Alzheimer Europe

Newsletter
JUNE 2025

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Alzheimer Europe Board
Chairperson: Maria do Rosário Zincke Dos Reis (Portugal); Vice-Chairperson: Mario Possenti (Italy); Honorary Secretary: Lorène Gilly (France); Honorary Treasurer: Marco Blom (Netherlands); Members: Stefanie Becker (Switzerland), René Friederici (Luxembourg), Andy Heffernan (Ireland), Martina Mátlová (Czechia), Mary-Frances Morris (United Kingdom - Scotland), Kevin Quaid, Chairperson of the European Working Group of People with Dementia (Ireland), Trevor Salomon, Chairperson of the European Dementia Carers Working Group (United Kingdom - England), Katariina Suomu (Finland), Jochen René Thyrian (Germany).

Alzheimer Europe Staff
Executive Director: Jean Georges; Communications Officers: Kate Boor Ellis and Margarita Reyes; Conference Coordinator: Isabelle Collot; Executive Assistant: Karim Elnaggar; Policy Officer: Owen Miller; Events Coordinator: Cristina Pencea; Finance Officers: Stefanie Peulen and Fiona Sligo-Young; Communications Assistant: Grazia Tomasini; Director for Research: Angela Bradshaw; Project Officers: Christophe Bintener; Cindy Birck and Lukas Duffner; Director for Public Involvement and Ethics: Dianne Gove; Public Involvement Lead: Ana Diaz; Public Involvement Officers: Sarah Campill, Sébastien Libert and Soraya Moradi-Bachiller.

WELCOME

June began with a jam-packed week of meetings in Brussels, including a Board meeting, a Company Roundtable, a Lunch Debate at the European Parliament on "Preparing for new Alzheimer's treatments in Europe", a Public Affairs meeting with members, a meeting of the European Dementia Carers Working Group, and our Annual General Meeting (AGM). We were delighted to share the latest edition of Dementia in Europe magazine, and a special supplement about the AI-Mind project, at these meetings.

I would like to share some of the important outcomes from the AGM, at which five new full member associations were welcomed, and our 2024 Annual Report was adopted. The report is available for download via our website, and printed copies will be available at our Annual Conference in Bologna in October. All five new full members (Alzheimer's Care Armenia, Dementia Lithuania, North Macedonian Institute for Alzheimer's Disease and Neuroscience, Serbian Association for Alzheimer's Disease and Nezabutni Ukraine), were unanimously approved by the AGM and warmly welcomed.

As always, our European Parliament Lunch Debate was a popular affair and I would like to say a big thank you to Sirpa Pietikäinen MEP (Finland), Romana Jerković MEP (Croatia) and Hilde Vautmans MEP (Belgium), Co-Chairs of the European Alzheimer's Alliance (EAA), for jointly hosting the session. We are very grateful for their support. I would also like to thank our speakers, Sebastiaan Engelborghs, Linus Jönsson and Miia Kivipelto, for making this such an interesting and engaging event. Finally, we are also grateful to all the members of the EAA who took the time to participate.

The EAA currently has 89 members from 22 Member States of the European Union, with the latest addition being Kristian Vigenin MEP (Bulgaria). We look forward to working with him!

Together with the Alzheimer Europe Foundation, we are delighted to announce the launch of our 2025 Anti-Stigma Award. This year, we would like to recognise a European artist using photography or painting to address stigma and convey a positive image of dementia and people living with dementia. The deadline for applications is 1 September, so if you would like to apply, or if you represent one of our national member associations and would like to nominate an artist / photographer for this award, please keep this deadline in mind and apply as soon as possible (with written consent of the person being nominated, please).

In other important news, I would like to announce that we have an open position in our Public Involvement team, and would encourage you to apply right away if interested, as the deadline is today, 30 June! It is also the deadline to register for our Annual Conference if you wish to take advantage of the Early Bird rates, so register now, to join the already over 1,000 delegates in Bologna!

Our next edition will cover July and August, so I wish you an excellent summer. See you in September!

Jean Georges, Executive Director

ALZHEIMER EUROPE

2 JUNE:

Alzheimer Europe Board meets in Brussels

The Alzheimer Europe Board held a meeting on 2 June 2025. The meeting took place in Brussels and was chaired by Maria do Rosário Zincke dos Reis, Chairperson of Alzheimer Europe. Angela Bradshaw, Director for Research, Dianne Gove, Director for Public Involvement and Ethics and Ana Diaz, Public Involvement Lead, were in attendance to provide the Board of Directors with updates on various financial and operational matters. These updates concerned Alzheimer Europe's 2025 activities and meetings, the upcoming Annual Conference in Bologna, EU project applications, the composition of the two new working groups (group of people with dementia and group of carers) and a number of staff changes (including four recent additions to the team).

The Board then reviewed budgetary matters and prepared itself for the Annual General Meeting of Alzheimer Europe on 4 June. Before closing the meeting, the 2026 work plan and Annual Conference were discussed as were possible host countries for the 2027 Annual Conference. The Alzheimer Europe Board will hold its next meeting online, on 29 September.

3 JUNE:

Alzheimer Europe presents the 48th edition of Dementia in Europe magazine

It is with great pleasure that we introduce the 48th edition of our Dementia in Europe magazine, which brings updates on interesting developments across Europe in relation to policy, research, culture, advocacy and dementia care, throughout the first few months of 2025.

The first section shares some of our own work, starting with an article about our successful Alzheimer's Association Academy held in January, focusing on the topic of "Engaging in health technology assessment and pricing and reimbursement processes" at which our national member associations were invited to learn from four excellent speakers: Neil Bertelsen from Patient Focused Medicines Development, Elizabeth Walker, Technical Advisor at the UK's National Institute for health and Care Excellence (NICE), Matteo Scarabelli, Associate Director for Market Access at the European Federation of Pharmaceutical Industries and Associations (EFPIA) and Jim Pearson, Deputy Chief Executive of Alzheimer Scotland.

The following article is an interview with Heike von Lützau-Hohlbein, Chairperson of the Alzheimer Europe Foundation, in which she looks back at over a decade of the Foundation's work, after which we report on a recent meeting of the European Working Group of People with Dementia (EWGPWD) that we were delighted to host in Luxembourg in March of this year. As part of this meeting, the EWGPWD provided feedback on digital exergame and Artificial Intelligence chatbot developed by the eBRAIN-Health project.

The final three articles in this section present work by other EU-funded projects in which we are involved, including ADIS, which has launched a Spanish-language brain health initiative on social media, aimed at young adults in their early twenties, LETHE, which is developing innovative digital tools to support older adults in enhancing their cognitive health, and INTEREST, which presents its recommendations for dementia research, care, and policy.

Our Policy Watch section opens with the excellent news that the Swedish Government has launched its second national dementia strategy, "Every Day Counts: National Dementia Strategy 2025-2028", which builds on the country's previous plan. We hear from Minister for Older People and Social Security, Anna Tenje, and from Liselotte Björk, Chair of Demensförbundet, our national member association in Sweden.

The remaining articles in this section move us from the national to the European level, where we first introduce the recently-launched EU Joint Action addressing Dementia and Health (JADE Health). Co-ordinators Elisabeth Garcia and Bernardino Morillo, tell us more. Up next, we explore the EU4Health Civil Society Alliance (CSA) campaign for sustainable funding, through the eyes of the CSA Secretariat, Clémentine Richer Delforge from the European Public Health Alliance and Yann Heyer from the European Patients' Forum. Finally, we approached Acting Head of Unit for Disability at the European Commission, Lucie Davoine, who outlines some key developments in disability policy and highlights their relevance for people living with dementia.

The third and final section of this magazine is the "Dementia in Society" section, where we begin with an article celebrating the 40th anniversary of our national member association in France. Lorène Gilly, who is responsible for public policy at France Alzheimer, tells us about the celebrations and shares

some highlights from the past four decades of vital work carried out by the organisation, to improve the lives of people with dementia and carers. Staying at the national level, we then look at an important photography project from our member in Ukraine. “Nezabutni” (“Unforgettable”), is spreading the message that people with dementia deserve happy and fulfilled lives, the same as everyone else, and the Ukrainian charity has put together a series of photo portraits of ten people with dementia and their family members, sharing their stories to help break down some of the stigma and misconceptions around the condition. We salute the hard work and “we never close” attitude of our Ukrainian colleagues, during this incredibly difficult time for the country and its people.

Turning next to the United Kingdom, we showcase the new “Dementia Trials Accelerator”, spearheaded by the UK Dementia Research Institute (UK DRI) and Health Data Research UK (HDR UK) and supporting the UK Government’s Dame Barbara Windsor Dementia Goals programme (formerly known as the Dame Barbara Windsor Dementia Mission). The Dementia trials Accelerator aims to tackle the historically low numbers of people enrolled into dementia trials in the UK. Prof. Siddharthan Chandran, UK DRI Director, and Prof. Andrew Morris, HDR UK Director, provide details.

Our closing article takes a look at documentary film “Human Forever”, a story about love for humanity told by people with dementia, in which 25-year-old humanitarian activist Teun Toebes takes the viewer on a three-year journey across four continents and through 11 countries, exploring how dementia is dealt with in other countries and what we can learn from each other. This impressive quest was captured by his good friend and filmmaker Jonathan de Jong.

We hope you enjoy this edition of our Dementia in Europe magazine and make the most of the summer months ahead! Download it here: https://bit.ly/DementiaInEurope48

3 JUNE:

Alzheimer Europe organises a Company Round Table meeting in Brussels

On 3 June, Alzheimer Europe (AE) hosted a Company Round Table meeting in Brussels, bringing together company representatives from Anavex, Biogen, BMS, Danone (Nutricia), Eisai, Eli Lilly, EFPIA, Johnson & Johnson, Novo Nordisk and Roche, alongside AE staff and members from 22 national Alzheimer organisations. The event was moderated by AE chairperson Rosário Zincke dos Reis and featured four presentations.

First, Cindy Birck, AE Project Officer, gave an update on our Clinical Trials Watch, an online database providing accessible and up-to-date information on clinical trials that are investigating drugs for Alzheimer’s disease and/or dementia. Next, Owen Miller, AE Project Officer, shared some updates on EU policy developments, noting the re-launch of the European Alzheimer’s Alliance (EAA) on World Alzheimer’s Day, 21

September 2024. The EAA now comprises 88 members of the EAA from 22 countries.

The next presentation was given by Angela Bradshaw, AE Director for Research, addressing advancements in anti-amyloid treatments, particularly focusing on the regulatory processes for lecanemab and donanemab in Europe. Then, Mario Possenti, AE Vice-Chairperson, and Angela Bradshaw gave a joint presentation, informing participants about Alzheimer Europe’s activities in 2025 including the annual conference. Finally, Lukas Duffner, AE Project Officer, presented the recent public opinion poll, launched by AE, aiming to examine attitudes towards dementia research participation and data sharing.

We would like to thank our sponsors and members for participating in this meeting and we look forward to welcoming them to the next Company Round Table meeting, which will take place online on 17 September 2025.

