Alzheimer Europe

Newsletter
JULY-AUGUST 2025

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WELCOME

This bumper edition of our newsletter covers both July and August. I hope that everyone has had a warm and pleasant couple of months and that you all managed to take a break somewhere nice.

We have had a lovely summer here in Luxembourg and the team has all managed to take some time off, but the wheels of Alzheimer Europe have kept turning, at quite a fast, pace despite the hot weather!

In July, we held another session of our popular online Alzheimer's Association Academy series – the fourth this year so far - focusing on the topic of awareness campaigns, where our member associations from Armenia, Austria Belgium and Lithuania presented their excellent work in this domain. Our next Academy session is scheduled for 16 September and will explore "Working with parliamentarians and parliamentary interest groups".

Another event in which we were delighted to participate was the 2025 Alzheimer's Association International Conference (AAIC25) in Toronto (Canada). It was a real pleasure to attend this vast and impressive event, together with 19,000 other delegates, from across North America and far beyond. My colleague Sarah Campill (Public Involvement Officer) travelled with Jan Runar Eliassen (member of the European Working Group of People with Dementia, from Norway) and his wife Marion Tur Eliassen to Toronto (Canada) to speak at and participate at AAIC25. The event highlighted the latest advances in dementia research and care, some highlights of which you can find in our "AAIC Watch" section beginning on page 19.

Speaking of important scientific developments, following a re-examination of its initial, negative opinion, the Committee for Medicinal Products for Human use (CHMP) of the European Medicines Agency (EMA) issued a positive opinion on Lilly's marketing authorisation application for donanemab for the treatment of early Alzheimer's disease (mild cognitive impairment and mild dementia due to Alzheimer's disease) on 25 July. In its opinion, the CHMP found that the benefits of donanemab for a restricted population outweighed its risks and therefore recommended approving the marketing authorisation application. Alzheimer Europe welcomes the positive opinion by the CHMP, which follows that of other regulators.

Following the launch, in June, of our call for applications for this year's Anti-Stigma Award, we spread the word, with the help of our members across Europe, and are delighted to say that, at the close of applications (1 September), we had received 46 applications. With so much excellent work to choose from, reviewing them all and shortlisting the top ones to present to our jury is a real challenge. Thank you to everyone who applied! We are in the process of responding to everyone.

And finally, our Annual Conference is taking place in just over a month, in Bologna (6 to 8 October). We can't wait to see everyone, there. If you haven't yet registered, please make sure you do so before 21 September, to benefit from the current registration rate, which will increase after that deadline.

Jean Georges, Executive Director

ALZHEIMER EUROPE

25 JUNE:

Alzheimer Europe's membership of the European Medicines Agency's Patients' and Consumers' Working Party is renewed

On 25 June 2025, the European Medicines Agency (EMA) informed Alzheimer Europe that its application for membership of the Patients' and Consumers' Working Party (PCWP) had been renewed, for the term 2025 to 2028.

Find out more about the EMA's PCWP here: https://www.ema.europa.eu/en/committees/working-parties-other-groups/comp-working-parties-other-groups/patients-consumers-working-party

The list of all the patients' and consumers' organisations that are involved in EMA activities can be viewed here: https://www.ema.europa.eu/en/partners-networks/patients-consumers/eligible-patients-consumers-organisations

1 JULY:

Alzheimer Europe article on dementia prevention and risk reduction published in latest edition of Open Access Government

The latest edition of "Open Access Government" was published on 1 July 2025, and includes an article written by Angela Bradshaw, Director for Research at Alzheimer Europe. Her article, entitled "European perspectives on dementia prevention: Can lifestyle changes reduce risk?", can be read on pp. 150-151 of the publication, which can be read and downloaded *via*:

https://www.openaccessgovernment.org/publication/open-access-government-july-2025/193511/

Open Access Government is a digital publication that provides an in-depth perspective on key public policy areas worldwide, including health and social care, research and innovation, technology, government, environment and energy.

10 JULY:

Alzheimer Europe invites people across Europe to participate in its public opinion poll, assessing attitudes towards dementia research participation and data sharing

Tell us what you think about dementia research!

Alzheimer Europe

We are inviting all European residents (aged 18+) to take part in our public opinion poll.

- No prior experience with dementia research needed
- Available in 12 languages
- Takes approximately 10 minutes to complete

Your input will help shape future research and data sharing

Scan here to participate!

Results will be published on the Alzheimer Europe website in October 2025

Representation in research is key to ensuring findings are relevant and applicable to the wider population, yet participation remains low and often limited to a select group. Alzheimer Europe recently launched a public opinion poll, aiming to identify what motivates or discourages people from taking part in dementia research and to understand how individuals feel about data sharing.

This initiative is part of a broader effort by Alzheimer Europe to increase involvement in dementia studies and to promote more effective data use in research. The poll was developed in collaboration with Alzheimer Europe's national member organisations, the European Working Group of People with Dementia and the European Dementia Carers Working Group.

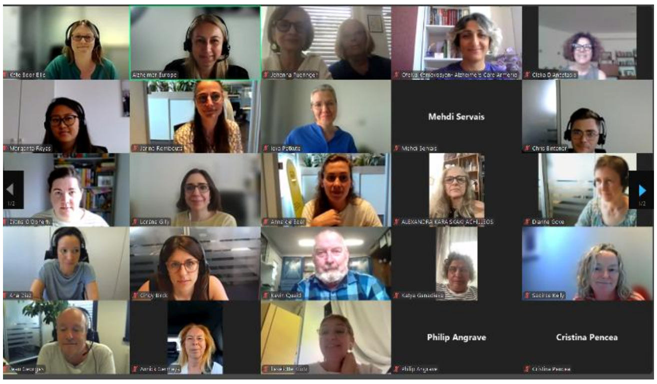
By gathering insights from people across different countries and backgrounds, the poll seeks to identify common barriers and facilitators to research participation. It also looks at past experiences with research and public perceptions of how data is handled and shared. The findings will be used to produce a comprehensive report and practical recommendations to improve recruitment in future dementia studies and promote responsible data sharing. Results will also be published in a dedicated section of the Alzheimer Europe website.

The poll takes approximately 10 minutes to complete and is open to anyone living in a European country, regardless of whether they have previously taken part in research. Both people with and without dementia are invited to participate. The poll is available in 12 languages: Czech, Dutch, English, Finnish, French, German, Italian, Polish, Portuguese, Slovak, Spanish and Swedish. Alzheimer Europe encourages everyone to take part and share the poll within their networks.

https://alzheimereurope.qualtrics.com/jfe/form/SV_efWN0hszkxA914O?Q_CHL=qr

15 JULY:

Alzheimer Europe hosts a session of its popular online Alzheimer's Association Academy, focusing on the topic of awareness campaigns



On 15 July, Alzheimer Europe hosted a session of its popular online Alzheimer's Association Academy, with a focus on awareness campaigns. The Academy is a series of online capacity-building workshops bringing together representatives of national Alzheimer's associations with members of the European Working Group of People with Dementia (EWGPWD) and European Dementia Carers Working Group (EDCWG), to learn about dementia advocacy, care, policy, research and treatment from experts in these fields.

The session on 15 July was the fourth Academy session of 2025 and was hosted by Kate Boor Ellis, Communications Officer, Alzheimer Europe. She welcomed 49 registered participants, including members from 20 countries across Europe, representatives from two pharmaceutical companies, Bristol Myers Squibb and Eisai, as well as members of the Alzheimer Europe staff.

There were five speakers, all of whom shared presentations about work they and their organisations are doing in countries across the European region, to raise the profile of dementia, both among the wider public and among more targeted groups such as policymakers, health and social care providers, and other groups that are of great importance in ensuring the best quality of life possible for people with dementia and their supporters, as well as ensuring their rights and dignity are upheld in daily life. Attendees learned about work being done in Austria, Armenia, Lithuania and Belgium.

Whilst different approaches are taken and different methods used, a vital common thread through all the presentations was that this work is being carried out with the involvement of people with dementia and their families, carers and supporters, ensuring the voices of those with lived experience are heard. Including people affected by dementia and ensuring they are an integral part of these campaigns not only helps raise awareness but also helps reduce stigma and misconceptions around the condition.

The first presentation was given by Johanna Pueringer and Angela Pototschnigg from Austria. Johanna Pueringer works for Demenz Selbsthilfe Austria and runs a support group for people with young onset dementia, called "Uber den berg kommen". She also supports Angela Pototschnigg, who is a member of the European Working Group of People with Dementia and a Peer Counsellor at Alzheimer Austria. Angela was diagnosed with a mixed form of dementia some eight years ago. Their talk was entitled "Selbsthilfe wirkt" (self-help works) and included a series of campaign videos. You can find out more about the campaign and watch the videos, here: https://www.demenzselbsthilfeaustria.at/kampagne/#selbsthilfewirkt

Up next was Ofelya Kamavosyan, a communications strategist and media producer who is the founder and producer of Second Start Armenia, a media platform dedicated to stories of longevity, transformation, and resilience. Ofelya currently serves as the Communications and PR Specialist at Alzheimer's Care Armenia, where she leads projects focused on advancing dementia care and public awareness. In addition, she is a producer and host at Public Radio of Armenia, continuing her mission to inform and inspire audiences through high-quality, meaningful content. Her talk covered many of Alzheimer's Care Armenia's advocacy and awareness campaigns and activities.

The third presentation was delivered by Ieva Petkuté, founder and lead of Dementia Lithuania. She is also an Atlantic Fellow at the Global Brain Health Institute, and an EdD (Doctor of Education) student at the Lithuanian Sports University. She leads local and international initiatives focused on accessibility, inclusivity, and the role of arts in brain health, dementia care, and well-being. Her cross-disciplinary work combines experimental content with traditional media and engages with policy, research, and education to ensure that the impact of her projects extends beyond their immediate scope. She discussed "The Power of Lived Experience in Advocacy Efforts in Lithuania" and shared a number of photographs from a photo voice project about the experience of implementing the person-public involvement initiative "Nepatyręs nesupras" (You won't understand if you haven't experienced).

Our last speaker at the Academy was Mehdi Servais from Ligue Nationale Alzheimer Liga (LINAL), Belgium. Mehdi works on projects and communications at LINAL and he shared some recent developments in advocacy and awareness raising in Belgium, on behalf of Baroness Sabine Henry, President of the Ligue Alzheimer & LINAL Belgium, and Olivier Constant, Advocacy and Awareness Raising Officer at the Flemish Alzheimer's Association (Alzheimer Liga Vlaanderen) who were unable to join the session.

A huge thank you to all speakers and participants at the Academy of 15 July and a huge thank you, also, to the European Union's Citizen's, Equalities, Rights and Values programme, and our Gold and Silver sponsors, Bristol Myers Squibb, Eisai, Lilly, Novo Nordisk and Roche, without whom our educational and healthcare-related activities, including these capacity-building Academy sessions, would not be possible.

The next edition of the Alzheimer's Association Academy is scheduled for 16 September 2025.

22 JULY:

Alzheimer Europe's research accreditation renewed by Luxembourg Government for a further five years

THE GOVERNMENT
OF THE GRAND DUCHY OF LUXEMBOURG
Ministry of Higher Education and Research

On 22 July, the Luxembourg Ministry of Research renewed the accreditation of Alzheimer Europe as a Luxembourg non-profit organisation in the field of research. This accreditation was first granted to us in 2015, for a five-year period, with the first renewal in 2020.

The renewal of this accreditation, which is for a further five years (to 2030), allows us to continue to participate in projects with the EU Joint Programme – Neurodegenerative Disease Research (JPND) or The Active and Assisted Living Programme (AAL). It also allows us to receive funding from the national funding agency "Fonds national pour la recherche" (FNR).

26-31 JULY:

Representatives from Alzheimer Europe and the European Working Group of People with Dementia participate in Alzheimer's Association International Conference in Toronto, Canada

In July, Sarah Campill (Public Involvement Officer, Alzheimer Europe) travelled with Jan Runar Eliassen (member of the European Working Group of People with Dementia, from Norway) and his wife Marion Tur Eliassen to Toronto (Canada) to speak at and participate in the Alzheimer's Association International Conference 2025 (AAIC25). The event brought together nearly 19,000 attendees from around the world, with over 6,400 scientific submissions, highlighting the latest advances in dementia research and care. Jean Georges (Executive Director, Alzheimer Europe) also attended the conference.

26 July: Spotlight on lived experience at AAIC pre-conference immersive session

On 26 July, Jan Runar, Marion and Sarah co-presented during the immersive pre-conference session, "Building Capacity for Collaborations Among Researchers and People with Lived Experience of Dementia: Global Perspectives." The trio shared Alzheimer Europe's approach to involving people with dementia and carers in its activities and European research projects, offering insights from their respective perspectives.

The session was co-organised by the Canadian Consortium on Neurodegeneration in Aging (CCNA), the Engagement of People with Lived Experience of Dementia (EPLED) and Knowledge Mobilization (KM) programmes, the International Society to Advance Alzheimer's Research and Treatment (ISTAART) through its Partnering with Research Participants Professional Interest Area (PIA), and the Global Brain Health Institute (GBHI).

