

# ALZHEIMER EUROPE NEWSLETTER

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## WELCOME



Firstly, I would like to wish you all a Happy New Year 2024 and I hope the year has started well.

Unfortunately, we ended 2023 with the sad news of the passing of our dear friend and former member of the

European Working Group of People with Dementia, Raul Grönqvist. Our deepest condolences to his wife Milja and all his family and friends.

On a lighter note, we are pleased to have been involved in a new e-book, published by the journal Frontiers in Neurology, as part of its "Research Topics" series, which are collections of at least ten articles, all centred on a particular subject. The e-book is titled "Impacts of public-private collaborative research on Alzheimer's disease: The case of the Innovative Medicines Initiative" and I was personally delighted to co-edit the publication, alongside esteemed colleagues Elisabetta Vaudano (Innovative Health Initiative - IHI), Monica Ensini (Health and Digital Executive Agency European Commission), Martin Hofmann-Apitius (Fraunhofer Institute for Algorithms and Scientific Computing, Germany) and Donald C. Lo (National Center for Advancing Translational Sciences, USA). Several of my colleagues are also co-authors of this publication and we are all very excited that it has now been launched. You can find it for download on our website.

We have also launched an important new publication which highlights continuing inequalities in access to dementia care and

treatment across Europe: the "European Dementia Monitor 2023". It is great to see that a number of countries were able to improve the situation of people with dementia and their carers. However, as in our previous editions (2020 and 2017), we can see that progress is not the same across all European regions. Our Monitor shows that there is still a clear East/West divide in Europe with most of the Western and Northern European countries scoring significantly higher than Eastern European countries. As a rule, countries with national dementia strategies scored better. It is time, therefore, that all European countries and in particular those in Eastern Europe recognise dementia as a national priority and develop national dementia strategies. The full report "European Dementia Monitor 2023: Comparing and benchmarking national dementia strategies and policies", which was launched at our most recent European Parliament lunch debate in Brussels, can be downloaded for free via the Alzheimer Europe website. I would like to express our gratitude to Deirdre Clune MEP (Ireland), Vice-Chairperson of the European Alzheimer's Alliance, for hosting this event. We held three other meetings whilst in Brussels: A Board meeting, a company roundtable and a public affairs meeting with members.

I would also like to say thank you to Essity for organising an important online session of our Alzheimer's Association Academy series, discussing sustainable continence care with our members, as well as to all of the speakers for their excellent contributions.

**Jean Georges**  
**Executive Director**

## IN MEMORIAM

### 26 November: In Memoriam Raul Grönqvist



We were deeply saddened to learn of the passing of Raul Grönqvist, on 26 November 2023. Raoul was a former and founding member of the European Working Group of People with Dementia (EWGPWD), from 2012-2016. He left the EWGPWD in 2016, after four years of service and contributions to the group.

Raoul was born in 1951 in Helsinki, Finland. He was a tribologist and a Doctor of Technology and spoke four languages. He liked to play classical guitar and also enjoyed walking his poodle. He was diagnosed with Alzheimer's disease and dementia with Lewy bodies at the age of 60 and was nominated by Muistiliitto to join the EWGPWD, which he was glad to do, as he wanted to contribute and to help other people with dementia. He was also part of a self-support group in Finland.

We offer our deepest condolences to Raoul's wife Milja and all his family and friends.

## ALZHEIMER EUROPE

### 29 November: Alzheimer Europe co-edits new Frontiers in Neurology e-book on "Impacts of public-private collaborative research on Alzheimer's disease: The case of the Innovative Medicines Initiative"



A new e-book, called "Impacts of public-private collaborative research on Alzheimer's disease: The case of the Innovative Medicines Initiative" has been published as part of the Frontiers in Neurology journal series called "Research Topics". These Research Topics are collections of at least ten articles, all centred on a particular subject. This new Research Topic e-book was edited by Elisabetta Vaudano (Innovative Health

Initiative - IHI), Jean Georges (Executive Director, Alzheimer Europe), Monica Ensini (Health and Digital Executive Agency European Commission), Martin Hofmann-Apitius (Fraunhofer Institute for Algorithms and Scientific

Computing, Germany) and Donald C. Lo (National Center for Advancing Translational Sciences, USA) and was published on 29 November 2023. It consists of an editorial article and a further 11 topic articles, about the work done by existing and former IMI (and IHI) projects in which Alzheimer Europe is or was a partner (AMYPAD, EPAD, EPND, Neuronet, IHI-Prominent and RADAR-AD). Contributing authors include Alzheimer Europe staff members Cindy Birck (Project Officer), Angela

Bradshaw (Director for Research and Policy), Ana Diaz (Public Involvement Lead), Dianne Gove (Director for Public Involvement and Ethics), Daphné Lamirel (Public Involvement Officer) and Soraya Moradi-Bachiller (Public Involvement Officer). You can download the e-book via the Alzheimer Europe website:

<https://www.alzheimer-europe.org/resources/publications/impacts-public-private-collaborative-research-alzheimers-disease-case>

### 4 December: Member of the European Working Group of People with Dementia Marguerite Keating speaks at Lilly symposium at our Annual Conference, inspiring new EU Observer article and video

"Be remembered" is the message from Eli Lilly & Co (Lilly) to policymakers in a newly-published EU Observer article titled "[Optimising Alzheimer's disease health care pathways across Europe](#)" and in its corresponding [animation video](#), inspired by the company's special symposium at the 33<sup>rd</sup> Alzheimer Europe Conference in Helsinki. At the symposium, "Optimizing Alzheimer's disease health care pathways today: best practices in action", European Working Group of People with Dementia member Marguerite Keating made vital and moving contributions as a speaker and her voice and story feature strongly in the new article. In the article and corresponding animation video, Lilly stresses that "policymakers have a unique opportunity to be remembered for improving the Alzheimer's



disease care pathway and transforming the way the disease is managed”.

Read the article: <https://euobserver.com/stakeholders/157773>

Watch the video:

<https://www.youtube.com/watch?v=3aMlamj5vho>

## 5 December: Alzheimer Europe organises a Company Round Table meeting in Brussels



On 5 December 2023, 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. It was attended by company representatives from Alzheon, Biogen, Bristol

Myers Squibb, Eli Lilly, EFPIA, Essity, Novo Nordisk, Nutricia and Roche, members of the AE staff and members of the AE Board. 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. Next, Angela Bradshaw, AE Director for Research and Policy, presented the AE Call for Action on anti-amyloid treatments. Owen Miller, AE Project Officer, shared then some updates on EU policy developments and European Parliament elections. Finally, Jean Georges, AE Executive Director, informed participants about Alzheimer Europe's activities in 2023 and the work plan and sponsorship opportunities for 2024. He also presented the future directions of the AE Company Round Table Meetings and opened the discussion with the audience.

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 in March.

## 5 December: New Alzheimer Europe publication highlights continuing inequalities in access to dementia care and treatment across Europe

On 5 December 2023, in a report launched at a lunch debate hosted by Deirdre Clune MEP (Ireland) in Brussels, Alzheimer Europe highlighted the continuing inequalities in access to dementia care and treatment across Europe.

The objective of the report entitled “European Dementia Monitor” was to provide a benchmark of national dementia policies in order to compare and rate the responses of European countries to the dementia challenge. The survey covered all Member States of the European Union (with the exception of Latvia), as well as Armenia, Iceland, Israel, Jersey, North Macedonia, Norway, Serbia, Switzerland, Turkey, United Kingdom (both England and Scotland) and Ukraine.

