 10 October 2024 in Geneva (Switzerland). If you were at the conference, we hope you enjoy looking back at some of the highlights from the event. If you were unable to join us in Geneva, we hope that this publication gives you a real flavour of our conference and encourages you to join us for a future event, perhaps even for our upcoming 2025 conference #35AEC taking place in Bologna, Italy, from 6 to 8 October 2025 under the banner “Connecting science and communities: The future of dementia care”.

This new publication, which is a supplement to the upcoming 47th edition of our "Dementia in Europe" magazine (to be launched at the end of February 2025), is currently available in an electronic format (see download link at the end of this article), while printed copies will be sent out together with the magazine during the month of March.

The conference supplement includes a “Warmup” section, where you will find coverage of a number of important pre-conference meetings. We then take a look at all of the conference plenary sessions (Opening Ceremony, Plenaries 1 to 5, Closing Ceremony).

On top of coverage of the ancillary meetings and plenary sessions in Helsinki, we are pleased to share some other aspects of the event, including:

- A special symposium on “Preparing for new AD treatments” organised by Alzheimer Europe and supported by the gold sponsorship from Lilly
- A special symposium presenting the work of ten early-stage researchers, who were selected by our jury to benefit from attendance bursaries provided by the Alzheimer Europe Foundation
- the “Rolling for Dementia” campaign led by Golnaz Atefi, a dementia researcher based at Alzheimer’s Centre Limburg, who skated over 1,000 km across Europe, on her way to Geneva, to raise awareness about the importance of diversity and representation in dementia research

- some of the many and varied research projects in which we are involved attending and presenting their work at the event
- some thoughts from our conference co-hosts, Alzheimer Switzerland and Alzheimer Geneva
- some highlights from social media
- a few thoughts from keynote speakers who attended and presented in Geneva
- and a few facts and figures surrounding the event.

**Photos and videos of 34AEC**

Throughout the publication, we include many photos, as well as links to videos of our recorded sessions (also available in French and German) so you can revisit them or view them for the first time, if you did not attend 34AEC.

For more photos, you can also view the conference photo gallery page (scroll to bottom of page, below the media links).

We hope you enjoy this very special conference publication!

Download it here: https://bit.ly/34AEC_Highlights_Supplement

### 24 FEBRUARY:

## Alzheimer Europe Board meets online

The Alzheimer Europe Board met online on 24 February 2025. During the three-hour meeting, the Board approved the Financial Report for 2024 which was audited by our registered accountants “Group Audit Luxembourg”. The Board also approved the report for Alzheimer Europe’s operating grant activities. The next meeting of the Alzheimer Europe Board will take place in Luxembourg, on 24 and 25 March.

### 27 FEBRUARY:

## Dianne Gove talks to touchNEUROLOGY about the stigma around dementia

Dianne Gove, Director for Public Involvement and Ethics at Alzheimer Europe has participated in a Q&A with touchNEUROLOGY, discussing how stigma affects those living with dementia, strategies to raise awareness, and future plans to combat stigma in 2025.

You can read her interview, here: https://touchneurology.com/insight/stigma-and-alzheimers-dementia-a-qa-with-dianne-gove-alzheimer-europe/

### 28 FEBRUARY:

## Alzheimer Europe presents the 47th edition of Dementia in Europe magazine

DEMENTIA IN EUROPE
THE ALZHEIMER EUROPE MAGAZINE

Alzheimer Europe

Issue 47
February 2025

Tilly Metz MEP
hosts European Parliament
lunch debate on the future of dementia research in Europe

Attila Beneda
Deputy State Secretary for Family Affairs outlines plans for Hungary's national dementia strategy

Magnus Renggli
wins Alzheimer Europe's Anti-Stigma Award for his documentary "Alzheimer mit 50"

Marine Uldry
outlines the forthcoming review of the EU's compliance with the United Nations Convention on the Rights of Persons with Disabilities

It is with great pleasure that we introduce the 47th edition of our Dementia in Europe magazine. Following the 34th Alzheimer Europe Conference (34AEC) in Geneva, (Switzerland), it has been a busy period with lots of interesting developments across Europe in relation to policy, research, culture, advocacy and dementia care.

In our first section on Alzheimer Europe’s work, we look back at our most recent European Parliament lunch debate, hosted by Tilly Metz MEP (Greens/EFA, Luxembourg). We also recount our Anti-Stigma Award dinner, hosted by Nina Carberry MEP (EPP, Ireland), at which the winner of the Award, Magnus Renggli and the runners-up Andreas Kreimaier and Ofelya Kamavosyan were able to showcase their fantastic work before accepting their prizes! We then look at the publication of our Dementia in Europe Yearbook 2024, focused on independent living and housing for people with dementia, identifying gaps and sharing good practice.

Turning to European projects, we are excited to introduce three new projects in which we are involved: Predict-FTD, which aims to validate a comprehensive set of biomarkers and develop a diagnostic tool that uses artificial intelligence (AI) for swift and accurate diagnosis; Dorian Gray, which aims to devise personalised risk stratification and holistic management for prevention of cognitive impairment in patients with different cardiovascular phenotypes; and, FluiDx-AD, which examines a novel test trio to detect amyloid beta peptides in saliva and blood for enhanced diagnosis and management of Alzheimer's disease.

We then speak to T. Rune Nielsen, who led the recently-concluded TIMING project, to find out about the project’s work on improving timely diagnosis of dementia in people from minority ethnic groups. In our final article in the Alzheimer Europe section, we learn more about how the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) have contributed their lived experience to the PANEUCARE project, which focuses on multidirectional knowledge transfer.

We open the Policy Watch section with positive news from Hungary, where a new dementia strategy is under development. We look at the conference on dementia, held by our national member in Hungary, the Social Cluster Association, before hearing from the Deputy State Secretary Attila Beneda about what to expect in the new strategy. Moving to the European level, we speak to the Co-Chairs of the European Alzheimer's Alliance about their priorities for the year ahead and how they intend to support our work to prioritise dementia. Continuing the focus on the EU, we look at some of the new College of Commissioners, focusing on those whose remits have the most relevance for people living with dementia. Our next article recaps our "Dementia Needs EU" European Election Campaign which ran throughout 2024, looking at the results of the campaign, as well as the activities of Alzheimer Europe and our members on the first ever "European Parliament Dementia Day" held on 10 December 2024, which officially marked the end of this campaign – a huge thank you to everyone who supported the campaign and helped raise awareness of dementia amongst European decision-makers!

Turning to international matters, we are pleased to feature an article from Marine Uldry of the European Disability Forum (EDF), who explains the forthcoming review of the EU by the Committee on the Rights of Persons with Disabilities, as well as EDF's work in developing a submission to the process. We close the policy section with a brief overview of the most recent meeting of the European Group of Governmental Experts on Dementia, held in Geneva just prior to 34AEC.

In our final section, Dementia in Society, we have an article about the participation of Kevin Quaid and Lieselotte Klotz, respectively Chair and Vice-Chair of the EWGPWD, at the European Day of Persons with Disabilities in November 2024. We then take a look at the importance of art and creativity for people living with dementia. In this two-part article, we first hear from Annick Germeys, a member of the EDCWG, who shares the story of her husband Geert's sculpture work. We then hear from former EWGPWD member Pia Knudsen, who recently got a new job teaching art, having lost her previous teaching post when she was diagnosed. Following this, Hassan Fadli details his impressive campaign "5 Ironmans Beat Alzheimer" for which he completed five "ironman" challenges in a year, to raise awareness about dementia and which his team has captured in a documentary film. Rounding off the magazine, Philip Van Kerrebroeck, Vice-Chair of the European Association of Urology, tells us about the "Urge to Act" campaign and its recent awareness-raising event involving the "Manneken Pis" statue in Brussels (Belgium).

Be sure to check out our special supplement to this magazine, focusing on our Annual Conference in Geneva. It looks back at some of the key moments from 34AEC, as well as reflections from keynote speakers and from our co-hosts Alzheimer Switzerland and Alzheimer Geneva.