Each organisation shared its approach to involving people with lived experience in dementia research, illustrating the diversity of methods, interpretations of terminology and levels of involvement used across different regions and contexts. While the terminology and practices varied, the session highlighted a shared commitment to inclusive research, the importance of listening to diverse perspectives and that there is a lot to learn from one another. The messages shared by speakers with lived experience resonated deeply, not only with the audience but also among fellow presenters, reinforcing a collective sense of purpose and solidarity in advancing meaningful involvement in dementia research.

"Take the time to create a safe and respectful environment where people with dementia feel valued and heard. Use simple, clear language, be patient and adapt interactions to their needs and pace. Actively listen to their perspectives and acknowledge their contributions as equal partners in the research. This fosters meaningful participation and ensures their voices are authentically represented", said Marion, addressing young researchers

"Being part of AE's work provides us with a lot of information and knowledge, which is very valuable and meaningful. It feels good to connect with others living with the same disease and to have the opportunity to learn from and support each other. With a disease for which there is still no cure, it is especially meaningful to contribute to research to ensure that those who come after us are met in a better way and one day can receive a cure for this disease", Jan Runar said in his closing statement.

27-28 July: Poster presentations on Public Involvement and participation pathways

On 27 July, Sarah presented a poster on behalf of Lukas Duffner (Project Officer, Alzheimer Europe) titled "Pathways to Participation: Understanding Barriers and Enablers to Participation in Dementia Research," which focused on recent findings from a publication exploring inclusive research practices.

On 28 July, Sarah presented her poster on "Informed Choices and Early Dementia Risk Disclosure in Home-Based Assessments in the PREDICTOM Study: A Public Involvement Approach," highlighting our recent work on Public Involvement in the IHI PREDICTOM project.

29 July: ISTAART Skills Workshop

On 29 July, Jan Runar, Marion and Sarah contributed to the ISTAART Skills Workshop, "Collaborating with People with Lived Experience in Dementia Research." The session, designed for early career researchers, facilitated small group discussions with people with dementia and care partners. Participants explored enablers and barriers to research participation and shared promising practices for inclusive research. The moment was documented by Michelle Memran (Documentary Filmmaker and Atlantic Fellow for Equity in Brain Health, GBHI), who expertly captured the special atmosphere in the room.

A Participant summarised the event later: "Ask the Experts wasn't just the name; it was the message. People with lived experience are the experts."

Both sessions and the posters were well received and sparked meaningful conversations around inclusive research practices. The conference also provided valuable opportunities to strengthen international collaborations and explore emerging trends in dementia research.

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6 AUGUST:

Detailed programme for 35th Alzheimer Europe Conference in Bologna available online: Register before 21 September!

The detailed programme for the 35th Alzheimer Europe Conference (#35AEC) is now available to view on our website. Browse through our programme and discover the topics and speakers from upwards of 70 sessions:

https://www.alzheimer-europe.org/conferences/2025-bologna/detailed-programme

Register today and join more than 1,250 delegates who have already registered, for what promises to be an exciting and interactive event in Bologna (Italy) from 6-8 October!

Special rates are available for people with dementia, students and member associations of Alzheimer Europe. Click here for more information.

Please make sure you register before the 21 September, to benefit from the reduced rate of EUR 640 (EUR 800 thereafter). Click here to register: https://www.alzheimer-europe.org/conferences/2025-bologna/conference-registration-portal

We look forward to seeing you in Bologna at #35AEC!

11 AUGUST:

A big thank you to the Emilia-Romagna Region for becoming an official supporter of the 35th Alzheimer Europe Conference in Bologna!

The upcoming 35th Alzheimer Europe Conference (#35AEC) will take place in Bologna from 6 to 8 October 2025. Together with our event co-hosts, Federazione Alzheimer Italia and Alzheimer Uniti Italia, we would like to express our gratitude to the Emilia-Romagna Region, for officially supporting and sponsoring our event.

Check out the Emilia Romagna Turismo website, to find out what this beautiful region has to offer: https://emiliaromagnaturismo.it/en/towns/bologna

AE NETWORKING

2 JULY	Dianne discussed the future launch of the French and German translation of Alzheimer Europe’s sex and gender guide with the Association Luxembourg Alzheimer and CESAS
2 JULY	Ana, Dianne and Sarah joined the members of the European Dementia Carers Working Group to welcome the new members of the group
2 JULY	Sarah attended European Medicine Agency’s annual training for patients, consumers and healthcare professionals (Amsterdam, Netherlands)
2 JULY	Owen attended an online webinar hosted by DG EMPL on persons with disabilities accessing healthcare
3 JULY	Owen attended a webinar hosted by DG EMPL on the EU Anti-Poverty Strategy
3 JULY	Angela attended a meeting of the European Medicines Agency’s Network Advisory Group for Raw Data
7-8 JULY	Angela participated in the “Mind the Future” roundtable meeting organised by the Fondazione Della Sostenabilita Soziale (Milan, Italy)
9 JULY	Angela joined a discussion of the European Medicines Agency’s Scientific Advice Working Party (SAWP)
14 JULY	Owen attended a webinar hosted by WHO Europe on the opportunities to engage in their work, including during the 75th Regional Committee
15 JULY	Alzheimer Europe organised a session of its online Alzheimer’s Association Academy, focusing on the topic of awareness campaigns, with sponsors, members and staff
22 JULY	Jean, Dianne and Ana welcomed Nicole Batsch to the office in Luxembourg for an informal discussion
23 JULY	Owen attended a webinar hosted by DG EMPL on the forthcoming EU Civil Society Strategy
26 JULY	Lukas attended a round table discussion on data sharing organised by the Alzheimer’s Disease Data Initiative
26 JULY	Sarah was a speaker at the ISTAART immersives workshop on Building Capacity for Collaborations Among Researchers and People with Lived Experience of Dementia: Global Perspectives at the Alzheimer Association International Conference (Toronto, Canada)
27 JULY	Sarah presented a poster on behalf of Lukas at the Alzheimer Association International Conference (Toronto, Canada)
28 JJULY	Sarah presented a poster for PREDICTOM at the Alzheimer Association International Conference (Toronto, Canada)
30 JULY	Sarah joined an ISTAART Skill Workshop on Collaborating with People with Lived Experience in Dementia Research at the Alzheimer Association International Conference (Toronto, Canada)
27 AUGUST	Soraya had a consultation with the members of the DORIAN GRAY Public Involvement Board

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SPONSORS OF THE MONTH

Alzheimer Europe would like to express its gratitude to the following sponsors in 2025:

BIOARCTIC MSD ucb

All corporate sponsors have provided sponsorship to support educational and healthcare related activities and have no input in the content or activities produced by Alzheimer Europe.

Read more about sponsorship opportunities here:
https://www.alzheimer-europe.org/about-us/governance/finances/2025-sponsorship-opportunities

EU PROJECTS

26 JUNE:

Fraunhofer SCAI hosts ADIS project symposium for earlier diagnosis of Alzheimer's disease

On 25-26 June, the Fraunhofer Institute for Algorithms and Scientific Computing hosted a symposium titled "Towards Earlier Diagnosis of Alzheimer's Disease" in Bonn (Germany) that marked the end of the ADIS project. ADIS stands for "Early Diagnosis of Alzheimer's Disease by Immune Profiling of Cytotoxic Lymphocytes and Recording of Sleep Disturbances", an interdisciplinary initiative coordinated by Fraunhofer SCAI. The meeting brought together leading researchers from across Europe to share insights from the project and beyond as well as to explore future collaboration opportunities.

The first day reviewed current research into the early diagnosis and biological characterisation of Alzheimer's disease (AD), covering clinical, biological and computational approaches. Taking a technology-agnostic view, the project has integrated a range of methods, from blood-based and immune biomarkers to digital tools for remote monitoring of sleep, cognition and behaviour. The programme was structured around four sessions, addressing perspectives on early diagnosis, immune profiling and single-cell sequencing, artificial intelligence and agent-based modelling, and digital biomarkers. Speakers included representatives from ADIS and related EU-funded projects PROMINENT, AD-RIDDLE and PREDICTOM.

The second day focused on prevention strategies and future directions. It opened with presentations on initiatives such as the Barcelona Brain Health Initiative and PatternCog, as well as a talk from Alzheimer Europe on involving the public to develop strategies to reach young adults to motivate them to improve their brain health. Participants then took part in two in-depth round table discussions. The first explored challenges such as closing knowledge gaps in AD research, evaluating early biomarkers and developing prevention pathways. In the second, groups presented their findings to all attendees and reflected on next steps.

The meeting marked the conclusion of the ADIS project, while also opening the door to continued collaboration. The organisers gratefully acknowledged the Fritz-Thyssen Foundation for supporting the event.

2 JULY:

LETHE project tests user-centred digital tools to support dementia risk reduction

On 2 July, researchers from Austria, Finland, Germany, Italy, Luxembourg, the Netherlands and Sweden published an article on the development of a digital platform for dementia prevention in JMIR Aging.

The study presents a mobile app for older adults and a clinical trial management system (CTMS) for professionals, both designed within the LETHE project to support a digitally enabled lifestyle intervention. Usability was tested among 156 participants enrolled in an ongoing 2-year randomised controlled trial across four countries.

Feedback collected one month after enrolment showed positive results. The mobile app received a median System Usability Scale score of 70 in the intervention group and 73 in the control group. The CTMS also received mostly favourable feedback, with personalised activities and real-time appointments seen as standout features.

While results are limited to participants with digital access and skills, the tools were well received and support further testing of digital interventions for cognitive health.

The article has been published open access and can be read here: https://doi.org/10.2196/66660

4 JULY:

Final LETHE project event presents key outcomes on dementia risk reduction

On 4 July, the LETHE project held its final event, showcasing major findings from four and a half years of research on dementia risk reduction. The event, organised as an online webinar, brought together project partners, researchers, and members of the public to share results from the LETHE feasibility trial, infrastructure setup, AI-based personalisation tools, and a newly developed Brain Health Literacy Portal.

lethe **Project Final Event**

Showcasing the main results and conclusions from research into dementia risk reduction

Friday 4th of July 2025, 09.30-11.00 CEST

For more information & registration, visit: www.lethe-project.eu/

Funded by the European Union

Coordinator Sten Hanke opened the webinar by outlining the project's aims and summarising the technical and scientific achievements. These included the completion of a two-year feasibility study with 156 participants across four countries, a high retention rate (only four dropouts), development of digital tools to support personalised prevention, and the creation of a rich dataset combining clinical and digital biomarkers.

Jeroen Bruinsma presented research on behavioural determinants of dementia risk reduction. Findings showed that many people were unaware of their own modifiable risk factors and perceived behaviour change as difficult or unrealistic. These insights informed the design of the LETHE app's goal setting and feedback functions, including a traffic light system to guide personalised support.

Helena Untersteiner provided preliminary results from the randomised controlled feasibility study. The trial showed high usability and sustained engagement with the app. While the CAIDE risk score did not show a significant difference between groups, adherence and app use remained high throughout the two-year period, including during the final months without in-person contact.

Mattia Pirani demonstrated the Brain Health Literacy Portal, a publicly accessible online platform providing reliable, tailored information on brain health. The portal allows healthcare professionals to upload validated content and gives users personalised access to materials based on their interests and preferences.

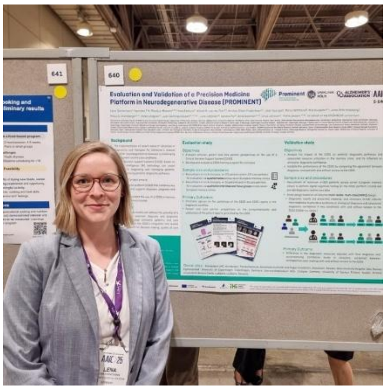
The LETHE project has now concluded, but its outcomes (including its digital tools, AI models, and portal) will continue to be used and further developed in future research initiatives.

The event recording is publicly available and can be viewed here: https://www.youtube.com/watch?v=lZh4qF20cyk&feature=youtu.be

31 JULY:

PROMINENT partners present at AAIC 2025 in Toronto

On 27 to 31 July, PROMINENT partners presented new work at the Alzheimer's Association International Conference (AAIC) 2025 in Toronto, Canada. In related conference news, Eisai and Biogen presented an interim two-year real-world analysis of lecanemab in 178 people with early Alzheimer's disease treated at US centres, reporting clinical stability in most patients, with amyloid-related imaging abnormalities and discontinuation rates consistent with label guidance and growing use of blood-based biomarkers.



PROMINENT, funded by the Innovative Health Initiative, is developing a digital platform to integrate diagnostic data and provide personalised decision support for clinicians managing cognitive impairment, starting with Alzheimer's disease.