Jean Georges, Executive Director of Alzheimer Europe, stated: “Our organisation has consistently called upon European governments to recognise dementia as a national public health and research priority, and to develop national dementia strategies. The aim of the European Dementia Monitor is to assess which countries provide the most dementia-inclusive policies and guarantee the best support and treatment of people with dementia and their carers. This third edition of our report shows continuing inequalities between European countries, and we hope that national governments will use this report to improve the lives of people with dementia and their carers in those areas where they are currently lagging behind.”

The European Dementia Monitor compares countries on 10 different categories:

1. The availability of care services
2. The affordability of care services
3. The reimbursement of medicines and other medical interventions
4. The availability of clinical trials
5. The involvement of the country in European dementia research initiatives
6. The recognition of dementia as a policy and research priority
7. The development of dementia-friendly initiatives
8. The recognition of legal rights
9. The ratification of International and European human rights treaties
10. Care and employment rights

According to the findings of the European Dementia Monitor, no country excelled in all 10 categories and there were significant differences between European countries. Some of the key findings were:

- Luxembourg scored highest on care availability with most services rated as sufficiently available, whereas Norway scored highest on care affordability as it ensured that these services were accessible and affordable for people with dementia and their carers. On both care availability and care affordability, Bulgaria ranked last.
- On the availability and reimbursement of medical interventions, Sweden scored highest as all included medical interventions (with the exception of Fortasyn Connect) were covered by the national reimbursement system. Armenia ranked last in this category as none of the medical interventions were reimbursed.





- As Europe is waiting for the authorisation by the European Medicines Agency of new anti-amyloid treatments for Alzheimer's disease, only Greece, Ireland, Slovakia, Sweden and the United Kingdom (England) had set up a working group or strategy to prepare for the introduction of these new treatments.
- France scored highest in the category of clinical trials as the only country where it was possible for people with dementia to take part in eight of the 10 phase III clinical trials which were studied for the report. The Netherlands, Spain and the United Kingdom came second, with seven clinical trials active in these countries. Armenia, Lithuania, Luxembourg, Malta and North Macedonia were on the other end of the scale, with no clinical trials available for people with dementia in those countries.
- France, Germany and the Netherlands were the countries that were the most active in European dementia research collaborations scoring 100% in that category, whereas Armenia, Cyprus, Greece, Iceland, Lithuania, Malta, North Macedonia, Serbia and Ukraine were not involved in the Joint Programme for Neurodegenerative Diseases Research (JPND) or any of the calls for European research collaboration.
- For recognition of dementia as a national policy and research priority, the United Kingdom (Scotland) came first with full marks whereas North Macedonia, Serbia and Ukraine did not score any points in this category.
- The United Kingdom (England and Scotland) had the most dementia-inclusive initiatives and communities, but Luxembourg, North Macedonia, Portugal and Serbia did not score any points in this category.
- Regarding the protection of the legal rights of people with dementia, a growing number of countries complied with Alzheimer Europe's five recommendations in this field (Austria, Croatia, Czech Republic, Denmark, France, Germany, Iceland, Ireland, Israel, Italy, Jersey, Netherlands, Norway, Portugal, Slovenia, Spain, Sweden and the United Kingdom (England)). However, Bulgaria, North Macedonia, Poland and Romania scored no points in this category.
- In relation to International and European Human Rights Conventions, there has been progress since earlier editions of the Monitor (2017 and 2020), with an increasing number of countries (Cyprus, Czech Republic, Estonia, Finland, France, Greece and Portugal) having signed and ratified all of the treaties. Israel was the country with the least number of conventions signed and ratified.
- The Czech Republic, the Netherlands and the United Kingdom (Scotland) were the three countries where all care and employment rights were recognised, whereas Armenia, Cyprus and Ukraine came last in this category with none of these rights recognised in legislation.

Deirdre Clune MEP (Ireland) welcomed the findings of the European Dementia Monitor:

"As a Member of the European Parliament and as Vice-Chairperson of the European Alzheimer's Alliance, I am interested in how European countries differ in their approaches to dementia care and treatment, and I hope that reports like this one can help identify good practices to be implemented in countries lagging behind. As an Irish MEP, I was happy to see that Ireland excelled in some key areas with the development of our national dementia strategy, the Irish Dementia Working Group and the recognition of legal rights. However, my country has some catching up to do in other areas, and more efforts need to be made to provide more accessible and affordable care services. Similarly, I would hope that more clinical trials will be conducted in Ireland to allow people with dementia to participate in research for the development of new and better treatments."

On the basis of the findings in the 10 identified categories, Alzheimer Europe established a ranking of countries (with each category contributing 10% to the overall score), with the Netherlands coming first with an overall score of 77.6%, followed by the United Kingdom (Scotland) (74.5%), the Czech Republic (74.2%), Germany (72.7%) and Sweden (70.7%). Compared to the 2020 edition of the Dementia Monitor, the Netherlands and the Czech Republic improved their scores and ranking the most, moving up from seventh to first and from 19<sup>th</sup> place to third place respectively. The United Kingdom (Scotland) and Germany also slightly improved their scores, but Scotland stayed in second place while Germany moved from fifth to fourth place. Sweden moved down from first to fifth place in this year's ranking, whereas the United Kingdom (England) and Belgium dropped out of the top five and moved to eighth and ninth place respectively.

Gerjoke Wilmink, CEO of Alzheimer Nederland, welcomed the findings:

"I was delighted to see that the Netherlands came first in this extensive survey of Alzheimer Europe. There has been a very strong commitment in my country to finding practical solutions and concrete support for the many people living with Alzheimer's disease and other types of dementia. We are happy to continue sharing our experiences and good practices with our partner organisations within Alzheimer Europe, and look forward to learning from those countries in categories where the Netherlands did less well."

Jean Georges, Executive Director of Alzheimer Europe, concluded:

"It was great to see that a number of countries were able to improve the situation of people with dementia and their carers. However, as in our previous editions, we can see that progress is not the same across all European regions. Our Monitor shows that there is still a clear East/West divide in Europe with most of the Western and Northern European countries scoring significantly higher than Eastern European countries. As a rule, countries with national dementia strategies scored better. It is time therefore that all European countries and in particular

those in Eastern Europe recognise dementia as a national priority and develop national dementia strategies.”

The full report “European Dementia Monitor 2023: Comparing and benchmarking national dementia strategies and policies” can be downloaded for free:

<https://www.alzheimer-europe.org/resources/publications/european-dementia-monitor-comparing-and-benchmarking-national-dementia>

## 5 December: Alzheimer Europe hosts lunch debate and launches European Dementia Monitor



Alzheimer Europe welcomed attendees to its lunch debate on 5 December 2023 in Brussels, Belgium, hosted by Vice-Chair of the European Alzheimer’s Alliance (EAA), Deirdre Clune MEP (Ireland). During the session, Alzheimer Europe launched its European Dementia Monitor and shared key messages for its forthcoming election campaign.

Ms Clune opened the session by noting that these events were a welcome opportunity to bring together stakeholders from across civil society, industry, governments, academia and people with lived experience to share knowledge, experiences and information. She further expressed her view that coming together from different countries and backgrounds was essential to ensure that dementia remains a political priority.

She welcomed the work on the Dementia Monitor 2023, explaining that benchmarking the situation in countries across Europe allowed for the identification of the gaps in policies and services within countries, whilst also identifying trends across Europe. Ms Clune stressed the need to better coordinate efforts at a European level to better utilise the knowledge and resources from different levels, to drive improvements in policy and practice.