We hope you enjoy this edition of our Dementia in Europe magazine! The magazine can be downloaded, here: https://bit.ly/DementiaInEurope47

## AE NETWORKING

| | |
|---|---|
| 4 FEBRUARY | Owen attended the European Federation of Pharmaceutical Industries and Associations (EFPIA) Patient Think Tank meeting |
| 4 FEBRUARY | Jean attended a meeting of the European Alzheimer's Disease Consortium (EADC) |
| 4 FEBRUARY | Ana, Angela and Chris attended the informal FluiDx-AD project kick off meeting |
| 6 FEBRUARY | Ana and Soraya attended the ADIS project consultation and the Public Involvement event with the members of the ADIS Advisory Board and the ADIS Young Adults Advisory Board (Barcelona, Spain) |
| 6 FEBRUARY | Angela participated in a workshop on real-world data, organised by the MetReal cluster |
| 6 FEBRUARY | Owen attended the European Disability Forum (EDF) European Non-Governmental Organisations meeting |
| 10 FEBRUARY | Angela met with representatives of Eli Lilly |
| 12 FEBRUARY | Ana participated in the Joint Action on Dementia and Health launched (JADE Health) kick-off meeting |
| 12-13 FEBRUARY | Angela attended a meeting organised by Roche (Basel, Switzerland) |

| | |
|---|---|
| 13 FEBRUARY | Cindy attended a webinar about the European Medicines Agencies Network Strategy (EMANS) to 2028 |
| 13 FEBRUARY | Owen attended the EU4Health Civil Society Alliance meeting |
| 14 FEBRUARY | Ana and Angela participated in the AD-RIDDLE project Steering Committee meeting |
| 18 FEBRUARY | Jean met with a representative of the World Dementia Council |
| 18 FEBRUARY | Lukas attended a meeting on mental health organised by the European Commission’s DG Research & Innovation (Brussels, Belgium) |
| 18 FEBRUARY | Owen attended a sub group of Civil Society Europe on the Civil Society State of the Union |
| 19 FEBRUARY | Lukas attended a meeting on rare neurological diseases organised by the European Federation of Neurological Associations: EFNA (Brussels, Belgium) |
| 21 FEBRUARY | Sébastien joined a hearing by the WHO Regional Office for Europe on “Health systems of the future: harnessing technology and innovation in health” |
| 24 FEBRUARY | The Alzheimer Europe Board met |
| 25 FEBRUARY | Owen attended the World Health Organization (WHO) launch of the European Health Report |
| 25 FEBRUARY | Sarah attended the REBALANCE project workshop on “Patient and Public Involvement in Translational Research: Challenges and Future Directions” (Riga, Latvia) |
| 26 FEBRUARY | Ana, Dianne, Lukas and Sébastien chaired a meeting of the European Dementia Carers Working Group to consult on palliative care and dementia for the AI4HOPE project |
| 27 FEBRUARY | Jean participated in the Virtual Advocacy Dialogue organised by the World Dementia Council |
| 27 FEBRUARY | Dianne participated in a workshop on Public Involvement in projects related to living and dying with dementia |
| 27 FEBRUARY | Dianne participated in the International Advisory Board of the INTERDEM Academy |
| 27-28 FEBRUARY | Cindy and Soraya attended the DORIAN GRAY project kick-off meeting (Brescia, Italy) |
| 28 FEBRUARY | Jean attended the Steering Committee of the Brain Health Mission |

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## SPONSORS OF THE MONTH

Alzheimer Europe would like to express its gratitude to two new sponsors in 2025:

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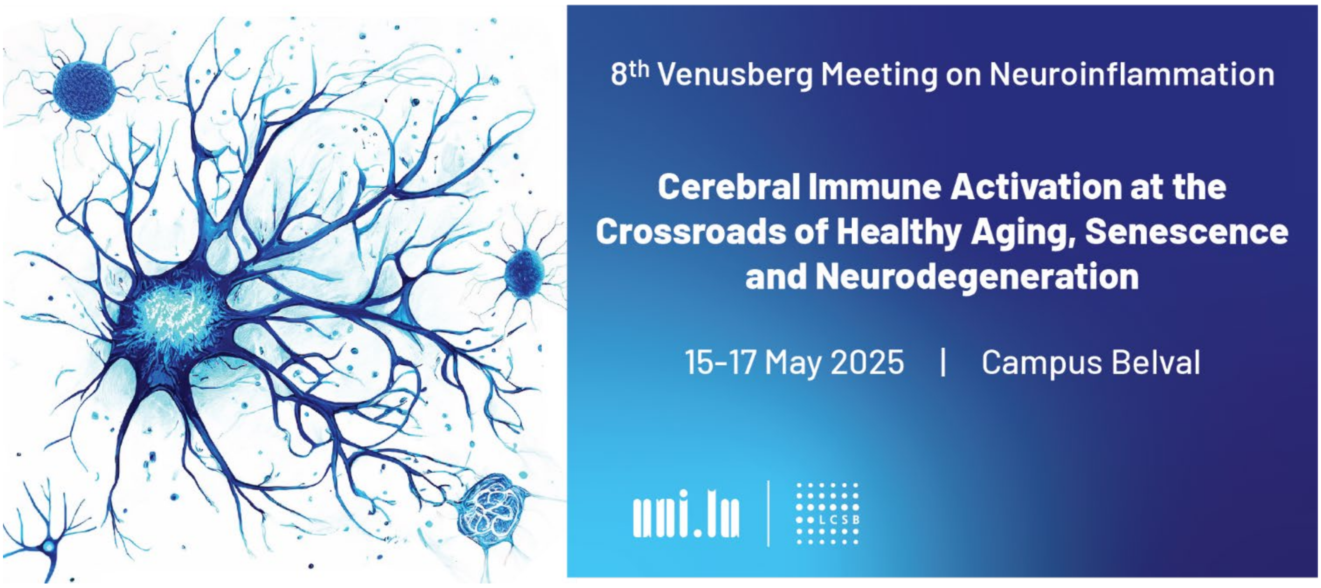
Read more about sponsorship opportunities here:
https://www.alzheimer-europe.org/about-us/governance/finances/2024-sponsorship-opportunities



8th Venusberg Meeting on Neuroinflammation

**Cerebral Immune Activation at the Crossroads of Healthy Aging, Senescence and Neurodegeneration**

15-17 May 2025 | Campus Belval

## 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:

LETHE - grant agreement 101017405 (https://www.lethe-project.eu/)
PREDICTOM - grant agreement 101132356 (https://www.predictom.eu/)
PROMINENT- grant agreement 101112145 (https://www.ihi-prominent.eu/)

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

# EU PROJECTS

20 JANUARY:

## PREDICTOM Public Ambassador Group meets online

In January, members of the Public Ambassador Group (PAG) for the PREDICTOM project were invited to participate in an online meeting and provide written feedback. This online consultation was organised in close collaboration with project partners from King's College London (UK) and focused on the second phase of the at-home participant journey for the PREDICTOM project. The members were sent two different at-home biofluid collection kits to try out and review. The main objectives of the consultation were to assess the user-friendliness of the provided test kits, evaluate the clarity of the instructions and gather feedback on the overall experience. The session was led by Sarah Campill, Public Involvement Officer at Alzheimer Europe. Research partners Zunera Kahn, Anna-Katharine Brem and Gabrielle Nieuwoudt provided on-the-spot responses and asked follow-up questions to the PAG members. The PAG feedback received was extremely valuable, offering insights and highlighting issues that need further development.

PREDICTOM is supported by the Innovative Health Initiative Joint Undertaking (IHI JU), under Grant Agreement No 101132356. JU receives support from the European Union’s Horizon Europe research and innovation programme, COCIR, EFPIA, EuropaBio, MedTechEurope and Vaccines Europe. The UK participants are supported by UKRI Grant No 10083467 (National Institute for Health and Care Excellence), Grant No 10083181 (King's College London), and Grant No 10091560 (University of Exeter). University of Geneva is supported by the Swiss State Secretariat for Education, Research and Innovation Ref No 113152304. For more details, see: www.ihi.europa.eu

31 JANUARY:

## PROMINENT Project holds online consultation with members of the public to develop ethically sound and accessible patient reports

On 31 January, Lena Sannemann and Jyrki Lötjönen from the PROMINENT project, and Sébastien Libert from Alzheimer Europe held on online consultation with the project’s Public Involvement Board (PIB) to support the development of patient reports for people diagnosed with dementia. Members of the PIB included two relatives of a person with dementia and one carer. The goal of this consultation was to improve the quality, accessibility and ethical aspects of patient reports providing results to patients following clinical tests to assess their cognitive capacities.

The consultation was an enriching experience involving constructive discussions between PIB members and the representatives from PROMINENT. During this consultation, the PIB members were invited to share their perspective on the draft patient reports, focusing on communication about diagnoses and suggested therapies, and their appropriateness for patients. Some of the points discussed also included improving the clarity of diagrams used to communicate the cognitive state of patients.

As a result of this consultation, researchers from the PROMINENT project will be able to refine these patient reports. Comments from the PIB members will also contribute to improving the capacity of European memory clinics and healthcare facilities to provide sensitive information to patients about their cognition in an ethical manner which protects their wellbeing. Outcomes of this consultation will also contribute to the general objectives of the PROMINENT project to set up a digital platform to improve the diagnosis and personalised treatment of people with Alzheimer’s disease coupled with other diseases. For more information about the PROMINENT project, visit: https://www.ihi-prominent.eu/

6 FEBRUARY:

## The ADIS Advisory Boards met for the first time for an event on Public Involvement in Alzheimer's disease research at the University of Barcelona

On 6 February, the ADIS Advisory Board (composed of people with Mild Cognitive Impairment due to Alzheimer's disease) and the ADIS Young Adults Advisory Board (composed of university students in their early 20s) gathered together for the first time. During the meeting, which was facilitated by Soraya Moradi-Bachiller (Public Involvement Officer at Alzheimer Europe, AE) and Ana Díaz (Public Involvement Lead, AE) and also attended by Jesús Rodrigo Ramos (Executive Director of the Confederación Española de Alzheimer y otras demencias, CEAFA), members addressed some topics related to the brain health campaign for young adults that they have been developing together over the past year.