On 27 July, Lena Sannemann (University of Cologne, Germany) presented the poster "Evaluation and validation of a precision medicine platform in neurodegenerative disease (PROMINENT)". "I had the opportunity to present the study design of the PROMINENT evaluation and validation studies as a poster presentation on the first day of the conference. The poster attracted considerable interest and allowed me to share the aims of the PROMINENT clinical studies and discuss the relevance of digital decision support solutions to assist clinicians in the diagnosis and treatment of neurodegenerative disorders. It was a great opportunity to introduce PROMINENT to a wider audience, and it was lovely to meet my colleagues working on the project!" said Lena Sannemann.

Further PROMINENT contributions included an oral presentation by Alina Solomon (University of Eastern Finland) on using digital biomarkers to monitor disease progression, and a poster by Sophie van der Landen (Alzheimer Center Amsterdam, Netherlands) on test-retest reliability and feasibility of the web-based cognitive assessment cCOG.

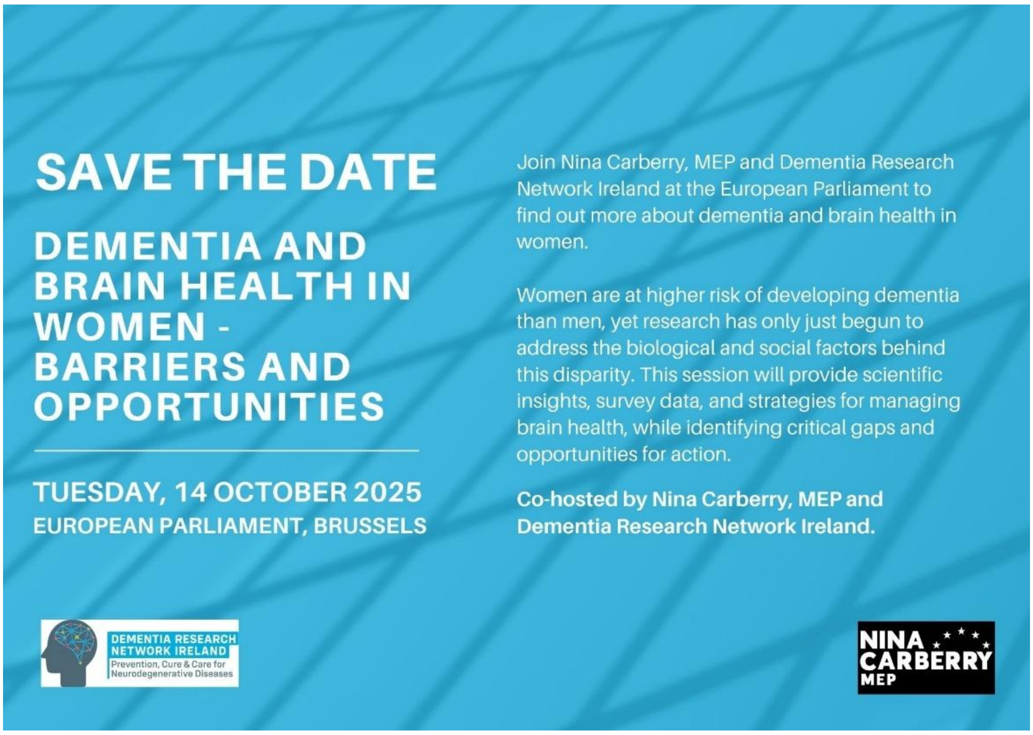
"I was pleased to present our findings on the test–retest reliability and feasibility of cCOG, a web-based cognitive assessment tool. During the conference, it became clear that digital cognitive testing is increasingly discussed alongside emerging biomarkers, such as blood-based biomarkers. This highlights the growing recognition that combining different types of digital and biological measures will be essential to improve early detection and monitoring of cognitive impairment. PROMINENT provides an ideal framework to integrate these complementary data sources and translate them into practical decision support for clinicians," reflected Sophie van der Landen.

Learn more about the project: https://linktr.ee/IHI_PROMINENT

MEMBERS OF THE EUROPEAN ALZHEIMER’S ALLIANCE

Currently, the total number of MEPs in the European Alzheimer’s Alliance (EAA) stands at **89**, 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 (EPP, Ireland); Tilly Metz (Greens/EFA, Luxembourg); Romana Jerković (S&D, Croatia); Sirpa Pietikäinen (EPP, Finland); Vladimir Prebilič (Greens/EFA, Slovenia); Hilde Vautmans (Renew Europe, Belgium) 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); Johan Van Overtveldt (ECR); Hilde Vautmans (Renew Europe). **Bulgaria**: Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Kristian Vigenin (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 (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); Emmanouil (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); Caterina Chinnici (EPP); Carlo Fidanza (ECR); Aldo Patriciello (PFE). **Lithuania**: Vytenis Povilas 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); 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); Romana Tomc (EPP); Milan Zver (EPP). **Spain**: Rosa Estaräs Ferragut (EPP); Juan Fernando López Aguilar (S&D); Idoia Mendia (S&D); Diana Riba i Giner (Greens-EFA); Ana Miranda Paz (Greens/EFA). **Sweden**: Pär Holmgren (Greens-EFA); Jonas Sjöstedt (S&D).



SAVE THE DATE

DEMENTIA AND BRAIN HEALTH IN WOMEN - BARRIERS AND OPPORTUNITIES

TUESDAY, 14 OCTOBER 2025
EUROPEAN PARLIAMENT, BRUSSELS

Join Nina Carberry, MEP and Dementia Research Network Ireland at the European Parliament to find out more about dementia and brain health in women.

Women are at higher risk of developing dementia than men, yet research has only just begun to address the biological and social factors behind this disparity. This session will provide scientific insights, survey data, and strategies for managing brain health, while identifying critical gaps and opportunities for action.

Co-hosted by Nina Carberry, MEP and Dementia Research Network Ireland.

EU DEVELOPMENTS

1 JULY:

EU4Health Civil Society Alliance publishes health blueprint

Alzheimer Europe has joined with members of the EU4Health Civil Society Alliance (EU4Health CSA), in supporting "Health4Europe", a blueprint the next EU Health Programme, designed to strengthen the European Health Union and ensure that health remains a top political and financial priority in the next Multiannual Financial Framework (MFF).

Building on the current EU4Health Programme, Health4Europe sets how the EU can prepare for the health challenges of the next decade. It builds on the Commission's 2024–2029 Political Guidelines, the Commissioners' Mission Letters and on key priorities of the CSA. This includes crisis preparedness, access to healthcare, disease prevention, women's health, digital transformation and civic participation. Specifically, the EU4Health CSA proposal:

Introduces a newer, broader geopolitical and competitiveness angle that was not explicit in the EU4Health Programme.

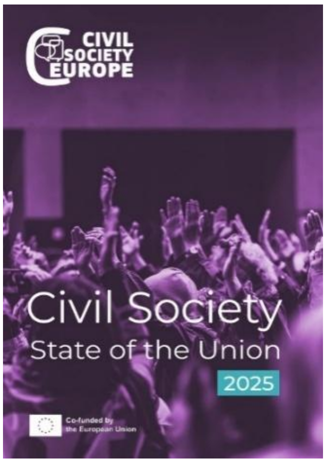
Brings cross-sectoral prevention into focus.

Ensures the necessary instruments are available to meet the goals under the Roadmap for Women's Rights.

Puts environmental health threats and antimicrobial resistance (AMR) into the resilience pillar.

Moves beyond civil society organisations (CSOs) consultation to institutionalised participatory governance.

The EU4Health Civil Society Alliance urges the European Commission and EU Member States to embrace this blueprint as a foundation for a stronger, healthier and more cohesive Europe. The blueprint is available at:
https://eu4health.eu/health4europe-a-blueprint-for-health-in-the-next-long-term-eu-budget/


CIVIL SOCIETY EUROPE
Civil Society
State of the Union
2025
Co-funded by the European Union

2 JULY:

Alzheimer Europe contributes to new "Civil Society State of the Union 2025" report

As the European Commission President prepares to deliver her State of the Union address on the current overall condition of the EU, how can civil society make its collective voice known on the matters that affect citizens the most? With this in mind, Civil Society Europe (CSE), together with a large group of civil society organisations including Alzheimer Europe, has developed the 'Civil Society State of the Union 2025' report. This document, published on 2 July 2025, is both a response and a proposal - it aims to present the EU's current state and propose solutions for positive change. Since 2023, CSE's working group on the state of the union has been working tirelessly to support civil society and citizens' participation in the EU, and follow-up on the Conference on the Future of Europe and its final proposals.

This document is split into six sections, each addressing a specific area:

1. Strengthening democracy, fundamental rights and civic space in the EU and the world
2. Enhancing freedom of movement and solidarity for a more inclusive European society
3. A socially just EU
4. Averting the planetary crisis through climate action, nature restoration and sustainable resource use
5. A digital transformation that leaves no one behind in the EU
6. Shielding European society through human-centred security & readiness policies.

When compared to CSE's 2023 State of the Union report, an alarming decline in democracy, human rights and the rule of law has continued across the EU. Amidst climbing global political tensions, the EU must incorporate a holistic approach, factoring in all sectors of our society, while reinforcing the role civil society plays.

"This report is crucial for the next period of EU decision-making to fill gaps in some areas and set the agenda in others. The rapid changes we all see require timely and sustainable responses. As independent civil society organisations representing a wide range of citizens' experiences and interests, we offer clear analysis rooted in lived experience and grassroots contexts" said Gabriella Civico, President of Civil Society Europe. We hope this document provides a sound basis as we work towards a democratic, socially, and environmentally just EU. Read the full report now

2 JULY:

European Commission launches life sciences strategy

The European Commission has launched a new strategy in an effort to make Europe more attractive place for life sciences by 2030. The strategy is supported by more than EUR 10 billion annually from the current EU budget, aiming to accelerate innovation, facilitate market access and build public trust in new technologies. The Strategy is broken down into three sections: proposes the following actions:

- Optimising the research and innovation ecosystem.
- Enabling rapid market access for life science innovations.
- Boosting trust, uptake and use of innovation.

The Commission will use EUR 300 million for life science innovation in areas such as climate change adaptation, next-generation vaccines and affordable cancer solutions. It will also set up a Life Science Coordination Group to align policies and funding across sectors, as well as support engagement with key stakeholders, including industry and citizens.

The full strategy is available at: https://research-and-innovation.ec.europa.eu/document/download/411698e8-6062-41af-96e5-af54474d70f5_en

16 JULY:

European Commission publishes proposals on Multiannual Financial Framework (MFF) 2028-2034

The European Commission has presented its proposal for its next Multiannual Financial Framework (MFF) for 2028-2034, with almost EUR 2 trillion of spending commitments.

The new MFF shifts the EU's policy focus towards competitiveness and industry, with less focus on components such as social policy and health. For example, despite calls from civil society, there is no reference to a stand-alone health programme. However, there is a proposal to double the budget of the next research framework programme. Other features of the new MFF:

The budget is intended to be streamlined and harmonised, to ensure that accessing funding opportunities is made easier.

- The introduction national and regional partnership plans for investments and reforms, to create targeted impact for economic, social and territorial cohesion.
- A greater focus on competitiveness, with particular focus on supply chains, scaling-up of innovation and technological development.
- A greater package of own resource measures to raise revenue for the EU, to minimise pressure on national finances.

Full details on the Commission's proposals are available at: https://commission.europa.eu/strategy-and-policy/eu-budget/long-term-eu-budget/eu-budget-2028-2034_en

23 JULY:

European Commission publishes EU4Health Work Programme 2025

The European Commission has published the EU4Health Work Programme for 2025 setting out the funding streams for the next six months. The overall budget for 2025 amounts to EUR 571, 347, 315, of which EUR 195,464,733 will be grants, EUR 281,702,582 will be procurement, EUR 2,730,000 will be other expenditures (all under direct management), and EUR 91,450,000 will be under indirect management.

Despite having signed Framework Programme Agreements with a number of civil society organisations, the Work Programme for 2025 does not include provision of Operating Grants. The programme contains a large number of measures for cancer and cardiovascular diseases, however, there are no measures addressing dementia or Alzheimer's disease.

The full EU4Health Work Programme for 2025 is available at: https://health.ec.europa.eu/publications/2025-eu4health-work-programme_en

POLICY WATCH

3 JULY:

UK Government publishes 10 year Health Plan for England including a blueprint for improving dementia care

On 3 July, the Government of the United Kingdom (UK) published its "Fit for the future: 10 Year Health Plan for England". The Plan outlines shifts in the way the National Health Service (NHS) works and it is encouraging to see that a commitment to a blueprint for improving dementia care is included.

"The plan shows us that the UK Government is listening to the thousands of people living with dementia, their family members and carers – everyone who wants to see better health care that's closer to home", commented our national member association in the UK, Alzheimer's Society.

