

HIGHLIGHTS

- Dementia Day brings together policymakers, Alzheimer’s associations and people with lived experience 2
- We host a lunch debate on dementia research 4
- Anti-Stigma Award winners are announced 6
- European Alzheimer’s Alliance gains two new members and Sirpa Pietikäinen MEP becomes a new Co-Chair 12

CONTENTS

- WELCOME 1
- SPOTLIGHT ON OUR 2024 EU ELECTIONS CAMPAIGN..... 2
- ALZHEIMER EUROPE 3
- SPONSORS OF THE MONTH 7
- AE NETWORKING 7
- EU PROJECTS 9
- MEMBERS OF THE EUROPEAN ALZHEIMER’S ALLIANCE 12
- EUROPEAN ALZHEIMER’S ALLIANCE 12
- EU DEVELOPMENTS..... 13
- POLICY WATCH..... 15
- SCIENCE WATCH..... 16
- MEMBERS’ NEWS 18
- DEMENTIA IN SOCIETY 21
- LIVING WITH DEMENTIA..... 22
- PUBLICATIONS AND RESOURCES..... 27
- AE CALENDAR 2024..... 27
- CONFERENCES 2025..... 27

WELCOME



I would like to wish you all a Happy New Year 2025. Ours begins with the excit-

ing news that we are hiring! Three new positions have opened up at Alzheimer Europe, all full-time, permanent and on-site in Luxembourg. We are seeking a Communications Officer, a Conference Coordinator and a Finance Officer. If you are interested, please check our website for details and apply by 31 January!

This newsletter is the last one of 2024 and we begin with news about our final meetings of the year, which took place in Brussels and included a Board meeting, a Company Round Table with sponsors, a Public Affairs meeting and a capacity-building workshop for members, as well as consultations with the European Working Group of People with Dementia and the European Dementia Carers Working Group.

10 December marked the first edition of “European Parliament Dementia Day”, which brought together Members of the European Parliament (MEPs) with representatives of Alzheimer’s associations from across Europe, as well as people with lived experience of dementia. This special day was the culmination of our “Dementia Needs EU” campaign which we launched at the start of 2024 and which was based on the principles of the Helsinki Manifesto. One of the three branches of the campaign was dedicated to ensuring we continue our work with MEPs, and following the European elections, we were proud

Jean Georges, Executive Director

to relaunch the European Alzheimer’s Alliance (EAA) with 75 members. Since the start of the new parliamentary term, seven more have joined, meaning we now have 82 MEPs in the EAA. Most recently, we welcomed Sirpa Pietikäinen MEP (EPP, Finland) who re-joined and who has accepted the position of Co-Chair of the group. We also welcomed new member Liudas Mažylis (EPP, Lithuania).

A series of meetings was held in and around the European Parliament in Brussels on Dementia Day, including a Lunch Debate on the topic of dementia research as a European priority, hosted by Tilly Metz MEP (Luxembourg, Greens/European Free Alliance), Co-Chair of the EAA, and a special award ceremony in the evening, where Alzheimer Europe and the Alzheimer Europe Foundation announced the winner and the runners-up of their third annual Anti-Stigma Award. These awards went to three European journalists for news stories or documentaries addressing the stigma attached to dementia. You can read more in our special article about the Award, in the Alzheimer Europe section of this newsletter.

Reflecting on 2024 and on our Dementia Needs EU campaign, I am truly delighted with the results and would like to thank and congratulate my colleagues who were involved in this campaign, as well as our members for all their hard work ensuring the campaign was such a success. We are excited to work with the EAA during the course of this new European Parliament and are looking forward to another successful year ahead. I wish you all every success in 2025, also!

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 Mártová (Czech Republic), Mary-Frances Morris (United Kingdom), 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), Katariina Suonu (Finland), Jochen René Thyrian (Germany).

Alzheimer Europe Staff

Executive Director: Jean Georges; Conference Coordinator: Gwladys Guilory; Executive Assistant: Tara Klassen; Events Coordinator: Cristina Pencea; Finance Officer: Stefanie Peulen; Director for Communication and Policy: Kate Boor Ellis; Policy Officer: Owen Miller; Communications Assistant: Grazia Tomasini; Director for Research: Angela Bradshaw; Project Communications Officer: Christophe Bintener; Project Officers: 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.

SPOTLIGHT ON OUR 2024 EU ELECTIONS CAMPAIGN

10 DECEMBER:

European Parliament Dementia Day brings together policymakers, Alzheimer’s associations and people with lived experience of dementia



On 10 December 2024, the first edition of “European Parliament Dementia Day” took place in Brussels, organised by Alzheimer Europe and bringing together Members of the European Parliament (MEPs) with representatives of Alzheimer’s associations from across Europe, as well as people with lived experience of dementia.

Dementia Day was the culmination of the European Election Campaign 2024 “Dementia Needs EU” which was launched by Alzheimer Europe and its national member associations at the start of the year and which was based on the principles of the [Helsinki Manifesto](#). The campaign saw 83 European and national organisations endorse the Helsinki Manifesto, over 7,500 individuals sign Alzheimer Europe’s Call to Action, and 79 MEPs join the European Alzheimer’s Alliance (EAA).

On this important day, representatives of national Alzheimer’s associations, members of the European Working Group of People with Dementia (EWGPWD) and European Dementia Carers Working Group (EDCWG) had the opportunity to talk to their MEPs, to give an update on the context of dementia at a national level and present Alzheimer Europe’s call to see dementia recognised as a priority in the European Union health and research programmes, as well as in European social and disability policies.

A series of meetings was held in and around the Parliament in Brussels on Dementia Day, including a European Parliament Lunch Debate on the topic of dementia research as a European priority, hosted by Tilly Metz MEP (Luxembourg, Greens/European Free Alliance), Co-Chair of the EAA, and a special award ceremony in the evening, where Alzheimer Europe and the Alzheimer Europe Foundation announced the winner and the runners-up of their third annual [Anti-Stigma Award](#). These awards went to three European journalists for news stories or documentaries addressing the stigma attached to dementia. You can read more in our special article about the Award, in the Alzheimer Europe section of this newsletter.

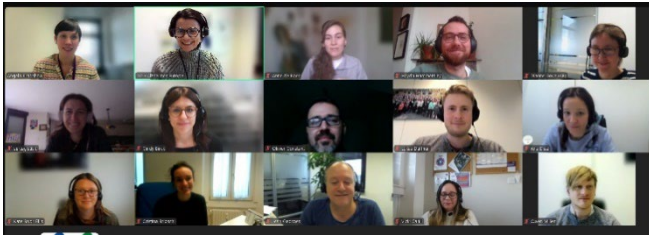
The various meetings that took place on European Parliament Dementia Day were attended by MEPs and their representatives hailing from Austria, Belgium, Croatia, Czechia, Greece, Hungary, Ireland, Luxembourg, Slovenia and Spain and we would like to thank each and every one of the MEPs involved for supporting our work and for taking time out of their busy schedules to attend and to meet with their national Alzheimer’s associations, as well as people with lived experience of dementia. They are:

- Nina Carberry MEP (EPP, Ireland), Co-Chair of the EAA
- Ondřej Dostál MEP (NI, Czechia), member of the EAA
- Romana Jerković MEP (S&D, Croatia), Co-Chair of the EAA
- Billy Kelleher MEP (Renew, Ireland), member of the EAA
- András Tivadar Kulja MEP (EPP, Hungary), member of the EAA
- Tilly Metz MEP (Greens/EFA, Luxembourg), Co-Chair of the EAA
- Ciaran Mulloly MEP (Renew, Ireland)
- Elena Nevado del Campo MEP (EPP, Spain), represented
- Nikos Papandreou MEP (S&D, Greece), member of the EAA
- Vladimir Prebilič MEP (Greens/EFA, Slovenia), member of the EAA
- Lena Schilling MEP (Greens/EFA, Austria), represented
- Hilde Vautmans MEP (Renew, Belgium), Co-Chair of the EAA
- Isabel Wiseler-Lima MEP (EPP, Luxembourg), member of the EAA
- Tomáš Zdechovský, MEP (EPP, Czechia), member of the EAA.

ALZHEIMER EUROPE

3 DECEMBER:

Alzheimer Europe holds its final Academy meeting of 2024 about Independent living and dementia



On 3 December 2024, Alzheimer Europe held its final academy workshop of 2024, welcoming representatives from 13 countries to discuss the status of independent living in Europe for people with dementia.

Hayden Hammersley, social policy coordinator from the European Disability Forum, presented the results of EDF's recent publication about transitioning from institutions to community-based independent living. He shared the recommendations that came from their work aimed at supporting individuals with disabilities to remain independent and maintain control over their own lives as much as possible, noting that their research determined that in some European countries, the rate of institutionalisation has risen in the last 10 years and the goal is to reverse this trend.

Anne de Boer, Advocacy Officer at Alzheimer Nederlands then presented their resource for dementia-inclusive housing and environments which focuses on preventative actions such as developing a stronger connection between formal and informal care situations within dementia-friendly communities, which are designed for all ages and to maximize the possibility of remaining in the community as long as possible.

Vicki Cahill, Policy and Public Affairs Officer at Alzheimer Scotland then provided insights from their Commission on the Future of Long Term Care. She provided an overview of the findings and recommendations from their report which was published in May 2024, noting that when people's needs increase, their options for long term care decrease, leading to a loss of choice and autonomy as their condition worsens, highlighting the importance of supporting informal carers through policy to be able to continue providing necessary care in the face of increasing shortage of formal care providers.

Finally, Owen Miller provided an overview of Alzheimer Europe's 2024 Yearbook on independent living which will be published in January 2025.

9 DECEMBER:

Alzheimer Europe Board meets in Brussels

The final Alzheimer Europe Board Meeting for 2024 took place in Brussels on 9 December. Angela Bradshaw, Director for Research, Dianne Gove, Director for Public Involvement and Ethics, Kate Boor Ellis, Director for Communication and Policy, and Ana Diaz, Public Involvement Lead, were in attendance to provide updates on meetings and projects that the teams have been involved in and are working on, updates on the Gender Equality Plan, outcomes from the 34th Alzheimer Europe Conference in Geneva and the upcoming Dementia in Europe Yearbook 2024 on the topic of independent living and housing.

Jean Georges, Executive Director, shared the encouraging amount of involvement in the 2024-2029 European Alzheimer's Alliance, which now includes 79 Members of the European Parliament (MEPs) from 21 countries. He also gave an overview of the operational finances which continue to see a surplus, with new projects beginning in 2025, and the plan to increase staff numbers to accommodate the increasing workload. He provided an update on the schedule, programme and topics for the 35th Alzheimer Europe Conference in Bologna (Italy) and the Board approved the conference budget.

The 2025 Work Plan budget was adopted by the Board, along with the proposed staff changes. Finally, the discussion about the 36th Alzheimer Europe Conference in 2026 is still underway with a decision on location to be made soon.