3 JUNE:

Alzheimer Europe hosts a European Parliament Lunch Debate on “Preparing for new Alzheimer’s treatments in Europe”

On 3 June, Alzheimer Europe held a lunch debate in the European Parliament in Brussels (Belgium), entitled “Preparing for new Alzheimer’s treatments in Europe” attended by national member organisations, civil society representatives, industry partners, policy makers and members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG). The event was attended by almost 100 people, including nine Members of the European Parliament (MEPs).

Three Co-Chairs of the European Alzheimer’s Alliance (EAA) jointly hosted the session, Sirpa Pietikäinen MEP (Finland), Romana Jerković MEP (Croatia) and Hilde Vautmans MEP (Belgium). We are hugely grateful to each of them for their

support and for welcoming us and our guests to this important event.

The session opened with welcome words from Sirpa Pietikäinen MEP (pictured, bottom left) who stated that the “EU must step up! By working decisively together on research, development, and clinical trials, we can lead the discovery of new treatments for Alzheimer’s and other memory-disabling diseases.”

Romana Jerković MEP (pictured, bottom centre) then spoke to delegates, saying "Alzheimer’s disease is a growing challenge for the European Union. As new treatments begin to emerge, we cannot ignore the persistent issue of late and underdiagnosis. Millions across Europe are suffering in silence and we owe them political focus, investment, and a coordinated response that matches the scale of this crisis."

Hilde Vautmans MEP (pictured, bottom right) shared that her interest in Alzheimer’s came from her personal experience with her father who passed away with Alzheimer’s dementia. She said "Europe must lead the way in transforming Alzheimer’s care. With innovative projects and new treatments, we have a unique chance to shift from late reaction to early action: offering patients not just more years, but better ones."

After these introductory words, the first of our three speakers, Sebastiaan Engelborghs (Co-Chairperson, European Alzheimer’s Disease Consortium, Belgium) delivered a presentation on “The advent of disease-modifying treatments for early Alzheimer’s disease in Europe”. He provided an update on the role of amyloid in Alzheimer’s disease and the development of anti-amyloid treatments. His key message was that, through the registration of the first disease-modifying therapy for Alzheimer’s disease in Europe, we are entering a new era, demonstrating that research pays off.

Up next, Linus Jönsson (Karolinska Institutet, Sweden) spoke about “Preparing for a new era of precision medicine in Europe”, giving an overview of the aims of the IHI-funded PROMINENT project. The project aims to develop a digital platform for precision medicine to improve the diagnosis and treatment of neurodegenerative disease and co-morbidities. He emphasised that “new diagnostic and treatment advances will improve care for Alzheimer’s and other dementias” also noting that decision support tools like those from IHI-PROMINENT will help clinicians apply these innovations effectively, which in turn “will ensure better outcomes for patients and greater value for society.”

The third and final speaker was Miia Kivipelto (University of Eastern Finland, Finland), whose talk on “New opportunities for early detection, prevention and treatment of Alzheimer’s disease” gave an update on the AD-RIDDLE project. AD-RIDDLE aims to develop a toolbox platform concept to enable healthcare systems and practitioners to improve the management of AD and dementia across diverse patient population. She noted that the field of Alzheimer’s disease was at a turning point, stressing that “AD-RIDDLE bridges scientific innovation and clinical practice with a flexible toolbox platform featuring validated blood biomarkers, digital cognitive assessments, and tailored lifestyle or pharmacological interventions for early detection and prevention."

Sirpa Pietikäinen MEP thanked the speakers and gave the floor to some of her fellow parliamentarians in attendance, EAA members Michał Szczerba MEP (Poland), Tomáš Zdechovský MEP (Czechia), Tsvetelina Penkova MEP (Bulgaria), Nikos Papandreou MEP (Greece) and Nina Carberry MEP (Ireland), giving each of them a moment to address delegates and highlight why dementia is important to them, how they advocate for people with dementia and for national dementia plans in their countries and where gaps exist, at national level and across the EU.

Alzheimer Europe thanks all the co-hosts, speakers, delegates and also its Gold and Silver sponsors for making this event possible. Our next European Parliament Lunch Debate will take place on 2 December.

3 JUNE:

22 countries represented at Alzheimer Europe's Public Affairs meeting in Brussels

Alzheimer Europe welcomed delegates from 22 member organisations to its Public Affairs meeting on 3 June in Brussels (Belgium). The session was moderated by Alzheimer Europe Chairperson Maria do Rosário Zincke dos Reis (Portugal) and the agenda covered two main topic areas:

The first part looked at "Preparing for new AD treatments in Europe" and was led by Director for Research Angela Bradshaw, who gave attendees some background on developments around anti-amyloid therapies for Alzheimer's disease (AD), shared Alzheimer Europe's recent activities around these therapies and then discussed some of the next steps. Following her presentation, members were invited to share learnings from national activities and campaigns in this area.

The second part of the meeting covered Alzheimer Europe activities on brain health and dementia risk reduction. Up first, Project Officer Lukas Duffner shared some of the initial findings from the SHARE survey, which looks to examine the prevalence of risk factors across countries in Europe. He then invited members to discuss whether they felt this survey was useful to their work, which additional subgroups they suggested to examine and how results should be presented, once available. Angela Bradshaw then took the floor again, to give an update on our work on various research projects and the upcoming Dementia in Europe magazine supplement on brain health scheduled for October. Delegates were then invited to discuss priorities for brain health and risk reduction at the EU level, before the meeting closed. The next Public Affairs meeting is scheduled for 2-3 December, and will again take place in Brussels.

3-4 JUNE:

The European Dementia Carers Working Group met in Brussels

On 3 and 4 June 2025, members of the European Dementia Carers Working Group (EDCWG) travelled to Brussels (Belgium) for two full days of in-person meetings. The meeting provided an opportunity to reflect on the group's ongoing contributions and to mark a moment of transition within the group. The Public Involvement team was represented by Dianne Gove, Ana Diaz, Soraya Moradi-Bachiller, Sarah Campill and Sébastien Libert during the meeting. Dianne, Ana, Sarah and Sébastien facilitated the discussions.

On the first day, the EDCWG members explored a range of topics including their understanding and views on technology, their views on culture, leisure and transport for people with dementia and their carers and discussed their contributions to the plenary session during the 2025 Alzheimer Europe Conference in Bologna (Italy). During the session dedicated to culture, leisure and transport, Owen Miller (Alzheimer Europe Policy Officer) joined the group to gather input for the organisation's 2025 Yearbook. At midday, the group attended Alzheimer Europe's lunch debate at the European Parliament, where they had the opportunity to meet with Members of the European Parliament (MEPs) and raise their demands and priorities. The event brought together leading scientists in the dementia field, national member organisations, industry partners and policymakers. Later that afternoon, the EDCWG members bid a warm farewell to two departing members: Sonata Mačiulskytė (Lithuania), former Chairperson and Vice-Chairperson of the EDCWG, and (online) Barry Northedge (UK – Scotland). In recognition of their invaluable contributions, both were presented with commemorative trophies by the Public Involvement team. The group expressed heartfelt thanks to Sonata for her pioneering leadership as the group's first Chairperson and to both departing members for their positive and lasting impact on the group's work and dynamic.

On 4 June, the second day began with an update on the AI4HOPE project, where Sébastien presented the final version of the palliative care information sheet and highlighted the group's contributions to its development. This was followed by

a session on the PREDICTOM project, focusing on the development of a decision-making tool to support participants in early detection studies. Next, Angela Bradshaw (AE Director for Research) joined the group to share an update on the European Platform for Neurodegenerative Diseases (EPND) project, particularly the design of the online lay glossary and the EPND website. These discussions were followed by a presentation of the Alzheimer Clinical Trial Watch webpage by Cindy Birk (AE Project Officer), where the group was invited to provide feedback on how to help improve its accessibility and usefulness. The final session of the day was dedicated to the Triple IHI Initiative, which brings together the PREDICTOM, AD-RIDDLE and PROMINENT projects to foster collaboration and avoid duplication of efforts in dementia research. Here the group was joined Ruth Stephen (AD-RIDDLE) for a discussion about the terminology surrounding Alzheimer's disease.
All the discussions were very dynamic and fruitful, leaving the visiting researchers as well as the Alzheimer Europe staff members grateful for the valuable feedback, views and insights that were shared with them.

4 JUNE:

Five new full members welcomed and 2024 Annual and Financial Report approved during Annual General Meeting in Brussels

Alzheimer Europe is pleased to welcome five new full member associations and to present its 2024 Annual and Financial Report. These are just two of the important outcomes from the organisation's Annual General Meeting (AGM), which took place this week in Brussels. At the AGM, held on 4 June 2025. 29 full members out of 36 were present or represented, ensuring the meeting had quorum. Five of Alzheimer Europe's provisional members were also in attendance, as was the staff and Board, together with various other guest observers.
Alzheimer Europe Chairperson Rosário Zincke dos Reis (Portugal) moderated the meeting, with the agenda including an in-depth review of the 2024-2025 activities and projects of Alzheimer Europe (presented by Honorary Secretary Lorène Gilly from France), as well as the finances of the organisation (presented by Honorary Treasurer Marco Blom from the Netherlands). As has been the case since the beginning of 2022, our core activities in 2024 were funded by an operating grant awarded by the European Commission's Citizens, Equality, Rights and Values (CERV) programme, ensuring we can continue providing a voice to people with dementia and their carers, making dementia a European priority, changing perceptions and combatting stigma, raising awareness of brain health and prevention, strengthening the European dementia movement, and supporting dementia research.

AGM delegates reviewed and unanimously adopted Alzheimer Europe's 2024 Annual and Financial Report and the report is now available on our website, as a PDF publication. Printed copies will available at our Annual Conference in Bologna in October.
Read our 2024 Annual and Financial Report, here: https://bit.ly/AE2024AnnualReport
The new terms of office of the European Working Group of People with Dementia (EWGPWD) and of the European Dementia Carers Working Group) have begun following the 2025 AGM, and the members, chairpersons and vice-chairpersons of both groups will be announced soon. Both the chairperson of the EWGPWD and chairperson of the EDCWG will be *ex-officio* members of the Alzheimer Europe Board, with full voting rights.
Kevin Quaid (Ireland), current Chairperson of the EWGPWD and Trevor Salomon (United Kingdom, England), current Chairperson of the EDCWG each gave a speech at the AGM, sharing the excellent work of their respective working groups over the past year and thanking Alzheimer Europe for its support and its commitment to ensuring the voices of people with dementia and carers are heard at the European level.
Alzheimer Europe's five provisional member associations in attendance, having applied for full membership, were then given the floor to present the work they are doing in their respective countries. Following, this the AGM voted unanimously to welcome all five of them as full members. Alzheimer Europe warmly welcomes all five of them. They are:

- Alzheimer's Care Armenia, represented by Ofelya Kamavosyan
- Dementia Lithuania, represented by Ieva Petkuté
- Institute for Alzheimer's Disease and Neuroscience, North Macedonia, represented by Jana Strashevska
- Serbian Association for Alzheimer’s Disease, represented by Željka Cvjetan Gortinski
- Nezabutni Ukraine, represented by Iryna Shevchenko.