Home > Health and social care > National Health Service > 10 Year Health Plan for England: fit for the future

Department of Health & Social Care

Prime Minister's Office 10 Downing Street

Policy paper

Fit for the future: 10 Year Health Plan for England - executive summary (accessible version)

Updated 15 July 2025

Professor Fiona Carragher, Chief Policy and Research Officer at Alzheimer's Society, said:

"The NHS 10 year plan's commitment to developing a blueprint for improving dementia care is a hugely positive step forward for the 826,000 people in England living with the condition. It has enormous potential to improve their lives. Done right, this plan can turbocharge improvements in diagnosis and ensure the treatment and support people receive is timely, tailored and local.”

She also noted, however, that there were still important questions about how swiftly these plans will be delivered, stressing that “People living with dementia have already waited too long”.

In conclusion, she noted that “Alzheimer’s Society is ready to continue working with the Minister for Care and local health leaders to ensure they see benefits quickly and that their voices shape change from the start.”

You can read the full response from Alzheimer’s Society, here: https://www.alzheimers.org.uk/news/2025-07-03/alzheimers-society-response-10-year-health-plan

You can read the UK Government’s Executive Summary of the new 10-Year Health Plan for England, here:

https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future/fit-for-the-future-10-year-health-plan-for-england-executive-summary

17 AUGUST:

BMJ Public Health article examines Italy’s policy response to dementia

A new paper “Advancing dementia care: a review of Italy’s public health response within the WHO Global Action Plan and European strategies” has been published in the British Medical Journal (BMJ) Public Health. The paper examines the Italian public health response to dementia, measured against global strategies such as the World Health Organization’s global action plan on dementia. Specifically, it examines those activities under the Italian Fund for Alzheimer’s and other Dementias (IFAD), which was established in 2020.

The paper notes that the refinancing of the IFAD will ensure the continuation of key activities detailed in the review, providing an opportunity to consolidate progress, overcome barriers and further develop future initiatives. For the 2024–2026 period, eight priority areas have been identified:

1. Disseminating and implementing the national guidelines
2. Updating the 2014 Italian national dementia plan
3. Revising guidance documents from the national committee
4. Developing a national training strategy for both professionals and caregivers
5. Evaluating dementia prevention strategies at individual and population levels
6. Identifying national indicators for dementia services
7. Defining national indicators for dementia-specific integrated care pathways
8. Supporting telerehabilitation evaluation activities.

The open access paper is available at: https://bmjpublichealth.bmj.com/content/bmjph/3/2/e002250.full.pdf

SCIENCE WATCH

25 JUNE:

"New Alzheimer’s detection strategies combat falling dementia diagnosis rates" - touchNEUROLOGY talks to Professor Bengt Winblad about research presented at EAN Congress

Coverage from: EAN 2025

New Alzheimer’s detection strategies combat falling dementia diagnosis rates

Bengt Winblad

Prof. Bengt Winblad shares insights EAN 2025 on the evolving landscape of Alzheimer’s diagnosis and treatment. He discusses the growing role of biomarkers, the balance between early detection and clinical...

In this expert interview, conducted at the 2025 EAN Congress, Prof. Bengt Winblad discusses dementia diagnoses falling post-COVID, and explores how expanding biomarker use, timely clinical assessment, and integrated therapeutic strategies, including both pharmacological and lifestyle interventions are reshaping clinical practice. He underscores the importance of balancing early detection with diagnostic caution to minimise misclassification and promote responsible patient care

Poster presented at EAN 2025: Impact of the COVID-19 Pandemic on Dementia Diagnoses in Sweden: Trends from 2015 to 2023. Abstract: 530620.

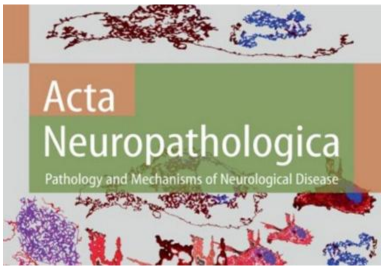
Check out the full discussion, here: https://touchneurology.com/insight/a-new-era-in-early-alzheimers-diagnosis-the-power-of-plasma-biomarkers/

30 JUNE:

ALZpath plasma p-Tau217 assay performs similarly to p-Tau181 but less accurately than Lilly p-Tau217 in postmortem-confirmed Alzheimer’s disease cohort

On 30 June, an international team of researchers published an article comparing plasma phosphorylated tau assays in Acta Neuropathologica Communications.

The study evaluated the performance of the new ALZpath p-Tau217 plasma assay in comparison with two established assays from Lilly: p-Tau217 and p-Tau181. Using samples from



72 participants in the Arizona Study of Aging and Neurodegenerative Disorders, researchers compared plasma biomarker levels with postmortem measures of amyloid plaques and neurofibrillary tangle densities.

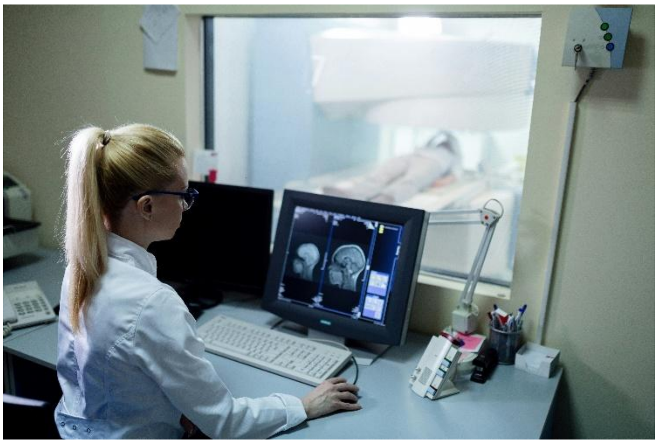
All three biomarkers showed significant correlations with plaque and tangle pathology. However, Lilly's p-Tau217 assay showed the strongest associations, particularly with neurofibrillary density scores, even when adjusted for plaque density. ALZpath's p-Tau217 assay and Lilly's p-Tau181 assay had similar performance in predicting Alzheimer's disease neuropathological change, Braak stage and CERAD plaque scores, with area under the curve scores (AUCs) between 0.74 and 0.79. Lilly's p-Tau217 assay outperformed both, with AUCs between 0.82 and 0.89.

The authors concluded that while ALZpath's p-Tau217 assay performs similarly to p-Tau181, it is less strongly associated with key pathological features than Lilly's p-Tau217 assay. Replication in larger, independent samples is recommended.

The article has been published open access and can be read here: https://doi.org/10.1186/s40478-025-02064-2

1 JULY:

DunedinPACNI method estimates pace of ageing from a single brain scan



On 1 July, an international team of researchers published an article describing the Dunedin Pace of Aging Calculated from NeuroImaging (DunedinPACNI) method in *Nature Aging*.

The study presents a new brain magnetic resonance imaging (MRI) biomarker that estimates how quickly an individual is ageing, based on a single scan. Using data from the long-running Dunedin Study, the researchers developed DunedinPACNI to calculate a rate of longitudinal ageing from cross-sectional MRI data.

They then applied the method to participants from the Alzheimer's Disease Neuroimaging Initiative, UK Biobank and BrainLat datasets. A higher DunedinPACNI score was associated with greater risk of cognitive impairment, faster brain atrophy, and progression to diagnosed dementia. It also predicted physical frailty, poorer health, increased likelihood of chronic diseases as well as higher mortality rates in older adults.

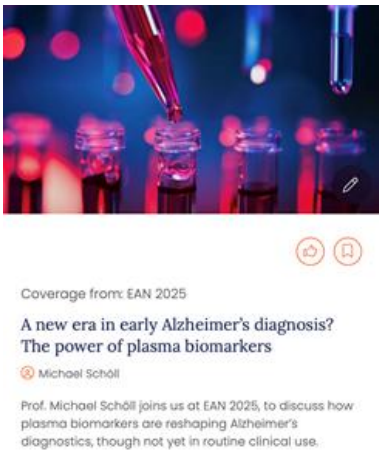
Compared with the brain age gap measure (a measure for the variation between chronological age and calendar age), DunedinPACNI showed similar or stronger associations with clinical outcomes, suggesting its potential as a more precise tool for the monitoring of the effects of ageing.

Although that DunedinPACNI and general aging biomarkers are research tools that require further validation before potential translation to the clinic, they could support research focussed at the links between ageing and health as well as the evaluation of potential anti-ageing interventions.

The article has been published open access and can be read here: https://doi.org/10.1038/s43587-025-00793-y

3 JULY:

"A new era in early Alzheimer's diagnosis? The power of plasma biomarkers" - touchNEUROLOGY talks to Professor Michael Schöll about research presented at EAN Congress



Coverage from: EAN 2025

A new era in early Alzheimer's diagnosis? The power of plasma biomarkers

Michael Schöll

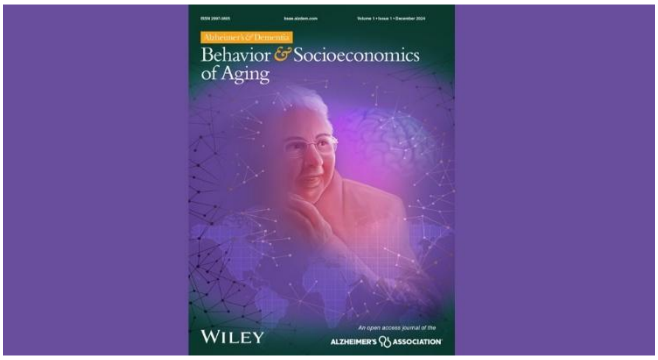
Prof. Michael Schöll joins us at EAN 2025, to discuss how plasma biomarkers are reshaping Alzheimer's diagnostics, though not yet in routine clinical use.

In this interview from EAN 2025, Prof. Michael Schöll discusses the evolving role of plasma biomarkers in Alzheimer's diagnosis and treatment, the challenges of clinical implementation, and the innovations he believes will transform care pathways. Prof. Michael Schöll is Professor of Molecular Medicine at the University of Gothenburg, Sweden, and Principal Research Fellow at University College London (UCL), based at the renowned Queen Square Institute of Neurology. His research focuses on molecular imaging, fluid biomarkers, and early diagnostics for neurodegenerative diseases, particularly Alzheimer's disease.

Check out the full discussion, here:
https://touchneurology.com/insight/a-new-era-in-early-alzheimers-diagnosis-the-power-of-plasma-biomarkers/

9 JULY:

Review identifies strengths and gaps in dementia health economic models



On 9 July, an international team of researchers published an article reviewing health economic models of dementia diagnosis in the journal Alzheimer's & Dementia: Behavior & Socioeconomics of Aging.

The review found that most models supported the cost-effectiveness of current diagnostic strategies, such as the use of cerebrospinal fluid (CSF) biomarkers to confirm Alzheimer's disease, with reported incremental cost-effectiveness ratios below standard willingness-to-pay thresholds.

Researchers systematically analysed 32 studies published between 2000 and 2024 that used decision modelling to evaluate diagnostic or assessment strategies across all dementia stages. These included fluid, imaging and genetic biomarkers, as well as early assessment methods before specialist referral. The studies were critically appraised using the Philips checklist and a narrative synthesis.

The models varied in approach and quality, with several methodological limitations identified. Most failed to account for capacity constraints or broader benefits and harms of diagnosis, and few considered test interdependencies or validated their findings externally.

The authors conclude that while current models support clinical guideline implementation, future studies should improve methodological robustness to support more credible decision-making. The article has been published open access and can be read here: https://doi.org/10.1002/bsa3.70027

10 JULY:

Patients and families describe motives for and against genetic testing in familial dementia

Researchers from the Netherlands recently published an article on patients' and families' views on genetic testing for familial dementia in the Alzheimer's & Dementia journal.

Among 138 patients eligible for genetic testing at the Alzheimer Center Amsterdam, 75 (54 percent) decided to undergo testing. Testers were more likely to have better cognitive performance, higher quality of life scores and an undetermined diagnosis.

Researchers used a mixed-methods approach, combining clinical data from 519 patients with qualitative data from 33 questionnaires and 21 interviews. They found that patients' decisions were guided less by factual information and more by intuitive, value-driven reasoning.

Testers often wanted to clarify the cause of symptoms and provide information to relatives. Non-testers highlighted concerns about emotional distress and poor timing. Across all groups, participants expressed a need for more information and support in decision-making.

The authors concluded that genetic testing is of interest to many families and that its potential psychosocial effects require further attention in dementia care.

The article has been published open access and can be read here: https://doi.org/10.1002/alz.70140

15 JULY:

How obstructive sleep apnoea links to Alzheimer's disease

In Farida Dakterzada, Nathalia Montero-Castilla, Anna Carnes-Vendrell and Gerard Piñol Ripoll's narrative review, the authors explore how obstructive sleep apnoea might contribute to Alzheimer's disease. Obstructive sleep apnoea is a condition where breathing repeatedly stops and starts during sleep, which has a high prevalence in patients with Alzheimer's disease and is also considered a risk factor of the latter. The study focuses on the potential physical effects of obstructive sleep apnoea (low oxygen levels during sleep and constant waking up) on brain health and its links to the progression and development of Alzheimer's disease.