After this meeting, members attended a public event organised by AE in collaboration with CEAFA and the University of Barcelona. The event, called 'Public Involvement in Alzheimer's disease research' focused on giving visibility to the ADIS project and the involvement of people affected by Alzheimer's disease and young adults in discussions about dementia research, brain health care and stigma around neurodegenerative diseases.

The first panel of the event featured presentations by Kina García del Moral, member of the ADIS Advisory Board and CEAFA's advisory board ("el PEPA"), the neurologist Raquel Sánchez-Valle and Jesús Rodrigo Ramos (Executive Director of CEAFA). Kina, who has mild cognitive impairment due to Alzheimer's disease, shared her experience of what it is like to live with Alzheimer's and, at the same time, care for her partner who had dementia due to Alzheimer's disease. Raquel and Jesús, on the other hand, gave the audience an overview of ADIS and the Public Involvement activities organised throughout this project.

The second panel featured Soraya Moradi-Bachiller (Public Involvement Officer at AE), Jaime Soto-Martínez and Francisco Sáez-González (members of the ADIS Young Adults Advisory Board) and José Antonio García García (who has mild cognitive impairment due to Alzheimer's disease and is also a member of the ADIS Advisory Board). While Soraya gave more theoretical details about Public Involvement and how to involve people in research in a timely and meaningful manner, Jaime, Fran and García talked about Public Involvement in their personal experience as part of the ADIS advisory groups. Fran and Jaime reflected on how Alzheimer's disease is currently perceived by university students and called for more practical experiences or awareness-raising activities at university that would allow students to connect with the human side of this disease. Only through information and empathy, they said, can we build a more supportive and understanding society in the face of this disease that affects so many.

During the last session of the afternoon, speakers Ana Díaz, Jesús Rodrigo and Inmaculada Fernández Verde (AFA Barcelona), focused on the work of patient organisations and how they can continue collaborating with researchers and members of the public to remove the stigma associated with Alzheimer's disease and provide the support needed to those affected by it.

Alzheimer Europe would like to say thank you to all the speakers for their time and their powerful insights and speeches, and to the audience for allowing us to bring together researchers, students, health and social care workers and patient organisations under the same roof, working towards the same goal.

25 FEBRUARY:

## Lethe project webinar "How can Public Involvement support research on dementia risk reduction?"

The Lethe project team, in collaboration with AD-RIDDLE and Pattern-Cog, invites you to a webinar on "How can public involvement support research on dementia risk reduction?" on Friday 14 March from 10.30 to 11.30am.

The webinar will explain how Public Involvement works in dementia research, how advisory boards are set up, and will feature first-hand experiences from advisory board members. Speakers will also discuss the impact of using advisory boards in research. In addition to the presentations, the session will include a panel discussion and a Q&A with the audience.

Register via:
https://docs.google.com/forms/d/e/1FAIpQLScxhfecq3tEdtat5q5zMieg1lwBwDZ5ZWK1r_mPzL5OCAj3VQ/viewform

## MEMBERS OF THE EUROPEAN ALZHEIMER'S ALLIANCE

Currently, the total number of MEPs in the European Alzheimer's Alliance (EAA) stands at **86**, representing **22** Member States of the European Union and seven out of eight political groups in the European Parliament. Alzheimer Europe is grateful to the Co-Chairs of the EAA: Nina Carberry MEP (Ireland, EPP), Tilly Metz MEP (Luxembourg, Greens/EFA), Romana Jerković MEP (Croatia, S&D), Sirpa Pietikäinen MEP (EPP, Finland); Vladimir Prebilič (Greens/EFA); Hilde Vautmans MEP (Belgium, Renew Europe) and Dainius Žalimas (Renew Europe, Lithuania) for their leadership and for hosting the organisation's European Parliament lunch debates on dementia. Alzheimer Europe would also like to thank the following MEPs for their support of the EAA:

**Belgium**: Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria**: Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D). **Croatia**: Biljana Borzan (S&D); Romana Jerković (S&D); Tonino Picula (S&D); Tomislav Sokol (EPP). **Cyprus**: Costas Mavrides (S&D). **Czechia**: Ondrej Dostal (NI); Tomáš Zdechovský (EPP). **Denmark**: Kira Marie Peter-Hansen (Greens/EFA); Christel Schaldemose (S&D). **Estonia**: Urmas Paet (Renew Europe). **Finland**: Maria Guzenina (S&D, Finland); Merja Kyllönen (The Left); Sirpa Pietikäinen MEP (EPP). **France**: François-Xavier Bellamy (EPP); Mélissa Camara (Greens/EFA); Laurent Castillo (EPP); David Cormand (Greens/EFA); Marie Dauchy (PFE); Christophe Gomart (EPP); Catherine Griset (PFE); Céline Imart (EPP); Isabelle Le Callennec (EPP); Nadine Morano (EPP); Philippe Olivier (PFE); Mounir Satouri (Greens/EFA); Majdouline Sbai (Greens/EFA); Marie Toussaint (Greens/EFA). **Germany**: Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Manuela Ripa (Greens/EFA); Terry Reintke (Greens/EFA). **Greece**: Tsiodras Dimitrios (EPP); Manolis Kefalogiannis (EPP); Nikos Papandreou (S&D); Elissavet Vozemberg-Vrionidi (EPP). **Hungary**: Tamás Deutsch (PFE); Enikő Győri (PFE); Kinga Gál (PFE); György Hölvényi (EPP), András Kulja (EPP). **Ireland**: Barry Andrews (Renew Europe); Lynn Boylan (The Left); Nina Carberry (EPP); Luke 'Ming' Flanagan (NI); Billy Kelleher (Renew Europe); Seàn Kelly (EPP); Aodhán Ó Ríordáin (S&D); Maria Walsh (EPP). **Italy**: Brando Benifei (S&D); Caterine Chinnici (EPP); Carlo Fidanza (ECR); Aldo Patriciello (PFE). **Lithuania**: Vytenis Andriukaitis (S&D); Petras Auštrevičius (Renew Europe); Vilija Blinkevičiūtė (S&D); Liudas Mažylis (EPP); Dainius Žalimas (Renew Europe). **Luxembourg**: Marc Angel (S&D); Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Isabel Wiseler-Lima (EPP). **Poland**: Elżbieta Katarzyna Łukacijewska (EPP); Michał Szczerba (EPP); Anna Zalewska (ECR). **Portugal**: Marta Temido (S&D); Catarina Martins (The Left). **Romania**: Vlad Vasile-Voiculescu (Renew Europe). **Slovenia**: Matjaž Nemec (S&D); Irena Joveva (Renew Europe); Vladimir Prebilič (Greens/EFA); Marjan Šarec (Renew); Milan Zver (EPP). **Spain**: Rosa Estaräs Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ana Miranda Paz (Greens/EFA). **Sweden**: Pär Holmgren (Greens-EFA); Jonas Sjöstedt (S&D).

## EUROPEAN ALZHEIMER'S ALLIANCE

31 JANUARY:

### Vlad Vasile-Voiculescu and Michal Szczerba join EAA

Alzheimer Europe is delighted to announce that Michal Szczerba (EPP, Poland) and Vlad Vasile-Voiculescu (Renew Europe, Romania) has joined the European Alzheimer's Alliance (EAA). We very much look forward to working with them to help ensure dementia is a policy priority at a European level.

The EAA is a non-exclusive, multinational and cross-party group, with two key objectives:

- Send out the political message that concerted action is needed in the field of prevention, diagnosis and treatment of Alzheimer's disease, as well as research and social policies.
- Promote actions to give dementia priority at European and national level.

24 FEBRUARY:

### Tomislav Sokol MEP joins European Alzheimer's Alliance (EAA)

Alzheimer Europe is delighted to announce that Tomislav Sokol MEP (EPP, Croatia) has also joined the European Alzheimer's Alliance (EAA), as of 24 February 2025.

The EAA now has 86 members. You can see the full list of Co-Chairs and members of the EAA at: https://www.alzheimer-europe.org/policy/european-alzheimers-alliance/members

## EU DEVELOPMENTS

11 FEBRUARY:

### Health civil society organisations express concern over funding restriction on activities

Alzheimer Europe has joined with members of the EU4Health Civil Society Alliance, representing 30 other health organisations (CSOs) across Europe, expressing concern about restrictions on funding for civil society organisations (CSO).