10 DECEMBER:

Alzheimer Europe organises a Company Round Table meeting in Brussels

On 10 December, Alzheimer Europe (AE) hosted a Company Round Table meeting in Brussels. The meeting was a hybrid event, with many participants attending in person and some joining remotely. The meeting brought together company representatives from AVP,



Alzheon, Biogen, Danone (Nutricia), Eisai, Johnson & Johnson and Roche, alongside AE staff and members from national Alzheimer organisations. During the meeting, four speakers provided updates on recent policy and research developments.

First, Cindy Birck, AE Project Officer, gave an update on our Clinical Trials Watch, an online database providing accessible and up-to-date information on clinical trials that are investigating drugs for Alzheimer’s disease and/or dementia. Next, Owen Miller, AE Project Officer, shared some updates on EU policy developments, European Parliament elections and AE European Parliament election campaign, noting that 83 organisations signed the Helsinki Manifesto.

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. The meeting was moderated by Jean Georges, AE Executive Director who also gave the final presentation of the meeting, informing participants about Alzheimer Europe’s activities in 2024. Looking ahead, he also shared plans for 2025, highlighting upcoming meetings aligned with AE’s strategic objectives.

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 1 April 2025.

10 DECEMBER:

Alzheimer Europe hosts a lunch debate on dementia research in the European Parliament in Brussels



On 10 December, Alzheimer Europe held a lunch debate in the European Parliament in Brussels (Belgium), entitled “Dementia as a research priority” 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 approximately 115 people, including nine Members of the European Parliament (MEPs).

Tilly Metz MEP (Luxembourg), Co-Chair of the European Alzheimer’s Alliance (EAA) hosted the session, welcoming participants and speakers, noting the importance of dementia research, as well as highlighting that in the new Parliament there

are already 79 MEPs from 21 countries who have joined the EAA. She shared that by 2025, 9.1 million people will be living with dementia in Europe and that by 2050, this number is estimated to reach 14.3 million. Furthermore, she noted:

- Recent studies have shown that up to 45% cases of dementia could potentially be prevented by focusing on key modifiable risk factors
- The development of biomarkers has made the detection and diagnosis of Alzheimer’s disease and other types of dementia easier
- Big data and artificial intelligence are supporting prediction and helping identify people at risk of developing brain diseases
- The European Medicines Agency recently announced its revised opinion recommending the authorisation of lecanemab.

Wiesje van der Flier, Director, Alzheimer Centre Amsterdam presented on progress in the prevention, diagnosis and treatment of Alzheimer’s disease (AD) and other types of dementia. She highlighted the need for a paradigm shift, reflecting the understanding of AD and the reality that the changes associated with the disease start many years before symptoms emerge. As such, she emphasised the vital importance of prevention, lifestyle and disease-modifying therapies, citing the risk factors and estimates from the [2024 Lancet Commission](#). She further noted that dementia research carried out through public-private partnerships and the projects funded under these have allowed for significant progress to be made, including in the use of biomarkers and tests for prediction, diagnosis, prognosis and monitoring, as well as tailored prevention strategies and the use of e-tools. She also noted that recent approvals for disease-modifying therapies represented a turning point but that the European Union (EU) should play a greater role in research in this area or risk being “left behind”.

Niklas Blomberg, Executive Director, Innovative Health Initiative (IHI), provided an overview of key research initiatives and projects funded through the Innovative Medicines Initiative (IMI) and the IHI. He noted that the specific purpose of public-private partnerships such as the IMI and IHI is to deliver effective health innovations that cover the entire spectrum of care, particularly in areas where there is an unmet public health need. Additionally, these partnerships are intended to turn health research and innovations into tangible benefits for patients, as well as making Europe’s health industries globally competitive.

He highlighted a range of projects related to dementia and Alzheimer’s disease, funded by these public-private partnerships, including [AD-RIDDLE](#), [PROMINENT](#), [RADAR-AD](#), [EPND](#) and [PREDICTOM](#), showing how each project addresses an important aspect of innovation for the detection, diagnosis and treatment of dementia.

Catherine Berens, Deputy Head of Unit D1, DG RTD, European Commission, discussed the future of dementia research in EU research programmes, highlighting that EUR 400 million

has been invested in dementia research under Horizon Europe, whilst noting that many unmet medical needs remain. She outlined the forthcoming “European Partnership on Brain Health” which is expected to commence in 2026, with a duration of ten years. The aim of the partnership will be to accelerate the delivery of preventive, diagnostic, therapeutic and care solutions to foster brain health in citizens and patients, as well as aligning efforts and funding from Member States/ Associated Countries in the brain health research area. Details for the partnership are under discussion as part of a dedicated Coordination and Support Action which commenced in November 2023, and which will run for two years. It was noted that work in this area ties into the broader work of the EU research agenda, as well as aligning with the Mission Letters and strategic priorities recently set out under the new College of Commissioners.

Following the presentations, a number of MEPs contributed to the session including:

- Romana Jerković (Croatia)
- Ondřej Dostál (Czechia)
- Ciaran Mullooly (Ireland)
- Nikos Papandreou (Greece)
- Vladimir Prebilič (Slovenia)
- Isabel Wiseler-Lima (Luxembourg)
- Tomáš Zdechovský (Czechia).

Michał Szczerba MEP (Poland) was also in attendance at the lunch debate.

Alzheimer Europe would like to thank Tilly Metz MEP and her office for all their support and hard work in organising and hosting this great event. A big thank you, also, to all of the speakers for their excellent presentations and to the MEPs who took part in the discussions, as well as to everyone who joined us at the Parliament. This lunch debate took part as part of our European Parliament Dementia Day, during which a number of activities and meetings were held to prioritise dementia at a European level. Read more about these activities, here:

<https://www.alzheimer-europe.org/news/european-parliament-dementia-day-brings-together-policymakers-alzheimers-associations-and>

10 DECEMBER:

18 countries represented at Alzheimer Europe’s final Public Affairs meeting of the year



Alzheimer Europe welcomed delegates from 18 member organisations to its final public affairs meeting of 2024, which took place in Brussels on 10 December and looked at advances in detection and diagnosis and ways to promote dementia research participation. Nicolas Villain from the Sorbonne University in Paris (France) discussed the International Working Group recommendations for biomarker-based diagnosis of Alzheimer’s disease (AD), detailing their new definition of AD as a cognitive-biological construct, and how that differs from the biological only definition given by the Alzheimer’s Association and National Association of Ageing in the US, which leads to a different approach to diagnosing AD.

Francesca Mangialasche of Karolinska Institutet (Sweden) continued with a presentation of the AD-RIDDLE research project’s potential for timely diagnosis and prevention, deploying the FINGER model to address prevention as well as looking at disease-modifying treatments. She pointed out the need for tailored interventions, noting that a one-size-fits-all solution would not work, and shared about the modular toolbox they have developed that can be applied as needed for the individual. She spoke about the digital engagement portal and asked the delegates whether they thought it would be useful in their countries.

After feedback from the delegates, Angela Bradshaw, Director for Research at Alzheimer Europe, presented the current status of Horizon 2020 research which has 222 research projects involving partners in 30 countries. She noted that nine EU countries are involved in 78% of the projects and stressed the need for data sharing in dementia research. Then, Lukas Duffner, Project Officer at Alzheimer Europe, presented the objectives for and structure and timing of the research he is conducting on European perspectives on research participation and data sharing. He asked delegates for their input for translations of the study into their local languages, to support piloting and disseminating the poll, and to share what they would like to see reflected in the study.

10 DECEMBER:

Swiss journalist Magnus Renggli wins Alzheimer Europe's Anti-Stigma Award at a special ceremony in Brussels on "Dementia Day"



On 10 December, at a special award ceremony as part of Alzheimer Europe's "European Parliament Dementia Day", Swiss journalist Magnus Renggli (pictured, left) was announced as the winner of the 2024 Anti-Stigma-Award for his documentary film *Alzheimer mit 56 – Das Familienleben nach der Diagnose* ("Alzheimer's at the age of 56 – family life after the diagnosis") which forms part of the "Reporter" series on Swiss Television. The programme documents the personal lives of the protagonists, married couple Stefan T. Müller and his wife Nadine Haldemann, as well as their family, over a long period of time. It captures the highs and lows, in order to demonstrate both the opportunities and the challenges faced by those affected by Alzheimer's dementia, as well as those close to them. The aim was to create more understanding in society and to help reduce the stigma surrounding the condition.

Alzheimer Europe launched a call for applications for the third edition of the annual Anti-Stigma Award in April 2024, with the aim of giving recognition to a European journalist for an article, new story or documentary which contributed to combatting stigma and promoting a positive image of dementia and people living with dementia. This year, the award consisted 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 was accompanied by a trophy.

Alzheimer Europe and the sponsors of the Award, the Alzheimer Europe Foundation, C2N Diagnostics, Lilly and Roche, warmly congratulate Magnus Renggli, who was nominated for the Anti-Stigma Award by Alzheimer Schweiz Suisse Svizzera.

Second place went to Ofelya Kamavosyan (pictured, centre) from Armenia for her public radio show "Second Start Armenia Radio Show". This initiative was launched in 2022 as the first-ever media initiative in Armenia dedicated to Alzheimer's disease and was conceived through a collaboration between the

NGO "Alzheimer's Care Armenia" and Public Radio Armenia. The primary objectives of the project are to raise awareness about dementia, particularly Alzheimer's disease, to inform the public about available services and regulations, and to share uplifting success stories to instil optimism.

Third place was awarded to Andreas Kreimaier (pictured, right) from Germany for his late-night talk show "Willkommen Alzheimer" ("Welcome Alzheimer's"). This was a special edition of the late-night talk show "Welcome Austria" produced by Superfilm Film Production on behalf of the Austrian national public broadcaster. The aim of the show was make the topic of dementia accessible to a broad audience in a humorous yet always respectful manner, to raise awareness and to help reduce the stigma around dementia.

The Anti-Stigma Award Ceremony and dinner was held on the evening of 10 December at the Thon EU hotel in Brussels. Heike von Lützu-Hohlbein, Chairperson of the Alzheimer Europe Foundation, Katarina Ivanković Knežević, Director of Social Rights and Inclusion at the European Commission, and Nina Carberry MEP (Ireland), Co-Chair of the European Alzheimer's Alliance welcomed guests to the event and invited the three finalists to present their initiatives, before the winner and runners-up were announced.

The Awards were presented by:

- Kevin Quaid, Jury Member and Chairperson of the European Working Group of People with Dementia, who presented third place to Andreas Kreimaier.
- Maria do Rosário Zincke dos Reis, Vice-Chairperson of the Alzheimer Europe Foundation and Chairperson of Alzheimer Europe, who presented second place to Ofelya Kamavosyan.
- Nina Carberry MEP (Ireland), Co-Chair of the European Alzheimer's Alliance, who presented first place to Magnus Renggli.

Congratulations to all the winners for their important work and a big thank you to all our presenters and to everyone who applied for the award this year. Alzheimer Europe also gratefully acknowledges the support of the sponsors of the Alzheimer Europe Anti-Stigma Award: Alzheimer Europe Foundation, C2N Diagnostics, Lilly and Roche.