### European Dementia Monitor

Alzheimer Europe’s Executive Director, Jean Georges, opened by introducing the objectives of the European Dementia Monitor. Following Jean’s presentation, attendees heard the thoughts and reactions from a panel comprised of people with lived experience of dementia and professionals working in the health field:

- Chair of the European Working Group of People with Dementia – Chris Roberts
- Chair of the European Dementia Carers Working Group – Sonata Mačiulskytė
- Executive Director of European Patients’ Forum – Anca Toma
- Senior policy advisor international affairs and dementia research, Netherlands Government – Abida Durrani

Chris stated that the report was excellent resource and commended Alzheimer Europe on its work, welcoming that progress had been made in a number of areas. He noted that financing and resources was a key barrier to action and progress in a number of areas. Additionally, he expressed surprise that so many countries do not recognise dementia as a disability, as well as the lack of training and support for informal carers, despite them being key to supporting people with dementia. He also expressed disappointment that so many countries were failing to take action on the misuse of anti-psychotic medications, particularly given the potential harm that such drugs have for people with dementia.

Sonata also welcomed the report, noting it was a useful exercise to compare and benchmark progress, especially for neighbouring countries, noting that the Baltic countries often compared their situation. She noted that it was helpful to have the “big picture” across Europe and to see the inconsistent progress across Europe – she highlighted that the presence of a dementia strategy wasn’t necessarily a guarantee of progress in all areas. She expressed her surprise at the lack of dementia-inclusive initiatives in so many countries, whilst also highlighting that availability and affordability of care services were crucial to the quality of life of individuals.

Anca shared that from her personal perspective, it was disappointing to see Romania ranked so lowly in many categories, reflecting on her own experience, with her mother caring for her grandmother who has Alzheimer’s. She noted that it was surprising to see so many countries not having ratified human rights treaties and that the EU needed to take further actions to embed basic rights-based approaches across Europe. She further noted that despite conversations about ageing demographics and about preparations for the future, there was still a lack of services and supports for people with dementia and carers now. However, she welcomed that the situation was improved compared to three years ago.

Abida expressed that she was pleased to see the Netherlands do well in many areas but that there was work still to do. She shared some of the activities ongoing in the Netherlands, including the 2021-2030 Dementia Strategy, which focuses on research and anti-stigma, as well as care and support, and assistive technologies. She further noted that the setup of the health and care systems and relevant legislation, was a key factor in ensuring people’s needs were covered – in the Netherlands there are three complementary pieces of legislation which ensure that everyone’s needs are covered. However, she also noted that as societies age, ensuring access

to care will become more difficult and that as such, preventative approaches were becoming more important as well.

#### **Alzheimer Europe election campaign 2024**

Alzheimer Europe Policy Officer, Owen Miller, presented on the organisation's plans for the 2024 European Parliament elections. He provided a brief overview of Alzheimer Europe's previous campaigning activities, including the Paris Declaration 2006 and the Glasgow Declaration 2014, as well as the European Parliament election campaigns of 2014 and 2019.

Setting out Alzheimer Europe's approach to the election, he outlined the key messages of the campaign, which would highlight the increasing prevalence and cost of dementia across Europe, the need for greater focus on dementia within health and research programmes, the need for dementia to be recognised as a disability and the need for greater support for informal caregivers.

He further explained that the campaign would have three distinct elements:

1. The Helsinki Manifesto – a document outlining specific demands of the European Commission and national governments, which will be the basis of Alzheimer Europe's public affairs work in the coming years.
2. A public Call to Action – a short statement highlighting the key figures associated with dementia cost and prevalence, to which members of the public will be invited to sign up to demand that European decision makers prioritise dementia as a priority issue.
3. The Dementia Pledge 2024 – a short commitment to which candidates standing for the European Parliament elections will be invited to sign, pledging their support, following their election, for dementia in the areas of health, research, disability policy and informal carers.

The campaign will begin officially launch in January 2024.

#### **Closing remarks**

Alzheimer Europe Chair, Maria do Rosário Zincke Dos Reis, closed the session, thanking the attendees for their participation and the panel members for sharing their reactions to the Dementia Monitor, noting that the report had highlighted the inequities for the diagnosis and treatment of dementia across Europe. She further noted the importance of all associations taking part in the European election campaign to convince decision makers to prioritise dementia as a policy issue. The videos of the presentations from the lunch debate can be watched here:

<https://www.youtube.com/playlist?list=PLO-PgQHI1WQVfFRfuNGYkClui9b4xQBtQ>



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## **5-6 December: Alzheimer Europe Public Affairs meeting brings together 18 member organisations from across Europe**



On 5-6 December 2023, Alzheimer Europe hosted its final in-person meetings of the year, in Brussels. The organisation was delighted to welcome representatives from 18 of its member associations from all across Europe, providing a forum in which to share learnings, challenges, and good practices regarding policy developments and campaigning activities at both national and European level.

The meeting started with a warm welcome from Maria do Rosário Zincke dos Reis, Chairperson of Alzheimer Europe (Portugal), followed by a series of presentations by Alzheimer Europe staff and from members. Topics included:

- **The Helsinki Manifesto:** Policy Officer Owen Miller shared some opportunities for EU advocacy activities, while Project Communications Officer Christophe Bintener shared some ideas and plans for national advocacy activities around the Manifesto.
- **The advent of anti-amyloid treatment for Alzheimer's disease in Europe:** Director for Research and Policy Angela Bradshaw presented Alzheimer Europe's call for action in this area.
- **The European Dementia Monitor:** Executive Director Jean Georges shared some opportunities for EU advocacy activities and ideas for collaboration with Members of the European Parliament, inviting member associations attending the meeting to share their reactions to the Monitor and discuss ideas for national advocacy around this new publication.
- **Brain health in national Alzheimer's associations:** Angela Bradshaw shared some highlights in the area of brain health and dementia, from the 33<sup>rd</sup> Alzheimer Europe Conference in Helsinki, while member associations from France (Lorène Gilly, France Alzheimer), Lithuania (Ieva Petkutė, Dementia Lithuania), Netherlands (Julie Meerveld, Alzheimer Nederland), United Kingdom - Scotland (Mary-Frances Morris, Alzheimer Scotland) and Switzerland (Stefanie Becker, Alzheimer Suisse) shared some examples of brain health programmes and activities in their



countries. A discussion session followed, around some of the needs of Alzheimer Europe's members, regarding their work to promote brain health activities at national level.

In closing, Jean Georges shared some of Alzheimer Europe's scheduled meeting dates and planned activities for 2024 and then gave the floor to Maria do Rosário Zincke dos Reis who closed the meeting, reminding national member organisations of the next Public Affairs meeting, on **19-20 March 2024**, in Brussels.

## 11 December: Alzheimer Europe and Essity co-host an Alzheimer's Association Academy session on sustainable continence care

### Speakers



On 11 December 2023, Alzheimer Europe and Essity co-hosted an online Alzheimer's Association Academy session discussing "Sustainable continence care".