A big thank you to all members who attended our 2025 AGM in Brussels, for the great discussions and for using their voices and their votes, thus helping to shape the future of our organisation and ensure our important collaborative work continues.

Pictured: Five new full members were welcomed during our AGM , represented by (left to right): Ieva Petkuté (Lithuania), Ofelya Kamavosyan (Armenia), Željka Cvjetan Gortinski (Serbia), Iryna Shevchenko (Ukraine) and Jana Strashevska (North Macedonia)

10 JUNE:

European Working Group of People with Dementia begins new mandate with five new members and says goodbye to departing members

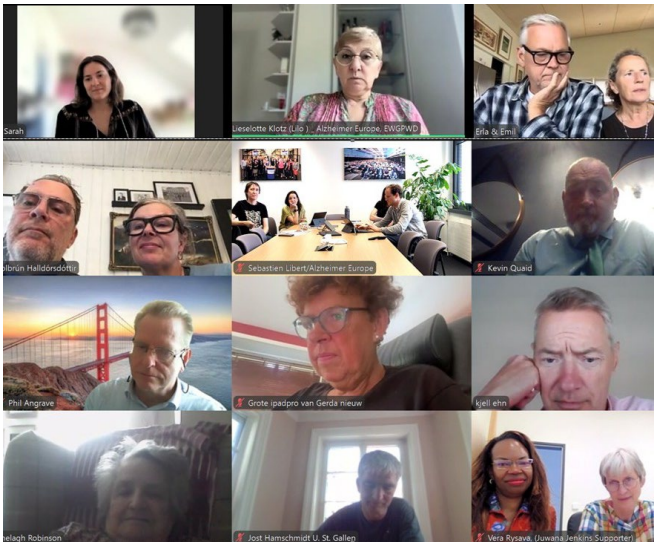
We are pleased to announce that the membership of the European Working Group of People with Dementia (EWGPWD) has been renewed and that the new incarnation of the group officially began its mandate after the Annual General Meeting of Alzheimer Europe (4 June 2025).

The EWGPWD is now composed of the following 15 members:

- Phillip Angrave, United Kingdom - England ♂(new member)
- Stuart Dougall, United Kingdom - Scotland ♂(new member)
- Kjell Ehn, Sweden ♂
- Jan Runar Eliassen, Norway ♂
- Hafsteinn Ágúst Friðfinnsson, Iceland ♂(new member)
- Katya Genadieva, Bulgaria ♀(new member)
- Jost Hamschmidt, Switzerland ♂(new member)
- Erla Jónsdóttir, Iceland ♀
- Minna Kinnunen , Finland♀
- Lieselotte Klotz, Germany ♀
- Angela Pototschnigg , Austria♀
- Kevin Quaid, Ireland ♂
- Shelagh Robinson, United Kingdom - England ♀
- Věra Ryšavá, Czechia ♀
- Gerda Van Tongerloo, Netherlands ♀.

The EWGPWD was launched by Alzheimer Europe and its member associations in 2012. The group is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently and members elect their own Chairperson and Vice-Chairperson. The Chairperson is also an *ex-officio* member on the Board of Alzheimer Europe, with full voting rights. In July, the group will vote in its Executive members and we will confirm their names in due course.

Alzheimer Europe would like to express its gratitude to outgoing EWGPWD members Chris Roberts (UK - Wales) and Margaret McCallion (UK - Scotland), for their important contributions and we wish them well. They will be sorely missed! The group also lost Nigel Hullah (United Kingdom - Wales), who passed away suddenly, earlier this year.



An online meeting was held on 12 June (pictured) to give the new and current members of the EWGPWD the chance to meet each other. Three of the new members - Jost Hamschmidt (Switzerland), Phillip Angrave (England, UK) and Hafsteinn Ágúst Friðfinnsson (Iceland) - were warmly welcomed to the group and had the chance to introduce themselves, ask questions about the group, get to know the other members and find out from them what it is like to be part of the EWGPWD. Two other new members - Stuart Dougall (Scotland, UK) and Katya Genadieva (Bulgaria) – were unable to join the meeting but will be welcomed to the group at the next meeting at the beginning of July when the new Chair and Vice Chair will be elected.

10 JUNE:

European Dementia Carers Working Group begins new mandate with two new members and says goodbye to departing members

We are pleased to announce that the membership of the European Dementia Carers Working Group (EDCWG) has been renewed and that the new incarnation of the group officially began its mandate after the Annual General Meeting of Alzheimer Europe (4 June 2025).

The EDCWG is now composed of the following 15 members:

- Bill Alexander, United Kingdom - Scotland ♂(new member)
- Peter Banda, Slovakia ♂
- Patrick Crosbie, Ireland ♂
- Sylva Dneboská, Czechia ♀
- Chris Ellermaa, Estonia ♀
- Emil Emilsson, Iceland ♂
- Annick Germeys, Belgium ♀
- Zornitsa Karagyozova, Bulgaria ♀
- Trevor Salomon, United Kingdom - England ♂
- Hatice Sertaç Süslü, Turkey ♀
- Liv Thorsen, Norway ♀
- Peter Thörngren, Sweden ♂(new member)
- Olivera Vasilevska Danev, North Macedonia ♀
- Rosylynn Vella, Malta ♀
- Christina Zioga, Greece ♀.

The EDCWG was launched by Alzheimer Europe and its member associations in 2022. The group is composed both of current carers, relatives and supporters of people with dementia, and of people with prior experience in a carer's role, within the five years prior to their first nomination to the group.

In tandem with the European Working Group of People with Dementia (EWGPWD) - a group composed entirely of people living with dementia themselves and set up by Alzheimer Europe and its members in 2012 – the carers group works to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of carers and supporters of people with dementia. The group operates independently and members elect their own Chairperson and Vice-Chairperson. The Chairperson is also an *ex-officio* member on the Board of Alzheimer Europe, with full voting rights. In July, the group will vote in its Executive members and we will confirm their names in due course.

Alzheimer Europe would like to express its gratitude to outgoing members Barry Northedge (United Kingdom - Scotland) and Sonata Mačiulskytė (Lithuania) for their important contributions and we wish them all the best for the future.

13 JUNE:

Alzheimer Europe invites artists using photography or painting to apply for its 2025 Anti-Stigma Award

Alzheimer Europe and the Alzheimer Europe Foundation are delighted to announce the launch of the 2025 edition of their Anti-Stigma Award, following the growing success of this Award since its beginnings in 2022. This year, they would like to recognise a European artist using photography or painting to address stigma and convey a positive image of dementia and people living with dementia.

Applications can be made by artists established in a member country of Alzheimer Europe themselves, or by a nominating national Alzheimer's association. In the latter case, the written consent of the nominated artist must be sought prior to making the application on their behalf. Submitted works must have been produced in the past three years (2022-2025) to be eligible for the Award.

The 2025 Award will consist of a cash prize of EUR 5,000 for first place, a cash prize of EUR 2,500 for second place and a cash prize of EUR 1,250 for third place, each of which will be accompanied by a trophy. The winning artists will be announced during a special Award Ceremony on 2 December 2025, in Brussels.

Interested artists or national Alzheimer's associations wishing to nominate a particular artist, should send in the completed application form by the deadline of 1 September 2025.

Applicants may be short listed and asked to present their art work or photography to the members of the Award Committee at an online meeting on 15 September. Travel and accommodation costs for the top three applicants will be covered by Alzheimer Europe, to attend the award ceremony in Brussels on 2 December.

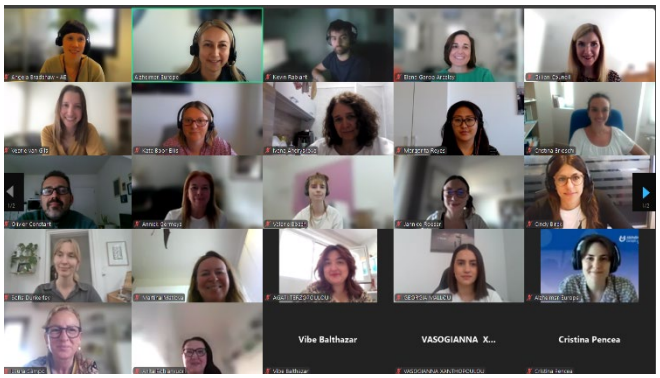
Pictured: Winners of the Anti-Stigma Award 2024 (left to right): Magnus Renggli, Ofelya Kamavosyan, Andreas Kreimaier

More information can be found at: https://www.alzheimer-europe.org/our-work/anti-stigma-award/anti-stigma-award-2025

The application form can be downloaded via: https://www.alzheimer-europe.org/sites/default/files/2025-06/anti-stigma_award_-_application_form_2025_0.pdf
Alzheimer Europe gratefully acknowledges the support of the sponsors of the Alzheimer Europe Anti-Stigma Award: Alzheimer Europe Foundation, C2N Diagnostics, Lilly and Roche.

24 JUNE:

Alzheimer Europe hosts a session of its popular online Alzheimer's Association Academy, focusing on the topic of "MCI: terminology, support and services"



On 24 June, Alzheimer Europe hosted a session of its popular online Alzheimer's Association Academy, with a focus on "MCI: terminology, support and services". 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 the latest advances in dementia care, policy, research and treatment from experts in these fields. The session on 24 June was the third Academy session of 2025 and was hosted by Angela Bradshaw, Director for Research, Alzheimer Europe. She welcomed 62 participants, including members from 18 countries across Europe, representatives from five pharmaceutical companies and members of the Alzheimer Europe staff to the session.
The first speaker was Veerle van Gils (Maastricht University), whose presentation was titled "Early detection and diagnosis of Alzheimer's disease in the MCI stage". Elena Garcia Arcelay (Roche Farma S.A) then spoke about the impact of informal caring for people with mild cognitive impairment in Spain. The third speaker was Gillian Councill (Alzheimer Scotland) who shared details of the Alzheimer Scotland Brain Health and Dementia Resource Centres. Kevin Rabiant (France Alzheimer), the fourth and final presenter at the event, spoke about France Alzheimer's "Mutual Support Group for people at the start of their disease journey".
Thank you to all speakers and participants at the Academy session and a huge thank you, also, to our Gold and Silver sponsors, (Bristol Myers Squibb, Eisai, Lilly, Novo Nordisk and Roche) and the European Commission's CERV programme (which provides our Operating Grant funding) for making this session possible. The next edition of the Alzheimer's Association Academy is scheduled for 15 July 2025 and will focus on Awareness Campaigns.

24 JUNE:

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

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**. No prior experience participating in dementia research is required and both people with and without dementia can participate. The poll is available in the following languages: Czech, Dutch, English, Finnish, French, German, Italian, Polish, Portuguese, Spanish and Swedish.

We invite you to complete the poll and share it via your social media network. It can easily be accessed on smartphone, laptop, or tablet just by clicking here or scanning the QR code. Thank you very much for your support!