11 DECEMBER:

Alzheimer Europe hosts an “Advocating with success” workshop in Brussels for its national members delivered by Fourtold as part of their pro bono programme



On the morning of 11 December, Alzheimer Europe was delighted to host a workshop on “Advocating with success”, delivered by the Fourtold team as part of their *pro bono* programme. Together with our members – national Alzheimer’s associations from across Europe – we discussed actionable recommendations on how to communicate effectively and integrate communications tools into impactful advocacy strategies.

A big thank you to the Fourtold team – Nicola Scocchi, Adam Kaznowski and Juan José Fernández Romero – for their insights and commitment to this initiative.

Fourtold is an international reputation management and policy advisory consultancy. Find out more: <https://www.fourtold.eu/>

SPONSORS OF THE MONTH

Alzheimer Europe would like to express its gratitude to a new sponsor in 2024:



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

AE NETWORKING

| | |
|-------------|--|
| 3 DECEMBER | Alzheimer Europe organised an Alzheimer’s Association Academy on “Independent living and dementia” |
| 5 DECEMBER | Angela participated in the first European Forum for Non-Pharmacological Interventions |
| 5 DECEMBER | Angela participated as a panelist at the LuxInnovation Horizon Europe day |
| 5 DECEMBER | Soraya and Lukas attended a stakeholder meeting organised by LuxInnovation |
| 7 DECEMBER | Ana, Sarah, Lukas participated in the AD RIDDLE WP7 task leaders meeting |
| 9 DECEMBER | The Alzheimer Europe Board met (Brussels, Belgium) |
| 10 DECEMBER | Alzheimer Europe organised a meeting with the European Working group of People with Dementia (Brussels, Belgium) |
| 10 DECEMBER | Alzheimer Europe organised a Company Round Table (Brussels, Belgium) |
| 10 DECEMBER | Alzheimer Europe organised a European Parliament lunch debate on “Dementia as a research priority” (Brussels, Belgium) |
| 10 DECEMBER | Alzheimer Europe organised a Public Affairs Meeting with members (Brussels, Belgium) |
| 10 DECEMBER | Alzheimer Europe organised the 2024 Anti-Stigma Award Ceremony (Brussels, Belgium) |
| 10 DECEMBER | Gwladys spoke at the Association of Association Executives seminar “Building inclusive events” |
| 11 DECEMBER | Alzheimer Europe and Fourtold organised an “Advocating with success workshop” (Brussels, Belgium) |
| 12 DECEMBER | Jean attended a meeting with Biogen (Amsterdam, Netherlands) |

| | |
|----------------|--|
| 12 DECEMBER | Lukas attended a WHO multi stakeholder meeting on social participation in policy |
| 12-13 DECEMBER | Angela attended the final General Assembly meeting for the PRIME project (Cologne, Germany) |
| 13 DECEMBER | Ana and Cindy attended the Multi-MeMo Christmas gathering with the members of the project's Advisory Board |
| 19 DECEMBER | Angela attended the European Academy of Neurology's Brain Health Forum |

Help us give a voice to people with dementia

Donate

- @AlzheimerEurope
- @alzheimer-europe
- AlzheimerEurope
- @alzheimer europe
- @AlzheimerEurope

EU project acknowledgements



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

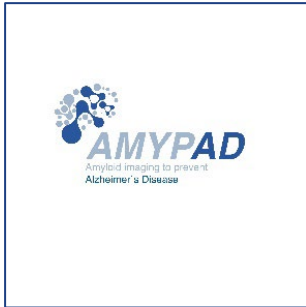
The projects in this newsletter are:

- LETHE - grant agreement 101017405 (<https://www.lethe-project.eu/>)
- PREDICTOM - grant agreement 101132356 (<https://www.predictom.eu/>)
- Prominent - grant agreement 101112145 (<https://www.ih-prominent.eu/>)

EU PROJECTS

20 NOVEMBER:

AMYPAD publishes Centiloid guidelines and recommendations for clinical context-of-use in Alzheimer’s disease



The members of the Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) project have announced the publication of a perspective review on the interpretability and clinical application of the Centiloid (CL) scale, a robust method for measuring amyloid plaques in the brain, a key

hallmark of Alzheimer’s disease (AD). Published in *Alzheimer’s & Dementia: The Journal of the Alzheimer’s Association*, this work includes the context-of-use recommendations and aims to provide guidelines for the implementation of the CL scale in clinical practice, ensuring its reliability and accuracy for diagnosing and monitoring AD across different settings.

In recent years, AMYPAD researchers have played a pivotal role in validating the CL scale as a robust and reliable method for quantifying amyloid deposition in the brain, independent of the radiotracer used in PET imaging. The CL scale provides a unified and standardised framework for comparing data across different PET imaging tracers and quantification pipelines, enabling a more accurate assessment of amyloid burden. These findings have been consolidated into an application for a Biomarker Qualification Opinion (BQO) to the European Medicines Agency (EMA). The EMA’s Committee for Medicinal Products for Human Use (CHMP) has recognised the Centiloid unit for measuring brain amyloid levels as a validated measure of global amyloid load in the brain, if properly used with quality control procedures.

The emerging era of anti-amyloid therapies relies heavily on amyloid-PET imaging for patient selection, evaluation of target engagement and assessment of drug effectiveness. For these therapies, the Centiloid scale offers a robust, tracer-independent and validated metric that accurately reflects the degree of amyloid pathology in the brain, making it an ideal tool for use in clinical settings.

<https://amypad.eu/news/recent-news/amypad-publishes-centiloid-guidelines-and-recommendations-for-clinical-context-of-use-in-alzheimers-disease/>

1 DECEMBER:

PRIME launches new, free e-learning course – Body and Brain: co-occurrence of cardiometabolic and mental diseases



The PRIME consortium has created an online e-learning course for healthcare professionals interested in the connection between insulinopathies and brain health and how to provide integrated care. The course aims to enhance the understanding and management of the co-occurrence of insulinopathies, such as type 2 diabetes (T2D) and obesity, with mental and neurological brain disorders.

PRIME is a European consortium of research institutes, medical centres, companies, and societal stakeholders that is funded through an EU Horizon 2020 grant. PRIME is unravelling the insulin-dependent mechanisms that underly conditions such as type 2 diabetes and obesity, and brain disorders such as Alzheimer’s disease, obsessive-compulsive disorder and autism spectrum disorders. Until now, very little attention has been paid to the role of insulin signaling in brain disorders, and the overlap (or ‘multimorbidity’) with somatic conditions.

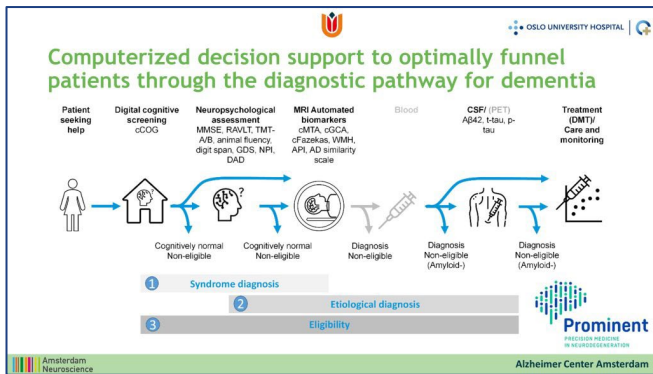
PRIME’s e-learning course has been created in collaboration with the European College of Neuropsychopharmacology (ECNP), and with support from the CANDY and TIMESpan consortia. The primary audience includes psychiatrists, psychologists, neurologists, neuroscientists, endocrinologists, dieticians, general practitioners and all other interested individuals.

By completing this course, participants will be able to recognise the frequent co-occurrence of insulinopathies and brain disorders, and understand how lifestyle, glycaemic control, and insulin signalling influences brain functioning and health. Participants will also learn to argue the importance of multidisciplinary treatment and integrated care for insulinopathies and brain disorders. Additionally, they will be able to adopt lifestyle interventions in clinical practice to improve both mental and physical health of their patients, apply clinical guideline recommendations to diagnose and treat individuals with insulin and/or somatic multimorbidities.

The course is available free of charge on the ECNP knowledge hub and offers on-demand, online learning materials, including video lectures, quizzes, and reading material. Participants can obtain 43 European CME credits upon completing the course. <https://knowledge-hub.ecnp.eu/all-courses/body-and-brain-co-occurrence-cardiometabolic-and-mental-diseases>

4 DECEMBER:

Stepwise dementia diagnostics in memory clinics with the help of a computer tool



Determining the most appropriate diagnostic test for a patient is not always straightforward. Researchers from Alzheimer-centrum Amsterdam have published an article on how a computer tool based on artificial intelligence can assist in this process.

Together with researchers from Finland, Sweden, Denmark, and Italy, they developed a data-driven method to efficiently and systematically conduct diagnostic tests.

The researchers focused on three key clinical questions:

1. What is the syndrome diagnosis? (control, MCI, or dementia)
2. What is the underlying etiological diagnosis? (Alzheimer’s disease, vascular dementia, Lewy body dementia, or frontotemporal dementia)
3. Is the patient a potential candidate for new Alzheimer’s disease medications?

All patients first underwent a digital cognitive screening test, cCOG. The computer tool, cNeuro, then determined which additional tests were needed, based on the clinical question and the certainty of the diagnosis. This approach allowed researchers to design accurate and efficient diagnostic pathways, offering doctors support from the computer tool in deciding which test would most contribute to a correct diagnosis.

Testing in seven European memory clinics

As a next step, the researchers will test this method in seven European memory clinics as part of the PROMINENT project. Physicians will assess patient cases with and without the stepwise method. The study will investigate whether the method helps in reaching a diagnosis faster, with fewer tests, and with greater confidence. Additionally, the researchers will gather

feedback from physicians, patients, and their families on their experience using the computer tools.

Read the full article:

[Computerized decision support to optimally funnel patients through the diagnostic pathway for dementia | Alzheimer’s Research & Therapy](#)

This research (4D FUTURE) was also supported by a Memorabel grant from ZonMW. Find out more about the PROMINENT project: <https://www.ihl-prominent.eu/>

9 DECEMBER:

PREDICTOM interviews Alzheimer Europe Public Involvement Officer Sarah Campill about “Involving members of the public to improve Alzheimer’s research and remove stigma”

The PREDICTOM project has published an interview with Alzheimer Europe Public Involvement Officer Sarah Campill, titled “Involving members of the public to improve Alzheimer’s research and remove stigma”.



For more information about the PREDICTOM project, please see: <https://www.predictom.eu/>

You can read the interview, which is part of a series of interviews by the project, here:

<https://www.predictom.eu/news/transforming-alzheimers-care-by-bringing-diagnosis-to-the-household-and-primary-care-1>

10-11 DECEMBER:

European Working Group of People with Dementia and European Dementia Carers Working Group meet in Brussels



On 10 and 11 December, after the Lunch Debate organised by Alzheimer Europe at the European Parliament, the European Working Group of People with Dementia (EWGPWD) and European Dementia Carers Working Group (EDCWG) held their face-to-face meetings.