Under new guidelines communicated at the end of 2024, funds from the LIFE operating grants can no longer be used to develop and implement policy and advocacy activities targeting EU policymakers. The programme provides EUR 15.5 million for grants to civil society, but has an overall budget of EUR 5.4 billion, including for nature conservation projects for 2021-2027. The CSOs expressed concern that this development could significantly limit the activities of CSOs in the EU and create a highly concerning precedent.

This adds to an already uncertain situation for health-focused CSOs. As of today, health CSOs still do not have information on the operating grants provided under the EU4Health programme for 2025, as the EU4Health Work Programme still has not been presented. This results in limitations to planning their activities, and overall, foreseeing for the future, and adds to previous concerns on the programme's future, following a disproportionate redeployment of EUR 1 billion from its budget in 2024.

The statement therefore calls on the EU to reconsider the limitations set on the LIFE programme and support a strong and vibrant civic space through sustainable public funding for CSOs, including policy and advocacy activities. Additionally, we ask for transparency and a clear timeline for the publication of the EU4Health 2025 Work Programme. The full statement is available at:
https://epha.org/wp-content/uploads/2025/02/eu4health-csa_statement_restrictions-cso-activities_final_100225.pdf

12 FEBRUARY:

### European Commission publishes 2025 Work Programme

The European Commission has published its Work Programme 2025, setting out the initiatives it will address in the first year of its mandate. The Work Programme is divided into sections including new initiatives, evaluations and fitness checks, pending proposals, withdrawals and envisaged repeals

Of particular interest for the work of Alzheimer Europe:

- A new action plan to implement the European Pillar of Social Rights (Q4)
- A new EU strategy to support, protect and empower civil society (Q3)
- Proposals for the post-2027 Multi-annual Financial Framework (Q3)
- Interim and mid-term evaluations of Horizon Europe, Cohesion Funding and the European Social Fund Plus (All Q2)
- The withdrawal of the proposed Council Directive on equal treatment (dating from 2008).

The full Work Programme is available at:
https://ec.europa.eu/commission/presscorner/api/files/document/print/en/ip_25_466/IP_25_466_EN.pdf

13 FEBRUARY:

### EU Polish Presidency, HMA and EMA host webinar on European Medicines Agencies Network Strategy to 2028

On 13 February, the EU Polish Presidency, the Heads of Medicines Agencies (HMA) and the European Medicines Agency (EMA) jointly organised a webinar to present and discuss the ongoing development of the European Medicines Agencies Network Strategy (EMANS) to 2028.

The webinar focused on the feedback received during the public consultation of the draft strategy, which took place from 9

October to 30 November 2024. EMA is currently reviewing this feedback and aims to adopt the final strategy by March 2025. The strategy, which aims to prepare the European medicines regulatory network to handle changes in the field of medicines regulation, highlights six key focus areas:

- Accessibility - facilitating access to medicines in the EU
- Leveraging data, digitalisation and artificial intelligence - improving decision-making, optimising processes and increasing efficiency
- Regulatory science, innovation and competitiveness - helping improve innovation and competitiveness in the EU healthcare sector
- Antimicrobial resistance and other health threats - preparing the EU for potential threats including antimicrobial resistance
- Availability and supply - strengthening availability of medicines to protect public and animal health
- Sustainability of the European medicines agencies network - ensuring available resources to support its scientific and regulatory decision-making.

During the event, Marcin Kolakowski from the Polish Medicines Agency delivered the opening remarks, followed by an introduction to the strategy. Stakeholder feedback on each of the six themes was presented.
Alzheimer Europe Project Officer Cindy Birck attended the webinar. A recording will be published after the event. For further details, visit the EMA event page: https://www.ema.europa.eu/en/events/european-medicines-agencies-network-strategy-emans-2028-webinar

### 20 FEBRUARY:

## European Disability Forum issues statement on future EU budget

The European Disability Forum (EDF) has issued a statement expressing concern about the potential reduction in support for marginalised groups, such as people with disabilities, during the ongoing discussions around the future of the Multi-annual Financial Framework (MFF), for the period 2028-2035.
The statement highlights that reduced funding would weaken programmes that improve the lives of EU citizens, such as the European Social Fund Plus, the Regional Development Fund and Erasmus+. Additionally, EDF expresses concern that the EU will reduce the budget for the Citizens, Equality, Rights and Values programme. The statement contains a number of specific calls, including the need to:

- Safeguard support for civil society working on equality and human rights as part of the Citizens, Equality, Rights and Values programme
- Ensure that Cohesion, Resilience and Values funding is governed by clear conditions, in line with the EU's human rights commitments (e.g. the UN Convention on the Rights of Persons with Disabilities)
- Include non-binding guidance on the use of EU funds, e.g. the need to follow EU Guidance on Independent Living and Inclusion in the Community for Persons with Disabilities.

The full statement is available at: https://www.edf-feph.org/publications/the-next-eu-budget-must-keep-supporting-marginalised-groups/

### 24 FEBRUARY:

## World Health Organization (Europe) publishes European Health Report 2024


World Health Organization European Region
European health report 2024
Keeping health high on the agenda

On 24 February, the WHO Regional Office for Europe (WHO Europe) published the European Health Report 2024, a report produced every three years setting out the state of health in the WHO Europe region. This edition focuses on the indicators included in the measurement framework of the WHO European Programme of Work 2020–2025 (United Action for Better Health).
The report is divided into multiple sections, including infectious disease, non-communicable diseases and mental health, amongst others. Under the section on mental health, there is a dedicated sub-section (section 6.3 – pp.130-132), which specifically examines dementia. The key messages from this section the report include:

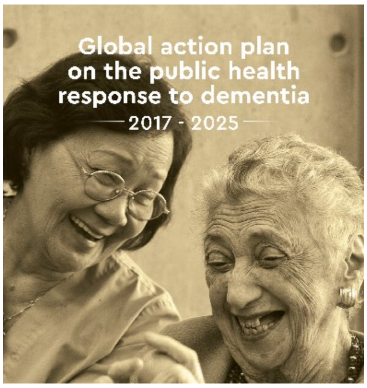
- In 2019 about 14 million people (one in 11 of those aged 65 years and older) were living with dementia in the WHO European Region
- The number of dementia-related DALYs rose from 3.7 million in 2000 to 7.8 million in 2021 in the Region, with twice as many for women than for men
- The prevalence of dementia is expected to double by 2030, anticipating a significant increase in the need for comprehensive and integrated care across all care settings, including long-term care
- The WHO Global action plan on the public health response to dementia 2017–2025 contributes to achieving the SDGs by improving timely diagnosis, treatment, care (long-term care) and rehabilitation for people with dementia and promoting population-wide risk reduction efforts for dementia.

The full European Health Report 2024 is available at:
https://www.who.int/europe/publications/i/item/WHO-EURO-2025-10668-50440-76183

# POLICY WATCH

10 FEBRUARY:

## World Health Organization Executive Board adopts recommendation on global dementia plan extension


Global action plan
on the public health
response to dementia
2017 - 2025

On 10 February, at the 156th meeting of Executive Board of the World Health Organization (WHO) adopted a recommendation on extending the Global Action Plan on the Public Health Response to Dementia 2017-2025, which would see it continue until 2031. The recommendation noted that none of the targets within the global action plan were on course to be met, whilst highlighting the continued relevance of the subject, particularly in the context of ageing demographics in many countries and regions. Specifically, the recommendation encouraged the World Health Assembly (WHA):

(1) to extend the global action plan on the public health response to dementia 2017–2025 to 2031, in line with the intersectoral global action plan on epilepsy and other neurological disorders 2022–2031;

(2) to request the Director-General to submit a progress report to the Health Assembly in 2027 and 2029 on the implementation of this decision, as part of the reporting on the WHO Global Comprehensive Mental Health Action Plan 2013–2030.

The 78th meeting of the WHA, at which the final decision will be made, will be held 19-27 May 2025.

The full recommendation is available at: https://apps.who.int/gb/ebwha/pdf_files/EB156/B156_36-en.pdf

Videos from the day, including session 10 of the meeting, where the extension of the global action plan was discussed, are available at: https://www.who.int/about/governance/executive-board/156th-session

# SCIENCE WATCH

19 JANUARY:

## The impact and needs of caregivers of children with dementia

Childhood dementia encompasses a group of rare, progressive neurodegenerative conditions that lead to significant cognitive decline and loss of developmental skills. Affecting approximately one in 2,900 births, these conditions are predominantly genetic and result in a shortened life expectancy, with only 29% of affected children reaching adulthood. While some research exists on the challenges faced by caregivers of children with dementia, the rarity and complexity of childhood dementia limit comprehensive studies.

In their study, Jason Djafar and colleagues aim to explore the quality of life of caregivers for children with dementia including both positive and negative impacts of caregiving and their perspectives on healthcare services. 40 Australian caregivers of children with dementia (on average 9.2 years old) participated in the study, most of them were mothers (36), with a few fathers (three) and one grandmother. The study's results show high levels of psychological distress among caregivers, with 72.5% reporting significant distress and 67% experiencing caregiver stress. 43% of caregivers reported living with chronic pain or discomfort and 87.5% indicated that their child's condition severely impacted their daily activities.