30 JUNE:

More than 1,000 delegates already registered for the 35th Alzheimer Europe Conference! If you want to join them register today to benefit from our Early Bird rates!

Our special Early Bird rates for the 35th Alzheimer Europe Conference (#35AEC) close today, 30 June, so make sure you don't miss out! Register right away, and join more than 1,000 delegates who have already registered, for what promises to be an exciting and interactive event in Bologna, Italy, from 6-8 October!

Find out more about registration fees: https://www.alzheimer-europe.org/conferences/2025-bologna/registration-fees
Click here to register: https://www.alzheimer-europe.org/conferences/2025-bologna/conference-registration-portal
The conference programme is available to view on our website: https://www.alzheimer-europe.org/conferences/2025-bologna/detailed-programme

AE NETWORKING

2 JUNE	The Alzheimer Europe Board held a meeting (Brussels, Belgium)
3 JUNE	Alzheimer Europe organised a Company Roundtable meeting with sponsors, members and staff (Brussels, Belgium)
3 JUNE	Alzheimer Europe organised a European Parliament Lunch Debate entitled “Preparing for new Alzheimer’s treatments in Europe” (Brussels, Belgium)
3 JUNE	Alzheimer Europe organised a Public Affairs meeting with members (Brussels, Belgium)
3-4 JUNE	The Public Involvement team met with the European Dementia Carers Working Group (Brussels, Belgium)
4 JUNE	Alzheimer Europe organised its Annual General Meeting (Brussels, Belgium)
5 JUNE	Lukas attended the NGO coordination meeting of the European Disability Forum
9 JUNE	Angela attended a sustainability meeting organised by the EPND project (London, UK)
10 JUNE	Soraya facilitated a project consultation with the DORIAN GRAY Public Involvement Board
10-11 JUNE	Angela, Dianne, Ana, Lukas and Cindy attended the AD-RIDDLE General Assembly Meeting (London, UK)
12 JUNE	The Public Involvement team met with the European Working Group of People with Dementia to welcome new members
12 JUNE	Angela joined the Annual Meeting of the EMA Patients’ and Consumers’ Working Party and FDA Patient Engagement Collective
13 JUNE	Angela was a speaker at a EURACTIV webinar on early detection and diagnosis
18 JUNE	Ana and Angela participated in a meeting on clinical study recruitment and retention, organised by Roche
19 JUNE	Sarah hosted an information meeting for the PREDICTOM project’s Public Ambassador Group
24 JUNE	Cindy attended the EU-X-CT Public Stakeholder Conference: Final recommendations launch

24 JUNE	Angela and Dianne joined a meeting of the EAN Dementia Guideline Taskforce
25 JUNE	Ana and Sarah facilitated a meeting with the Dutch AD-RIDDLE Advisory Board
25-26 JUNE	Chris and Soraya attended the ADIS final symposium (Sankt Augustin, Bonn, Germany)
26 JUNE	Angela joined an online policy workshop organised by EU4Health, on access to healthcare for persons with disabilities

SPONSORS OF THE MONTH

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

Johnson & Johnson

Eisai

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/2024-sponsorship-opportunities

EU PROJECTS

22 MAY:

A strategic reorientation in the AI-Mind consortium structure

On 22 May 2025, the AI-Mind consortium, joined by the Project Officer and external experts, convened for a pivotal review meeting to assess project progress and plan the final steps ahead of its conclusion in February 2026. Discussions centred on actions to maximise the scientific, clinical and societal impact of AI-Mind in its final phase. This strategic reorientation began in early 2024 with a revision of the consortium's structure, reflecting a shift in focus from foundational development to the implementation of the AI-Mind solution and ensuring its long-term sustainability. As part of this evolution, DET NORSKE VERITAS® (DNV) officially concluded its involvement on 31 December 2023, having successfully delivered its contributions. Simultaneously, three new partners: the University of Oslo (UiO), Pre Diagnostics AS and Roche joined the consortium on 1 January 2024, each bringing unique expertise to support AI-Mind's next phase.

As AI-Mind enters its final stretch, its mission remains unchanged: to support early dementia diagnosis and reduce the burden of neurodegenerative diseases across Europe and globally. Now comprising 17 active partners spanning academia, healthcare, and industry, AI-Mind is well-positioned to accelerate the implementation of its cutting-edge dementia risk prediction tools. These tools offer new hope to individuals at risk of mild cognitive impairment (MCI) and dementia.

https://www.ai-mind.eu/blog/a-strategic-reorientation-in-the-consortium-structure/

26 MAY:

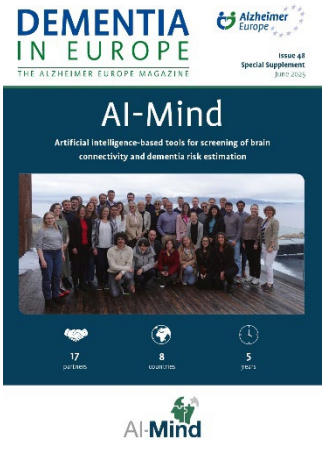
Members of the DORIAN GRAY Public Involvement Board met online to discuss apps and devices that promote fitness and health

On 26 May and 10 June, members of the newly set up DORIAN GRAY Public Involvement Board (PIB) gathered online. Some members of the DORIAN GRAY research team - Nicola Francesco Lopomo, Leonardo Angelini, Ugo Eb-Levadoux, Carlo Emilio Standoli, Carla Dei and Louise Droste zu Senden – attended both sessions which were facilitated by Soraya Moradi-Bachiller (Public Involvement Officer, Alzheimer Europe). During the consultation, members of the DORIAN GRAY-PIB were asked about their lifestyle and the use they make of apps and devices to stay fit and healthy. Then, members were presented with information about the DORIAN GRAY app, its possible features and general functions. Researchers then discussed with the DORIAN GRAY-PIB how to develop an app that is engaging, accessible and appealing enough for the future participants of the DORIAN GRAY study.

Members who attended these sessions (both part of the same consultation) participated actively and provided insightful feedback that will help the DORIAN GRAY research team develop a successful app.

3 JUNE:

AI-Mind project supplement published with new Dementia in Europe magazine



The AI-Mind research project has published a special supplement about its work, together with the 48th edition of Alzheimer Europe's "Dementia in Europe" policy magazine. Both publications are available for download, as well as available in print.

The Special Supplement to the 48th edition of Dementia in Europe is dedicated to the AI-Mind project, which is an initiative funded by the European Union's Horizon 2020 research and innovation programme. At the heart of the AI-Mind project is the development of innovative Artificial Intelligence (AI)-based tools designed to screen brain connectivity and estimate dementia risk. These tools are designed to assist healthcare professionals in diagnosing dementia, ultimately enabling timely interventions for patients.

AI-Mind is a five-year research and innovation programme that has been growing since its launch in March 2021, expanding from 15 to 17 partners across eight European countries. It brings together professionals from multiple sectors, including academic institutions, medical centres, small and medium-sized enterprises, spin-off companies and patient associations, with a common goal of providing future patients with a better and personalised diagnosis.
We hope you enjoy this special publication! Download it here: https://bit.ly/AI-Mind_Supplement

6 JUNE:

Showcasing Lethe Project Results at the EGI 2025 Conference

The EGI Conference 2025 was held in Santander, Spain from 2 to 6 June 2025. It is an annual event that brings together international scientific communities, computing and service providers, European projects, security experts, community managers, and policymakers gather to advance research and innovation in data-intensive processing and analytics in a safe and open environment with room for in-depth discussion, new insights, networking, and more.
This year, the Lethe project team was once again in attendance hosting a booth to showcase the preliminary project results. It was also a fantastic opportunity to generate interest about the project by allowing attendees to interact with some of the technologies used, such as the Fauna audio glasses and the TEMI robot. The TEMI robot was a standout crowd pleaser, capturing the curiosity of many participants at the conference who were interested in knowing how the robot was used to help reduce the risk factors that cause dementia.
The conference was a success and provided a chance to interact with representatives from other organisations, projects and industries and inform them about the project, the software and technologies that have been developed and trialled during Lethe.

https://www.lethe-project.eu/

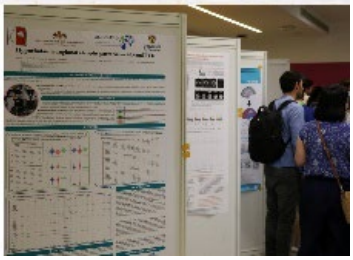
10 JUNE:

AD-RIDDLE convenes its second General Assembly in London

The second General Assembly meeting of the AD-RIDDLE ("Real-World Implementation, Deployment, and Validation of Early Detection Tools and Lifestyle Enhancement") project took place in London on 10-11 June. Hosted by Imperial College London, this two-day event brought together representatives from 24 partner organisations across academia, healthcare, industry and non-profit sectors to discuss different work packages and facilitate partnerships.
AD-RIDDLE centres around a toolbox platform concept, providing a series of validated tools at each key step to enable healthcare systems and practitioners to improve the management of Alzheimer's disease (AD) and dementia across diverse patient populations. The AD-RIDDLE platform aims to transform how AD is detected and diagnosed, prevented and treated across healthcare settings.
The first day concluded with an inspiring talk by Trevor Salomon, Chairperson of the European Dementia Carers Working Group (EDCWG), who shared his personal experiences as a caregiver. Within the consortium, Alzheimer Europe leads two work packages concerning facilitation of the real-world implementation of AD-RIDDLE (e.g., ethical, policy, health economic considerations) as well as communication and public involvement. Angela Bradshaw (Director for Research), Dianne Gove (Director for Public Involvement and Ethics), Ana Diaz (Public Involvement Lead), Cindy Birck (Project Officer) and Lukas Duffner (Project Officer) joined the meeting on behalf of Alzheimer Europe.
https://www.ad-riddle.org/resources/ad-riddle-convenes-its-second-general-assembly-in-london

16 JUNE:

The Euro-PAD community holds a scientific symposium in Barcelona



On 16-17 June, the Euro-PAD community convened a scientific symposium in Barcelona. During these two days, almost 100 participants gathered to discuss the latest advancements in neuroimaging and biomarkers for Alzheimer's disease, as well as to share updates from the Euro-PAD initiative over the past year.

The event commenced with two workshops focusing on clinical trials in Alzheimer's disease and blood-based biomarkers, organised by Ace Alzheimer Center Barcelona (ACE) and Barcelonaβeta Brain Research Center (BBRC), respectively. These sessions set the stage for the symposium's broader discussions.

The opening session of the symposium featured a warm welcome from the organisers, establishing a collaborative atmosphere for the event. An overview of the Euro-PAD community highlighted the significant progress made over the past year. The symposium's agenda included a series of scientific sessions, providing attendees with opportunities to present their latest research findings. This year, participants were also invited to submit abstracts for poster presentations and short talks, enriching the exchange of ideas.

Throughout the event, delegates engaged in lively discussions and explored potential collaborations. The symposium underscored the Euro-PAD community's commitment to advancing research in the early detection and prevention of Alzheimer's disease.