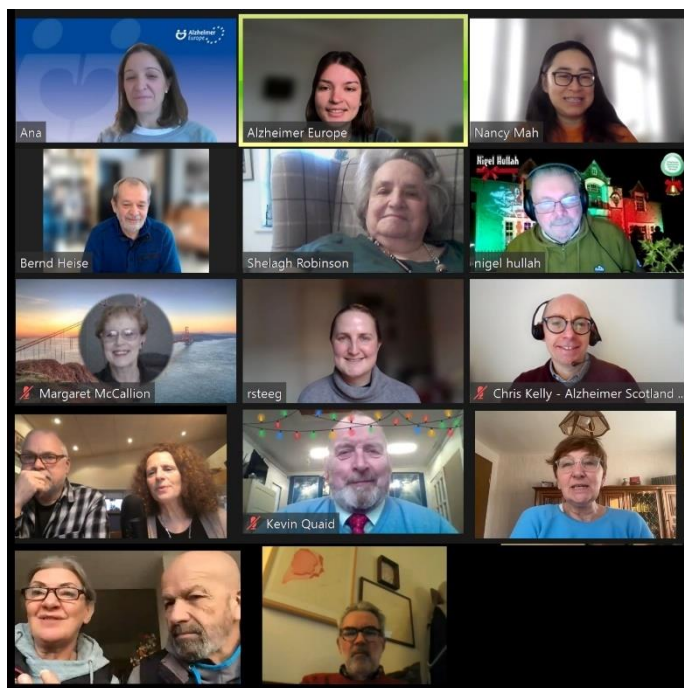
Speakers included:

- Sofia Kriegsman (Essity), who chaired the Academy session
- Paul van Houten, a specialist in elderly care, whose presentation was on "Dementia - Toileting & Containment Care process"
- Trevor Salomon, Vice-Chairperson of the European Dementia Carers Working Group, who shared his personal story and experience of encountering incontinence through his wife's dementia
- Torbjörn Rudmark, Global Brand and Sustainability Manager for Essity's continence care brand TENA, whose talk was on "Sustainable Continence Care – Doing more with less"
- The fourth and final speaker was Matthijs Pauwels, Product Specialist for TENA SmartCare at Essity, who presented "Digital Health Technology – Optimising the care process".

Alzheimer Europe would like to express its gratitude to Essity for organising this important and interesting session of our Alzheimer's Association Academy series and to all of the speakers for their excellent contributions. Continence care is such an important topic that is not talked about enough and we were delighted to help shed some light on an area where there is still a lot of shame and stigma. We hope this session and others like it will help reduce the stigma and increase understanding and the sharing of good practices. Our next

Academy session is scheduled to take place online, on **23 January 2024**.

## 13 and 15 December: EWGPWD meets for an online consultation to share their perspectives with the EBiSC Biobank



On 13 and 15 December, the EWGPWD met online for a consultation with the European Biobank, EBiSC. EBiSC is a biobank that stores cells so that they can make them available to other researchers. The EBiSC biobank is a not-for-profit which was initially founded through a European project and is now operated in the UK and Germany.

During the meeting, members of the EWGPWD were asked about their first impressions and opinions about EBiSC. Members also commented on how understandable the EBiSC website page is for the general public. The members were then asked about whether they had any concerns about commercial companies using such biological material and the pros and cons of sharing IPS cells. All the EWGPWD participated actively during the meeting, sharing very helpful feedback and opinions.

## 15 December: Alzheimer Europe signs Memorandum of Understanding with Joint Artificial Intelligence Network Foundation

This December, Alzheimer Europe has signed a Memorandum of Understanding to collaborate with JAIN Foundation ([Joint Artificial Intelligence Network](#)) during their World JAIN Challenge (WJC) in April 2024. Alzheimer Europe's goals of advancing dementia care and research aligns with JAIN, a community developing e-health products and services for people with Alzheimer's and other dementias, with the purpose of increasing their self-reliance and quality of life, to extend the time that they can remain independent at home, to support

informal carers, family, and healthcare professionals and by promoting affordable healthcare.

JAIN plans to involve representatives from the European Working Group of People with Dementia and the European Dementia Carers Group in the evaluation of submitted proposals and products related to dementia care and research, with the facilitation of Alzheimer Europe.

### **18 December: EWGPWD meets online for an end-of-year social gathering!**



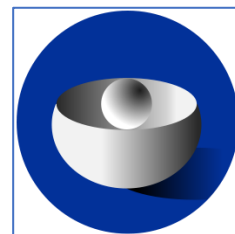
On 18 December, the members of the EWGPWD and supporters gathered online with Ana Diaz (Public Involvement Lead) and Daphné Lamirel (Public Involvement Officer) to celebrate the end of the year. During the meeting, the members played a game where they looked at photos of them from the past and were asked if they recognised who was in the picture. Some members also talked about some of their national festive traditions. The meeting ended with Ana and Daphné thanking all the members of the EWGPWD for all their impressive and

invaluable work in 2023 and wishing all members their best wishes for the new year.

### **19 December: Alzheimer Europe continues to comply with European Medicines Agency's strict eligibility criteria**

On 19 December 2023, the European Medicines Agency (EMA) confirmed that Alzheimer Europe continues to comply with its strict eligibility criteria, as defined by its Management Board, and can continue to be involved in its activities. The list of all the patients' and consumers' organisations that are involved in EMA activities can be viewed here:

<https://www.ema.europa.eu/en/partners-networks/patients-consumers/eligible-patients-consumers-organisations>



**Help us give a voice to people with dementia**

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## **ALZHEIMER EUROPE NETWORKING**

On 1 December (Steinfurt, Luxembourg), Chris attended a course about Google Ad Grants.

On 1 December, Ana attended the kick-off meeting of the INTEREST project.

On 4 December (Brussels, Belgium), the Alzheimer Europe Board met.

On 4 December, Angela participated in the EMA/HMA Big Data Stakeholder Forum.

On 5 December (Brussels, Belgium), Alzheimer Europe organised a company round table meeting.

On 5 December (Brussels, Belgium), Alzheimer Europe organised a lunch debate "Inequalities in access to dementia care and treatment in Europe".

On 5 December, Ana and Soraya facilitated a consultation with the Predictom Advisory Board.

On 5 and 6 December (Brussels, Belgium), Alzheimer Europe organised a public affairs meetings with its national member organisations.

On 7 December, Angela participated in a meeting of the EMA Network Advisory Group on Raw Data.

On 8 December, Jean met with Marjolein de Vugt to discuss the collaboration between Alzheimer Europe and INTERDEM.



On 11 December, Alzheimer Europe and Essity organised an Alzheimer's Association Academy meeting on "Sustainable Continence Care".

On 12 December (Paris, France), Angela participated in the 17<sup>th</sup> Rencontres France Alzheimer.

On 12 December, Soraya participated in the ADIS Advisory Board Xmas get together.

On 12 December (Florence, Italy), Gwladys attended Italian Knowledge Leaders, The Exchange.

On 13 December (Florence, Italy), Gwladys met with OIC.

On 13 and 15 December, Ana, Soraya and Daphné facilitated a consultation of the EWGPWD with the European bio-bank EBISC.

On 15 December, Jean met with the EFPIA AD Platform.

On 15 December, Jean attended a meeting with national representatives to explore collaboration with the upcoming EU Joint Action on Dementia.

On 18 December, Ana and Daphné participated in the EWGPWD Xmas get together.

On 19 December, Ana and Cindy participated in the EU-FINGERS and Lethe Advisory Boards' Xmas get together.

On 22 December, Angela participated in a preparatory meeting for BRIDGE-AD.

## Sponsors of the month

Alzheimer Europe would like to express its gratitude to two new sponsors for 2024!

Read more about sponsorship opportunities here:

<https://www.alzheimer-europe.org/about-us/governance/finances/2023-sponsorship-opportunities>



in people with mild cognitive symptoms from the European Prevention of Alzheimer's Dementia (EPAD) Longitudinal Cohort Study, considering the influence of memory performance. A total of 442 participants aged >50 years with a Clinical Dementia Rating (CDR) score of 0.5 completed the Pittsburgh Sleep Quality Index questionnaire and underwent neuropsychological assessment, magnetic resonance imaging acquisition, and CSF sampling. Authors analysed the relationship of sleep quality with CSF AD biomarkers and cognitive performance in separated multivariate linear regression models, adjusting for covariates. Poorer cross-sectional sleep quality was associated with lower CSF levels of phosphorylated tau and total tau alongside better immediate and delayed memory performance.