Key findings suggest that the repeated drops in oxygen (intermittent hypoxia) and disrupted sleep (sleep fragmentation) caused by obstructive sleep apnoea lead to inflammation and damage of the blood vessels in the brain, leading to an acceleration in the buildup processes of harmful proteins i.e. amyloid-beta and tau; thus accelerating the clinical Alzheimer's disease progression. The review highlights that intermittent hypoxia and sleep fragmentation are two of the most important players in this regard, working together and possibly leading to oxidative stress and inflammation in the brain. Consequently, connections between brain cells are damaged (cerebrovascular dysfunctionality). Moreover, poor sleep quality due to repeated sleep interruptions and lack of sleep impact memory consolidation and affect the glymphatic system which cleans out waste products in the brain.

The authors point out the need to learn more about whether treating sleep apnoea with a device which helps keep airways open during sleep can modify Alzheimer's disease biomarkers and its effectiveness on the cognitive evolution of patients with Mild Cognitive Impairment and/or Alzheimer's disease. It will also be of importance to know more about sex differences for developing treatment strategies.

https://link.springer.com/article/10.1007/s40675-025-00340-0

16 JULY:

Global Neurodegeneration Proteomics Consortium releases its v1 dataset, including >250 million protein measurements across 23 cohort studies

The Global Neurodegeneration Proteomics Consortium (GNPC), a public-private partnership established by Janssen Research & Development LLC and Gates Ventures in 2023, has announced the release of the first GNPC dataset, via the Alzheimer's Disease Data Initiative's AD Workbench. The dataset includes approximately 250 million protein measurements from nearly 35,000 plasma, serum and cerebrospinal fluid samples contributed by 23 neurodegeneration research cohorts. These samples are linked to harmonised clinical, demographic and cognitive data from participants with Alzheimer's disease, Parkinson's disease, frontotemporal dementia and amyotrophic lateral sclerosis, among other neurodegenerative conditions.

Participating cohorts include the Swedish BioFINDER study, Imperial College's CHARIOT-PRO study (UK), the international Parkinson's Progression Markers Initiative, together with others from the Netherlands, Spain, Sweden and US. Most samples were analysed using the SomaScan 7k proteomics platform, and a subset have additional validation using mass spectrometry and other assays. Over 40% of samples are longitudinal, supporting the study of within-individual biological changes over time.

Members of the global research community can request access to the dataset through the AD Workbench, which is a cloud-based data platform that provides researchers with secure, remote access to large datasets from cohorts studying Alzheimer's disease and other neurodegenerative disorders. By enabling comparisons across diseases, study designs and geographies, the GNPC dataset supports efforts to identify disease mechanisms, new biomarkers and potential therapeutic targets. This may ultimately help improve diagnostic accuracy, inform clinical trial recruitment and guide treatment selection, particularly for conditions with overlapping or mixed pathologies.

The public release of GNPC version 1 is accompanied by a set of peer-reviewed publications in *Nature Medicine*, which describe the consortium, methods, initial analyses and early findings. These articles can be accessed at the following links:

https://www.nature.com/articles/s41591-025-03834-0
https://www.nature.com/articles/s41591-025-03833-1
https://www.nature.com/articles/s41591-025-03831-3
https://www.nature.com/articles/s41591-025-03835-z

A second version of the dataset, including new biosamples, platforms and expanded metadata, is under development.

23 JULY:

Roche receives CE Mark for blood test to help rule out AD

On 23 July, the biotechnology company Roche announced it has received CE Mark for its Elecsys pTau181 test to measure phosphorylated Tau (pTau) 181 protein which is an indicator of amyloid pathology, a hallmark of Alzheimer's disease (AD). The test, which has been developed in collaboration with Eli Lilly and Company, can be used by clinicians in conjunction with other clinical information to rule out AD.

Current methods to confirm amyloid pathology, including positron emission tomography (PET) and cerebrospinal fluid (CSF) assessment, can be expensive, difficult to access and invasive. With a negative Elecsys pTau181 blood test, people can avoid further unnecessary investigations for AD using CSF or PET and can identify the care pathway that is right for them. Clinical study results support that the test can be implemented effectively across care settings, including primary care, where most patients first seek help for cognitive concerns.

The CE mark was based on data from a prospective and multicentre study, which included 787 participants across the US, Europe and Australia. The study showed the test was able to rule out AD with a high negative predictive value of 93.8% based on a 22.5% prevalence of amyloid positivity according to PET scans, with 83.6% sensitivity.

https://www.roche.com/media/releases/med-cor-2025-07-23b

24 JULY:

Long-term exposure to air pollution linked to higher dementia risk

On 24 July, an international team of researchers published an article on air pollution and dementia risk in *The Lancet Planetary Health* journal.

Researchers conducted a systematic review of primary observational studies of adults in MEDLINE, Embase, Cochrane Library, CINAHL, Global Health, PsycINFO, Scopus, and Web

of Science Core Collection for studies published until October 2023.

After application of the in- and exclusion criteria they conducted a meta-analysis of 32 observational studies including over 24 million participants. They extracted harmonised effect estimates for pollutants when reported by three or more independent studies. Risk of bias was mostly low and the overall certainty of the evidence was assessed as moderate.

The study confirms a significant association between long-term exposure to certain air pollutants and increased risk of dementia. A strong link was found for fine particulate matter (PM2.5), with a pooled hazard ratio of 1.08 per 5µg/m³ increase in exposure. Associations were also found for nitrogen dioxide (HR 1.03 per 10µg/m³) and black carbon (HR 1.13 per 1µg/m³). No significant association was found for PM10, nitrogen oxides or annual ozone.

The authors conclude that reducing exposure to air pollution could lower dementia incidence and that stricter air quality standards would likely benefit public health and reduce societal costs. The article has been published open access and can be read here: https://www.thelancet.com/journals/lanplh/article/PIIS2542-5196(25)00118-4/fulltext

25 JULY:

Alzheimer Europe welcomes the positive European Medicines Agency opinion on donanemab

On 25 July, following a re-examination of its initial, negative opinion, the Committee for Medicinal Products for Human use (CHMP) of the European Medicines Agency (EMA) issued a positive opinion on Lilly's marketing authorisation application for donanemab for the treatment of early Alzheimer's disease (mild cognitive impairment and mild dementia due to Alzheimer's disease). In its opinion, the CHMP found that the benefits of donanemab for a restricted population outweighed its risks and therefore recommended approving the marketing authorisation application.

Alzheimer Europe welcomes the positive opinion by the CHMP, which follows that of other regulators. Donanemab had previously been approved by the US Food and Drug Administration (FDA) in July 2024, as well as by regulatory agencies in the United Arab Emirates (March 2024), Qatar (October 2024), Japan (October 2024), United Kingdom (October 2024), China (December 2024), Bahrain (December 2024), Mexico (January 2025), Kuwait (January 2025), Singapore (March 2025), Taiwan (April 2025), Brazil (April 2025) and Australia (May 2025).

The CHMP opinion also addresses many of the concerns highlighted in Alzheimer Europe's official response to the initial CHMP decision, enabling patients to discuss treatment options and make informed choices based on their individual circumstances, preferences and values, including to the acceptability of risks and benefits.

In particular, Alzheimer Europe highlighted the risks associated with amyloid-related imaging abnormalities (ARIA) which can present as small bleeds in the brain or oedema. The organisation therefore appreciates and supports the careful approach that the EMA has taken to identify patients likely to benefit from treatment and to exclude those at greatest risk of harmful side-effects, such as people with two copies of the ApoE4 gene.

During the re-examination, the CHMP also considered data on a modified titration regimen for donanemab. In this modified regime, the dose of the drug is gradually increased over the four first infusions, compared to the original regime in which a lower dose is provided during the first three infusions, then stepped up for the fourth infusion. Data from the TRAILBLAZER-ALZ6 study showed that this small change led to a 41% reduction in relative risk of ARIA.

The CHMP has also mandated additional measures to reduce risk, including a controlled access programme and regular MRI scans for safety monitoring. The opinion states that donanemab should be administered under the supervision of a clinical team trained in detection, monitoring and management of ARIA, with experience in detecting and managing infusion-related reactions. The company will also establish an EU-wide registry study to monitor the incidence and severity of side effects and gather real-world data on disease progression, particularly in the context of donanemab's limited-duration treatment approach. These measures, together with the approved modified titration regimen, have improved the benefit-risk balance for donanemab with the aim of protecting people at greatest risk of harmful side effects.

Alzheimer Europe welcomed the November 2024 approval of the anti-amyloid therapy lecanemab, following re-examination by the CHMP. However, the organisation was disappointed by the delays caused by the Standing Committee for Medicinal Products for Human Use (SCMP) asking the CHMP to reconsider its positive opinion and then failing to reach a qualified majority decision in favour or against the treatment, requiring escalation to the Appeal Committee, which similarly did not reach a decision. On 15 April, five months after the November positive opinion of the CHMP, the European Commission finally decided to follow the CHMP's initial positive opinion and provided a marketing authorisation for lecanemab - far beyond the 67 days foreseen under the EU's centralised procedure for authorising medicines. Alzheimer Europe calls for similar delays to be avoided for donanemab.

Jean Georges, the Executive Director of Alzheimer Europe stated: "The positive opinion on donanemab marks an important step forward, offering a second approved disease-modifying therapy for early Alzheimer's disease in Europe and expanding treatment options through its distinct dosing and stopping regimen. We hope that this opinion will lead to a prompt marketing authorisation by the European Commission, so that discussions on access, pricing, and reimbursement can proceed at national level. As with all anti-amyloid therapies, concerns around safety remain, and ongoing vigilance will be essential to ensure a favourable benefit-risk balance in real-world use."

The positive opinion from the CHMP is an important advance for Europeans affected by Alzheimer's disease. At the same, Alzheimer Europe recognises that donanemab will only benefit a small fraction of people with the disease. The organisation therefore reiterates its call for continued research into other treatment options, including symptomatic therapies, treatments for people in more advanced stages of the disease and with other types of dementia. In addition, Alzheimer Europe remains committed to a holistic approach where treatments are included alongside counselling, support and care of people with dementia and their carers throughout the disease process. EMA information on the positive opinion can be accessed here:

https://www.ema.europa.eu/en/medicines/human/EPAR/kisunla

1 AUGUST:

A recent study suggests that the context surrounding physical activity may influence mental health more than the amount of exercise *per se*

Physical activity is frequently considered beneficial for mental health. In particular, there is evidence that supports that physical activity is associated with less depression, anxiety and fatigue. These are therefore reasons for healthcare professionals to advise people to stay or become more physically active. However, little is known about the influence that the settings and the experience surrounding the activity (i.e. the how, where and why) have on the mental health outcomes.

In a recent study published in the journal of Medicine & Science in Sports & Exercise (American College of Sports Medicine), a team of researchers, including Dr Patrick O'Connor as a co-author (Mary Frances Early College of Education's Department of Kinesiology, University of Georgia), suggests that the influence physical activity has on mental health does not only depend on the amount of exercise (i.e. dose and calories burned) but on the how, where and why someone exercises.

According to the authors, the amount of exercise has been the way research has tried to understand the association between physical activity and mental health, and how the former influences the latter. To analyse this association in detail, the team of researchers reviewed three types of studies. These included epidemiological studies (which examined health patterns in populations), randomised clinical studies (where some groups of people received exercise treatments while others did not), and a set of investigations studying contextual factors surrounding the physical activity.

Based on the evidence and findings from epidemiological and randomised clinical studies, physical activity is associated with better mental health, including reduced levels of depression and anxiety. It seems, therefore, that the adoption of leisure-time physical activity, at any starting level, correlates with better mental health outcomes. However, the importance of the context and how this can make the same physical activity feel very different depending on who the activity was done with, where, when and how are less clear in the literature.

Context, the team of researchers explained, can range from peer dynamics to the instructor or even to the weather conditions (when the activity is happening outdoors) and the time of the day. For example, having an instructor that you like or don't like when taking a group exercise class may determine the impact that the exercise will have on your mental health. Abusive sport coaches, for example, are another contextual factor that will harm the mental health of those exercising in such conditions.

Although there is need for research on this topic, it is clear, for the authors, that mental health outcomes derived from physical activity are not only about the frequency, the intensity, and the duration of such activity. It is the whole experience around that activity, i.e. who we exercise with, whether we have fun, whether we are cheered or booed and whether we leave the experience feeling proud and accepted, or not, that determines the impact of the physical activity on the individual's mental health.

Authors remind us that physical activity always occurs within a context (i.e. at some time, in some place and alone or with other people). It is therefore important that, if healthcare professionals want to help people's mental health with exercise, they don't forget that the meaning, the settings and the experience matter too.

https://journals.lww.com/acsm-msse/abstract/2025/05000/up_for_debate__does_regular_physical_activity.17.aspxxercise

5 AUGUST:

Smell testing followed by targeted CSF testing predicts Lewy body pathology with high accuracy

On 5 August, an international team of researchers published an open access article in *Nature Communications* describing a two-step approach to predict Lewy body pathology, which is present in conditions such as dementia with Lewy bodies, Parkinson's disease and in some cases of Alzheimer's disease.