On 10 December, and as part of the INTEREST project, members of the EWGPWD and the EDCWG addressed various issues related to social health, unmet needs, technology and inequality in dementia care in Europe. This session was followed by the TEF-Health project which is a tool that helps companies navigate and comply with the EU requirements and regulations on the use of Artificial Intelligence (AI) and robotics in healthcare. Members were asked about the need for AI and robotics in the health domain and any areas of the healthcare system in which they would like to see more AI solutions, as well as about any ethical concerns they had regarding the accreditation platforms being developed for AI-based medical devices.

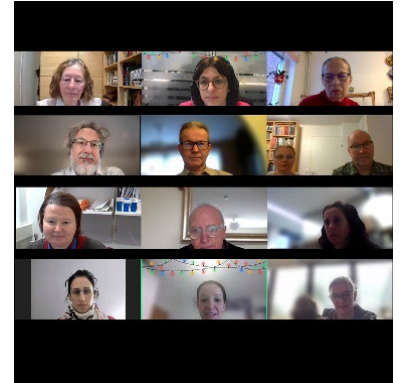
On the second day, members were asked to provide feedback on an online survey that Alzheimer Europe has developed, in the context of the Gates Ventures 2 project, about participation in dementia research and factors that motivate or put people off taking part in dementia research. Two other projects were discussed during the meetings, PANEUCARE and HOMEDEM. As part of these projects, members discussed the disparities in how dementia care is managed between Western and Northern Europe compared to Central and Eastern Europe (PANEUCARE project) and provided feedback and guidance to doctoral students about their research projects which focus on codesign within the context of people's homes (HOMEDEM project).

Alzheimer Europe would like to thank all members of the EWGPWD and the EDCWG for their very active contributions during all these meetings, as well as the doctoral students from HOMEDEM and the researchers from INTEREST, PANEUCARE and TEF-Health who co-moderated the various consultations, together with AE staff.

13 DECEMBER:

Members of the Multi-MeMo Advisory Board enjoy a social gathering before Christmas

On 13 December, the members of the Multi-MeMo Advisory Board gathered for a social event to celebrate the upcoming holiday season. The meeting provided an opportunity for members to share their holiday plans and reflections on the year ahead in a warm and friendly atmosphere. The project's partners took a moment to thank the board members for their continued support and contributions, expressing how much they valued working together. The meeting was closed by wishing everyone a happy festive season. Alzheimer Europe, in close coordination with the other partners, is responsible for the coordination of the Advisory Board. AE Public Involvement Lead Ana Diaz and Project Officer Cindy Birck participated in the event. For more information about the Multi-MeMo project, visit:



<https://www.multi-memo.eu/>

18 DECEMBER:

LETHE webinar explores AI in dementia from risk detection to treatment

Alzheimer Europe is pleased to announce the third event in the LETHE webinar series. The upcoming session, titled "Beyond the hype: AI in dementia – from early risk detection to disease treatment," will take place on 17 January from 10.30-11.30am CET.



This webinar highlights work among several EU-funded projects, including LETHE, AI-Mind, ADIS and PROMINENT. These initiatives are at the forefront of exploring how Artificial Intelligence (AI) is being applied across different stages of dementia research, focusing on prevention, early diagnosis, and intervention.

Presentations include:

- **Markus Bödenler** (LETHE, FH Joanneum): LETHE's approach to AI in dementia prevention and risk assessment.
- **Ainar Drews** (AI-Mind, University of Oslo): AI-Mind, focusing on AI tools designed for early risk detection of cognitive decline.

- **Sophia Krix** (ADIS, Fraunhofer SCAI): Work from the ADIS project, which aims to enable earlier diagnosis of Alzheimer's disease by profiling immune cells and analysing sleep disturbances.
- **Antti Tolonen** (PROMINENT, Combinostics): A presentation on how AI and machine learning are

being used in PROMINENT to advance precision medicine in neurodegeneration.

To join the discussion and learn more register for the webinar:
[Register for the webinar](#)

MEMBERS OF THE EUROPEAN ALZHEIMER'S ALLIANCE

Currently, the total number of MEPs in the European Alzheimer's Alliance (EAA) stands at **82**, representing **21** Member States of the European Union and seven out of eight political groups in the European Parliament. Alzheimer Europe is grateful to the Co-Chairs of the EAA: Nina Carberry MEP (Ireland, EPP), Tilly Metz MEP (Luxembourg, Greens/EFA), Romana Jerković MEP (Croatia, S&D), Sirpa Pietikäinen MEP (EPP, Finland); Hilde Vautmans MEP (Belgium, Renew Europe) and Dainius Žalimas (Renew Europe, Lithuania) for their leadership and for hosting the organisation's European Parliament lunch debates on dementia. Alzheimer Europe would also like to thank the following MEPs for their support of the EAA:



Belgium: Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchuk (Renew Europe); Tsvetelina Penkova (S&D). **Croatia:** Biljana Borzan (S&D); Romana Jerković (S&D); Tonino Picula (S&D). **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:** Merja Kyllönen (The Left); Sirpa Pietikäinen MEP (EPP). **France:** François-Xavier Bellamy (EPP); Mélissa Camara (Greens/EFA); Laurent Castillo (EPP); David Cormand (Greens/EFA); Marie Dauchy (PFE); Christophe Gomart (EPP); Catherine Griset (PFE); Céline Imart (EPP); Isabelle Le Callennec (EPP); Nadine Morano (EPP); Philippe Olivier (PFE); Mounir Satouri (Greens/EFA); Majdouline Sbai (Greens/EFA); Marie Toussaint (Greens/EFA). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Manuela Ripa (Greens/EFA); Terry Reintke (Greens/EFA). **Greece:** Tsiodras Dimitrios (EPP); Manolis Kefalogiannis (EPP); Nikos Papandreou (S&D); Elisavet 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); Seán Kelly (EPP); Aodhán Ó Riordáin (S&D); Maria Walsh (EPP). **Italy:** Brando Benifei (S&D); Caterine Chinnici (EPP); Carlo Fidanza (ECR); Aldo Patriciello (PFE). **Lithuania:** Vytenis Andriukaitis (S&D); Petras Auštrevičius (Renew Europe); Vilija Blinkevičiūtė (S&D); Liudas Mažylis (EPP); Dainius Žalimas (Renew Europe). **Luxembourg:** Marc Angel (S&D); Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Isabel Wiseler-Lima (EPP). **Poland:** Elżbieta Katarzyna Łukacijewska (EPP); Anna Zalewska (ECR). **Portugal:** Marta Temido (S&D); Catarina Martins (The Left). **Slovenia:** Matjaž Nemeč (S&D); Irena Joveva (Renew Europe); Vladimir Prebilič (Greens/EFA); Marjan Šarec (Renew); Milan Zver (EPP). **Spain:** Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ana Miranda Paz (Greens/EFA). **Sweden:** Pär Holmgren (Greens-EFA); Jonas Sjöstedt (S&D).

EUROPEAN ALZHEIMER'S ALLIANCE

19 DECEMBER:

European Alzheimer's Alliance gains two new members and Sirpa Pietikäinen MEP becomes a new Co-Chair

Alzheimer Europe is delighted to announce that Sirpa Pietikäinen MEP (EPP, Finland) has re-joined the European Alzheimer's Alliance (EAA) and has accepted the position of Co-Chair, alongside five of her colleagues, existing Co-Chairs: Nina Carberry MEP (EPP, Ireland), Romana Jerković MEP (S&D, Croatia), Tilly Metz MEP (Greens/EFA, Luxembourg), Hilde Vautmans MEP (Renew, Belgium), and Dainius Žalimas

MEP (Renew, Lithuania). Her renewed membership, together with the membership of Liudas Mažylis (EPP, Lithuania) brings the current total to 82 members of the EAA from 21 Member States of the European Union.



Sirpa Pietikäinen MEP is a long-time supporter and former Board member of Alzheimer Europe and we very much look forward to continuing to work with her and to beginning a new working relationship with Liudas Mažylis, 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.

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

28 NOVEMBER:

European Medicines Agency hosts fifth edition of its Big Data Stakeholder Forum

On 28 November, the European Medicines Agency (EMA) hosted its fifth annual Big Data Stakeholder Forum. This multi-stakeholder event presents and celebrates progress of the European Regulatory network, towards its vision of data-driven regulatory decision-making. Structured around a series of keynote presentations, with interventions and comments from national regulatory agencies, patient organisations, healthcare professional bodies, industry and academia, the event brought together experts from across Europe.

Following opening remarks from Marco Greco (European Patients’ Forum) Rui Santos Ivo (Infarmed, Portugal) and Lorena Boix Alonso (Deputy Director-General, DG Sante at the European Commission), the first session focused on the delivery of the Heads of Medicines Agencies (HMA)/EMA big data priority recommendations, hearing from stakeholders on gaps and priorities. These recommendations include the delivery of a platform for accessing and analysing “real-world data” (data derived from “real-world” sources such as electronic patient records or insurance records) and developing network skills for Big Data. The second session continued on a similar theme, exploring the critical role of evidence generation in enhancing regulatory decision-making and the key progress being made for the use of real-world data and clinical trial raw data. Bruno Sepodes, who is the current Chair of the Committee for Medicinal Products for Human Use, outlined the vision for using different data sources to generate clinical evidence, underlining the core role for the patient voice to provide guidance at each step along the regulatory decision-making path.

Our Director for Research, Angela Bradshaw, participated in a session entitled “Evidence Generation to Advance Regulatory Excellence: Preparing for Tomorrow”, which explored novel sources of real-world data to support regulatory assessment. Experts from the EMA and Italian national regulatory agency showed how mHealth and social media data could be useful to provide insights on “real-world” outcomes that are valued by patients and their families. In her intervention, Angela high-

lighted the need to ensure inclusion when identifying and using novel data sources, stressing the need to consider challenges relating to digital inclusion that may inadvertently exclude groups that do not use social media or mHealth applications. The final session, “Unlocking the Value of Data within the European Medicines Regulatory Network Strategy” explored how to maximise the generation of evidence, and the use and exchange of data to support regulatory decision-making. For this, a robust network data strategy is essential to ensure the network data assets are appropriately managed and have a high level of interoperability, standardisation and quality. Peter Arlett, co-Chair of the EMA Big Data Steering Group, drew the Forum to a close, thanking all attendees for their active participation.

<https://www.ema.europa.eu/en/events/fifth-ema-hma-big-data-stakeholder-forum>

28-29 NOVEMBER

Highlights from the European Day of Persons with Disabilities 2024 and Access City Award 2025



On 28 and 29 November, Kevin Quaid, Chair of the European Working Group of People with Dementia (EWGPWD), and Liselotte Klotz, Vice-Chair of the EWGPWD, attended the European Day of Persons with Disabilities 2024 conference and

the Access City Award 2025 ceremony in Brussels, Belgium, to represent the interests and voices of people living with dementia. They were joined by Alzheimer Europe's Public Involvement Officers, Sarah Campill and Sébastien Libert.