Congratulations to the authors: Laura Stankeviciute, Jonathan Blackman, Núria Tort-Colet, Ana Fernández-Arcos, Gonzalo Sánchez-Benavides, Marc Suárez-Calvet, Álex Iranzo, José Luis Molinuevo, Juan Domingo Gispert, Elizabeth Coulthard, Oriol Grau-Rivera. You can read the paper here:

<https://doi.org/10.1111/jsr.14108>

## EU PROJECTS

**30 November: New EPAD paper out investigating the association between subjective sleep measures and CSF biomarkers of AD**



Sleep disturbances are prevalent in Alzheimer's disease (AD), affecting people during its early stages. In a new paper published in the Journal of Sleep Research, Spanish researchers from the Barcelonaβeta Brain Research Center (BBRC) investigated associations between subjective sleep measures and cerebrospinal fluid (CSF) biomarkers of AD

**12 December: Members of the ADIS Advisory Board get together before the festive season**



On 12 December, the members of the ADIS Advisory Board (ADIS AB) participated in a social gathering before the end of the year. During the meeting, Alzheimer Europe Public Involvement Officer Soraya Moradi-Bachiller shared an overview of the activities organised with the ADIS AB in 2023 and how the feedback provided by the members was used by the ADIS research team. After this summary, the members shared their plans for the upcoming festive season. At the end

of the meeting, and on behalf of the project's partners, Soraya thanked the group for all the great work done and all the contributions made, noting that it had been a pleasure to work with all of them.

For more information about the ADIS project and its Advisory Board, please visit: [homepage - a-dis-project.eu](https://homepage-a-dis-project.eu)

## 14 December: The Multi-MeMo project launches its website



The Multi-MeMo project stands for "Shorter- and longer-term mechanisms of multimodal interventions to prevent dementia". Funded by the EU Joint Programme – Neurodegenerative Disease Research (JPND), the European project officially started in Q2 2023 and has a duration of three

years. On 14 December, the Multi-MeMo consortium announced the official launch of its website. For more information about the project, please visit the project's website: <https://www.multi-memo.eu>

## 18 December: AI-Mind study achieves its recruitment target across four European countries



In a ground-breaking development, the AI-Mind study, launched in January 2022, has successfully reached its recruitment target of 1,000 participants with Mild Cognitive Impairment (MCI) across four European countries (Finland, Italy, Norway and Spain). This marks a significant achievement

for the largest study of its kind in Europe, aimed at developing and validating Artificial Intelligence (AI)-based tools to predict who is likely to develop dementia.

The study has seen complete enrolment in Norway, Italy, and Spain, while in Finland, efforts are ongoing to recruit additional participants to meet the national target of 250 participants. At the moment, participants, aged between 60 and 80 years, are visiting the clinical sites for their second and third visits. This milestone is a significant accomplishment for the study team, who expressed gratitude to all those who joined them. The commitment of participants demonstrates their dedication to advancing research in the field.

Participants in the study play a crucial role in the development and validation of AI-based tools designed to predict the likelihood of dementia. The study involves interviews with researchers, procedures to measure electrical activity in the brain (electroencephalography and magnetoencephalography),

cognitive tests, and blood tests, providing a multifaceted approach to understanding and predicting dementia risk.

Recently, the AI-Mind members released its second study newsletter, offering an in-depth look at the advancements in dementia research, the ongoing progress of the AI-Mind project and the dedicated team of researchers working on it. The newsletter not only delves into the study's goals and methodologies but also provides valuable information on the prevalence of dementia and the Alzheimer's disease continuum. You can read the newsletter here: [https://www.ai-mind.eu/wp-content/uploads/sites/39/2023/12/AI-Mind\\_Study\\_Newsletter\\_issue2\\_EN.pdf](https://www.ai-mind.eu/wp-content/uploads/sites/39/2023/12/AI-Mind_Study_Newsletter_issue2_EN.pdf)

The study newsletter will be released every four months. If you are interested to receive the latest updates and insightful content, subscribe to the AI-Mind newsletter at <https://www.ai-mind.eu/subscribe/>

"It is truly heartening to hear about the motivation and willingness of our participants. Their enthusiasm significantly contributes to the success of the AI-Mind research.", said Ira Haraldsen, the AI-Mind project coordinator.

## 19 December: Members of the EU-FINGERS and LETHE Advisory Boards enjoy a social gathering before Christmas



On 19 December, the members of the EU-FINGERS and LETHE Advisory Boards participated in a joint social gathering before Christmas. During the meeting, members spoke about the recent face-to-face meeting organised in Luxembourg and shared their plans for the holidays and thoughts about the upcoming festive time. It was a nice atmosphere and the project's partners thanked the group and highlighted that it had been a pleasure to work with all members this year. 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 both Advisory Boards. AE Project Officers Cindy Birck and Ana Diaz participated in the event.

For more information about EU-FINGERS and LETHE projects, visit: [www.eufingers.com](http://www.eufingers.com) and [www.lethe-project.eu](http://www.lethe-project.eu)



## EU project acknowledgements



A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon2020 or from the Innovative Medicines Initiative, Innovative Medicines Initiative 2, and the Innovative Health Initiative Joint Undertakings. The Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA. The projects in this newsletter are:

**AI-MIND** – grant agreement 964220

**LETHE** – grant agreement 101017405

**EPAD** – grant agreement 115736



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

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

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

## Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at **87**, representing **26** out of 27 Member States of the European Union and seven out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance (EAA):

**Austria:** Claudia Gamon (Renew Europe); Monika Vana (Greens/EFA). **Belgium:** Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D). **Cyprus:** Costas Mavrides (S&D). **Czech Republic:** Tomáš Zdechovský (EPP). **Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe); **Finland:** Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France:** François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). **Greece:** Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraiki (EPP); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland:** Barry Andrews (Renew Europe); Deirdre Clune (EPP); Ciarán Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke 'Ming' Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Grace O'Sullivan (Greens/EFA). **Italy:** Isabella Adinolfi (EPP); Brando Benifei (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:**



Vilija Blinkėvičiūtė (S&D). **Luxembourg:** Marc Angel (S&D); Charles Goerens (Renew Europe); Tilly Metz (Greens/EFA); Isabel Wiseler-Lima (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). **Poland:** Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP). **Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP). **Romania:** Cristian-Silviu Busoi (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (Renew Europe); Matjaž Nemec (S&D); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens/EFA); Ernest Urtegas (Greens/EFA). **Sweden:** Peter Lundgren (ECR).



## EU DEVELOPMENTS

### 30 November - 1 December 2023: Representatives from Alzheimer Europe and the European Working group of People with Dementia attend European Day of Persons with Disabilities in Brussels



On 30 November-1 December 2023, Kevin Quaid (Vice-Chair of the EWGPWD) and his wife Helena attended the European Day of Persons with Disability, together with Daphné Lamirel (Public Involvement Officer at Alzheimer Europe).

The event brought together over 400 disability advocates and experts from all around Europe and was organised by the European Commission and the European Disability Forum. Several experts as well as people with disabilities were invited to present on various topics, and attendees had the opportunity to ask questions and make comments at the end of each panel discussion.

The first part of the event focused on the topic of the right of people with disabilities to vote and to stand for elections. Secondly, as 2023 marks the European Year of Skills, the event also focused on exploring how to support the inclusion of persons with disabilities in the labour market. The final part of the event consisted of presentations about the current progress made by the EU Strategy for the rights of persons with disabilities. Discussions centred around what has been achieved in the last 3 years and what remains to be done to achieve a Union of equality where persons with disabilities can fully enjoy their rights.