19 JUNE:

PREDICTOM launches Dementia Risk Reduction Leaflet

The PREDICTOM project has recently launched a new information leaflet designed to help people better understand how to reduce their risk of developing dementia. Currently it is available in English, French, German and Spanish, the leaflet can be accessed both as a downloadable PDF and in an easy-to-navigate online format via the project website: www.predictom.eu

Based on the latest findings from the 2024 Lancet Commission report on dementia prevention, intervention and care, the leaflet presents evidence-based guidance in a clear, accessible way. It highlights key lifestyle factors that influence brain health and offers practical, everyday tips to inspire people to take the first steps toward reducing their risk of developing dementia.

During the development of this resource, members of PREDICTOM's national and European Public Involvement Groups, which constitutes of lay people from diverse backgrounds and nationalities, played an important role in shaping the final product. Their feedback helped refine the leaflet's design, visuals and content to ensure it resonates with the general public.

The leaflet was developed through a close partnership between icometrix (https://www.icometrix.com/) and Alzheimer Europe, in collaboration with the University of Geneva, on behalf of the PREDICTOM consortium.

To explore the leaflet and learn more about how you can support brain health, follow the links below:

- Online version: https://www.predictom.eu/our-research/did-you-know-that-you-can-reduce-your-risk-of-developing-dementia
- PDF versions: https://www.predictom.eu/resources

19 JUNE:

PREDICTOM Public Involvement groups attend online talk on hearing loss and cognition

On 19 June, 11 members from the national and international Public Involvement (PI) groups of the PREDICTOM project came together online for an information session. Participants from Ireland, Italy, Spain and UK. joined the event, which featured a talk by Sigurd Brandt (Denmark), titled “The Hearing Loss and Cognition Link.” Sigurd Brandt (pictured) is the Medical Director at GN BrainWorks, part of the GN Group, which is one of the industry partners in the PREDICTOM project. The session was hosted by Sarah Campill (Alzheimer Europe Public Involvement Officer).

The presentation focused on the growing body of research exploring the links between hearing, cognitive health and the potential impact of hearing aids. The second half of the session was dedicated to an open Q&A, allowing attendees to ask

questions, share reflections and raise concerns. The presentation was well received, with one participant describing it as “thought-provoking” and another noting that, despite some findings seeming “counter-intuitive at first”, it made a lot of sense in hindsight.

For further information about PREDICTOM, please visit the project’s website:
www.predictom.eu

EU project acknowledgements

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

AI-MIND – grant agreement 964220 (https://www.ai-mind.eu/)
AD-RIDDLE – grant agreement 101132933 (https://www.ad-riddle.org/)
Dorian Gray - grant agreement 101156266 (https://www.doriangray-horizon.eu/)
Lethe – grant agreement 101017405 (https://www.lethe-project.eu/)
PREDICTOM - grant agreement 101132356 (https://www.predictom.eu/)

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).

EUROPEAN ALZHEIMER'S ALLIANCE

3 JUNE:

Kristian Vigenin MEP joins European Alzheimer's Alliance (EAA)

Alzheimer Europe is delighted to announce that Kristian Vigenin (S&D, Bulgaria) has joined the European Alzheimer's Alliance (EAA). We very much look forward to working with him to help ensure dementia is a policy priority at a European level.

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

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

The EAA currently has 89 members from 22 Member States of the European Union.

A full list of Co-Chairs and members of the EAA is available at: https://www.alzheimer-europe.org/policy/european-alzheimers-alliance/members

EU DEVELOPMENTS

4 JUNE:

Continence Health Interest Group launched in the European Parliament

On 4 June 2025, the Urge to Act campaign launched the MEP Interest Group on Continence Health during a breakfast meeting at the European Parliament in Brussels.

The purpose of the group is to support and empower people affected by continence health problems across the EU; women, children, men, the elderly, people coping with other health conditions and their carers. The Interest Group promotes a society where continence health problems can be openly talked about and where people can have the right access to preventative measures and care when needed.

The meeting was hosted by Maria Walsh MEP, who is also the Chair of this Interest Group. Alzheimer Europe was represented at the meeting by Dianne Gove, Director for Public Involvement and Ethics, who presented Alzheimer Europe's report and guidelines on continence care.

Find out more: https://uroweb.org/news/continence-health-interest-group-launched-in-the-european-parliament

12 JUNE:

Alzheimer Europe signs joint call to protect patient involvement in European Medicines Agency

Alzheimer Europe has joined more than 70 patient organisations in supporting a joint statement authored by Rare Diseases Europe (EURORDIS) and the European Patients' Forum (EPF), calling for the safeguarding of meaningful patient involvement in the European Medicines Agency (EMA), as part of reforms to the EU's pharmaceutical legislation.

EURORDIS and EPF have warned that Council position risks removing patient representatives' voting rights in the EMA's Committee for Medicinal Products for Human Use (CHMP), as well as reducing the number of voting patient members in the Pharmacovigilance and Risk Assessment Committee (PRAC).

The European Commission's original proposal marked a milestone in formalising patient involvement in EU medicines regulation, introducing provisions for four patient representatives with voting rights on the CHMP and two on the PRAC. However, the Council agreement adopted on 4 June significantly weakens these provisions. It falls short of both the Commission's ambition and the European Parliament's position adopted in April 2024 in terms of patient involvement.

The statement notes that reducing patient involvement or removing voting rights would not only undo decades of progress, it would also send a damaging signal that patient perspectives are no longer valued in decisions that directly affect their lives.

Trilogue negotiations between the Council, the Parliament and the Commission are set to begin on 17 June. The joint statement is available at: https://www.eu-patient.eu/globalassets/joint-statement-epf-x-eurordis.pdf

21-22 JUNE:

European Disability Forum holds event on legal capacity and Annual General Assembly in Vilnius (Lithuania)

On 21-22 June, Kevin Quaid, Chair of the EWGPWD, and Dianne Gove represented Alzheimer Europe at the EDF General Assembly in Vilnius, Lithuania. There was a very interesting meeting prior to the GA on legal capacity and supported decision making. Yannis Vardakastanis, President of the EDF, stated in his opening words that legal capacity is not just a legal technicality but a gateway to human dignity, adding that legal capacity is the foundation for autonomy, equality and inclusion and that too many people with disability across Europe are still denied this right.

Prof. Jonas Ruškus from Vyautas Magnus University (Lithuania) emphasised the important role that families play in helping clarify what constitutes the best interpretation of a person's will and preferences. Rosie Harding, Professor of Law and Soci-

ety, Birmingham Law School (UK) added that advance directives are really important but that these are not enough and should not override people's current wishes. She also pointed out that controls of people's mental capacity are often based on far stricter criteria than for people without dementia (or intellectual disability or autism) in that they are expected to show higher levels of understanding and to justify every reason for their decision, often to an expert or someone they might not know or trust, whereas other people aren't. Dr Markus Schefer, Member of the Committee on the Rights of Persons with Disabilities gave an interesting talk about article 12 of the UN CRPD and on the difference between having and exercising rights. Markus concluded that laws need to be changed so that everyone can exercise their rights irrespective of mental capacity, and urged countries not to rely on Ministers of Justice or lawyers at law faculties.

There was an update on progress in different countries with the European Disability Card and European Parking Card. It became clear that there may be considerable differences with regard to eligibility criteria.

24 JUNE:

The EU-X-CT initiative launches recommendations at its Public Stakeholder Conference

The EU-X-CT Initiative, a pan-European public-private partnership aiming to facilitating cross-border access to clinical trials, launched its final practical recommendations at its Public Stakeholder Conference held in Brussels on 24 June. The hybrid event brought together key stakeholders and policy makers who shared insights, experiences and best practices for cross-border access to clinical trials across Europe.

Over the past two years, members of the initiative collected information from multiple stakeholders on the regulatory, ethical, social security and organisational conditions, experiences and best practices for cross-border access to trials in many European countries. The data has been used to populate a publicly accessible EU-X-CT website and to draft recommendations on various aspects of cross-border trials, which were published for public consultation in February 2025. This document was developed in consultation with over 100 members from 32 countries. More information about the initiative and the recommendations can be found here: https://eu-x-ct.eu/

SCIENCE WATCH

21 MAY:

Dementia in the MENA region: Gaps in research, care and data

On 21 May, a team of researchers from Egypt published an article on dementia in the Middle East and North Africa (MENA) region in the journal "npj Dementia". They report that dementia cases in the region are projected to increase by 367% by 2050, making it the fastest-growing region globally. The authors conducted a narrative review of peer-reviewed articles and regional reports from 19 countries, analysing prevalence data, risk factors and health system challenges. They identify major limitations, including inconsistent diagnostic tools, small study sizes and gaps in epidemiological coverage, particularly in conflict-affected areas. The article highlights the need for large-scale, longitudinal studies, standardised cognitive assessments, improved training for healthcare workers and regionally adapted interventions. The authors conclude that dementia must be integrated into national health strategies through evidence-based reforms and regional collaboration.

The article has been published open access and can be read here: https://doi.org/10.1038/s44400-025-00009-z

23 MAY:

Prothena discontinues birtamimab development and announces corporate restructuring

On 23 May, the clinical-stage biotechnology company Prothena Corporation, announced that its Phase III AFFIRM-AL clinical trial of birtamimab did not meet its primary endpoint of improving time to all-cause mortality. The study also failed to show benefit in either of its secondary measures: the 6-minute walk test distance and Short Form-36 version 2 Physical Component Score. Birtamimab was generally safe and well-tolerated, consistent with its established safety profile.

Based on these results, the company will discontinue all development of birtamimab, including stopping the open label extension of the AFFIRM-AL clinical trial. The company is initiating a broad corporate restructuring. A substantial workforce reduction, estimated at approximately 63%, has recently been announced to substantially reduce the operating costs to those necessary to support the remaining wholly owned programs, the obligations to partnered programs and the anticipated business development activities.

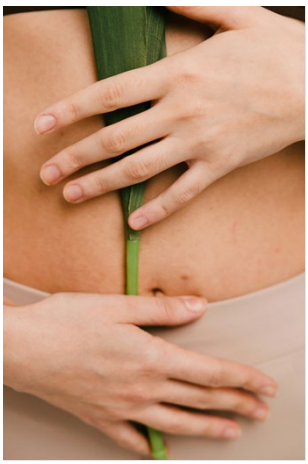
The Phase 3 AFFIRM-AL clinical trial was a global, double-blind and placebo-controlled study that enrolled 207 newly diagnosed people with amyloid light-chain (AL) amyloidosis, which is the most common form of systemic amyloidosis. They received birtamimab or placebo by intravenous infusion monthly and also received concurrent standard of care therapy consisting of a first line regimen that contains a drug called bortezomib. Despite the setback, Prothena is looking forward to the initial data from Phase I ASCENT clinical trials of its PRX012 programme in Alzheimer's disease expected in August and is following partnered programmes being developed for a number of other neurodegenerative diseases.