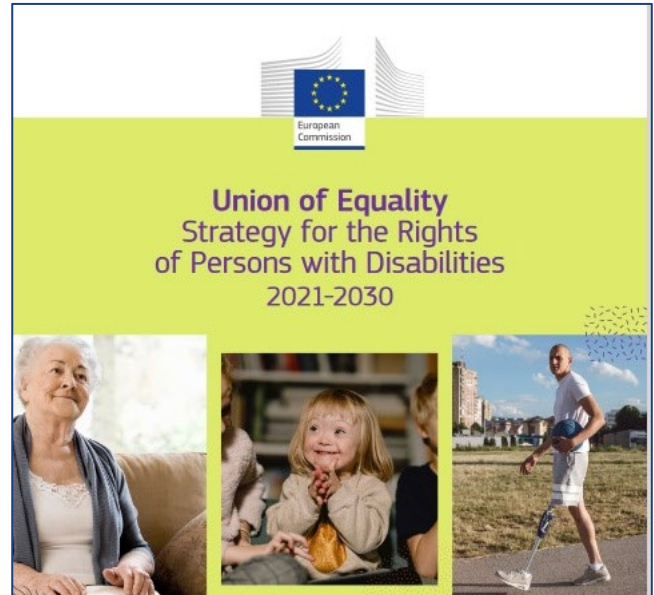
Every year, the EPED provides an excellent opportunity to network with patient organisations and people with disabilities, allowing for the exchange of successful strategies, discussions on key issues and the difference in needs within the community. An example and a yearly highlight is the Access City Award, which awards cities for their efforts to improve accessibility. This year's winners were:

- First place: Vienna, Austria, for embedding accessibility at the heart of its urban strategy, seamlessly integrating advanced technology and inclusive planning throughout all aspects of city life.
- Second place: Nuremberg, Germany, for its proactive promotion of disability inclusion in city planning and the close collaboration between the Nuremberg Disability Council and city planners to ensure accessible public spaces.
- Third place: Cartagena, Spain, for making accessibility a cornerstone of its urban development, highlighted by the standout project 'Beach for All', which offers assisted bathing services for persons with disabilities, complete with trained staff, amphibious wheelchairs and accessible showers.

Another highlight of the conference was the panel on accessible and inclusive cities, held on the second day. During this panel, Kevin Quaid took the opportunity to speak about the challenges and stigma faced by people with invisible disabilities, such as dementia. He reminded attendees that while developing accessible urban environments is progress, it is equally important to train people to recognise the hidden signs of disabilities.

3 DECEMBER:

Civil society organisations write to Equality Commissioner



On 3 December, Alzheimer Europe joined over 100 European disability organisations in an open letter coordinated by the European Disability Forum (EDF), urging the new European Commissioner for Equality, Hadja Lahbib, to update the EU Disability Rights Strategy.

The Strategy was launched in 2021 and runs until 2030. It has led to the development of different policies such as the European Disability Card law, however, it only contains actions until the end of this year, which have all been completed or are near completion. As such, the open letter expresses concern that as there is no commitment to update the strategy for the remainder of its lifespan, this may lead to the EU's commitment to disability rights stalling.

The EDF has previously raised concerns about this matter, including the European Commission President's political guidelines failing to mention disability rights, the Equality portfolio being downgraded in the College of the Commissioners and Commissioner Lahbib's failure to commit to updating the Strategy during her Commissioner hearing.

The signatories of the letter call for the Strategy to be updated as soon as possible, encouraging the Commission to make this commitment in advance of the review of the EU's implementation of the UN Convention on the Rights of Persons with Disabilities, which is scheduled for March 2025. The full letter is available at:

<https://www.edf-feph.org/publications/commissioner-lahbib-keep-momentum-disability-rights/>

POLICY WATCH

29 NOVEMBER:

As Ireland decided on a new Government, The ASI campaigned for change



The General Election 2024 took place in Ireland on 29 November 2024. The Alzheimer Society of Ireland (The ASI) launched an effective election campaign called ‘Deliver on Dementia – Make a Pledge to Keep Dementia a Priority’ which called on all candidates to pledge their support for those living with the condition and their family carers. Political engagement is a cornerstone of The ASI advocacy strategy. Long-term improvements in community care and support for carers are just some of the issues they look for in government support.

In Ireland, elections provide a key opportunity for advocacy, as the political system opens up. Politicians must reconnect with communities, outline achievements, and share future plans. For three weeks, even senior leaders knock on doors to seek votes.

The ASI created a concise list of requests for candidates to endorse improved dementia assessment and treatment, more home care hours, better pay and conditions for employees, and addressing service gaps, particularly in rural or disadvantaged areas. Although the national media agenda was dominated by issues like housing and the economy, it capitalised on its unique strengths. Two advocacy groups—the Irish Dementia Working Group (composed of people living with dementia) and the Dementia Carers Campaign Network (made up of carers)—brought the campaign to life. These groups connected with candidates and engaged with local media.

The ASI secured 265 pledges from approximately 640 candidates across all political parties. Advocates met with leaders of all seven major parties, either formally or informally, presenting The ASI’s manifesto. Of those who pledged support, 86 were elected to the Irish Parliament (Dáil Éireann), comprising nearly half of the 174 members. This significant representation underscores growing recognition of dementia as a critical social issue. Currently, The ASI is working to influence the Programme for Government, advocating for six key priorities. “We must ensure that dementia remains a priority for the

new Government and through our advocate groups we can give a voice to creating a more dementia inclusive Ireland”, said The ASI.

You can find out more about the campaign, at: www.dementialedge.ie

12 DECEMBER:

WHO Regional Office for Europe organises event about social participation within the context of non-communicable diseases

Meaningful social participation in health policy is key to building resilient systems that address the challenges of non-communicable disease, including dementia. On 12 December, Alzheimer Europe attended a



virtual event titled “Institutionalizing Social Participation: Shaping a More NCD and Mental Health-Resilient WHO European Region”, organized by the WHO Regional Office for Europe. The event aimed to facilitate discussions and exchanges between policymakers and civil society organizations on the topic of meaningful involvement throughout the policy cycle.

The meeting featured presentations and panel discussions with leading experts in the field, including Jonathan Titter (Aston University, UK), Ainuru Altybaeva (Forum of Women, Kyrgyzstan), Abdulkarim Harakow (UN Youth Delegate, Denmark), Anca Toma (European Patients’ Forum), and Vesna Kerstin Petrič (Ministry of Health, Slovenia). The panelists highlighted the importance of ensuring adequate representation of patient organizations in policy-making processes and outlined practical steps to achieve meaningful involvement. These steps include recognizing the value of social participation, ensuring diversity among stakeholders, and fostering the sustainability of representation mechanisms. The event was framed by a resolution from the 2024 World Health Assembly, which seeks to strengthen and sustain meaningful social participation in health-related decision-making processes. Complementing this effort, the WHO has published a comprehensive report detailing practical approaches to integrate and institutionalize social participation within these processes. The report can be accessed here: <https://iris.who.int/handle/10665/379583>

SCIENCE WATCH

22 NOVEMBER:

Assessing A β status before disease-modifying therapies: Findings from a 10-year real-world study



On 22 November, a study published in *Alzheimer's Disease & Dementia: Diagnosis, Assessment & Disease Monitoring* explored how amyloid beta (A β) status can be assessed efficiently in patients with suspected Alzheimer's disease (AD) ahead of potential treatment with disease-modifying therapies. The research team, led by Matthias Brendel, used data collected over a 10-year period through two independent cohorts in university memory clinics.

With the emergence of disease-modifying therapies, accurately determining A β pathology is essential for patients with suspected AD. The study evaluated A β levels in cerebrospinal fluid (CSF) and positron emission tomography (PET) in real-world clinical settings to propose a practical diagnostic algorithm.

The study included 402 patients from Ludwig Maximilian University in Germany and 144 patients from the Medical University of Vienna. The researchers compared CSF A β 42/40 ratios with A β PET scans to determine optimal thresholds and validated these findings across both cohorts.

Results showed that a CSF A β 42/40 ratio of $\geq 7.1\%$ was associated with a low risk of a positive A β PET scan (negative predictive value: 94.3%). For patients with intermediate results (CSF A β 42/40 ratio between 5.5% and 7.1%, defined by the authors as borderline levels), A β PET imaging was beneficial, with 44% to 52% of these patients testing positive for A β pathology.

The study supports a two-cutoff approach, combining CSF A β 42/40 testing and A β PET imaging for intermediate cases. This approach provides a cost-effective and reliable way to assess A β status in clinical practice, ensuring that appropriate patients are identified for potential treatment with disease-modifying therapies.

As anti-amyloid therapies approach potential approval in Europe, these findings could guide clinicians in optimising biomarker assessments. The two-cutoff method helps reduce unnecessary PET scans while ensuring accurate diagnosis. The study has been published open access and can be read here: <https://doi.org/10.1002/dad2.70031>

1 DECEMBER:

A recent study suggests that maternal immune activity is associated with the offspring's long-term brain health

Alzheimer's disease (AD) is a neurodegenerative disorder that is expected to increase in the next years affecting more women than men. Although AD has often been associated with brain ageing it is known for developing across the lifespan. However, the effect of foetal antecedents on brain health later in life, and the role sex differences play in this process are still unclear.



In a recent study published in the journal of *Molecular Psychiatry* (Springer Nature), a team of researchers led by Dr Jill M. Goldstein from Harvard Medical School (Boston, US) investigated the foetal origins of memory performance and the effect of sex differences.

This research involved a cohort of a total of 17,741 pregnancies that were followed between 1959 and 1966 as part of the New England Family Study (NEFS). Maternal prenatal immune abnormalities (i.e. elevated levels of proteins that control inflammatory processes, such as IL-6 and TNF- α) were assessed in blood collected from the women during the beginning of the third trimester of pregnancy, as this is one of the key periods of the sexual differentiation of the human brain. The prenatal cohort included 204 individuals exposed or unexposed to elevated levels of IL-6 and TNF- α and followed into early midlife (i.e. 50 years later), including detailed assessments at the age of 7. The researchers then measured the impact that early exposure to these inflammatory markers has on the offspring's brain regions associated with associative and verbal memory using brain imaging techniques.

The team found that dysregulated utero maternal immune environment (i.e. elevated levels of IL-6 and TNF- α during pregnancy) impacts memory performance, memory circuitry function, and immune responses in midlife for men and after menopause for women. Moreover, researchers found that the con-

sequences of being exposed to these pro-inflammatory molecules can be seen even earlier, by the age of 7, impacting the cognitive performance of the offspring.

Although this study has some limitations (e.g. executive memory should be considered in future studies to fully investigate the impact of maternal prenatal immune abnormalities on the risk for AD), the results of this study suggest that a dysregulation of the maternal immune system function impacts memory performance and memory circuitry in the offspring in the long-term and with sex-dependent effects.

<https://www.nature.com/articles/s41380-024-02798-w>

9 DECEMBER:

Vivoryon Therapeutics announces topline Phase II VIVA-MIND study results in early AD



On 9 December, Vivoryon Therapeutics N.V., a clinical stage biotechnology company focused on developing innovative small molecule-based medicines, announced topline data from its Phase II VIVA-MIND study evaluating varoglutamstat in people with early Alzheimer's disease

(AD). The trial, conducted in the US, aimed to assess the safety and efficacy of varoglutamstat, a 600mg twice-daily dose, over 18 months.