### 5 December: European Commission publishes EU4Health Work Programme 2024

The European Commission has adopted the EU4Health Work Programme 2024, which allocates EUR 752.4 million of funding, to address health-related issues across the EU. The adoption of the work programme follows a positive opinion from Member States in the EU4Health Programme Committee on 28 November.

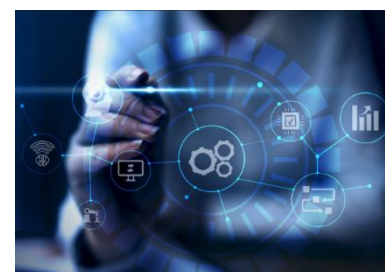


Key areas of focus include increasing the EU's crisis preparedness through the European Health Preparedness and Response Authority (HERA), ensuring the rollout of digital initiatives such as the European Health Data Space (EHDS) and delivering on policy areas such as the Pharmaceutical Strategy for Europe.

Of particular note, the importance civil society organisations in supporting the implementation of EU health policies is recognised, with operating grants of EUR 9 million made available for 2024, with a commitment to publish a call for Framework Partnership Agreements for 2025 to 2026. Further information on the Work Programme is available at: [https://health.ec.europa.eu/publications/2024-eu4health-work-programme\\_en](https://health.ec.europa.eu/publications/2024-eu4health-work-programme_en)

### 9 December: EU announces provisional agreement on the landmark Artificial Intelligence Act

First proposed by the European Commission in April 2021, the European Parliament has agreed to the world's first ever comprehensive legal framework on Artificial Intelligence (AI). This ground-breaking Act is a risk-based approach designed to protect citizens and guide AI developers and deployers. It must be formally adopted by both the Parliament and Council to become EU law and will come into full effect in 2026. The Act does not cover AI used for military/defence, research/innovation or individual, non-professional use.



AI systems that manipulate human behaviour to circumvent a citizen's free will or exploit vulnerable people are considered an 'unacceptable risk' and are prohibited, including emotional recognition in the workplace, untargeted scraping of facial images from CCTV/internet to create facial recognition databases and Biometric identification.

AI systems are 'high risk if they could potentially risk a citizen's life or health and are subject to a mandatory fundamental rights impact assessment (amongst other requirements) prior to approval. This includes AI systems for critical infrastructures, medical devices, the education system, recruitment, border control, the justice system, and biometric identification, categorisation and emotion recognition systems. Law enforcement use of AI biometrics is limited to targeted searches for victims or specific criminals and prevention of specific terrorist attacks.

General AI systems and models capable of quick expansion/development with a potential threat of systemic risks will be subject to additional binding obligations, requiring mandatory codes of practice.

'Minimal risk' AI systems (a category most current AI systems fall into) have no obligations, but companies can voluntarily apply codes of conduct for use. These are deemed to pose little to no risk to a citizen's rights or safety (e.g. AI-enabled recommender systems or spam filters). 'Specific transparency risk' applies to AI systems such as chatbots which must be labelled as such to ensure that the user is aware that they are interacting with AI.

Looking forward to the development and implementation, a new European AI office will be established to monitor and enforce, the first of its kind globally. National market surveillance authorities will supervise implementation at a national level, and the EU continues its work towards trustworthy AI at an international level with the OECD, G7, G20 and UN. Read the European Commission's press release: [https://ec.europa.eu/commission/presscorner/detail/en/IP\\_23\\_6473](https://ec.europa.eu/commission/presscorner/detail/en/IP_23_6473)

## 12 December: "Civil Society for EU" campaign launched



In the run up to the 2024 European election campaign, Civil Society Europe and Social Platform have launched a campaign, "Civil Society for EU", which advocates for better recognition, protection and support to civil society in the EU.

The campaign has a dedicated website and a manifesto which

has been endorsed by more than 170 civil society organisations and networks. The manifesto calls on decision-makers to reverse the trends of shrinking civic space and limited opportunities of dialogue between civil society and policy makers, through the adoptions of two concrete policy measures: adopting a Civil Society Strategy and concluding a Civil Dialogue Agreement. Alzheimer Europe has endorsed the

manifesto. The campaign website and manifesto can be found at: [www.civilsocietyforeu.eu](http://www.civilsocietyforeu.eu)

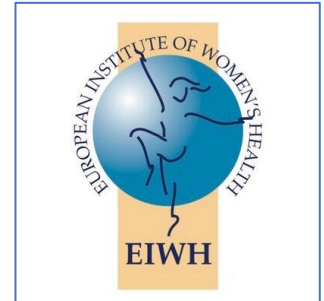
## 13 December: Alzheimer Europe endorses EU Manifesto for Women's Health 2024

Alzheimer Europe has endorsed the European election manifesto of the European Institute of Women's Health (EIWH) – "EU Manifesto for Women's Health 2024".

The manifesto highlights that action must be taken to improve women's health in Europe by integrating sex and gender in research, disaggregating data by sex, gender and age, and translating sex and gender differences into regulatory and healthcare practice. In addition, it calls on the EU must invest in a life course approach to health promotion and disease prevention. The manifesto further notes that the current approach is "one size fits all", leaving many disadvantaged.

As part of this, the EIWH calls for an EU Strategy for Women's Health, as well as the creation of a Women's Health Interest Group in the European Parliament to focus on women's health issues and drive gender equity in health agenda in Europe. The manifesto can be found at:

<https://eurohealth.ie/2024-womens-health-manifesto/>



## 14 December: European Economic and Social Committee adopts position on EU Disability Card

The European Economic and Social Committee (EESC) has adopted its position on the proposals put forward by the European Commission for the EU Disability Card.



The EESC has welcomed the Commission's proposal for a European Disability Card and a European Parking Card, as well as supporting the Commission's decision to extend the Directive to third country nationals legally residing in a Member State.

The EESC has recommended that the scope of the proposal be extended to allow Disability Cards to be used to obtain access to benefits linked to public social policies and/or national social security systems on a temporary basis when a person with a disability has moved to a Member State, throughout the process of getting the disability re-assessed and certified.

Additionally, the opinion sets out that legislative proposals should state clearly that the Disability Card is free of charge and voluntary i.e., there should be no direct issuing of the Card unless the person has asked for it or it is embedded as part of a country's disability assessment.

The full decision can be accessed at: <https://www.eesc.europa.eu/en/our-work/opinions-information-reports/opinions/european-disability-card-and-european-parking-card-persons-disabilities>

## POLICY WATCH

### 21 November: CEAFA calls on new Spanish Government to prioritise dementia



During its 10<sup>th</sup> National Alzheimer's Congress, the President of CEAFA, Mariló Almagro, spoke of the need to recognise and address Alzheimer's disease and dementia as conditions in their own right, and called on the newly formed Spanish government to prioritise

dementia in its policies, including ten key actions:

1. To become truly aware of the dimension of Alzheimer's disease and its consequences for the individual, the family and society.
2. To recognise the economic impact that dementia has on the country's economy in general and on people in particular.
3. To recognise the new profiles of people affected and to lay the foundations for understanding the specific needs they present throughout the evolution of the disease.
4. To set in motion as soon as possible the mechanisms that will enable a National Alzheimer's Plan to be drawn up, taking into account from the outset an adequate budget allocation in terms of quantity and quality.
5. Review current policies affecting people with Alzheimer's disease and objectively analyse the care and resources available.
6. Encourage contact and communication between the Ministries of Health and Social Rights, Consumer Affairs and Agenda 2030, in order to create a favourable breeding ground for progress towards social and health integration strategies.
7. Generate new channels of communication between the different ministries, so as to establish a cross-cutting approach to dementia, taking into account all those areas that are influenced or affected by its consequences.
8. Recognise dementia as its own, independent and specific entity, avoiding treating it within other groups with which it maintains a certain affinity, but from which it is separated by more elements or factors that mean that dementia must be considered in a specific way.
9. Initiate the processes that will allow the State to prepare itself to adequately welcome the arrival of the next specific treatments for Alzheimer's disease.
10. Greater openness towards entities linked to Alzheimer's, including those in the third sector, seeking greater communication and dialogue.