Press release announcing the results of the AFFIRM-AL clinical trial: https://ir.prothena.com/investors/press-releases/news-details/2025/Prothena-Announces-Phase-3-AFFIRM-AL-Clinical-Trial-for-Birtamimab-in-Patients-with-AL-Amyloidosis-Did-Not-Meet-Primary-Endpoint/default.aspx

Press release outlining Prothena's corporate restructuring plan: https://ir.prothena.com/investors/press-releases/news-details/2025/Prothena-Announces-Corporate-Restructuring/default.aspx

30 MAY:

Compositional and functional gut microbiota alterations in mild cognitive impairment: links to Alzheimer's disease pathology



Recent research suggests that gut and brain health are linked, and this connection goes both ways. Scientists are now exploring how imbalances in the gut microbiome, the community of bacteria living in our digestive system, might play a role in Alzheimer's disease and memory problems.

In a recent study, researchers Kang-Chen Fan, Chen-Ching Lin, Yen-Ling Chiu, Seong-Ho Koh, Yi-Chien Liu and Yi-Fang Chuang looked at the gut bacteria of people with mild cognitive impairment (MCI), which can be an early sign of Alzheimer's. They focused on how changes in specific bacterial species were linked to signs of Alzheimer's, such as brain changes, memory performance and other biological markers.

The study involved 439 people, including 119 with MCI. The researchers compared the types and amounts of gut bacteria with brain scans, blood tests and genetic information related to Alzheimer's disease. What they found:

- They identified 59 bacterial species that were clearly linked to MCI and Alzheimer's markers. Interestingly, some bacteria from the same family had opposite effects. One species, *Akkermansia muciniphila*, was linked to lower levels of amyloid in the brain, which may mean it has a protective effect.
- They also found that certain bacteria were involved in processes like energy use and inflammation in the brain. The way these bacteria interact with each other seems to play a role in brain health.

These results suggest that looking at bacteria at the species level (rather than just the family or genus level) gives a clearer picture of their role in Alzheimer's. The study highlights the gut microbiome as a possible target for future treatments to slow down memory loss and brain decline.

https://link.springer.com/content/pdf/10.1186/s13195-025-01769-9.pdf

1 JUNE:

A recent study suggests that physical activity boosts cognitive performance

There are three mutually exclusive activities people can allocate time to across the 24 hours that days have; sleep, sedentary behaviour (SB) and physical activity (which can be also classified as light physical activity (LPA), moderate physical activity and moderate-to-vigorous physical activity (MVPA)). Although sleep, SB and physical activity are associated with cognitive performance and the risk of dementia, increasing or decreasing the time people spend on one of these behaviours requires taking away the time that they spend on the others, which has also an impact on health outcomes. Previous research has analysed lifestyle behaviours linearly. However, and despite the recognition that all behaviours influence cognitive performance, little is known about the optimal balance of time spent in each one of these (i.e. sleep, SB and MVPA) to maximise cognitive performance.

In a recent study published in the journal of Age and Ageing (Oxford University Press), a team of researchers led by Dr Audrey M. Collins from the AdventHealth Research Institute (Orlando, Florida, US) investigated how different uses of time impact brain health.

The researchers recruited a group of 585 cognitively healthy adults aged 65 to 80 years old. Then, they examined the associations between time spent in sleep, SB, LPA, and MVPA across the 24-hour day, and cognitive performance.

The team found that, on average per day, participants spent around 7.5 hours sleeping, 12.0 hours in SB, 4.0 hours in LPA, and 0.5 hours in MVPA. Higher levels of MVPA (i.e. physical activity that is performed at higher intensities and increases the heart rate and breathing) were related to better cognitive performance. Specifically, MVPA improved how fast the brain thinks, how well we plan and focus and the ability someone has to store information for a short time. This was true regardless of whether time was taken away from sleep, SB or LPA. The opposite was also true, that is, lower levels of MVPA were associated with worse cognitive performance. However, these findings did not extend to episodic memory or to visuospatial function outcomes (i.e. the what, when and where of an event and the ability to navigate through spaces and recognise places, respectively).

Although the results of this study need to be tested longitudinally and experimentally to inform future dementia prevention guidelines, they showed that how people choose to spend their time during the 24-hour day matters and is related to our brain health. Prioritising moderate-to-vigorous physical activity in late adulthood is key and may be beneficial for cognitive performance.

https://academic.oup.com/ageing/article/54/4/afaf072/8106300

3 JUNE:

New Alzheimer's disease drug development pipeline report is out

The latest edition of the annual Alzheimer's disease (AD) drug development pipeline report, led by Dr Jeffrey Cummings, a renowned Alzheimer's clinician-scientist, has been published in Alzheimer's & Dementia: Translational Research & Clinical Interventions. This comprehensive review provides an in-depth analysis of the current state of AD clinical trials and the drugs under investigation.

The paper describes the AD drug development pipeline and provides a comprehensive overview of agents in Phase 1, 2, and 3 clinical trials, reporting the trial characteristics, clinical outcome measures and biomarkers.

As of 1 January 2025, there were 182 active clinical trials assessing 138 drugs in the AD pipeline. This included 48 trials assessing 31 drugs in Phase 3; 86 trials assessing 75 drugs in Phase 2; and 48 trials assessing 45 drugs in Phase 1. Of the 182 trials, 16 were long-term extensions of agents in prior trials.

The AD drug development pipeline is comprised primarily of biological disease-targeted therapies (DTTs). Biomarkers play an important role in current trials to determine trial eligibility and as outcomes of trials. Repurposing is a developmental pathway that plays an important role in the 2025 AD pipeline. Repurposed agents represent a third of the pipeline agents. Additionally, all stages of the AD continuum are represented in current clinical trials.

The 2025 pipeline has more trials and more drugs compared to the 2024 pipeline, which had 164 trials and 127 drugs. There has been a marked increase in Phase 1 activity with nearly twice as many trials (48 vs. 26) and drugs (45 vs. 25) in 2025 compared to 2024.

https://doi.org/10.1002/trc2.70098

19 JUNE:

NICE publishes final guidance recommending against routine NHS use of donanemab and lecanemab

On June 19, the UK's National Institute for Health and Care Excellence (NICE) published its final draft guidance appraising the use of two new disease-modifying therapies for Alzheimer's disease: lecanemab (marketed by Eisai and Biogen) and donanemab (marketed by Eli Lilly). Both drugs have been evaluated for treating adults with mild cognitive impairment (MCI) or mild dementia due to Alzheimer's disease who are heterozygous for apolipoprotein E4 (APOE4) or non-carriers.

In NICE's final guidance documents, which have been published after an extended consultation process, neither lecanemab nor donanemab are recommended for routine use or managed access in the National Health Service (NHS). While clinical trials (Clarity AD for lecanemab and TRAILBLAZER-ALZ for donanemab) showed that both drugs slowed cognitive decline compared to placebo, the benefits were considered modest. For example, lecanemab reduced clinical decline by 27-33% (on the CDR-SB scale of cognition and function) over 18 months, and donanemab by 23-29% (CDR-SB) over 76 weeks. While the NICE committee concluded that both drugs had clinically meaningful effects, the treatment effects were deemed to be small.

Cost-effectiveness was a key barrier. Both drugs require regular hospital infusions (every two weeks for lecanemab and every four weeks for donanemab), frequent MRIs, and intensive monitoring for side effects such as amyloid-related imaging abnormalities. NICE found that the cost per quality-adjusted life year (QALY) for each drug substantially exceeded the thresholds considered acceptable for NHS funding. NICE acknowledged the significant unmet need for disease-modifying therapies in Alzheimer's disease and the considerable burden on patients and carers. However, it concluded that neither treatment currently offers sufficient value for NHS adoption. Further data on long-term benefits and improved cost-effectiveness would be required for reconsideration.

Responding, the Alzheimer's Society expressed deep disappointment at the decision by NICE, calling for long-term investment in the NHS to fundamentally change dementia diagnosis - so healthcare systems are ready to deliver disease-modifying treatments such as lecanemab and donanemab, which rely on an early diagnosis and access to specialist diagnostic tests.

The draft guidance has been sent to consultees for this appraisal, who have 15 working days to consider whether they wish to appeal against it and/or notify NICE of any factual errors. Both Eisai and Eli Lilly have stated their intention to appeal against the decision.

Access the final NICE guidance documents:

Donanemab: https://www.nice.org.uk/guidance/indevelopment/gid-ta11221/documents

Lecanemab: https://www.nice.org.uk/guidance/indevelopment/gid-ta11220

25 JUNE:

Recent study shows how investing in women's brain health improves brain capital

Published in Nature Mental Health on 12 May 2025, a new perspective reveals that advancing women's brain health is a strategic pathway to strengthening global brain care. Led by the Women's Brain Foundation (Basel, Switzerland) with collaborators in Australia and the USA, the article details the persistent brain health gap women face due to decades of underrepresentation in research, biased clinical practices, and limited policy focus on their specific neurological and psychiatric needs.

The authors argue that addressing this gap is key to enhancing brain capital—mental skills, emotional well-being, and social abilities vital for learning, work, and overall productivity. Women's brain health is often overlooked, with neurological and psychiatric conditions frequently misdiagnosed due to differences influenced by hormones, life stages, and social factors. Failure to account for these differences has led to underdiagnosis, misdiagnosis, and inadequate care. Despite living longer, women spend an average of nine more years in poor health—including higher rates of chronic brain and mental health conditions—than men. This creates significant burden not only for personal well-being, care and disease management, but also impacts work, education and daily life.

The authors propose four areas to tackle these disparities:

- Destigmatise psychiatric and neurological disorders across the lifespan, highlighting women's specific challenges.
- De-bias brain health care by creating sex- and gender-informed guidelines and ensuring equitable access to diagnosis and treatment.
- Advance supportive policies, including brain disorder coverage in health plans and life stage–specific screenings and treatments.
- Invest in research through national and regional funding to better understand sex differences in brain health across the lifespan.

Overall, tackling these issues means investing in steps to an earlier diagnosis and better treatment, reducing healthcare

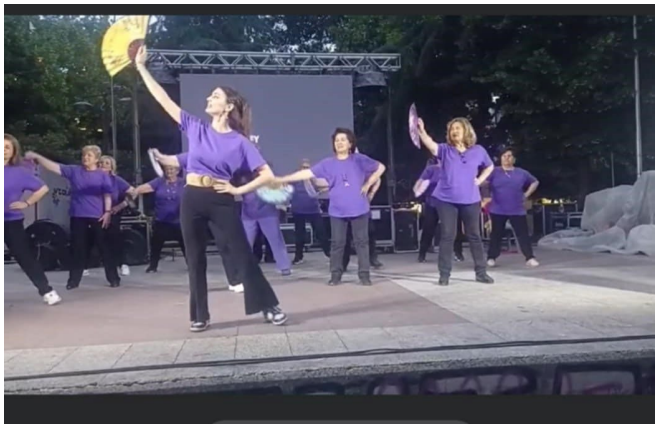
costs. Closing the women's brain health gap isn't just a health matter—it's an economic opportunity with global impact and potentially high returns. The article estimates that addressing sex- and gender-based disparities could generate USD 250 billion (EUR 213 billion) in global GDP gains by 2040. In turn, this would allow societies the opportunity to strengthen their brain capital, support healthier populations, build more inclusive economies, and boost collective resilience.