Based on their findings, the research team identified areas for improving healthcare services. These include the need for training and education for clinicians, the importance of providing integrated family-centred care, the necessity for psychosocial support and more opportunities for respite care. Additionally, the need for increased research, particularly focusing on treatment pathways and support structures and the significance of cross-sector coordination in reducing the burden on caregivers was mentioned.

‘Fighting every day’: exploring caregiver quality of life and perspectives on healthcare services for children with dementia – a cross-sectional, mixed-methods study | Archives of Disease in Childhood

29 JANUARY:

## READ-OUT dementia blood test study recruits UK participants

The Real Word Dementia Outcomes (READ-OUT) study has recruited its first participants at Warneford Hospital in Oxford. This UK-wide study, led by Dementias Platform UK (DPUK), based at the University of Oxford and University of Cambridge, aims to recruit over 3,000 participants from 28 memory clinics and mobile community testing units across the UK.

READ-OUT will access blood tests for detecting different types of dementia, such as Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy bodies. The study will also explore whether these blood tests can detect dementia at various stages of the disease and if the results need to be adjusted in people from different ethnic backgrounds or with other health conditions like kidney disease.

This research is part of the Blood Biomarker Challenge, a multi-million-pound programme supported by Alzheimer's Society, Alzheimer's Research UK, National Institute for Health and Care Research, Gates Ventures and players of People's Postcode Lottery. The aim of the programme is to generate the evidence needed for dementia blood tests to be validated for use in the National Health Service (NHS) within the next 5 years.

https://www.alzheimersresearchuk.org/news/uk-wide-study-into-dementia-blood-tests-recruits-first-participants/

### 1 FEBRUARY:

## European Commission asks EMA to consider new safety information on lecanemab

Last November, the European Medicines Agency's (EMA) Committee for Medicinal Products for Human Use (CHMP) issued a positive opinion on the marketing authorisation application for lecanemab, an anti-amyloid immunotherapy for early Alzheimer's disease which is marketed by Eisai and Biogen. The European Commission is the authorising body for all products approved by the EMA, and is responsible for issuing centralised marketing authorisation which is then valid in all EU member states, and in Iceland, Liechtenstein and Norway. This process must be completed within 67 days of receipt of a positive CHMP opinion.

On January 31, Biogen and Eisai announced that the European Commission, as part of its decision-making process, has asked the CHMP to consider information on the safety of lecanemab that became available after the adoption of a positive opinion in November 2024. The European Commission has asked the CHMP to consider whether this information requires an update of the opinion, and whether the wording of the risk minimisation measures in the opinion is clear enough to ensure correct implementation. These measures will be discussed at the CHMP meeting in February. Read the news update: https://investors.biogen.com/news-releases/news-release-details/update-regulatory-review-lecanemab-early-alzheimers-disease-1

### 1 FEBRUARY:

## A recent study suggests that social engagement may help delay dementia onset by five years

Strategies to reduce the risk of developing dementia or delay its onset seem critical in today's society where dementia-related neurodegenerative diseases are estimated to impact over 50 million adults worldwide. Among all the factors to prevent dementia that have been investigated, social engagement is associated with less cognitive decline and a lower risk of developing cognitive impairment. Within social engagement, different domains and aspects should be considered, i.e. social activity, social network size, marital status, social support and loneliness. Although social activity may provide stimuli that could help the brain develop the resilience that buffers against neurodegeneration, little is known about the impact that it has on the average age of dementia onset.

In a recent study published in Alzheimer's & Dementia: The Journal of the Alzheimer's Association, a team of researchers led by Dr Yi Chen from Rush Alzheimer's Disease Center (Rush University Medical Center, Chicago, US) examined the associations of social activity with incident dementia and Mild Cognitive Impairment (MCI), with a particular focus on how different levels of social activity are associated to the age of MCI and dementia onset.

The study included 1,923 participants without dementia who are also part of the Rush Memory and Aging Project, an ongoing longitudinal study of conditions related to aging. The participants involved in this study were approximately 80 years old and had completed, on average, 15 years of education. Social activity was measured using a questionnaire that asked the participants whether or not they had engaged, over the previous year, in six social activities that involved social interaction, and how frequently. Cognitive function was then assessed using different tests that evaluate memory, among other cognitive functions.

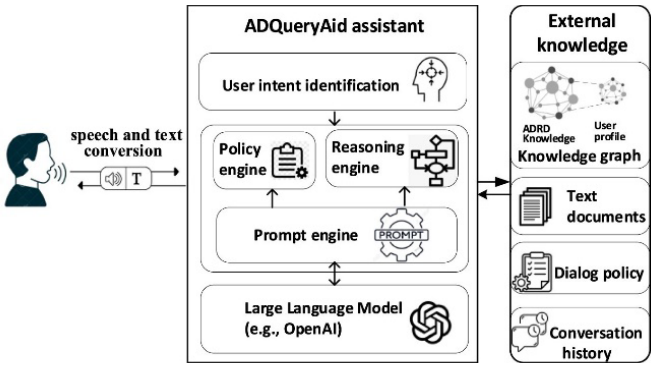
Over an average of five years, a total of 545 participants developed dementia, and 695 developed MCI. Higher levels of social activity were associated with a 38% lower risk of developing dementia. Loneliness was also associated with incident dementia, increasing the risk by 40%. There was also a strong association between social activity and the age of diagnosis. For the individuals who were less socially active, the mean age of dementia onset was 87.7 years whereas for those more socially active, this onset was delayed by almost five years. Similarly, social activity was associated with a 21% lower risk of developing MCI. The mean age of MCI onset was 78.4 years for the least socially active, approximately three years earlier than for the most socially active participants.

The team found that, in older adults and during an average of five years, individuals who were more socially active showed reduced rates of dementia and delayed onset. This five-year difference in the age of onset was also observed for the participants who developed MCI. Although the study does not provide the mechanism by which social activity impacts the development of cognitive problems, it provides important public health metrics for understanding the link between social activity and cognitive health. More studies, in more diverse populations, are needed to confirm these findings and to determine whether interventions aimed at increasing social activity later in life can prevent or delay cognitive impairment and decline.

https://alzjournals.onlinelibrary.wiley.com/doi/epdf/10.1002/alz.14316

6 FEBRUARY:

## Empowering Alzheimer’s caregivers with conversational AI: a novel approach for enhanced communication and personalised support



Researchers from the United States recently published a study in “npj Biomedical Innovations” on ADQueryAid, a conversational Artificial Intelligence (AI) system designed to support caregivers of people with Alzheimer’s disease and related dementias (ADRD).

ADQueryAid uses “Retrieval-Augmented Generation”, combining a Large Language Model with external ADRD knowledge sources to generate responses based on both general AI reasoning and specific, retrieved information. This approach improves accuracy and relevance, reducing the risk of misleading or incorrect answers.

A user study compared ADQueryAid to ChatGPT 3.5, showing that the tailored model provided more useful and contextually relevant responses. It was particularly effective in helping caregivers with limited medical knowledge or literacy by offering structured, accessible information. Participants noted its ability to provide emotional support, though the study does not address whether AI can fully replace human interaction in coping with caregiving stress.

While the findings suggest AI can be a valuable tool, caregiving remains a deeply social experience that benefits from human support networks. Future research should refine these models and integrate them into broader caregiving support systems, ensuring they complement, rather than replace, human interaction. The study has been published open access and can be read here: https://www.nature.com/articles/s44385-024-00004-8

Image credit: Credit: npj Biomedical Innovations (2024). DOI: 10.1038/s44385-024-00004-8

8 FEBRUARY:

## Intranasal oxytocin leads to some reduction in apathy in people with frontotemporal dementia

Intranasal oxytocin for apathy in people with frontotemporal dementia (FOXY) administered every third day is well tolerated and leads to a modest reduction in apathy, new research has shown. Apathy is a significant and debilitating symptom of frontotemporal dementia (FTD), for which no approved treatments currently exist. Previous research suggested that intranasal oxytocin may improve apathy ratings in the short term, prompting a multicentre, randomised, double-blind, placebo-controlled, adaptive, crossover, phase 2a/2b trial. Conducted across 11 expert dementia clinics in Canada and the US, the study aimed to evaluate the effects of longer-term oxytocin administration on apathy symptoms. Participants aged 30-80 years with probable FTD and an apathy score of at least 2 on the Neuropsychiatric Inventory were enrolled.

Findings from the trial suggest that intranasal oxytocin, administered intermittently, has potential as a treatment for apathy in FTD. While the observed effects were modest, future studies could explore alternative dosing regimens or more potent formulations to enhance therapeutic outcomes. Given the substantial impact of apathy on quality of life and caregiver burden, continued research into oxytocin and other pharmacological strategies remains a priority for clinical practice.