### 29 November: Dementia Social Council established to support the implementation of National Dementia Programme in Hungary



Hungary does not yet have an accepted national dementia strategy; however, there are numerous service elements and commendable initiatives within the healthcare and social care system to support people with dementia. A National Dementia Programme has been developed, focusing on dementia as a public health issue, reducing risk factors, early diagnosis and knowledge expansion. The programme highlights the importance of family carers and providing guidance and effective support to those living with dementia and those who care for them, both informal carers and professionals. The National Dementia Programme will soon be presented to decision-makers, and with ministerial and governmental support, dementia will soon receive greater attention in Hungary.

In response to this upcoming presentation, the Dementia Social Council was established on 29 November 2023. Its aim is to monitor the implementation of the National Dementia Programme, conduct periodic assessments, and supplement or refine the programme through professional consultations. Additionally, members of the council will work to expand the public's understanding of dementia and raise awareness about dementia through media appearances.

Committed, credible, and renowned healthcare and social professionals form the membership of the Dementia Social Council, disseminating information about the programme through media appearances. Council members include Dr Tibor Kovács, an expert from the Semmelweis University Neurology Clinic; Dr Lóránd Erőss, representing the National Institute of Neurology, Neurosurgery and Mental Health; and Czibere Károly from the Reformed Church Charity. Dr Ágnes Egervári (pictured, furthest left) represents the Social Cluster Association within the Council. The Social Cluster Association has been a full member of Alzheimer Europe since the year 2000.



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## SCIENCE WATCH

### 6 November: Brexpiprazole reduces agitation in Alzheimer's dementia



Treatment with brexpiprazole led to a significant improvement in agitation for people with Alzheimer's dementia, according to results from a clinical trial recently published in JAMA Neurology.

The study was a randomised, multicentre

and double-blind Phase III clinical trial evaluating the efficacy, safety and tolerability of brexpiprazole in people with agitation in Alzheimer's dementia. In total, 345 participants received either placebo or brexpiprazole (2 or 3mg/day) daily over 12 weeks. The study was conducted at 123 clinical trial sites in Europe and the United States. Participants included people with agitation in Alzheimer's dementia in a care facility or community-based setting. The primary end point was change in the Cohen-Mansfield Agitation Inventory (CMAI) total score from baseline to week 12. The secondary endpoint was change in the Clinical Global Impression Severity of Illness (CGI-S) and Improvement (CGI-I) scales and the Neuropsychiatric Inventory-Nursing Home (NPI-NH) Agitation/Aggression domain score. Safety was assessed by standard measures, including treatment-emergent adverse events.

According to results, completion rates were 86.8% for participants taking brexpiprazole and 88.9% for those receiving placebo. Researchers reported statistically significant improvement in the brexpiprazole group compared with those given placebo in CMAI total score and CGI-CS score as related to agitation. In addition, brexpiprazole was generally well tolerated over 12 weeks. The findings support the US Food and Drug Administration approval of brexpiprazole for the use in the treatment of agitation associated with dementia due to Alzheimer's disease.

<https://jamanetwork.com/journals/jamaneurology/fullarticle/281162>

### 27 November: ADvantage Therapeutics has commenced enrolment for its Phase 2b trial of AD04 for AD

On 27 November, ADvantage Therapeutics, a company developing therapies to treat neurodegenerative conditions with a central focus on Alzheimer's disease (AD) announced the start of its Phase IIb clinical trial in Europe investigating AD04 for the treatment of mild AD. AD04, the company's lead candidate, has been used as an adjuvant in human and animal vaccination programs. In a previous study, a 2mg dose of AD04 used in a control arm exhibited a statistically significantly slower decline in cognitive and quality of life measures compared to other arms of that trial.

The Phase IIb randomised, double-blind and placebo-controlled trial aims to confirm proof-of-concept and establish the safety and efficacy of AD04 in people with mild AD. Participants are randomly assigned to receive either AD04 or a placebo for one year. The primary endpoint of the study is to evaluate changes in cognitive function at 12 months using a composite score that integrates the Alzheimer's Disease Assessment Scale-Cognitive Subscale (ADAS-Cog), the Alzheimer's Disease Cooperative Study-Activities of Daily Living Scale (ADCS-ADL) and the Clinical Dementia Rating-Sum of Boxes (CDR-SB). Other measured outcomes include hippocampal volume, the Neuropsychiatric Inventory (NPI) and the patient quality of Life-Alzheimer's disease.

The study is authorised to be conducted in Austria, France, Poland, Bulgaria and Slovakia, and is expected to expand to Germany and the UK in the coming months. The first participant was enrolled in Austria.

<https://advantagetherapeutics.com/news/advantage-therapeutics-has-commenced-enrollment-for-its-phase-2b-clinical-trial-of-ad04-for-treatment-of-alzheimers-disease/>

### 1 December: Recent article explores how involve people with dementia living in long-term care institutions in research

Over 80% of older adults in long-term care (LTC) institutions live with cognitive

impairment/dementia, yet the perspective of people with advanced dementia has still not been sufficiently explored in research. This group of people is systematically excluded from a lot of research, often because of ethical and methodical issues and legal barriers.

With this in mind, a recently-published article in the open access journal "Social Sciences & Humanities Open" looked closely at the ethical considerations and challenges which arise in qualitative research with people living with advanced dementia. The article, "'Take me to the back, or they'll think I am not normal' - Ethical reflections on narrative research with people with dementia living in long-term care institutions" was written by researchers Verena C. Tatzer and Elisabeth Reitingner.

In their paper, they present ethical issues in research using a design inspired by ethnography with the aim to encourage future research in this field. Methods applied were observations, interviews and informal talks with people diagnosed with moderate and severe dementia. Two different long-term care institutions were researched: a specialised dementia-care unit and an institution based on a community-oriented household model. Participants were older adults with dementia, and data were collected over a period of two years.



Staff and next of kin were included in data collection. A thematic and narrative analysis was performed.

Challenges linked to ethical and methodological issues were experienced throughout the whole research process, which included getting approval from a local ethical committee, gaining access to the field, dealing with process consent and complex qualitative analysis, representing the participants' stories in a respectful way, enabling reciprocity, as well as dealing with difficult situations in long-term care and questions of the vulnerability of both the participants and the researcher.

The authors concluded that it is possible to include vulnerable adults living with advanced dementia in qualitative research and that this should be done more extensively in order to make the experience of a group that is growing in numbers visible. Strategies of reflexivity have to be carefully planned and organised in advance, they note, because methodological and ethical aspects are strongly intertwined. In contemporary qualitative narrative research, they recommend to not only present the participants' stories, but also the researcher's own story, that exerts influence on the research process. Their paper also highlights that approaches derived from care- and process-ethics, as well as appreciative inquiry, can provide valuable support throughout the research process. Read the full paper: <https://doi.org/10.1016/j.ssaho.2023.100491>

## 6 December: Researchers identify a new protein linked to frontotemporal dementia



In a paper published in the journal *Nature*, scientists have identified abnormal aggregates of a protein called TAF15 in the brains of people with early-onset dementia, known as frontotemporal dementia. Frontotemporal dementia results from the degeneration of the frontal and temporal lobes of

the brain, which control emotions, personality and behaviour, as well as speech and understanding of words. It tends to start at a younger age than Alzheimer's disease, often being diagnosed in people aged 45 to 65, although it can also affect younger or older people.