The researchers assessed a workflow that begins with smell-function testing to identify people with reduced smell, followed by confirmatory cerebrospinal fluid (CSF) α-synuclein seed amplification testing only for those individuals. In a study of 358 autopsied participants, this approach predicted postmortem Lewy body pathology with 94% accuracy overall and similar accuracy within clinical subgroups. The method reduced the need for CSF testing by 43% overall.

In an independent in vivo cohort of 1,209 participants, the workflow predicted CSF α-synuclein test status with 79% accuracy and reduced CSF testing by 26%.

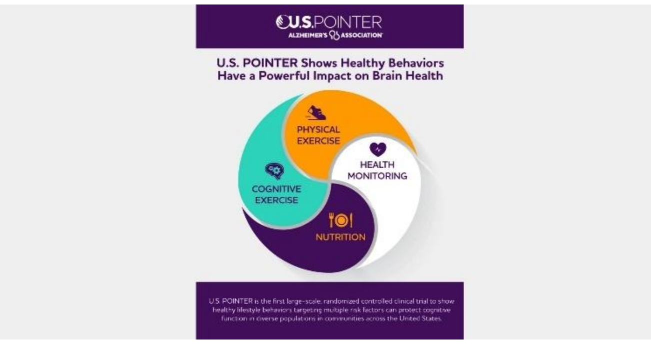
The authors note that this strategy could lower healthcare costs, reduce the burden of invasive lumbar punctures and support more efficient case finding for research and clinical purposes. The article has been published open access and can be read here:

https://doi.org/10.1038/s41467-025-62458-7

AAIC WATCH

28 JULY:

Structured lifestyle changes improve cognition more than self-guided approach in major US study



On 28 July, an international group of researchers published an article on the cognitive effects of lifestyle interventions in older adults in *The Journal of the American Medical Association (JAMA)* and presented their findings at the Alzheimer's Association International Conference (AAIC).

The two-year U.S. POINTER trial found that a structured programme of physical exercise, dietary changes, cognitive and social stimulation, and cardiovascular monitoring led to significantly greater improvements in global cognitive function than a lower-intensity, self-guided version. The structured group's global cognitive composite score increased on average by 0.243 standard deviations (SD) per year, compared to 0.213 SD per year in the self-guided group.

The randomised trial included 2,111 participants aged 60-79 at risk of cognitive decline due to sedentary lifestyles and other risk factors. Participants were assigned to either a structured or a self-guided group, both focusing on the same five lifestyle goals but differing in intensity, supervision and accountability. The structured intervention had a consistent effect in participants regardless of APOE ε4 status and showed a greater benefit in people with lower baseline cognitive scores. Serious and non-serious adverse events were slightly less frequent in the structured group.

The study confirms that higher-intensity, structured lifestyle changes can produce greater improvements in cognition than self-directed efforts. Long-term follow-up and biomarker analysis will be important to determine clinical relevance and sustainability. The article has been published open access and can be read here: https://jamanetwork.com/journals/jama/fullarticle/2837046

29 JULY:

Alzheimer’s Association issues clinical guideline on use of blood-based biomarkers for diagnosing Alzheimer’s disease in specialist settings

On 29 July, the Alzheimer’s Association published a clinical practice guideline on the use of blood-based biomarkers (BBMs) in diagnosing suspected Alzheimer’s disease (AD) within specialised care settings in the journal *Alzheimer’s & Dementia*. The guideline was presented at the Alzheimer’s Association International Conference 2025 in Toronto.

An international panel of clinicians and experts conducted a systematic review to assess the diagnostic accuracy of blood-based biomarkers (BBM) biomarkers, including phosphorylated-tau (p-tau) variants and amyloid-beta (Aβ) ratios, compared with cerebrospinal fluid biomarkers, amyloid PET imaging, or neuropathology. The review applied the GRADE framework to evaluate the evidence and develop recommendations.

The guideline recommends BBM tests with at least 90% sensitivity and 75% specificity as triage tools. Tests reaching 90% sensitivity and specificity can substitute for amyloid PET or cerebrospinal fluid testing in patients with cognitive impairment evaluated by specialists. The panel notes variability in test accuracy across commercially available BBMs and stresses that BBMs should complement, not replace, comprehensive clinical assessments.

These recommendations are brand-agnostic and performance-based, intended to adapt with ongoing evidence updates. The guideline highlights emerging approaches, such as biomarker combinations and multi-threshold testing, which may improve diagnostic precision in the future.

The Alzheimer’s Association intends this guideline as the first in a series supporting dementia specialists through ALZPro™, its central resource hub for dementia care and research.

The article has been published open access and can be read here: https://doi.org/10.1002/alz.70535

30 JULY:

Roche presents data on investigational antibody and diagnostics for Alzheimer’s disease at AAIC

From 27 to 30 July, researchers from Roche presented new data from across their Alzheimer’s disease diagnostics and pharmaceutical portfolios at the Alzheimer’s Association International Conference (AAIC) in Toronto.

Findings from the Phase Ib/IIa Brainshuttle™ AD study showed that trontinemab, an investigational bispecific monoclonal antibody, led to rapid and sustained clearance of amyloid plaques. In the highest dose cohort, 91% of participants became amyloid PET negative (below 24 centiloid positivity threshold) after 28 weeks of treatment, with <5% experiencing “amyloid-related imaging abnormalities-edema/effusion” (ARIA-E).

Roche also shared the design of its upcoming Phase III TRONTIER 1 and 2 studies, which will evaluate trontinemab in early symptomatic Alzheimer’s disease. A separate Phase III trial is planned to take place in 2025 in preclinical Alzheimer’s disease for individuals at high risk of cognitive decline.

In diagnostics, Roche presented real-world evidence supporting the pTau217 blood test as a reliable standalone tool to rule in or rule out amyloid pathology. Results showed comparable performance to PET scans and cerebrospinal fluid measures, with the advantage of a less invasive and more accessible procedure. The test will be used in the TRONTIER trial screening process to support broader participation.

The official press release can be read here:
https://www.roche.com/media/releases/med-cor-2025-07-28.htm

30 JULY:

New study shows a federal food assistance programme may help slow cognitive decline

A new long-term study presented at the Alzheimer's Association International Conference (AAIC 2025) shows that participation in the US Supplemental Nutrition Assistance Program (SNAP) is associated with slower cognitive decline among older adults over a ten-year period.

Analysing data from the Health and Retirement Study (HRS), researchers compared two groups of adults aged 50 and older across 2010 and 2020: 1,131 SNAP participants (average age 63 years) and 1,216 eligible non-participants (average age 66 years).

SNAP participants showed a 0.10-point slower decline in overall cognitive function, or two to three additional years of cognitive health over the 10-year period. Although all racial and ethnic groups saw benefits, White SNAP participants observed much stronger benefits and slower decline than other groups. Researchers highlighted the potential of food assistance programmes to support cognitive health in the aging population and pointed to the need for additional efforts to reduce disparities in cognitive aging across different racial and ethnic groups. They also underscored the need for public health policies that ensure equitable access to programs like SNAP, which helps low-income individuals and families buy food, particularly for populations that may face additional barriers to enrolment.

https://aaic.alz.org/releases-2025/snap-nutrition-program-linked-slower-cognitive-decline.asp

31 JULY:

Anavex presents new findings of oral blarcamesine for early AD

On 31 July, Anavex Life Sciences Corp., a clinical-stage biopharmaceutical company focused on developing innovative treatments for central nervous system disorders including Alzheimer's disease (AD) shared findings from its Phase IIb/III extension trial for blarcamesine at the 2025 Alzheimer's Association International Conference (AAIC) in Toronto.

The ATTENTION-AD open-label extension Phase IIb/III treatment trial followed an initial 48-week double-blind clinical trial for a total of up to 192 weeks (≈ 4 years). The trial was designed to evaluate the safety and tolerability of blarcamesine as well as its long-term effects on cognition (ADAS-Cog13) and function (ADCS-ADL) in people with early AD.

Participants treated with blarcamesine continue to show benefits through up to 4 years, as measured by the prespecified clinical endpoints ADAS-Cog13 and ADCS-ADL. In the intent-to-treat population, delayed-start analysis of treatment with oral blarcamesine was significant for both cognition and function. For ADAS-Cog13, results showed a significant difference between the early-start and late-start treatment groups at week 192. For ADCS-ADL, statistical significance was reached at week 192, also favouring the early-start group.

https://www.anavex.com/post/anavex-life-sciences-announces-positive-precision-medicine-results-from-up-to-4-years-of-oral-blarca

1 AUGUST:

New data from real-world study of lecanemab is presented at AAIC, showing continued efficacy over 4 years

Lecanemab, an intravenous treatment that targets amyloid protein buildup in the brain, was the first disease-modifying therapy for early Alzheimer's disease (AD) to be authorised in Europe. The positive opinion from the European Medicines Agency was based on 18 months of data collected during the CLARITY-AD Phase 3 trial of lecanemab, which evaluated the safety and efficacy of the drug in almost 1,800 participants. At the 2025 Alzheimer's Association International Conference (AAIC), clinical experts presented interim data from the Open Label Extension of CLARITY-AD – showing continued efficacy over 4 years.

Lecanemab received traditional approval from the US Food and Drug Administration in July 2023, for the treatment of mild cognitive impairment (MCI) or mild dementia due to AD. At AAIC, experts presented data from 178 individuals with early AD, who were treated with lecanemab as part of the American open label extension (OLE) to CLARITY-AD. The average age of participants was 74.2 years, and a majority (57.6%) had a diagnosis of MCI due to AD. Of the 178 patients, amyloid-related imaging abnormalities (ARIA; a side effect linked to small bleeds or swelling in the brain) were observed in 12.9%, with no serious bleeding events or deaths reported. Overall, around 76% of patients remained at the same clinical stage, with 6.7% showing clinical improvement, going from mild dementia to MCI.

The company also presented real-world data on the impact of ApoE4 status on long-term safety and efficacy of lecanemab. As well as being a genetic risk factor for AD, carrying two copies of ApoE4 confers a substantially higher risk of ARIA during treatment with anti-amyloid antibodies. In the core CLARITY-AD study, 45% of participants carrying two copies of ApoE4 experienced ARIA, over double the rate of participants carrying a single copy of ApoE4 (19%). In the group evaluated during the OLE, the incidence of ARIA in participants with two ApoE4 copies was lower, at 20%. A similar, lower trend was observed for people with one or no copies of ApoE4. Looking at the 4-year efficacy of lecanemab in people with different ApoE4 genotypes, patients with one or no copies of ApoE4 were more likely to remain stable or improve (88% and 85.2%, respectively), compared to patients with two copies of ApoE4 (73.3% remaining stable or improving).

https://investors.biogen.com/news-releases/news-release-details/two-year-real-world-study-leqembir-united-states-presented

MEMBERS' NEWS

19-21 JUNE:

Alzheimer's Larissa participates in Pineios River Festival to raise awareness of dementia

From 19-21 June, Alzheimer's Larissa (EENAL) participated in the three-day Pineios River festival organised by Larissa Deputy Mayor of Culture.

On 19 June, EENAL volunteers opened the curtain on activities with multisensory memory games aiming at informing people about Alzheimer's disease (AD), promoting mental and psychosomatic health *via* non-pharmaceutical treatments and developing dementia-friendly networks. The presentation of memory games impressed adults and children alike, who asked to learn more about their function and how to adopt them into their daily lives.

On 20 June, "Along with Ricky" was presented by volunteer Katerina, to groups of adults and children. Participants were informed about the therapeutic role of companion dogs for people with dementia, about the operation of EENAL's laboratory and about the emotional support and wellness services offered by "Ricky".

On 21 June, the "Merry-go-round" activity took place. The president of EENAL., Eleni Nifli, read a story to groups of parents and children. It was an experiential story written by someone called Christos about his grandfather who had AD twelve years ago. The story sensitised everyone with its message about acceptance of AD, and intergenerational care. A creative dialogue followed, and various mental exercises took place, triggered by the text.

The participation in the festival with these two actions, helped debunk myths around dementia, thereby tackling stigma and creating a climate of acceptance and positive social impact, as parents with children and teenagers came to EENAL for information and to participate.

25 JUNE:

The Alzheimer Society of Ireland launches its pre-budget submission campaign

On 25 June, The Alzheimer Society of Ireland (The ASI) launched its pre-budget submission 2026: A stepping stone to a more dementia-inclusive Ireland, calling on the Irish Government to make targeted investments in dementia care and support. Grounded in the lived experience of dementia, the campaign event received strong cross-party support, with 66 elected representatives in attendance. It also attracted national media coverage, helping to amplify the message across Ireland.

The submission outlines a proposed EUR 9 million investment to:

- Expand community day care services
- Increase access to dementia advisors
- Enhance dementia-specific home care
- Provide counselling for people with dementia and their carers
- Support dementia research.