To learn more about this publication, please visit: https://www.nature.com/articles/s44220-025-00406-6

MEMBERS' NEWS

23 MAY:

Greek association Alzheimer Larissa recently participated in an initiative called "Together as one embrace – Mazi mia agkalia"



On 23 May, Alzheimer Larissa (Greece) participated in the initiative "Together as one embrace – Mazi mia agkalia" of the Prefecture of Larissa with the experiential workshop "Rhythmokinisi". The workshop was presented by 15 women with mild cognitive impairment, aged 60–86 years, from diverse educational backgrounds. After a two-month training with the interdisciplinary team and under the guidance of the choreographer, the 15 performers transformed the following musical pieces into choreographies: "White, red, yellow, blue little boats" and "Marco Polo". They used their bodies, scarves, and fans as props.

The presentation of the "Rhythmokinisi" experiential workshop took place in the central square of the city, among numerous organisations and citizens of all age groups. The 15 performers, with rhythm, coordination, and theatrical expression, impressed both younger and older people, conveying a variety of emotions and messages. Through body language, they expressed messages of courage, self-confidence, extroversion, and brain activation. The audience was thrilled by the original and outstanding performance art of the Hellenic Alzheimer's Association (E.E.N.A.L.) and journalists captured and broadcast the event through digital media. The presentation of "Rhythmokinisi" highlighted hidden skills in people and revealed pathways to psychosomatic balance and quality of life.

26 MAY:

Turkish Alzheimer Association opens its 22nd branch in Tunceli

On 26 May, the Turkish Alzheimer Association officially opened its 22nd branch in Tunceli to raise awareness of Alzheimer's disease and support caregivers. The new branch aims to bring hope to people with dementia and their families in the region.

In line with the association's objectives, the Tunceli branch will focus on the following key activities:

- Supporting diagnosis, treatment, and rehabilitation processes for people with Alzheimer's
- Advocating for the establishment of day care centres, residential care facilities, and long-term care homes
- Creating psychosocial support groups for caregivers
- Organising training programmes for healthcare professionals
- Raising public awareness through brochures, books, media broadcasts, and digital content
- Contributing to academic research by collecting local health data.

The opening ceremony was attended by the President of the Turkish Alzheimer Association, Dilek Şahinöz, Corporate Communications Coordinator, Arzu Kartum, representatives from the Tunceli provincial Directorate of national education and the provincial Directorate of family and social services, healthcare professionals, civil society organisations, and many citizens. The importance of early diagnosis, strengthening care processes, and the continuity of social support were emphasised during the speeches.

Dilek Şahinöz stated: "Today's opening is more than the launch of a branch, it's a powerful step for awareness and community solidarity. Alzheimer's patients and their families in this region now have stronger support mechanisms." The funding members of the Tunceli branch are Hanife Bozkurt,

Hande Polat, and Elif Gündüz Bilge. The branch is chaired by Elif Gündüz Bilge, who shared during her speech: “It all started with just three of us, Hanife, Hande, and myself. And today, we are becoming a big family.”
Initial steps toward establishing the branch began with the “Act for Alzheimer’s” meetings held on 7-8 June 2024, as part of the Alz-Bilinç project, supported by the Sabancı Foundation. The events attracted students, teachers, health officials, and the Tunceli Governorate’s protocol members.
The initiative was led by Prof. Dr Başar Bilgiç, Chair of the Association’s Medical Board. Following discussions with the Tunceli Foundation for education and health on 20 January 2025, a medical screening was conducted by a team from Istanbul Medical Faculty on 15 April 2025. The Tunceli Branch aims to bring a more structured and sustainable approach to Alzheimer-related services in the region. Its goal is to build community-based support systems in collaboration with healthcare professionals, volunteers, and caregivers.

15-16 JUNE:

American students visit Alzheimer Hellas units in Greece as part of an educational initiative

For the past four years, students from a university in Florida (USA) have been visiting Thessaloniki (Greece) as part of an educational initiative to explore the work and facilities of the Greek Association of Alzheimer’s Disease and Related Disorders (Alzheimer Hellas). These visits have included guided tours to Alzheimer Hellas’ units such as its day care centres “Agia Eleni”, “Agios Ioannis”, and the “Panagia Glykophilousa” residential facility. During their visit this year, on 15-16 June, the students were introduced to the association’s operational model, therapeutic programme, and holistic approach to dementia care.
Staff members provided detailed explanations of the cognitive interventions offered, as well as the strategies used in managing and supporting patients with Alzheimer’s disease. At the end of each visit, students were asked to create a presentation reflecting on their experience and to offer suggestions or ideas for future improvements. Overall, the feedback from the students was overwhelmingly positive and underlined that Alzheimer Hellas was the best of the five NGOs they had visited. They expressed great interest in the organisation’s methodology, the professionalism and dedication of the staff, not to mention the warm hospitality. These annual visits serve as a valuable opportunity for cross-cultural exchange and the promotion of best practices in dementia care.

19 JUNE:

Alzheimer Switzerland has launched a new community platform named “alzpeer”

Alzheimer Switzerland has launched alzpeer, the first of its kind digital community platform in Switzerland for people with dementia and their loved ones, which combines personal exchange among peers with expert knowledge, thus offering support throughout the entire course of the disease
Alzpeer empowers those affected to share lived experiences, find encouragement, and strengthen self-efficacy. It is available 24/7 in three official languages (German, French and Italian). It bridges the real-world offers in the 21 regional sections of Alzheimer Switzerland with the online option. The platform can serve for getting in touch as well as staying in contact over time and complements the services.
Key features include:

- Peer programme: One-on-one conversations with others who share similar experiences
- Open forum: A space to ask questions, share stories anonymously, or simply read along
- Themed groups: Local or online groups for specific topics or additional languages
- Resources: Community recommendations on tools, books, and more
- Podcast “Chopfsach – nachgefragt”: A new eight-episode series with expert insights and lived experiences, available on major podcast platforms and on www.alz.ch/podcast

The platform is monitored by Alzheimer Switzerland to prevent misuse. Visit community.alz.ch to learn more and join the conversation.

19 JUNE:

The Alzheimer Society of Ireland participated in key events throughout June recognising the vital role of family carers

The Alzheimer Society of Ireland (The ASI) had the privilege of participating in key events throughout June, recognising the vital role of family carers and the broader community's commitment to supporting people living with dementia. Team ASI was honoured to be invited by President Michael D. Higgins to the community Garden Party at Áras an Uachtaráin (the official residence and principal workplace of the President of Ireland). This annual event celebrates the incredible work of individuals and organisations contributing to community projects and initiatives that align with the values of the Irish presidency. It was a wonderful opportunity for the team to personally thank President Higgins and his wife for their continued support, as well as to connect with other community groups across Ireland.

Additionally, to mark National Carers Week (9-16 June), which celebrates the invaluable role of family carers across Ireland, Lord Mayor of Dublin Emma Blain hosted a special afternoon tea at the Mansion House in Dublin (the official residence of the Lord Mayor of Dublin). The event honoured members of the Dementia Carers Campaign Network (DCCN) and the Dementia Research Advisory Team (DRAT), both of which are supported by The ASI. This occasion celebrated the dedication of family carers, who play an essential role in the care and support of people living with dementia. Staff from The ASI also attended the event.

The **DCCN** is a group of carers and former carers who advocate for improved services, support, and policies for those caring for people with dementia.

The **DRAT** consists of people living with dementia and family carers who collaborate with the research community to ensure the lived experience of dementia remains central to the research process.

Led by **Carers Alliance Ireland**, National Carers Week recognises the invaluable work of family carers across Ireland. The ASI has been a proud partner of this initiative for over a decade.

Pictured - Irish President Michael D. Higgins with Carol Beattie, Chair of the Cavan Branch of The Alzheimer Society of Ireland (The ASI), and Maureen Mannion, Dementia Adviser at The ASI, at the Community Garden Party at Áras an Uachtaráin.

Pictured – Members of the Dementia Carers Campaign Network (DCCN), Dementia Research Advisory Team (DRAT), and staff from The Alzheimer Society of Ireland at the Afternoon Tea hosted by Lord Mayor of Dublin, Emma Blain, in celebration of National Carers Week 2025.

19-21 JUNE:

Alzheimer Bulgaria Association participates in a public event on ageing at Sofia University

On 19-21 June, at an international workshop and a public outreach event titled “Stories of ageing and care”, held at Sofia University “St. Kliment Ohridski” (SU), Alzheimer Bulgaria participated as a key contributor to the evolving public conversation on ageing in Bulgaria. The events were organised by Prof. Galina Goncharova, coordinator of the Sofia project team, and brought together scholars, psychologists (Dr Jenya Milusheva, representing the association), writers, and undergraduate students in cultural studies to reflect on personal and collective experiences of ageing and caregiving.

Discussions were grounded in biographical interviews conducted with older adults, caregivers, and professionals within the framework of the international project SEEAGE (“Transforming anxieties of ageing in Southeastern Europe: Political, social, and cultural narratives of demographic change”), funded by the Volkswagen Foundation. The project unites scholars from Albania, Austria, Bulgaria, Germany, Hungary, Romania and Serbia combining area studies and ageing studies to transform the dominant narratives of ageing, shifting away from catastrophic representations towards more inclusive, empowering, and diverse understandings (transforming-anxieties.ios-regensburg.de).

Guest lectures by Prof. Iliya Iliev (SU) and Prof. Daniela Koleva (Bulgarian Academy of Sciences, SU) explored oral history and anthropological approaches to ageing and care under socialism and post socialism. Prof. Desislava Vankova (Medical University of Varna) introduced the method of narrative medicine as a tool for reframing care and healing in older age. Maya Marinova from Alzheimer Bulgaria, presented the organisation’s mission and long-standing dedication to supporting people living with dementia and their families.

The outreach event was formally opened by Prof. Sonya Karabelyova, Dean of the faculty of Philosophy at Sofia University, who encouraged participants to envision and create frameworks for dignified ageing. Prof. Ulf Brunnbauer, project leader and Executive Director of the Institute for East and Southeast European Studies (IOS) in Regensburg, also delivered introductory remarks emphasising the urgent need for research and public engagement to reshape societal attitudes toward ageing, a goal the SEEAGE project aims to meet.

20 JUNE:

Info-Zenter Demenz launches “VergiessMechNet” – The Luxembourg edition of a “forget me not” campaign to raise awareness and shine a positive light on dementia

Vergiess MechNet
Zesummen ass Demenz méi liicht

Similar to existing initiatives throughout the world, the Info-Zenter Demenz in Luxembourg has launched “VergiessMechNet”, a fresh awareness campaign aimed at reframing public perceptions of dementia and encouraging people with dementia. The heart of the campaign centres on positivity, dignity, and empathy — encouraging society not to forget those confronting memory challenges.