Read the full study results, here: https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(24)00456-3/abstract

10 FEBRUARY:

## The Scottish Medicines Consortium rejects lecanemab for use on NHS in Scotland

On 10 February, the Scottish Medicines Consortium (SMC), which advises on newly licensed medicines for use by NHS Scotland, announced its decision to reject lecanemab for the treatment of early Alzheimer's disease (AD).

While lecanemab has been approved in multiple countries (i.e. USA, Japan, China, South Korea, Hong Kong, Israel, Great Britain and Europe), the SMC concluded that the available evidence did not demonstrate sufficient clinical benefits to justify its high cost within the NHS budget.

"SMC welcomed the submission for lecanemab and recognises the need for new therapies for Alzheimer's disease. Having considered all the evidence, we were unable to accept lecanemab for treatment in the NHS in Scotland. The committee felt that there remains uncertainty around what the modest clinical benefit means for patients and their families and, in addition, the cost-effective estimates supplied by the company were too high.", said SMC Chair Dr Scott Muir.

Lecanemab, developed by pharmaceutical companies Eisai and Biogen, is a disease-modifying drug used in the treatment of early AD (mild cognitive impairment and mild dementia due to Alzheimer's disease). The drug works by using the body's immune system to reduce the build-up of amyloid proteins in the brain, which are associated with the disease.

Despite the approval of lecanemab by the UK Medicines and Healthcare products Regulatory Agency (MHRA), the SMC's decision aligns with that of the National Institute for Health and Care Excellence (NICE), which rejected lecanemab for use on the NHS in England and Wales six months ago.

Alzheimer Scotland expressed disappointment with the SMC's decision. Henry Simmons, Chief Executive of Alzheimer Scotland, stated: "We know this decision by the SMC will be disappointing for many people. This remains the first new drug shown to slow down the progression of Alzheimer's disease, rather than simply treating the symptoms. We remain optimistic that these initial hurdles will be overcome and, after decades of waiting, that new treatments will be approved for NHS use soon." After announcing its decision, the SMC said it would "welcome a resubmission from the company with changes to address the uncertainties".

For more information, you can access the SMC's decision news release here https://scottishmedicines.org.uk/about-us/latest-update/february-2025-decisions-news-release/ and read the Alzheimer Scotland's response here:
https://www.alzscot.org/news/our-response-to-the-scottish-medicines-consortiums-assessment-of-lecanemab

15 FEBRUARY:

## Recent publication examines the potential for dementia risk reduction in Italy

The potential for dementia risk reduction may differ regionally within and between countries due to existing differences in risk factor distributions and demographic characteristics. A recent publication in the Journal of Prevention of Alzheimer's Disease set out to estimate differences in modifiable dementia risk factors across 19 Italian regions.

For this study, researchers from the Italian National Institute of Health and the University of Modena and Reggio Emilia calculated a metric called the population attributable fraction. This metric represents the proportion of dementia cases attributable to a certain risk factor and is commonly used to quantify preventative potential, for instance, in the report of the Lancet Commission for Dementia Prevention, Intervention, and Care. Population attributable fractions take into account the prevalence of a given risk factor, the strength of association with dementia and the overlap between different risk factors. The researchers included 11 of the 12 risk factors presented in the Lancet Commission report, namely: lower education, hearing loss, traumatic brain injury, hypertension, alcohol consumption, obesity, smoking, depression, social isolation, physical inactivity, diabetes, and air pollution.

They found that, at the national level, 39.6% of dementia cases were attributable to these risk factors, with hypertension and physical inactivity carrying the most weight. They also observed that in the southern regions, the proportion of potentially preventable cases was higher than in the northern regions. Estimating the effect of a partial reduction in risk factors, the researchers suggest that a 10% reduction across risk factors could correspond to nearly 55,000 dementia cases potentially prevented in Italy. When assessing the alignment between regional dementia strategies and preventative potential, they found that in some regions, there is a mismatch between prevention policies and the actual opportunity for risk reduction. The full study can be read here (open access):

https://pubmed.ncbi.nlm.nih.gov/39809612/

28 FEBRUARY:

## European Medicines Agency reaffirms positive opinion on lecanemab to European Commission

On 28 February, the European Medicines Agency reaffirmed its positive opinion on lecanemab, following discussions at the February Committee for Medicinal Products for Human Use (CHMP) meeting.

On 31 January, Biogen and Eisai announced that the European Commission, as part of its decision-making process, had asked the CHMP to consider new information on the safety of lecanemab, their anti-amyloid immunotherapy for early Alzheimer's disease. Lecanemab had previously received a positive opinion from the CHMP in November 2024, however the European Commission had asked the CHMP to consider whether this new information might require an update of the opinion. In particular, there were questions around the wording of the risk minimisation measures, and whether the opinion was clear enough to ensure correct implementation of these measures.

Following discussions at the February CHMP meeting, the European Medicines Agency announced that no updates would be required to its November opinion. This response has been provided to the European Commission, which will now resume the decision-making process for lecanemab.

Read more: https://www.ema.europa.eu/en/medicines/human/EPAR/leqembi

# MEMBERS' NEWS

14-15 JANUARY:

## The Memorable project kick off took place in Sofia hosted by Alzheimer Bulgaria

MEMORABLE

Co-funded by the European Union

On 14-15 January, the Memorable project was officially launched in Sofia, Bulgaria, hosted by Alzheimer Bulgaria. This initiative, funded by the Erasmus+ programme, is dedicated to creating a dementia-friendly society by integrating art and culture to strengthen connections between individuals living with dementia and their communities.

Bringing together five European partners, the Memorable consortium includes: Alzheimer Bulgaria (coordinator), SHINE 2Europe (Portugal), AFEdemy (Netherlands), ISIS Institut für Soziale Infrastruktur (Germany) and Dublin City University (Ireland). During the kick-off meeting, partners outlined the project's goals and action plan. Key activities in the next months include desk research on dementia-friendly cultural practices in partner countries and interviews with people living with dementia, informal caregivers, and experts to co-create impactful project outcomes.

The Memorable project will focus on empowering volunteers, caregivers, artists, and cultural professionals through training to create dementia-friendly cultural spaces. It will support museums, galleries, and cultural venues in becoming more accessible to individuals with dementia. You will soon be able to find updates regarding the project on its website: https://memorable-project.eu/

10-11 FEBRUARY:

## Alzheimer Polska takes part in Patient Organization Forum in Warsaw

The Patient Organization Forum organised by the Institute of Patient Rights and Health Education took place in Warsaw on 10-11 February 2025. This Forum brought together over 200 patient organisations from all over Poland. For the first time, one of the panels was devoted to brain diseases.

Representing the Ministry of Health, Director Dagmara-Korbasinska Chwedczuk, said that the first Polish Dementia Plan is being developed at the Ministry. Dr Edyta Ekwinska (pictured, left) from Alzheimer Polska spoke about the situation of people living with dementia in Poland.

23 FEBRUARY:

## Deutsche Alzheimer Gesellschaft (DAlzG) published 13 political demands addressed to the democratic parties about people with dementia

Deutsche Alzheimer
Gesellschaft e.V.
Selbsthilfe Demenz

1.8 million people with dementia live in Germany. Most of them are supported, cared for and looked after by their relatives. This number is expected to increase significantly in the coming years and decades. However, the German healthcare system is not adequately prepared for this challenge, either medically, in terms of caregiving, or in its social support structures. On 23 February, in the lead-up to the national parliamentary elections, Deutsche Alzheimer Gesellschaft (DAlzG) published 13 political demands addressed to the democratic parties so that they can provide answers to these pressing problems.

The DAlzG's demands focus on the following areas:

1. Addressing the increasing number of affected individuals
2. Enabling participation for people with dementia
3. Ensuring access to participation services
4. Guaranteeing timely diagnosis and therapy
5. Expanding the range of non-medicinal therapies
6. Establishing process-based support for people with dementia and their carers
7. Supporting and promoting self-help initiatives
8. Ensuring nationwide availability of qualified nursing and care services
9. Limiting the financial burden of care for those in need
10. Supporting dementia prevention
11. Strengthening the inclusion of dementia-specific content in medical and nursing education
12. Increasing support for research
13. Ensuring the long-term continuation of the national dementia strategy.