The study was discontinued early following negative results from a parallel European Phase IIb trial, VIVIAD, which missed all of its endpoints in March 2024. The VIVA-MIND study, originally planned to enroll a total of 414 participants, ultimately enrolled 112 randomised participants, with 109 receiving treatments in the Phase IIa portion, which focused on adaptive dose-finding.

Similar to the VIVIAD study, VIVA-MIND failed to meet its primary endpoint of measuring clinically meaningful and statistically significant differences, assessed through Clinical Dementia Rating – Sum of Boxes (CDR-SB) scores. The study also did not achieve its key secondary endpoints, including Cognitive Function Composite 2 (CFC2) and Alzheimer's Disease Assessment Schedule-Cognitive Subscale (ADAS-Cog) 13.

However, varoglutamstat demonstrated a favorable safety and tolerability profile in VIVA-MIND with no new safety signals detected. In addition, the study revealed a statistically significant improvement in kidney function in participants treated with varoglutamstat compared to those on placebo, reinforcing similar findings from the completed VIVIAD study. This data supports the company's development strategy to advance into a Phase II study in diabetic kidney disease.

<https://www.vivoryon.com/vivoryon-therapeutics-n-v-presents-topline-phase-2-data-fromviva-mind-strongly-supporting-varoglutamstats-potential-toimprove-kidney-function/>

9 DECEMBER:

Neuroinflammation in Alzheimer Disease



In their comprehensive review article, Michael Thomas Heneka, Wiesje Maria van der Flier, Frank Jessen, and colleagues explore the critical role of immune processes in the pathogenesis of Alzheimer's disease. The review's focus lies on understanding the role of immune processes, specifically neuroinflammation, in the pathogenesis of Alzheimer's disease, further looking into how different parts of the immune system, both the immediate and more specialised responses, play a role in causing and worsening Alzheimer's disease.

The research team found that inflammation in the brain, driven by the immune system, plays a significant role in Alzheimer disease. Key players in this process are microglia and astrocytes, which are types of brain cells that become overactive and cause damage. The study also noted that genetic factors and lifestyle choices, like diet and exercise, can influence how these immune responses affect the brain. The authors emphasise the importance of understanding these mechanisms for developing new therapeutic strategies targeting neuroinflammation, which are currently being tested in clinical trials.

In the review, several remaining questions were mentioned, such as the question about the temporal dynamics, i.e., the precise timing of immune activation in relation to the stages of Alzheimer disease progression, or the cell-specific roles, contributions, and interactions in different contexts of the disease.

[Neuroinflammation in Alzheimer disease | Nature Reviews Immunology](#)

10 DECEMBER:

CervoMed's experimental drug fails to meet its endpoints in Phase II study for dementia with Lewy bodies



On 10 December, CervoMed, a clinical-stage company focused on developing treatments for age-related neurologic disorders, announced topline data from its Phase IIb RewinD-LB clinical trial of neflamapimod in people with dementia with Lewy bodies (DLB). The randomised 16-week, double-blind and placebo-controlled trial enrolled 159 participants with early-stage DLB across 43 sites in the US, UK and Netherlands.

The trial did not meet statistical significance thresholds for its primary endpoint, a change in the Clinical Dementia Rating Sum of Boxes (CDR-SB), nor did it achieve any of its key secondary endpoints, including the Timed Up and Go (TUG) test, the Neuropsychological Test Battery (NTD) and the Clinician's Global Impression of Change (CGIC). Neflamapimod demonstrated a favorable safety and tolerability profile consistent with previous clinical studies, with no new safety signals identified.

According to John Alam, Chief Executive Officer of CervoMed, the company is pausing all preparations for the previously planned Phase III trial in early-stage DLB until the full analysis is complete. The full data set from the double-blind phase of the RewinD-LB trial is expected to be available in January 2025. Participants continue to receive neflamapimod during the open-label extension with data anticipated in the second quarter of 2025.

<https://ir.cervomed.com/news-releases/news-release-details/cervomed-announces-topline-data-rewind-lb-phase-2b-clinical>

MEMBERS' NEWS

3 DECEMBER:

Alzheimer Bulgaria Association participated at the forum "Rethinking Alzheimer's Disease Pathway: From Diagnosis to Care" organised by MEP Tsvetelina Penkova



On 3 December, Alzheimer Bulgaria Association participated at the forum "Rethinking Alzheimer's Disease Pathway: From Diagnosis to Care", held at the European Parliament in Brussels. Representatives of Alzheimer Bulgaria Association took part in the panel discussion "Alzheimer's disease and brain health: a national and European Public Health Priority" and presented the main challenges in healthcare and social services for people with dementia, as well as key initiatives of the association focused on improving care for people with dementia and providing support to their relatives and caregivers.

The main organiser and host of the forum was MEP Tsvetelina Penkova (pictured, right), who worked with the European Brain Council to realise the event. Ms Penkova formally extended an invitation to Alzheimer Bulgaria Association to par-

ticipate at the forum, providing a valuable opportunity to consolidate collaboration between Bulgaria and European institutions. It not only highlighted Bulgaria's efforts in the fight against dementia, but also created conditions for future partnerships with leading specialists and organisations

The event featured presentations from leading experts including Helen Rochford-Brennan, Vice-Chair of the Irish Dementia Working Group, and Frédéric Destrebecq, Executive Director of the European Brain Council, who presented key conclusions from a report by the organisation. These discussions highlighted the importance of early diagnosis, individualised therapies and systematic support for the families affected.

10 DECEMBER:

The Alzheimer Society of Ireland staff and advocates privileged to take part in impactful discussions and events with Alzheimer Europe in Brussels

Staff and advocates from The Alzheimer Society of Ireland (The ASI) participated in the Dementia Day at the EU Parliament in Brussels on 10 December 2024, which involved national Alzheimer's associations and people with lived experience of dementia.

The ASI's Head of Advocacy, Research and Public Affairs Cormac Cahill, Advocacy Manager Philippe Carr, Patrick Crosbie (member of the European Dementia Carers Working Group), and Kevin Quaid (Chairperson of the European Work-



ing Group of People with Dementia) were all privileged to participate in key events and impactful discussions on dementia at a European level.

The team was very grateful for the engagement with Irish MEPs while in Brussels including Billy Kelleher, Brian Cowen, Barry Andrews, Aodhán Ó Riordáin, Seán Kelly, Regina Doherty, Maria Walsh, Michael McNamara and Ciaran Mullooly. The ASI extends a special thanks to Co-Chair of the European Alzheimer's Alliance Nina Carberry MEP for her ongoing support and engagement. The ASI was heartened to see so many working towards making dementia a public health priority at EU level.

The Brussels events culminated in the Anti-Stigma Awards hosted by Alzheimer Europe and the Alzheimer Europe Foundation, where the winner and runners-up of this important annual initiative were announced.

It was a fantastic opportunity for Team ASI to discuss the importance of recognising dementia as a priority in European health, research, social, and disability policies.

A heartfelt thank you to Alzheimer Europe from The ASI for



organising such a meaningful day dedicated to raising awareness, fostering collaboration, and addressing stigma.

Pictured left to right): Katarina Ivanković Knežević, Patrick Crosbie, Nina Carberry MEP, Kevin Quaid and Cormac Cahill attend that Anti-Stigma Awards in Brussels on 10th December

10 DECEMBER:

Spominčica (Alzheimer Slovenia) participated in supermarket chain Mercator “friendly neighbourhood” campaign

Spominčica (Alzheimer Slovenia) has been recognised by retail chain Mercator as one of the organisations that wholeheartedly contribute to improving the quality of life in communities.

Through its participation in the friendly neighbourhood campaign, Spominčica – Alzheimer Slovenia was given an opportunity to present and enhance its activities for people with dementia and their families. The Mercator campaign, which promotes mutual support and community connections, ran from 14 November to 31 December. During this time, customers could vote for selected organisations by using codes received with the purchase of products marked with the friendly neighbourhood label. The collected votes would determine the amount of donations Mercator would allocate to support organisations across Slovenia.

Spominčica's activities within the campaign

Spominčica actively participated in the campaign alongside its branches, dementia-friendly points, volunteers and members by organising presentations of its activities in numerous Mercator stores throughout Slovenia. These efforts further raised awareness of the organisation's mission, which include:

- Spreading knowledge about dementia
- Encouraging understanding and mutual support within the community
- Reducing the stigma surrounding dementia
- Providing support for people with dementia and their families.

Participation in the friendly neighbourhood campaign marked a significant step for Spominčica in reaching a broader audience and strengthening its programmes. The votes of Mercator's customers will support the organisation to continue creating dementia-friendly environments and intensify efforts towards an inclusive society.

“May the friendly neighbourhood campaign inspire greater kindness and connection throughout Slovenian communities. Together, we create friendly neighbourhoods!” said Spominčica.

13 DECEMBER:

Malta Dementia Society is proud to announce that Charles Scerri has been appointed to the National Order of Merit

The Malta Dementia Society is proud to announce that Charles Scerri has been appointed to the National Order of Merit during the Republic Day award ceremony on 13 December, by the President of Malta. He received the honour on the 50th anniversary of Malta becoming a Republic.

This award recognises the milestones he has achieved and his impressive work for people with dementia in Malta throughout his career. It also comes at the end of the Malta Dementia Society's 20th year.

<https://timesofmalta.com/article/malta-2024-republic-day-honours-list-recipients.1102423>

16 DECEMBER:

Romanian Alzheimer Society gives us an update on their initiatives on promoting active ageing for older people



The Erasmus+ project "On Stage in the Golden Age: Theatre for Healthy Aging" (AGE_THEA) highlights the transformative power of theatre in addressing loneliness, isolation, and social exclusion among older adults, issues significantly exacerbated by

the COVID-19 pandemic, while also fostering friendly and inclusive communities. Through a cross-disciplinary approach, this initiative seeks to improve the psychosocial health and well-being of European older people (65+), including those with dementia, Alzheimer's disease, and neurological disorders, with special attention to marginalised and low-income individuals.

The AGE_THEA project will span two years, from 15 December 2023 to 14 December 2025, and is implemented through a transnational partnership comprising the Romanian Alzheimer Society and Habilitas – Center for Resources and Professional Training (Romania); APS Le Compagnie Malviste (Italy); EDRA (Kinonikes Sineteris Drastiriotes Epathon Omadon) and the University of West Attica (Greece) and Rightchallenge (Portugal).

Key outputs of the project include: 1) a transnational report on theatre's impact on older adults' well-being, 2) a joint training programme for social, cultural, and health professionals, and 3) participatory theatre activities promoting active ageing for older people, including those living with Alzheimer's or other forms of dementia. The transnational report "The role of theatre in enhancing health and psychosocial well-being of older people" (first result of the project, now complete) brings together insights from focus groups, theatre activities in partner countries (Romania, Greece, Italy and Portugal) and literature reviews, showing how theatre can be a powerful tool to support active ageing and improve mental health.