The campaign features three interconnected components:

1. **A website (www.vergiessmechnet.lu) and newsletter** including uplifting stories, information on upcoming national events, tips for maintaining connection and insights from experts in German and French. To subscribe send an email to info@demenz.lu

2. **Instagram presence**
Info-Zenter Demenz's new Instagram channel brings the campaign to life through visuals, personal stories, and practical suggestions. Follow and engage with the community here: https://www.instagram.com/infozenter_demenz/

3. **Stickers**
Beautifully designed stickers featuring the forget-me-not flower are available free of charge at the Info-Zenter Demenz office (www.demenz.lu). These serve both as a sign of solidarity and conversation starters to challenge the stigma surrounding dementia.

Residents of Luxembourg and abroad are warmly invited to subscribe to the newsletter, follow the campaign on Instagram, and collect a sticker to show solidarity and help amplify a positive vision of living with dementia. For further information and feedback, contact info@demenz.lu

20 JUNE:

The Alzheimer Society of Ireland welcomes announcement of National Dementia Registry

The Alzheimer Society of Ireland (The ASI) welcomed the announcement by Minister of State for Older People and Housing, Kieran O'Donnell TD, to move forward with the implementation of a National Dementia Registry for Ireland. A National Dementia Registry is critical to mapping available services, identifying key needs and ensuring equitable access to care, and will be essential in guiding all aspects of dementia service provision and future planning.

For several years, The ASI has advocated for the creation of such a registry, recognising that being able to quantify the number of people diagnosed with dementia in Ireland and their geographical locations will enable a more responsive and effective allocation of resources and services. This significant announcement represents an important step forward in improving access to vital services and supports for people living with dementia in Ireland. The Minister's proactive engagement and interest in this issue are very encouraging.

Commenting on the announcement, The ASI CEO Andy Heffernan (pictured) said: "I am very encouraged by the announcement by Minister O'Donnell to commence the National Dementia Registry. The development of a registry is essential to support the development, operation and quality of dementia-related health and social care services. In 2016, The ASI commissioned a study establishing the feasibility of a National Dementia Registry. A report published by The HSE in 2021 outlined a National Dementia Registry model, the required minimum dataset, costs and recommendations. The ability to quantify the number of people diagnosed with dementia in Ireland and where they live will facilitate responsive and appropriate allocation of resources and service planning. A National Dementia Registry will underpin all aspects of dementia service provision and planning and ensure an equitable approach. The new registry will assist in addressing service gaps and help to plan services for the increasing number of people with dementia across Ireland.

The ASI has lobbied for several years on this issue, and it is included as a key commitment in the programme for Government. The ASI is very encouraged by the Minister's engagement and interest in progressing this area."

LIVING WITH DEMENTIA

4 JUNE:

Pia Knudsen, former member of the European Working Group of People with Dementia, writes about how her service dog Charlie has changed her life

Hi, my name is Pia, I'm 62 years old, from Aarhus, Denmark. I used to live and work as a teacher at a folk high school in western Jutland. My life was very social, filled with great colleagues and young people. I loved my life and thought it would last for many years to come, but when I was 56, six years ago, I was diagnosed with dementia, and I lost everything. I lost my beloved job, my home, and my partner.

I moved back to Aarhus, where I'm originally from, but because of my new life situation, I had far too many hours at home, alone. So, I ended up getting a dog to ease the loneliness. His name is Charlie. He's a curly-haired guy, full of energy and always in a good mood, and he's now become my life companion. It wasn't easy at first. I knew nothing about having a dog, and Charlie had a hard time being around both people and other dogs, so my life narrowed in to contain mostly me and Charlie.

Then one day, my neighbour Ulla knocked on my door and told me that people with Alzheimer's dementia could now get their dog trained to become a service dog. We quickly submitted an application, and just two weeks later there was another knock at the door. It was Trine, who said: "Are you ready to train your dog?" So began a year and a half of intensive training, for both me and Charlie, that changed our lives.

Charlie liked to be in charge, but he's no longer allowed to call the shots. Now we have a shared language and a partnership that allows Charlie to go everywhere with me. We can even have guests over and enjoy it. When I put on his vest and say the command "stay close", he knows he's at work. When I click my tongue, he sits and stays put, for example, when we have visitors. As a certified service dog, Charlie is allowed to go everywhere with me: into stores, cinemas, on planes, trains, to meetings with politicians, and everywhere else you can imagine. This means that Charlie and I can experience and explore the world together, and that his little heart is always close to mine, reminding me that I am never alone.

NEW PUBLICATIONS AND RESOURCES

23 MAY:

Heike von Lützau-Hohlbein takes part in German-language podcast series "Damit die Guten gewinnen" for a special episode called "How do we change the way we deal with dementia?"

On 23 May, a special episode of German-language podcast "Damit Die Guten Gewinnen" ("So that the good guys win") called "How do we change the way we deal with dementia?" was published on YouTube and Spotify. In an interview with podcast host Thomas Mühlnickel, Heike von Lützau-Hohlbein, founder and former longstanding Chairperson of the German Alzheimer Association (Deutsche Alzheimer Gesellschaft, DAlzG), former Chairperson of Alzheimer Europe and current Chairperson of the Alzheimer Europe Foundation, spoke

about how dementia should be handled with dignity for those living with the condition, their relatives and society as a whole, providing deep insights into her work and personal experiences. She argues in favour of a dementia-friendly society - with more knowledge, more empathy and more courage to remove the taboo. She talks about humour as a survival strategy, about systemic weaknesses in care and politics - and

about her vision of a society in which growing old does not mean retreat, but participation until the end.
YouTube:
https://www.youtube.com/watch?v=RnvLZ79qf1o&list=PLV0xd6s5ndLQPJDSfdZY0X97A9z0jr0h6&index=3

Spotify:

https://open.spotify.com/show/1dLFdwUDlNQNag44RAibgx

4 JUNE:

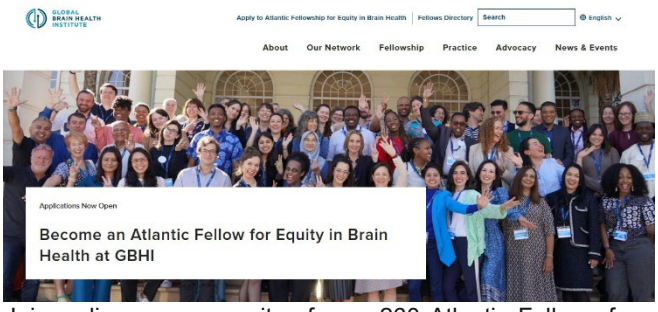
TouchNEUROLOGY publishes new podcast "How are biomarkers shaping Alzheimer's disease, and what's next?"

The number of people aged 65 and older living with Alzheimer's disease in the US is expected to double by 2050. In the latest episode of touchNEUROLOGY's "Visionary Voices" podcast, Dr Anthony Caggiano, Chief Medical Officer at Cognition Therapeutics, explores how biomarkers are transforming our understanding of Alzheimer's disease, from diagnosis and disease progression to drug development and the future of clinical care.
Check out the podcast, here: https://touchneurology.com/podcast/how-are-biomarkers-shaping-alzheimers-disease-and-whats-next/

EDUCATION

3 JUNE:

Become an Atlantic Fellow for Equity in Brain Health at GBHI - Applications now open!



Join a diverse community of over 260 Atlantic Fellows from over 60 countries worldwide dedicated to protecting the world's ageing populations from threats to brain health. The Atlantic Fellows for Equity in Brain Health programme at the Global Brain Health Institute (GBHI) provides innovative training, networking, and support to emerging leaders focused on improving brain health and reducing the impact of dementia in their local communities and on a global scale. It is one of seven global Atlantic Fellows programmes to promote fairer, healthier, and more inclusive societies.
The programme is for professionals from a wide range of disciplines, including the arts, sciences, economics, policy, medicine, journalism, community-based practice and much more.
The deadline to apply is 19 September 2025.
Find out more and apply, via: https://www.gbhi.org/apply?trk=public_post_reshare-text

JOB OPPORTUNITIES

17 JUNE:

We are hiring! We need a Public Involvement Officer (full-time, permanent contract)

Alzheimer Europe (AE) is looking to immediately fill the following Luxembourg-based position: Public Involvement Officer (m/f/x) (full time, permanent)

As the Public Involvement Officer, you will:

- Become an active member of the organisation's Public Involvement team and support all Public Involvement activities of Alzheimer Europe
- Collaborate with and support the European Working Group of People with Dementia and the European Dementia Carers Working Group and their contributions to AE's work and involvement in research projects
- Support the development of the Public Involvement Pool and of new consultation methods to include the views of people at risk of developing dementia
- Help with the writing of dementia-inclusive publications
- Contribute to scientific publications on Public Involvement in European dementia research
- Help with the dissemination of EU-funded research projects
- Support the communication of medical and research developments to the wider dementia community and

the general public via the organisation's newsletter, magazine and website
- Contribute towards literature reviews and discussions with relevant stakeholders about the ethical and social implications of topics of relevance to people with dementia and carers in the context of research projects

You should have the following experience and qualities:

- Good people skills and the ability to work and communicate with people with dementia and their carers
- Completed university education in a scientific field (such as dementia studies, psychology, sociology, anthropology, philosophy or similar)
- Experience in a similar position (background in Public Involvement would be considered an advantage)
- A good understanding of dementia research and the contributions to research of people with dementia and their carers
- A perfect knowledge of English (knowledge of other European languages would be a plus)
- Excellent writing and communication skills, including communicating scientific concepts in easy-to-understand language
- Experience of social media
- Proficiency in Microsoft Office applications
- A keen sense of responsibility, initiative and ability to work in a small team
- Willingness to travel abroad and present at project meetings, scientific conferences and other networking opportunities.

Please apply by sending your CV, together with a cover letter (both documents in English), **by 30 June 2025**, to: Alzheimer Europe a.s.b.l., 5B, Heienhaff, L-1736 Senningerberg or via e-mail to info@alzheimer-europe.org
Find more information about salaries and careers at Alzheimer Europe, in the full job advert on our website: https://www.alzheimer-europe.org/news/we-are-hiring-we-need-public-involvement-officer-full-time-permanent-contract-interested-apply?language_content_entity=en

AE CALENDAR 2025

DATE	MEETING	AE REPRESENTATIVE
1 July	EU4Health policy workshop on "Informed consent and healthcare professionals' competences, and cost-benefit analysis on accessibility"	Angela
2 July	Annual training for patients, consumers and healthcare professionals (Amsterdam, Netherlands)	Sarah
2 July	Welcome meeting for new members of the European Dementia Carers Working Group	Public Involvement Team
3 July	Meeting of the EMA Network Advisory Group on Raw Data	Angela
10 July	"Science of EPND" webinar, organised by the EPND project	Angela
15 July	Alzheimer's Association Academy on "Awareness Campaigns"	Alzheimer Europe staff and members
26 July	ISTAART Immersives workshop on Building capacity for Collaborations Among Researchers and People with Lived Experience of Dementia: Global Perspectives	Sarah
27-31 July	Alzheimer Association International Conference AAIC 2025 (Toronto, Canada)	Sarah, Jean

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
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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