Swen Staack, first chairman of DAlzG, says: “The issue of caregiving has hardly featured in the current election campaigns of the parties, even though it concerns many people in our country. The looming insolvency of care insurance funds, caregiving as a risk for poverty, quality problems and a lack of available spots in both inpatient and outpatient care are increasingly burdening people. People with dementia and their relatives find it particularly difficult to access support. We therefore call on all parties to face up to these problems and tackle solutions. The parties elected to the 21st German Bundestag must face up to the enormous task in caregiving in general, and of providing support and care for people with dementia in particular!“

24 FEBRUARY:

## Final year for The Alzheimer Society of Finland’s project on culturally sensitive memory work

Financed by the Funding Centre for Social Welfare and Health Organizations (STEA), The Alzheimer Society of Finland’s project on culturally sensitive memory work has entered its final year. As Finnish society is becoming more and more multicultural, the project aims to further open up to working with migrant clients and volunteers and involves changing staff’s attitudes and encouraging self-reflection. During training and workshops, staff are encouraged to question assumptions and address the risk of stereotyping, thus effectively reimagining the encounter between staff and migrant clients. Particular focus has also been on recruiting and training migrant volunteers and understanding them as a vast unused resource in the voluntary sector.

These volunteers are spreading information on dementia prevention in their own mother tongues to their own communities. They also carry out concrete tasks like visiting people with dementia from minority ethnic groups. Whilst receiving training through the project, their greatest value quite often lies in sharing the same language and birth culture as the person with dementia. Cooperation with migrant organisations has been key to reaching many of these volunteers. Building up that trust base can sometimes rightfully take time, but once established, the benefits for both sides have been remarkable. Various regional society members have adopted migrant volunteers, thus laying groundwork for lasting change. The Alzheimer Society of Finland, as an umbrella organisation, has codified diversity in its official strategy. Work is ongoing to ensure that learnings from the project gradually find their way into day-to-day activities and client encounters.

24 FEBRUARY:

## Alzheimer's Care Armenia launches Support Café for Artsakh Elders

Alzheimer's Care Armenia is pleased to announce the launch of the Support Café for Artsakh Elders. This project creates a supportive environment for displaced Artsakh older adults. The project is funded by the generosity of the Armenian General Benevolent Union (AGBU) for a 12-week pilot programme.

This initiative creates a secure environment by supporting their mental health during this profound adjustment period and provides psychosocial interventions that include art therapy approaches with the goal of promoting socialisation and healing. Music, handicrafts, and cognitive-stimulating exercises in a compassionate group setting will help improve mental health, promote social inclusion, facilitate emotional expression, strengthen cognitive abilities, and encourage physical activity.

"The Artsakh Support Café provides a beacon of hope to our displaced elders by providing much needed psychological support" says Dr Jane Mahakian, founder of Alzheimer's Care Armenia. The programme is implemented by a multidisciplinary team consisting of psychologists, social workers, and art therapists. Additionally, the professional team undergoes weekly training conducted by a psychologist specialised in trauma therapy.

The Support Cafés operate in two locations, in Gyumri and in Yerevan. Each group accommodates up to 25 participants. To participate, individuals must register by calling 098 444 893 for Gyumri or 096 777 908 for Yerevan. Upon completion of the pilot project, the aim is to sustain the Support Cafés in Yerevan and Gyumri and develop additional Support Cafés in other regions that have a high concentration of elders, such as the Syunik and Vanadzor regions.

## DEMENTIA IN SOCIETY

### 19 FEBRUARY:

### Alzheimer Centrum Limburg Launches “We Are the Medicine Ourselves” Booster Campaign

A growing body of research suggests that a significant proportion of dementia cases may be linked to modifiable risk factors, which can be tackled both on individual and policy levels. Raising awareness of these factors in the general public is thus crucial for promoting brain-healthy behaviours. On 19 February, the Alzheimer Centrum Limburg (Maastricht University) launched a booster campaign titled “We are the medicine ourselves” (“We zijn zelf het medicijn” in Dutch).

This initiative aims to enhance public awareness of both established and emerging risk and protective factors for dementia. The campaign, rolled out in various parts of the Netherlands, features posters and other visual materials in public spaces, and social media, along with advertisements on local radio and television and a dedicated website. Presented materials centre around the following recommendations:

1) Eat healthily - Follow a Mediterranean diet rich in fruit and vegetables, whole-grain products, nuts, olive oil and fatty fish
2) Be physically active
3) Stay curious - Engage in cognitive and social activities
4) Take good care of your heart – Avoid smoking, limit salt and alcohol intake and regularly monitor your weight, blood pressure, blood sugar and cholesterol level.

This effort builds on the original campaign launched in 2018, which also introduced “MyBraincoach” (“MijnBreincoach”), a free app designed to help individuals assess their personal dementia risk and identify lifestyle areas for improvement. Similar awareness campaigns have, among others, been introduced in Belgium (“Twee voor de prijs van één”, Expertisecentrum Dementie Vlaanderen) and Denmark (launched by Alzheimerforeningen) and the UK (launched by Alzheimer’s Research UK). For more information on the campaign in Dutch, please visit: https://wezijnzelfhetmedicijn.nl/

# LIVING WITH DEMENTIA

20 FEBRUARY:

## Annick Germeys, member of the European Dementia Carers Working Group, helps her husband Geert, who has young-onset dementia, to fulfil his dreams

On Sunday 6 April, my husband Geert will be at the starting line of the Milan Marathon. This is not his first running experience, Geert has already completed ten marathons, and he is incredibly proud of that.

When Alzheimer's enters your life, everything is turned upside down. Your future suddenly becomes very uncertain. You have no idea what is happening to you. The diagnosis has a significant impact on your life, especially when your partner is only 53 years old. Young-onset dementia sneaks into your life far too soon and never leaves. Incurable, no chance of improvement. Those are the words you hear as a caregiver. Suddenly, there are a thousand and one questions about what comes next.

Fortunately, Geert is not someone who dwells in negativity. He quickly managed, together with me, to shift his focus to everything he can still do. Every good day, every moment that we can create new memories together, is a gift. Time is running out, and we are making the most of what we still have.

Geert’s biggest passion is running. And despite Alzheimer’s, he is still doing remarkably well. Ten years ago, we both joined our local athletics club and began a ‘Start to Run’ programme. Since then, running has become like a drug for Geert. It makes him happy, brings peace to his mind, and, most importantly, provides positive feedback and a sense of accomplishment.

We know that what’s good for the heart is also good for the brain, more than ever this is an extra motivation. A combination of exercise, a healthy diet, good cardiovascular health management, and memory training can help slow cognitive decline. That’s why I continue to support Geert as much as possible in everything he still can and wants to do, for as long as he is able.

Geert dreams of completing the Six Marathon Majors. So far, he is well on his way: he ran New York before the COVID-19 pandemic, Chicago in 2022, just one week before his diagnosis, Berlin in 2023 and London in 2024. That leaves Tokyo and Boston. However, getting an entry for these races is challenging. These marathons are highly sought-after, and the only way to get a bib is through a lottery system. Because time is running out for Geert, I tried to secure a spot through alternative methods, including a call for help in Running.be magazine, our local Newspaper and on national radio (Klara) during World Dementia Day, but without success.

As an alternative, I suggested the Milan Marathon. For me as a caregiver, this is a much easier option: not too far, not in a huge city, and not as crowded. I have to manage everything alone, and at major events, that is challenging. There are massive crowds, and as a caregiver, you are not allowed to accompany your partner to the starting area. The organisation assigns numbers and letters for start zones, lockers, etc., but for Geert, this is not easy to navigate. Hopefully, the weather will be dry and not too cold, and I will be able to keep his spare clothes until he crosses the finish line after 42.195 kilometres. We will arrive well in advance to make a lot of arrangements to ensure we find each other easily, such as identifying the location where Geert has to start and where I will wait for him after the marathon. In case of an emergency, I can always track him using his tracker.

Now, we just hope his training goes smoothly, that there are no injuries, and that he can complete the marathon without any issues. These are all the worries I, as a caregiver, carry from the moment we leave home until the entire trip is over. For Geert, this is a challenge, but for me, it is a stress from start to finish.

There will come a time when Geert will no longer be able to run. Every step he takes is controlled by his brain, and unfortunately, his brain is deteriorating. But today is not that day. That is why Geert wants to run marathons while he still can, and we want to make the most of every single day. Geert remains incredibly positive, and that means everything.

If there is one message we want to share, it is this: Don’t postpone what you love doing until tomorrow, do it today. And it doesn’t have to be a marathon!

*Pictured: Geert at the Berlin marathon in 2023*

# EDUCATION

12 FEBRUARY:

## University of Stirling Dementia Services Development Centre set to launch its new "LGBTQ+ Inclusivity in Ageing and Dementia" training at online event

A new training course on "LGBTQ+ Inclusivity in Ageing and Dementia", provided by the University of Stirling Dementia Services Development Centre (DSDC), will be launched at an online event on 24 March 2025.

Speakers include the course co-authors:

- Dave Wilson-Wynne, DSDC's Senior Dementia Consultant
- Arlene Bunton, Scottish Care and PhD student at the University of Stirling
- John Angel Bond, PhD student at the University of Stirling.