Discover how theatre is changing the lives of older adults and helping to support mental health in communities. Our report is

now ready, visit our website to learn more and download the full report in English or your preferred language:

- English: https://age-thea.eu/?page_id=937
- Romanian: https://age-thea.eu/?page_id=946
- Greek: https://age-thea.eu/?page_id=944
- Portuguese: https://age-thea.eu/?page_id=705

Stay updated on the project and join the conversation on our social media:

- Facebook: <https://www.facebook.com/profile.php?id=61558862768566>
- Instagram: <https://www.instagram.com/age.thea2023/>

19 DECEMBER:

Trinity Centre for Ageing & Intellectual Disability and The Alzheimer Society of Ireland celebrate Research Impact Award success



In December, The Alzheimer Society of Ireland (The ASI) attended the Health Research Charities Ireland (HRCI) Joint Funding Scheme celebration event which reflected on this year's funding scheme successes and learnings.

ASI Board Member Ann Twomey presented the HRCI Research Impact Award 2024 to Prof. Mary McCarron from the Trinity Centre for Ageing and Intellectual Disability - an international and multi-disciplinary research centre at Trinity College, Dublin (Ireland). This Award recognises the impact of research under the scheme which has made a positive difference to people's lives.

In 2020, The ASI co-funded this project led by Prof. McCarron and the team at Trinity Centre for Ageing and ID, which focused on producing Post-Diagnostic Dementia Support Guidelines for People with Intellectual Disability. The ASI sincerely congratulates Prof. McCarron and all the team involved in this piece of work.

The project was funded through the HRB/HRCI Joint Funding Scheme. You can read these Guidelines here: <https://www.tcd.ie/tcaid/assets/pdf/postdiagnosticguidelines.pdf>

Pictured (left to right): Avril Kennan, CEO of Health Research Charities Ireland; Prof Mary McCarron from the Trinity Centre for Ageing and Intellectual Disability; ASI Board Member Ann Twomey

DEMENTIA IN SOCIETY

21 NOVEMBER:

The Finnish Centre for Cultural Diversity and Memory MUKES organises “50 Shades of Memory Work” webinar on “Bridging Generations and Cultures in Memory Care”



Held on 21 November 2024, the “50 Shades of Memory Work” webinar organised by the Finnish Centre for Cultural Diversity and Memory (MUKES) attracted around 120 participants from around the world. The event provided a platform to delve into issues surrounding intergenerational cooperation and culturally sensitive memory work, offering valuable insights into how memory work can support various minority groups and how intergenerational interaction can enrich communities and families.

The webinar featured a diverse group of speakers who shared their thoughts and practical examples from their own research and fields of work. Dr Alexandra Withnall from the UK explored the significance of intergenerational learning and cultural diversity in later life. Her presentation emphasised how interaction between generations can foster cross-cultural understanding and promote active ageing.

Dr Tiina Tambaum from Estonia addressed the challenges of intergenerational cooperation, emphasising that such collaboration does not happen spontaneously. She explained that careful planning and professional methods are essential to achieving sustainable and truly impactful results. Dr Erika Marek from Hungary highlighted the specific challenges related to healthy ageing among the Roma population, underlining the critical role of intergenerational support in improving the well-being of elderly Roma individuals.

Representing Malta, Dr Anthony Scerri delved into issues of gender and sexuality in the context of dementia, offering a generational perspective on this topic. Dr Josefina Antoniadis

from Australia focused on the diverse backgrounds of caregivers in dementia care, shedding light on how practical love and traditions blend into caregiving practices in Australia.

Domestic speakers brought Finnish perspectives to the webinar. Susanna Lehtovaara shared the experiences of families with foreign backgrounds in Finland, particularly how intergenerational support can strengthen immigrant communities. Siiri Jaakson, the Executive Director of MUKES, discussed the importance of intergenerational memory work with elderly immigrants and presented MUKES’s work through practical examples.

The webinar created an inspiring opportunity for learning, discussion, and networking. It highlighted how intergenerational cooperation can serve as a resource in memory work and provided participants with new tools to support various minority groups. The day emphasized the importance of combining research, practice, and community in order to develop and extend culturally sensitive memory work to reach those who need support the most. MUKES warmly thanks all the speakers and participants who made this event unforgettable!

Find out more about MUKES via:
https://mukes.fi/about_mukes.php

26 NOVEMBER:

Prestigious International Emmy Award for Belgian television programme “Restaurant Misverstand”



An International Emmy Award was given to Belgian television channel VRT 1’s programme “Restaurant Misverstand” (the restaurant that makes mistakes) with host Dieter Coppens, which gives recognition to people with young-onset dementia. The programme has won an International Emmy Award in the category of Non-Scripted Entertainment. In the VRT 1 programme, host Dieter Coppens and chef Seppe Nobels run a restaurant together with eight people with early-onset dementia. At first, things don't always run smoothly, but gradually the team becomes a well-oiled machine. It is a way to show the outside world what people with young-onset dementia can still do after their diagnosis. Due to their illness, they often face misunderstanding and are sometimes forced to stop working. One of the people with dementia

featured in the programme is Geert (pictured, bottom left), whose wife and carer Annick Germeys is a member of Alzheimer Europe’s European Dementia Carers Working Group.

The prestigious International Emmy Awards recognise the best non-American programmes in the U.S. “Restaurant Misverstand”, a production by Roses Are Blue, won over and above South Africa's 'Die brug', Mexico's 'Me caigo de risa', and Australia's 'The summit'.

Read original article (in Flemish), on the VRT website:

<https://www.vrt.be/vrtnws/nl/2024/11/26/restaurant-mis-verstand-van-dieter-coppens-wint-emmy/>

5 DECEMBER:

Women’s Brain Foundation launches new campaign aimed at raising awareness and supporting research on sex and gender considerations in Alzheimer’s disease clinical development

Alzheimer’s disease disproportionately affects women, whether as patients or caregivers. “But do women deserve to bear this unequal burden?” This is the critical question the Women’s Brain Foundation (WBF) is inviting all stakeholders to reflect



upon through its newly-launched campaign aimed at raising awareness and supporting research on sex and gender considerations in Alzheimer’s disease clinical development.

WBF’s scientific work highlights how sex and gender differences impact even key clinical outcomes, such as the Clinical Dementia Rating-Sum of Boxes (CDR-SB), as demonstrated in their recent publication in the journal Nature Aging. By addressing these disparities, the Foundation aims to transform Alzheimer’s research and care to better serve women globally.

Through this campaign, WBF is calling for collaborative action across academia, industry, regulatory bodies, and patient organisations to create a more equitable and effective approach to Alzheimer’s disease management. Find out more about WBF via: <https://www.womensbrainproject.com/>

LIVING WITH DEMENTIA

27 NOVEMBER:

“There’s still so much that’s possible, including going on vacation” writes Annick Germeys, member of the European Dementia Carers Working Group



My husband Geert and I both love to travel. For Geert, who was diagnosed a few years ago with young-onset dementia, Alzheimer’s type, it’s quite an experience. He really wants to keep traveling for many more years, but at the airport, we run into his limitations. What used to be easy and routine for years has now become stressful and difficult.

Everything needs to go smoothly and quickly, but for people with Alzheimer’s, that’s no longer so simple. To make this more comfortable for Geert, I began searching for solutions. I contacted Brussels Airlines at Brussels Airport to ask if there was a special process for people with young-onset dementia who are still physically very capable (don’t need extra assistance or a wheelchair) but who, even with support, get overwhelmed by stress and find it harder to function smoothly. I asked what they could do to help with the security process, where in Brussels there can easily be hundreds of people ahead of you in line, all impatient to start their holiday. The last few times we flew, we also had additional checks at the security . Coincidence? Geert

can appear very nervous because he doesn’t always understand the staff’s instructions, which I think may trigger suspicion. This causes him enormous stress. Simple things, like taking off his belt or watch, become difficult. Boarding and getting on the plane is also stressful — people push in the line, and others become impatient because things aren’t going as quickly as they’d like. And if you’re unlucky, you don’t sit next to each other on the plane unless you pay extra.

Luckily, we received a quick response from the medical service at Brussels Airlines. We are very grateful to Brussels Airlines for this. Their approach really deserves a compliment. Here’s what we could expect:

- Seats at the front of the plane, next to each other
- A separate line at security
- Priority boarding
- Disembark last

We found these adjustments to be truly special. The calm at security, the understanding, the reduced stress for my partner — it made a huge difference compared to our previous trip. Everything went smoothly. It’s wonderful that this is available to us.

One small comment: because Geert doesn’t appear to have any obvious disabilities — no wheelchair, still mobile — I had to explain each time to every new person we met what his limitation was. How can we make this process smoother in the future, so we don’t have to explain each time that there is indeed a limitation? I will definitely share this feedback with Brussels Airlines so they can continue working on this. We hope that other airlines and airports will follow this example, so they too can tailor their services to the needs of people with dementia. We now have the European Disability Card — can we also expand its use to transportation?

I’m happy that - just before our trip - I received a questionnaire from Alzheimer Europe asking Geert, as a person with dementia, about his experience with accessibility at airports. I’m very curious to see how Europe will take further steps in this regard and reduce barriers for people with dementia, so they can still enjoy a carefree trip.

29 NOVEMBER:

"Highlighting the power of collaboration and lived experience" - Nigel Hullah, member of European Working Group of People with Dementia reflects on 34th Alzheimer Europe Conference

The 2024 Alzheimer Europe Annual Conference successfully brought together a wide array of stakeholders to discuss pressing issues in dementia care. This year there was a healthy balance between research and practice. The event highlighted the need for ongoing research, collaboration, and advocacy to improve the lives of those affected by dementia.

This conference had a warm, engaging approach and all delegates felt supported, with many thought-provoking presentations that offered reality and future direction. As a person with lived experience of dementia I felt supported and valued by Improvement Cymru so that my voice and experiences are equal and promoted.

An overview of my contribution to the conference

I delivered two poster presentations for Lleisiau Dementia promoting our work with Improvement Cymru at the Alzheimer Europe Conference, which effectively showcased the collaborative efforts to enhance dementia care and support across Wales. The presentations highlighted the importance of integrating lived experience into dementia services and emphasised the impact of community-driven and hospital initiatives. I felt the posters were well-structured, providing clear and concise information on key topics, including:

- A focus on improving the quality of life for individuals living with dementia and their caregivers.
- Outlined the Wales Dementia Care programme focusing on the national and regional framework in place to improve dementia care as a nation working together.
- Outlining the methods used to gather data, including surveys, interviews, and engagement. This helped demonstrate the thoroughness of the dementia programme.
- Showcasing how lived experiences of people with dementia informed service development and delivery. This highlighted the value of co-production in creating relevant and effective support systems.
- Actionable recommendations for policymakers and practitioners, emphasising the need for ongoing collaboration and the importance of prioritising the voices of those affected by dementia.