These measures aim to improve access to services, reduce reliance on residential care and enhance quality of life for people living with dementia and their families. The submission was developed following months of consultation with key stakeholders, including ASI staff, the Irish Dementia Working Group, and the Dementia Carers Campaign Network. You can learn more and read the full submission on The ASI's website here.

1 JULY:

Dementia Carers Campaign Network in Ireland contributes to a new book offering practical and science-based advice for carers

The Dementia Carers Campaign Network (DCCN), an advocacy group supported by The Alzheimer Society of Ireland (The ASI), has contributed to a widely praised new book by Irish psychologist and neuroscientist Dr Sabina Brennan. "Still Me: A neuroscientist's guide to caring for someone with dementia", offers practical, science-based advice for carers and has been well received. 16 DCCN members reviewed chapters of Dr Brennan's latest publication. Their insights, drawn from lived experience, helped shape the book's practical advice and emotional resonance. Several members also contributed caring tips that were included in the final edition.

Dr Brennan said: "I am deeply grateful to the advocates from the Dementia Carers Campaign Network who read early drafts of 'Still Me'. Their lived experience, suggestions and advice enriched the book in ways I could not have achieved alone. Their feedback was both insightful and encouraging. This generous collaboration was made seamless by the wonderful coordination of Judy Williams, one of The ASI's Advocacy, Engagement and Participation Officers, who leads the work with the Dementia Carers Campaign Network."

Since its release, "Still Me" has received strong reviews for its compassionate and evidence-based approach to dementia care. It was featured on Davina McCall's popular podcast, "Begin Again", where Dr Brennan discussed brain health, caring, and the importance of self-care for carers. The book has also been recognised as a bestseller in Ireland and praised for its accessibility and relevance to carers across Europe. This collaboration illustrates how the DCCN - made up of carers and former carers - continues to amplify the voices of dementia carers in Ireland and contribute to resources that support caring in Ireland and beyond.

Pictured: Dr Sabina Brennan and Helena Quaid, Chair of the Dementia Carers Campaign Network, at the launch of "Still Me: A neuroscientist's guide to caring for someone with dementia".

4 AUGUST:

UK celebrities launch Alzheimer's Society's Forget Me Not Appeal with striking new portraits

Alzheimer's Society (United Kingdom – England, N. Ireland and Wales) recently released a new photography series to launch its 2025 Forget Me Not Appeal which aims to "end the devastation caused by dementia".

Alzheimer's Society celebrity ambassadors Anna Richardson (TV presenter), Gareth Locke-Locke (reality TV star) and Meera Syal CBE (comedian) feature in a powerful and intimate series of images – Unforgettable Frames – shot by celebrity photographer Sam Riley.

Unforgettable Frames sees the celebrities, who all have personal experience of dementia, opening up family photo albums to share intimate photos of their lives before dementia devastated their families, and their personal reasons for wearing their Forget Me Not badge. Read the full story, here:

https://www.alzheimers.org.uk/news/2025-06-02/celebrities-launch-our-forget-me-not-appeal-striking-new-portraits

Watch a video about the initiative, here:

https://www.youtube.com/watch?v=0yrXaB3jsSQ

Pictured: Meera Syal's portrait for the "Unforgettable Frames" series. Photo credit to Alzheimer's Society, Sam Riley and David Harrison (1)

12 AUGUST:

The Deutsche Alzheimer Gesellschaft welcomes the establishment of the German Society for Frontotemporal Degeneration

Frontotemporal degeneration (FTD) is one of the rare causes of dementia. Those affected usually become ill at a relatively young age, often between 50 and 65 years of age, and sometimes much earlier. Atypically for dementia, the clinical picture initially presents itself with personality changes, changes in social behaviour, or even speech disorders - while memory and orientation usually remain unaffected until the later stages of disease. Due to the young age of onset and the significantly different symptoms associated with FTD, people living with this condition and their families require specialised services and, above all, counsellors, doctors, therapists, and nursing staff who are familiar with the disease. The German Alzheimer's Society (Deutsche Alzheimer Gesellschaft; DAlzG) has been actively involved for more than 20 years in raising awareness of FTD, providing information, and supporting the development of FTD support groups for people affected and their families.

In their "Alzheimer Info" magazine published earlier this year, our colleagues at DAlzG featured an article on a newly established society called the German Society for Frontotemporal Degeneration (DGFTD). The DGFTD was founded in 2024, to further advance awareness, networking, and the expansion of services for FTD. The main goals of the organisation are public relations, promoting the visibility of care services, building a network of all FTD experts in Germany, and creating training opportunities for physicians, nurses, counsellors, and family members. It also aims to support the development of new care and treatment options. Financial support for families in particularly difficult cases may be available at a later date, depending on the success of their ongoing fundraising campaign.

The DGFTD website provides a nationwide overview of services for diagnostics and medical support, care and support, counselling centres, and support groups for people affected by FTD. A list of online and in-person events can be found on the homepage, and a subpage provides information on current research studies on FTD in Germany.

The DAlzG welcomes this new offering from the DGFTD, explaining that they will work together as closely as possible to raise awareness of the disease pattern of frontotemporal degeneration and its unique challenges, and to develop support services. Visit the DGFTD website (in German):

https://www.dgftd.de/

26 AUGUST:

Estonia highlights dementia prevention at Paide Opinion Festival

On 26 August, the Estonian NGO Life with Dementia (MTÜ Elu Dementsusega) moderated a Nordic Council debate at the Paide Opinion Festival titled "Did you know that dementia can be prevented?" Experts from Estonia and the Nordic Welfare Centre discussed how lifestyle and community action can reduce dementia risk and support brain health. Speakers stressed that while Alzheimer's disease cannot be fully prevented, healthy habits such as regular exercise, good sleep, balanced diet and social engagement can delay cognitive decline. The Finnish FINGER model was presented as an evidence-based example, showing the benefits of combining several lifestyle changes. The discussion also highlighted Estonia's need for a national dementia prevention strategy. Panellists underlined that prevention is not only an individual responsibility but also a societal one. Reducing stigma, promoting inclusion and ensuring community support were seen as key steps towards improving life with dementia. You can watch the debate here: https://youtu.be/9H7l3gQpBpw?si=6VRvhMzkfuYC3Cb9

28 AUGUST:

Radio broadcasts on dementia organised in collaboration with Solidarity Association of Heraklion (Greece)

On 28 August, “Solidarity" of Heraklion, in collaboration with the radio station of the Holy Archdiocese of Crete (LIVE24.GR 99.7), organised a series of informative speeches on the topic of dementia, which are broadcast every 15 days, covering a variety of topics. The show has established itself as an authority on the disease, which is one of the greatest public health challenges of the 21st century. The goal is to provide answers and practical solutions to the issues faced by patients and their families.

Despite the prevalence of new media, radio continues to be one of the most powerful and timeless media for information and entertainment, maintaining an important role in the public's everyday life. The scientific responsibility for the show lies with Dr Fotini Kounti-Zafeiropoulou, neuropsychologist, supported by the organisation's scientific team, consisting of psychologists and social workers. Every second Monday, at noon, experts present topics related to dementia, care and healthy ageing.

Topics that have been presented include:
- Benefits of physical exercise
- Psychotherapeutic intervention and caregivers
- Safety and autonomy
- Self awareness
- Grief and dementia
- Behaviour and psychiatric symptoms in dementia
- Anger management
- The importance of hugging
- Cognitive reserve.

DEMENTIA IN SOCIETY

19 AUGUST:

Applications are now open for the Alzheimer’s Insights AI Prize

On 19 August, the Alzheimer’s Disease Data Initiative (AD Data Initiative) announced that applications had opened for the Alzheimer’s Insights AI Prize, a USD 1 million global competition designed to accelerate breakthrough discoveries in Alzheimer's and dementia research.

The AD Data Initiative calls on researchers, technologists, and innovators to leverage agentic AI – AI that can plan, reason, and act autonomously – to generate a leap in the pace, scale, and reach of Alzheimer's research. From hypothesis generation to dataset harmonisation to experimental design, their belief is that this technology can create exciting opportunities in research.

They welcome applicants and multi-disciplinary teams from a wide variety of backgrounds, including AI and ML engineering, computational biology, ADRD research, clinicians and clinical trial experts, technologists and pharmaceutical sciences.

Up to eight semi-finalist teams will be selected to present at a pitch event around the Clinical Trials on Alzheimer's Disease (CTAD) Conference in December 2025. Up to three finalist teams will be invited to a final "show and prove” event around the AD/PD Conference in March 2026.

The winning AI tool will be made publicly available via AD Data Initiative’s AD Workbench, a free, secure, cloud-based research environment that allows scientists around the world to share, access and analyse data across platforms.

Submissions deadline is 12 September. Find out more and apply, via: https://www.alzheimersdata.org/alzinsights-prize-for-adrd-research

LIVING WITH DEMENTIA

18 JULY:

Irish carer Carmel Geoghegan shares her experience of attending tenth edition of University of Limerick’s annual Public Patient Involvement Summer School

At the end of June, I attended the tenth edition of the University of Limerick’s annual Public Patient Involvement Summer School, together with Helen Rochford-Brennan (Global Dementia Ambassador, Vice Chair of the Irish Dementia Working Group and former Chairperson of the European Working Group of People with Dementia).

This was the first year that I attended the Summer School and I was really impressed! It was a great mix of researchers, Public Patient Involvement (PPI), academics, advocates and funders.

The plenaries were incredible. Ghislaine Rouly from Canada was an inspiration and the work she has achieved is incredible:

Ghislaine Rouly, CPCRN Patient Partner, named as co-director of the Canada Research Chair | Canadian Primary Health Care Research Network

Workshops covered Ethics, co-creating PPI framework and incorporating PPI in grant applications.

The most thought-provoking was Plenary 2 which looked at “A Decade of PPI in Ireland - Hope, Hurdles and Honest Reflections”. This really was the beginning of an open and honest conversation which will definitely continue around how PPI is developing in Ireland. We have come along way with PPI, here, but unfortunately, like any life experiences, there is good and bad. The theme that emerged at the session was the experience by several of bullying on both sides of the fence. This is something that has been brewing for some time but had not been spoken about at any event I have attended so far.

I have been involved in PPI since 2013, and then got completely immersed in 2016 when I was invited to join the https://primarycaretrials.ie/. Helen and I are both members of the Public Advisory Board • PPI Ignite Network.

Link to full story on UL website: University of Limerick putting patients first in collaborative research at 10th annual UL PPI event | news.myScience / news

Pictured (left to right): Laura O'Connor, Network Manager, Denis Mocker, John Gaffey from the PPI Ignite Network National Office, Carmel Geoghegan, Helen Rochford Brennan

8 AUGUST:

Pia Knudsen, former member of the European Working Group of People with Dementia, has a new website about her life with dementia

The question I have been tasked with answering is: Why are you making a website about your life with dementia? It's an exciting challenge, and my answer is that there is not just one reason, but several different ones. Here are some of them:

Living with Alzheimer's dementia has been challenging, but also an eye-opener for me. The diagnosis has forced me to see life from a whole new angle and has allowed me to appreciate small and big moments in my life. Although I have experienced loss and stigma, I have also found strength in new friendships and communities. I have had the honour of speaking at major conferences and collaborating with politicians, health professionals and many, many more. In an attempt to improve the lives of those of us who have dementia, I will share my experiences through my website and give a voice to those who cannot or do not dare to speak out about their life with dementia. I would also like to pass on my own thoughts and those of others who live with early-onset dementia, about how Denmark and other countries can become better places for us to live in. Here are some examples:

Dementia-friendly initiatives are often made without input from people living with dementia. We should be involved in initiatives that affect our lives, because we are the ones who are affected by the decisions that are made. Including those of us living with dementia in advocacy work is crucial, too, if we want real change, because to make the right decisions we need the voices of those with lived experience. Being part of a community, with like-minded people, gives life with a terminal diagnosis joy and value, and we know that it is life-prolonging. On the other hand, it is equally destructive and leads to increased vulnerability when the ties are cut and that community is suddenly closed off to us, without taking into account the consequences it has for our lives. I share several thoughts on a good life with early onset, on my website, in an attempt to spread knowledge about how YOU can help us.

Of course, I must also tell visitors to the website about my life with dementia, so you get an insight into a life that is very different from what most people associate with living with dementia. For example, I was drinking coffee with Queen Silvia (pictured), when I gave a speech in Sweden! I also share my experience of going by myself to a large concert for the first time in my life, where Norah Jones played her music. I did that because I want to challenge myself, and because I use her music to comfort me when I feel lonely and scared of what the future might bring. I still create art, still exhibit my art, and I still teach art to all 60 of my students, four times a year at the Folk High School where I used to be a teacher. Ever since I entered the world of dementia, the wonderful people I have met have been a watershed in my experience of a valuable life. Once such person is my dear friend Jens and you can watch a video of a conversation I had with him at Aarhus Cathedral, on my website.