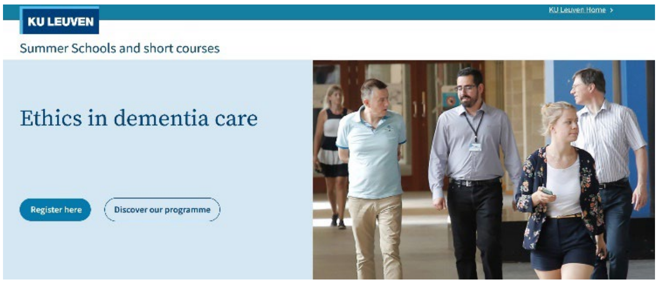
Guest speakers include:

- Janice Cameron, National Lead at Scottish Care
- William McGregor, Regional Manager, Sanctuary Care
- Tammy Collins, Social Care Worker, Sanctuary Care.

You can find out more about the training and register for the online launch event, via:
https://www.eventbrite.co.uk/e/launch-of-lgbtq-inclusivity-in-ageing-and-dementia-training-tickets-1237295446989?aff=ebdsshother&utm_share_source=listing_android

12 FEBRUARY:

## Registrations are open for KU Leuven 2025 Summer Course on Ethics in Dementia Care



The Centre for Biomedical Ethics and Law of the KU Leuven is organising the 11th edition of the Summer Course on Ethics in Dementia Care, taking place in Leuven, Belgium, from 8-11 July. The language of instruction will be English.

The objective of the course is to foster exchanges on foundational, clinical-ethical and organisational-ethical approaches to dementia care practices. This course adopts an interdisciplinary approach, incorporating philosophy, theology, medicine, social sciences, nursing, as well as both normative and empirical ethics. Throughout the course, national and international experts will deliver presentations on a range of ethical topics related to dementia care. Ample time will be allocated for in-depth discussion and interaction.

The course is designed for participants from diverse professional backgrounds, including healthcare administration, medicine, nursing, psychology, social work, philosophy and theology. It is open to healthcare and social workers, university and university college staff, members of patient associations, ethics committees, and PhD students in these areas.

For this 11th edition of the summer course, the list of countries eligible for a reduced registration fee has been expanded to include several middle-income countries, such as Argentina, Brazil, China, South Africa, and Turkey.

The deadline for Early Bird registrations (reduced cost) is **15 May 2025** and the final deadline for course registration is **15 June 2025**.

Detailed information on programme, funding opportunities, registration and payment can be found at: https://www.kuleuven.be/english/summer-schools/ethics-in-dementia-care-11th-edition-2025/ethics_in_dementia_care

# PUBLICATIONS AND RESOURCES

31 JANUARY:

## EMPOWER Dementia Network Plus aims to empower a meaningful life for all

The EMPOWER Dementia Network Plus, launched in April 2024, is a UK-based initiative dedicated to creating a fair and inclusive future for dementia care. The network brings together people with dementia, family carers, researchers, health and social care professionals, and charities to address inequalities in access to dementia care and ensure that everyone, regardless of background or circumstance, can live a meaningful life.

A key focus of the network is the co-creation of a shared vision for inclusive dementia care, shaped directly by the experiences and insights of people living with dementia and their carers. Through a series of creative workshops, participants have explored what excellent dementia care should look like, what barriers need to be removed, and what resources are essential to achieving this vision. Using metaphorical themes such as a tree, compost heap, and tool shed, discussions have centred on defining core principles, identifying outdated or inequitable practices that need to be left behind, and pinpointing the practical tools required to drive meaningful change.

These workshops have been crucial in ensuring that the network's direction is firmly rooted in lived experience, particularly for individuals from ethnic minority backgrounds, rural communities, and those needing greater support in accessing care. The co-creation process will continue in 2025, with further opportunities for people affected by dementia to contribute their perspectives and shape the network's vision.

In 2025, the network will launch its website as a hub for collaboration, resource-sharing, and community engagement. A Policy Lab in March will translate the network's vision into tangible actions, while a community partner networking event in June will provide a space to share good practice and explore innovative projects.

Additionally, the network will introduce funding opportunities to support small-scale projects that advance inclusive dementia care. These funds will be available to community organisations working in partnership with researchers, encouraging creative and practical solutions to improve access to high-quality dementia care across the UK.

EMPOWER Dementia Network Plus is led by Catherine Evans (King's College London) and Emma Wolverson (University of West London). The network invites anyone passionate about improving dementia care to join and contribute to its mission. For more information, please contact EMPOWER_Dementia_Network@kcl.ac.uk

18 FEBRUARY:

## TouchNEUROLOGY publishes new video of expert panel discussing best practices in management of agitation in Alzheimer's dementia and potential of new pharmacological approaches

In this activity, three experts consider best practice in the management of agitation in Alzheimer's dementia and the potential of new pharmacological approaches that target aspects of the underlying pathophysiology. The discussion is guided by pre-canvassed questions provided by healthcare professionals involved in the management of people living with dementia associated with Alzheimer's disease.

Watch the video, "Pharmacological management of agitation in Alzheimer's dementia: Rationale and evidence for new and emerging treatment options", here: https://touchneurology.me.org/panel-pharmacological-management-of-aad/

# AE CALENDAR 2025

| DATE | MEETING | AE REPRESENTATIVE |
|---|---|---|
| 3 March | Alzheimer Europe Foundation Board | Jean |
| 4 March | TEF-Health workshop on “Driving Innovation in Health Data and Digital Health” (Brussels, Belgium) | Angela |
| 4 March | 2nd subgroup meeting for Civil Society Europe on the Civil Society State of the Union | Sébastien |
| 4 March | Dutch AD Riddle project Advisory Board meeting | Ana and Sarah |
| 5 March | Nobody Left Outside initiative’s meeting on “Health Equity for Marginalised Voices – EU’s Path Forward” (Brussels, Belgium) | Sébastien |
| 6-7 March | PANEUCARE project consortium meeting (Berlin, Germany) | Soraya |
| 10 March | Meeting with CEOi Initiative on AD | Jean |
| 10-11 March | Remote-AD Consortium Meeting (Magdeburg, Germany) | Sébastien |
| 12 March | PREDICTOM project Advisory Board meeting | Sarah |
| 12 March | FluiDx-Ad project kick-off meeting | Ana and Chris |
| 14 March | LETHE project webinar on Public Involvement | Ana, Chris, Cindy and Soraya |
| 14 March | European Commission DG EMPL exchange of views on European Semester 2025 | Owen |
| 20 March | Multi-MeMo project Advisory Board consultation | Ana, Cindy and Sarah |
| 21 March | Innovative Health Initiative coordination meeting for AD projects (Brussels, Belgium) | Ana and Angela |
| 24-25 March | Alzheimer Europe Board (Senningerberg, Luxembourg) | AE Board and staff |
| 25-27 March | European Working Group of People with Dementia meeting (Senningerberg, Luxembourg) | Ana, Dianne, Sarah, Sébastien and Soraya |
| 26 March | European Parliament workshop on “Unlocking Europe’s future: Prioritising health under the next multiannual financial framework” (Brussels, Belgium) | Jean |
| 31 March | Multi-Memo project General Assembly meeting | Ana, Cindy and Sarah |

# CONFERENCES 2025

| DATE | MEETING | PLACE |
|---|---|---|
| 13-14 March | Dementia Lab Conference, University of Aveiro, https://www.dementialabconference.com/ | Aveiro, Portugal |
| 20-22 March | 19th World Congress on Controversies in Neurology (CONy), https://cony2025.comtecmed.com/ | Prague, Czechia |
| 1-5 April | International Conference on Alzheimer's and Parkinson's Diseases and Related Neurological Disorders (AD/PD™ 2025) https://adpd.kenes.com/partners-related-events/ | Vienna, Austria |
| 15-17 May | The 8th Venusberg meeting on Neuroinflammation, https://neuroinflammation.uni.lu/ | Belval, Luxembourg |
| 3-6 June | 15th edition of the National Alzheimer Conference, http://www.alzcongres.ro | Bucharest, Romania |
| 21-24 June | 11th Congress of the European Academy of Neurology, Neurology within society, https://www.ean.org/ | Helsinki, Finland |
| 24-26 September | 21st EuGMS Congress, https://eugms2025.com/ | Reykjavík, Iceland |
| 6-8 October | 35th Alzheimer Europe Conference, "Connecting science and communities: The future of dementia care", https://www.alzheimer-europe.org/conferences | Bologna, Italy |
| 12-15 October | XXVII World Congress of Neurology, https://wcn-neurology.com/ | Seoul, South Korea |
| 4-5 February 2026 | 2nd International Conference on the Prevention of Alzheimer's Disease (ICOPAD 2026), https://www.hug.ch/en/evenement/2nd-international-conference-prevention-alzheimers-disease-icopad-2026 | Geneva, Switzerland |

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# 35th Alzheimer Europe Conference

## Connecting science and communities: The future of dementia care

Bologna, Italy

6 - 8 October 2025 #35AEC

www.alzheimer-europe.org/conferences

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