We ensured that the posters were designed to be visually engaging, with a clear layout and a logical flow to make it easy for conference attendees, including those with dementia, to follow the information presented. We had many people stop and discuss the topics which highlighted how many countries are also working to promote similar themes and better dementia care. During the conference, we engaged with attendees, bringing our friendly Welsh humour and chat that encouraged questions and discussion, and people felt we were able to discuss the significance of our work in a friendly relatable manner. This interaction fostered a positive atmosphere and allowed for valuable networking opportunities.

The poster presentations underscored the critical need for person-centred approaches in dementia care. By sharing insights from both Improvement Cymru and Lleisiau Dementia, the presentation resonated with a broad audience, highlighting the importance of community involvement in addressing the challenges faced by individuals living with dementia. Overall, our presentations at the Alzheimer Europe Conference were a commendable effort that effectively communicated the significance of co-production, community and hospital support in dementia care. I felt our work in Wales and the approaches we use inspired attendees to consider how they can incorporate lived experiences into their own work. The collaboration between the two organisations exemplifies a model for future initiatives aimed at improving the lives of those affected by dementia.

Find out more and view the posters, via:

<https://www.improvementcymru.net/en/2024/11/29/highlighting-the-power-of-collaboration-and-lived-experience/>



10 DECEMBER:

Lieselotte Klotz, Vice-Chairperson of the European Working Group of People with Dementia, writes “The Three Dimensions of a Complete Life – A perspective from someone living with Lewy Body dementia”



Martin Luther King Jr’s sermon “The Three Dimensions of a Complete Life” has inspired generations to lead lives filled with meaning and depth. As Vice-Chair of the European Working Group of People with Dementia (EWGPWD) and as someone living with Lewy Body Dementia, I find not only comfort but also a vision in King’s words, a guide to living a fulfilling life despite the diagnosis. The three dimensions – length, breadth and height – offer a framework for actively shaping my life and contributing my perspective.

Length – Self-realisation despite challenges

The length of life, as King described, symbolises personal self-realisation. This dimension requires loving oneself and taking responsibility for one’s own life. For me, this means embracing my diagnosis while also holding onto my strengths. Dementia may complicate aspects of my life, but it has also taught me new ways to be creative and share my knowledge. As a speaker and co-creator in research projects, I have experienced the power of growth and the importance of contributing my lived experiences.

Breadth – Love and service to the community

The breadth of life represents love for others and service to the community. This dimension resonates deeply with my advocacy for people with dementia and their caregivers. Altruism, for me, is not just a choice but a source of strength and purpose. Despite my diagnosis, I have the privilege of being part of a network that champions social justice and inclusion. My goal is to ensure that the voices of those affected by dementia are not just heard but recognised as essential in research and policy-making.

Height – Spirituality and inner strength

The height of life reflects one’s connection to a higher power or spiritual principles. For me, this dimension is closely tied to acceptance and hope. My spirituality helps me navigate the challenges of my condition and see my role within a larger community. In moments of uncertainty, I find strength in the belief that every person – even with limitations – can make a meaningful contribution.

A holistic perspective

The three dimensions of a complete life are not abstract concepts for me but a guide to how I invest my time and energy. Martin Luther King Jr’s message reminds me that a fulfilling life is not defined by health or success but by how we love, learn, and give. As someone living with Lewy Body dementia, I see the world through new eyes – and this perspective enables me to walk my path and bridge the dimensions of my life with those of the community. A complete life is possible, despite/or perhaps because of the challenges posed by illness. It is the integration of these three dimensions that shows us: every day brings the opportunity to grow and touch others’ lives.

15 DECEMBER:

“2024 – A year of unexpected opportunity” writes Trevor Salomon, Chairperson of the European Dementia Carers Working Group

Sometimes opportunity surfaces when you’re not looking for it and when you least expect it.

That’s pretty much what happened to me in 2024. Back in March, I found myself on the guest list of attendees at a reception at 10 Downing Street, the official residence of the British Prime Minister (then Rishi Sunak), for the announcement of a GBP 6 million (EUR 7.23 million) funding boost for clinical trials and innovation, including work on how AI can be used to support dementia diagnosis and research looking at how ‘biomarkers’ found in blood can help detect the disease early.

A few months later, I met Sir Keir Starmer, who succeeded Rishi Sunak in the UK’s June general election, at the launch of the Government’s consultation process on the ten-year strategy to rebuild the UK’s National Health Service to make it fit for the



country's projected population growth and health needs. I thought that would probably be the culmination of my interaction with Government, but I was wrong.

In November, I was invited by Alzheimer's Society to join people affected by dementia at a special Alzheimer's Society parliamentary event (pictured), held in Westminster, calling on the UK Government to make dementia training mandatory for the social care workforce in England. Statistically only 29% of care workers have ever received any dementia training. At the event, Alzheimer's Society launched its "Because we're human too" report (<https://bit.ly/3DaaVmX>) which highlights why dementia training matters and how to deliver it. The research showed that scaling up dementia training for the social care workforce is economical when using person-centred, evidence-based programmes like "Wellbeing and Health for People Living with Dementia" (WHELD) and "New Interventions for Independence in Dementia" (NIDUS) Professional.

150 Members of Parliament (MPs) turned up at the event, the largest attendance achieved by Alzheimer's Society at any occasion held at Westminster. Many of those attending were new MPs following the election, and this was possibly their first exposure to dementia and the lobbying work of Alzheimer's Society. I was asked to share my story as a carer with as many of them as I could speak to on a one-to-one basis. And so, as 2024 draws to an end and I reflect on my campaigning support for dementia and the outstanding lobbying work instigated by Alzheimer's Society, I cannot help but wonder what 2025 has in store for me.

17 DECEMBER:

European Working Group of People with Dementia Chairperson Kevin Quaid reports on his participation in the recent European Day of Persons with Disabilities conference



On 24-25 November 2024, I attended the European Day of Persons with Disabilities conference organised by the European Disability Forum in Brussels (Belgium), alongside European Working Group of People with Dementia Co-Chairperson Lieselotte Klotz and colleagues from Alzheimer Europe. There were over 450 delegates from all over Europe. It was a good two days and the highlight of the event was the Accessibility Award. This award is a wonderful thing and goes to different countries every year, but there was a general feeling of a little bit of frustration among many of the delegates, as there seem to be a lot of promises made each year and not so much delivered. Our hope is that the next five years of the new European Parliament can only bring better and bigger changes.

At the conference, I pointed out that, while great emphasis is put on people who have wheelchairs or who are visually impaired or indeed anyone that has a visible disability, people with invisible disabilities and their families, including people affected by dementia and their families, are not really included and are very badly affected by this. There

are approximately eight million people who have dementia across Europe and that's not including their families, so whilst it is a wonderful thing having public transport made accessible, if the staff who are driving trains or buses, or those working at the stations are not trained to cater for people with invisible as well as visible disabilities, then we have a lot of work to do.

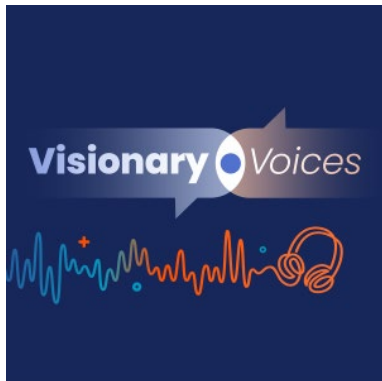
It was also pointed out that people with invisible disabilities, especially people with dementia, need to be included in the panel discussions and that more needs to be done, because people who have invisible disabilities tend to suffer more from social isolation, especially those who live in rural areas.

There was also a very strong feeling among delegates that the European Health portfolio should be a portfolio in its own right, as the portfolio currently covers Health and Animal Welfare. An argument can be made that this is because people may contract different things from animals, but surely there is such a major problem with health on its own, all over Europe, that it's a portfolio that needs to stand alone. Overall, I believe that whilst the European Day of Persons with Disabilities event was really interesting and it was great to be involved, the voice of people with invisible disabilities needs to be louder, needs to be heard and needs to be listened to!

PUBLICATIONS AND RESOURCES

12 DECEMBER:

Listen to touchNEUROLOGY’s new Visionary Voices Podcast episode discussing the creation of BrainGPT and its practical applications in neuroscience



The latest touchNEUROLOGY Visionary Voices Podcast welcomes Bradley Love, Professor of Cognitive and Decision Sciences at UCL, Fellow at the Alan Turing Institute and European Lab for Learning & Intelligent Systems (ELLIS), and the creator of

BrainGPT, to discuss the app’s creation and explore its practical applications in neuroscience. Prof. Love and podcast host Nicky Cartridge discuss how this large language model is poised to assist researchers in advancing their work. As well as providing his insights into BrainGPT’s creation and practical applications in neuroscience, Prof. Love shares his vision for AI’s evolving role in the field. Listen to the podcast, here: <https://touchneurology.com/podcast/braingpt-advancing-neuroscientific-research-with-ai/>

AE CALENDAR 2024

| DATE | MEETING | AE REPRESENTATIVE |
|---------------|---|-----------------------------|
| 7 January | Recording for the Genetics Podcast | Ange |
| 13-14 January | ADIS project General Assembly meeting (Senningerberg, Luxembourg) | Soraya and Chris |
| 15-16 January | AI4HOPE Consortium meeting (Bonn, Germany) | Dianne, Lukas and Sébastien |
| 23 January | World Dementia Council Virtual Dialogue “Lessons From Treatment” | Jean |
| 23-24 January | PREDICT-FTD Kick-Off Meeting (Rotterdam, the Netherlands) | Ange and Soraya |
| 28 January | Alzheimer's Association Academy: Engaging in health technology assessment and pricing and reimbursement processes | AE members and staff |
| 29 January | Pattern-Cog Executive Management Board Meeting | Cindy and Soraya |

CONFERENCES 2025

| DATE | MEETING | PLACE |
|----------------|--|----------------------|
| 13-16 February | 14 th Panhellenic Conference on Alzheimer's Disease and 6 th Mediterranean Conference on Neurodegenerative Diseases, https://www.alzheimer-conference.gr/index.php/en/ | Thessaloniki, Greece |

| | | |
|-------------------|--|---------------------|
| 20-22 March | 19 th World Congress on Controversies in Neurology (CONy), https://cony2025.comtecmed.com/ | Prague, Czechia |
| 1-5 April | International Conference on Alzheimer’s and Parkinson’s Diseases and Related Neurological Disorders (AD/PD™ 2025) https://adpd.kenes.com/partners-related-events/ | Vienna, Austria |
| 15-17 May | The 8 th Venusberg meeting on Neuroinflammation, https://neuroinflammation.uni.lu/ | Belval, Luxembourg |
| 3-6 June | 15 th edition of the National Alzheimer Conference, http://www.alzcongres.ro | Bucharest, Romania |
| 21-24 June | 11 th Congress of the European Academy of Neurology, Neurology within society, https://www.ean.org/ | Helsinki, Finland |
| 6-8 October | 35 th Alzheimer Europe Conference, “Connecting science and communities: The future of dementia care”, https://www.alzheimer-europe.org/conferences | Bologna, Italy |
| 12-15 October | XXVII World Congress of Neurology, https://wcn-neurology.com/ | Seoul, South Korea |
| 4-5 February 2026 | 2 nd 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 |

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