Despite the fact that I try to live by the motto: “Embrace this damn life, grab it, catch it before it's over”, it's difficult some days. The fear of the future has become a condition of my life, which means that I try as much as possible to fill my calendar with meaningful appointments, so I don't have too much time at home, alone, to think, feel and fear. My life with a deadly disease is all of this and much more, and I want to tell everyone in the world about it, so I try to do that in this way, as well as in many other places. And at the same time, I save memories, both for my children and myself. Visit https://mindemens.dk/ and share it wherever you can think of. You are all welcome, and it is always open. You have to bring your own coffee, but I try to provide a topic of conversation. And please come and visit often, because I'm not done yet. I have a lot more on my mind!

26 AUGUST:

“Gender sensitivity must be at the core of dementia care” writes Lieselotte Klotz, member of the European Working Group of People with Dementia

I recently started work on a project which is looking at gender and dementia, both of which are topics that I am passionate about. Dementia affects women and men differently, both in terms of symptoms and care. The new ParGenDA research project is investigating these differences and developing gender-specific approaches to improve support for people with dementia and their families. A steering group of ten people including myself as a person with dementia (Lewy Body dementia) and caregiving relatives (mother with Alzheimer's and brother with a brain tumour) will accompany the entire process together with the project team. This will ensure that real perspectives are at the heart of the research.

I am a woman, a mother and a daughter. My life has been profoundly shaped by gendered experiences, many of them negative and some of them deeply traumatic. Some of these experiences led to health problems, such as struggles with anorexia in my youth, an attempt to regain control in a world that I felt had claimed, judged, and harmed my body. Despite facing many difficulties in my life and my relationships, I refused to be diminished. I was a single mother, without a university degree, but I worked my way up to become the CEO of a company. I faced constant battles against stereotypes, arrogance, and power games but, nonetheless, I carved out my place.

In 2017, I received a diagnosis of Lewy Body dementia. Another blow and another label. My experiences with the healthcare system have often been that, as a woman, I was dismissed and not taken seriously. Doctors spoke to me with arrogance and condescension, as if I were not a person but merely a case study. In both my professional and personal life, I have faced hardships that I feel were overwhelmingly related to my gender, with people seeming to view my gender as an open invitation to cross my boundaries.

All the gender issues we are now researching are not abstract theories to me, but are lived reality: care, illness, participation, power, protection, vulnerability and the relentless search for dignity and recognition. For all those who have had similar experiences and are in a similar position, I call for more gender-sensitivity in dementia care. Gender-sensitive perspectives should not be an “add-on,” but rather should be central, not just to dementia care, but also to research, medicine, and in wider society. I hope that the project I am working on, and all the other work being done in this area, will lead to real change. Because behind every gender issue, there is a life. My life.

27 AUGUST:

Lieselotte Klotz, member of the European Working Group of People with Dementia, writes about an initiative to increase awareness of dementia among police in Rheinland-Pfalz

Netzwerk Demenz
im Rhein-Hunsrück-Kreis

fokus 2. lebenshälfte
Beratung | Schulung | Konzeptentwicklung

In spring 2025, the dementia network in the Rhein-Hunsrück district of Germany, together with *fokus2.lebenshälfte* and the Rheinland-Pfalz Police Academy, organised a series of five awareness-raising workshops. The aim was to better prepare police officers for encounters with people living with dementia, as they are often the first point of contact in search operations or emergencies in public spaces. Two workshops were held on site, and three were delivered online. A total of 88 officers participated.

The programme was planned by Christine Telser (Rheinland-Pfalz Police Academy) and Andrea Kynast (*fokus2.lebenshälfte*) and the workshops were conducted by Andrea Kynast together with “experts by experience” Volkmar Schwabe and myself, Lieselotte Klotz. The online sessions were particularly participatory: Volkmar and I, who are both living with different forms of dementia, shared our personal experiences, describing how we perceive certain situations and what kind of support helps us most. These authentic perspectives complemented the theoretical content and made the workshops particularly engaging and memorable for participants. Christine Telser reflected: “That was really useful, not only professionally, but also personally”, while another participant commented: “I’ll take this with me into my next assignment. Thank you!” The positive feedback was unanimous. Officers described the workshops as practical and highly relevant, not only for their work, but also for their private lives. The personal accounts of people with dementia were particularly valued: “It’s much better to hear directly from those affected than from someone speaking without firsthand experience,” summarised one participant. The speakers also shared a very positive conclusion: From my side, I emphasised the appreciative and open atmosphere, noting that my perspective as a person with dementia had encouraged reflection and real shifts in participants’ views. Volkmar Schwabe highlighted the empathy and commitment of the police officers, which he found both surprising and encouraging. Andrea Kynast stressed that involving people with dementia is essential in breaking down prejudices and fears, whilst also providing authentic insights into their perceptions and needs. Overall, the workshop series demonstrated the value of collaboration between professionals, law enforcement, and those affected. It also showed how targeted trainings can help officers make the right decisions in difficult situations, ensuring that people with dementia are treated with dignity and given appropriate support. We are working together to facilitate another series of workshops.

Virtual Dementia Care Research Conference

6 November 2025 - 9:30am to 4:30pm (BST)

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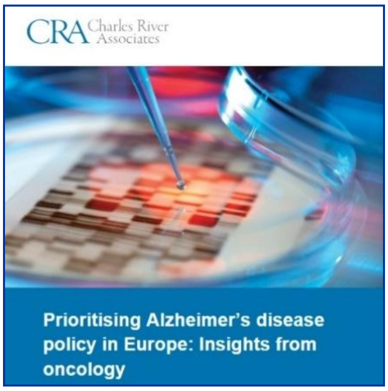
NEW PUBLICATION AND RESOURCES

15 JULY:

New report "Prioritising Alzheimer's disease policy in Europe: Insights from oncology" published together with factsheet



The impact of Alzheimer's disease (AD) on health and care systems in Europe is increasing. However, current levels of policy development do not reflect the urgency for change, especially given the progress made in understanding the disease and new developments emerging in diagnosis and treatment.

A new report, funded by Biogen and authored by Charles River Associates (CRA) with multi-stakeholder expert input, assesses lessons for policy action in AD from oncology, as a disease area where there has been sustained and impactful policy prioritisation. Drawing on a panel of AD and oncology experts, the report authors found that "there is consensus that the current level of AD policy development in Europe does not reflect the growing burden of the disease and the need for a more comprehensive approach. The evidence base on the benefits of policy action is maturing rapidly, and our comparison between AD and oncology indicates that the time is right for a renewed focus on AD and the need for policies that address its urgent and growing burden."

The policy recommendations from this report include:

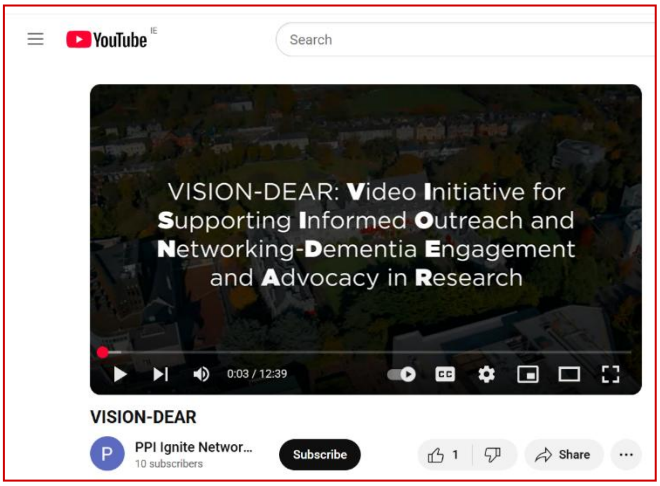
- Reframe AD as a manageable disease with a long presymptomatic phase that affects patients throughout adulthood.
- Support development of AD patient registries and data collection, including centralised EU data collection.
- Focus on early-stage diagnosis and improving access to testing that enables this.
- Adopt reimbursement and funding models that enable patient access to treatments and reflect the holistic value of these therapies.
- Support the development of additional AD specialists through dedicated training and the creation of specialist AD centres to increase treatment capacity.

Link to the report: https://media.crai.com/wp-content/uploads/2025/05/15114238/CRA-Biogen_Prioritising-Alzheimers-Disease-Policy-in-Europe_May-2025-1.pdf

Link to the factsheet: https://www.alzheimer-europe.org/sites/default/files/2025-07/cra_biogen_onco-ad_0.pdf

22 JULY:

New collaborative video created as part of "VISION-DEAR" project showcases impact of Patient and Public Involvement in Dementia Research



VISION-DEAR: **V**ideo **I**nitiative for **S**upporting **I**nformed **O**utreach and **N**etworking-**D**ementia **E**ngagement and **A**dvocacy in **R**esearch

VISION-DEAR

We are pleased to share a new video produced through a collaborative effort between University College Cork (UCC), Dementia Ireland Empowering Communities, and the Alzheimer Society of Ireland as part of the VISION-DEAR project. This resource highlights the critical role of Patient and Public Involvement (PPI) in dementia research, demonstrating how meaningful engagement with people living with dementia and their carers can shape more relevant and impactful studies.

Dementia research has made significant strides, but involving those with lived experience remains key to ensuring research addresses real-world needs. This video presents perspectives from people living with dementia, family carers, and researchers, emphasising the value of co-production and partnership in the research process.

In addition to explaining what PPI entails, the video shares practical insights on successful collaboration, the benefits of PPI for research outcomes, and guidance on how researchers and public contributors can become involved. It is designed to inspire researchers, healthcare professionals, policymakers, and advocates across Europe to embed PPI more deeply within their work.

This video serves as an important tool to raise awareness and promote the voices of those affected by dementia, ultimately supporting the development of research that leads to better care and support. We invite you to watch the video and share it within your networks to help advance the culture of inclusion and partnership in dementia research. Watch the video on YouTube here: http://bit.ly/4lCW7OS

1 AUGUST:

Toolkit for Young Dementia Supporters aims to raise awareness among children and teenagers

The Alzheimer Society of Ontario published the *Toolkit for Young Dementia Supporters*, a practical guide designed for children and young people aged nine and over who want to understand dementia and take supportive action in their communities.

The toolkit offers age-appropriate information about dementia, communication tips, and activity ideas, including a template to develop an individual or group Action Plan. It is suitable for use in schools, scouting groups or youth clubs.

The material is divided into short modules, combining facts with interactive exercises, reflection prompts and real-life stories to promote empathy and understanding. It also includes myth-busting sections to correct common misconceptions about dementia.

The toolkit was co-developed with input from young people, families and people living with dementia. It supports young learners to explore the impact of dementia and equips them with tools to make a difference in their local environment. The toolkit is freely available and can be downloaded here:

https://www.alzheimer.ca/on/sites/on/files/documents/YDS%20Toolkit%20-%20PRINT%20AT%20HOME.pdf

AE CALENDAR 2025

DATE	MEETING	AE REPRESENTATIVE
1 September	Consultation with the members of the DORIAN GRAY Public Involvement Board	Soraya
2 September	Online meeting about “Hop On Facility” proposal with FluiDx-AD project consortium and potential new consortium member	Chris
3 September	Consultation with members of Alzheimer Europe’s two European working groups who will be speaking at the Joint Plenary session during the Annual Conference in Bologna	Dianne and Soraya
3 September	Online Discussion Meeting with EMA	Dianne
4 September	DORIAN-GRAY project extraordinary General Assembly Meeting	Cindy
8 September	Consultation with the European Working Group of People with Dementia	Ana, Dianne, Sarah and Soraya
11 September	Expert meeting for the Regulatory Science Network of the Netherlands	Angela
11 September	Civil Society Europe meeting on a Socially Just EU	Owen
11-12 September	Hybrid Workshop (Prague, Czechia)	Sarah
16 September	Alzheimer Europe Alzheimer’s Association Academy	Alzheimer Europe Board, members and staff
18 September	EU4Health Civil Society Alliance	Owen
22- 23 September	General Assembly of Predictom project (Thessaloniki, Greece)	Sarah and Dianne

23-24 September	European Medicines Agency Patients' and Consumers' Working Party Meeting (Amsterdam, Netherlands)	Angela
25 September	Roundtable on new Alzheimer's disease diagnostics and therapeutics at the EFPIA Life Sciences Week (Brussels, Belgium)	Angela
25-26 September	REMOTE-AD consortium meeting (Berlin, Germany)	Soraya

CONFERENCES 2025

DATE	MEETING	PLACE
11 September	Alzheimer's Society Annual Conference, https://www.alzheimers.org.uk/dementia-professionals/conferences-and-events/annual-conference	London and online
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
14 October	Dementia and Brain Health in Women,	Brussels, Belgium
6 November	Virtual Dementia Care Research, https://nhswales.awardsplatform.com/	Wales (UK) & online
6-7 November	13th International congress of Person Centered Medicine, "Person Centered Medicine and Care in Dementia", https://events.bizzabo.com/icpcm	Reykjavik, Iceland
12-13 November	How to ensure access to new Alzheimer treatments? http://www.ipecad.org/conference	Glasgow, Scotland
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
14-16 April 2026	Alzheimer's Disease International Conference, https://www.alzint.org/what-we-do/adi-conference/	Lyon, France

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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