While amyloid assembly of TDP-43 or tau is the hallmark of the majority of cases of frontotemporal lobar degeneration (FTLD), the assembled protein that characterises the remaining approximately 10% of cases, was previously unknown. New research led by scientists from the Medical Research Council (MRC) Laboratory of Molecular Biology, in Cambridge, UK, used cryogenic electron microscopy (cryo-EM) to study protein aggregates from the brains of four people who had this type of frontotemporal dementia. They found abundant TAF15 amyloid filaments in brain regions associated with motor neuron disease. Scientists are now studying whether aberrant aggregated TAF15 is present in people who have motor neurone disease in the absence of frontotemporal dementia.

This study was funded by the Medical Research Council, Alzheimer's Research UK, the US National Institutes of Health,

the Alzheimer's Society, the Association for Frontotemporal Degeneration, the Swiss National Science Foundation, and the Leverhulme Trust.

<https://www.nature.com/articles/s41586-023-06801-2>

## 6 December: Results of the COMCID study have been published in JAMA Network Open

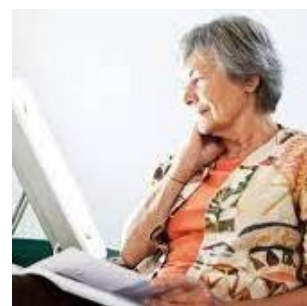
On 6 December, Japanese researchers published findings from the COMCID trial in the journal *JAMA Network Open*. The COMCID trial was a double-blind and Phase II randomised clinical trial investigating the efficacy and safety of cilostazol in people with Mild Cognitive Impairment (MCI). Participants received either placebo or cilostazol (50mg) orally twice daily for up to 96 weeks in Japan. The primary end point was the change in the total Mini-Mental State Examination (MMSE) score from baseline to the final observation.

Results showed that there was no statistically significant difference between the placebo and cilostazol groups for the primary outcome. The study did not demonstrate any efficacy in preventing disease progression. However, the findings revealed some interesting observations about the potential effects of cilostazol on beta-amyloid. The research showed that the blood concentrations of the albumin and  $\beta$ -amyloid complex (albumin-A $\beta$  complex) in participants receiving cilostazol increased following treatment compared with those receiving placebo, suggesting that cilostazol may have promoted the clearance of  $\beta$ -amyloid from the brain into the blood, consistent with the results of past animal experiments. Safety analyses included all adverse events. Authors concluded that the study demonstrated the safety of cilostazol in people with MCI and that the efficacy of cilostazol should be tested in future trials. The researchers plan to identify a group of patients for whom cilostazol is effective (cilostazol-responders) to enable investigation of its anti-dementia effects.

<https://pubmed.ncbi.nlm.nih.gov/38048134/>

## 6 December: New study evaluates the effect of light therapy on sleep disorders and psycho-behavioural symptoms in people with AD

Although Alzheimer's disease (AD) mainly affects cognitive function, it is often accompanied by sleep disorders and psycho-behavioural symptoms. In a new study published in the journal *PloS One*, Chinese researchers from the School of Nursing at Weifang Medical University evaluated the efficacy of light therapy in improving sleep disorders and psycho-behavioural symptoms in people with AD. They conducted a meta-analysis by identifying randomised controlled studies on light therapy



for AD in the literature up to December 2022. They found 15 studies involving 598 people with AD, performed in 7 countries and selected them for further analysis.

In the case of sleep disorders, the meta-analysis revealed that light therapy significantly improved sleep efficiency, increased interdaily stability (a measure of the strength of circadian rhythms) and reduced intradaily variability (a measure of how frequently someone transitions between rest and activity during the day). Light therapy also alleviated depression and reduced agitation and caregiver burden. Given the limited sample sizes in studies included in this meta-analysis, the authors advocate for larger future studies. They conclude that light therapy could lead to significant improvement in sleep and psycho-behavioural symptoms and is associated with relatively fewer side effects in people with AD.

<https://pubmed.ncbi.nlm.nih.gov/38055651/>



## MEMBERS' NEWS

### 30 November: How the Hellenic Basketball Federation and Greek Women's National Basketball Team made a difference for a dementia day centre in the city of Chalkida



A partnership between the Hellenic Basketball Federation - a leading sports organisation in Greece - and REMIND-Alzheimer Chalkida - an organisation supporting people with dementia and their families - is "game-changing"! Brain health is a field closely linked with mental health, in which there is rapid development of

scientific knowledge regarding the factors that can contribute to the maintenance and improvement of health and functionality at every stage of life, with wider social impact on quality of life.

On the occasion of the Greek Women's National Basketball Team match, in the city of Chalkida during November 2023, the Hellenic Basketball Federation and REMIND-Alzheimer Chalkida developed a partnership, with the aim of raising brain and mental health awareness. Before and during the game, specialised staff informed the public about brain health and memory changes and distributed specially-designed material for students who attended, bringing the attention of the public to mental health issues and dispelling negative stereotypes.

At the Agia Irini day centre in Chalkida, where people with memory changes attend physically and mentally empowering programmes, the whole week had a "festive" atmosphere too,

on the occasion of one of the biggest sporting events in the city. The day centre's specialised staff had planned a series of themed activities that the beneficiaries enjoyed, including appropriate decoration for the occasion. As part of the game-changing cooperation, the Secretary General of the Hellenic Basketball Federation, Nikos Nikolopoulos, and the Head of women's basketball and member of the Hellenic Basketball Federation Board of Directors, Anne Konstantinidou, visited the Agia Irini centre, where they were informed about the programmes for older adults and caregivers and showed special interest. They donated ticket proceeds to help support older adults' physical exercise programmes for remote areas, as well as donating a national team t-shirt with the athletes' signatures. REMIND-Alzheimer Chalkida would like to warmly thank the Hellenic Basketball Federation, representatives Mr Nikolopoulos and Mrs Konstantinidou, and congratulate their initiative to actively support the elderly with an emphasis on mental health. This is the first step of a more impactful partnership!

### 30 November: Hungary's recent Conference brings experts and government together



This November, a conference titled "Generations Together - Collaboration of Generations for the Mental Health of Society" brought distinguished foreign and domestic experts as well as policymakers together to share best practices and seek a collective response to the challenges affecting people with mental health issues and their families.

The conference which boasted more than 200 participants and nearly 30 domestic and international speakers, aims to initiate a policy dialogue on promoting intergenerational cooperation and exploring opportunities, tools and tasks for improving mental health. Participants also focused on examining challenges related to family bonds and different family types, as well as the role of the family in dealing with elderly family members struggling with mental health issues.

The conference featured presentations by János Csák, Minister for Culture and Innovation, Ágnes Hornung, State Secretary for Families, and Prof. Carlo Casalone, Coordinator of the Scientific Department of the Pontifical Academy for Life and Madeleine



Wallin, Secretary-General of the European Federation of Parents and Carers.

The situation of the elderly generation in society is special, especially that of the elderly living with dementia. The issue of support for family carers was highlighted in Prof. Casalones' presentation and also in the round table discussion.

The conference also served as preparation for Hungary's upcoming presidency of the Council of the European Union in 2024. Key themes for the Hungarian presidency include challenges related to demography and mental health, among other priorities."

### **13 December: Irish Dementia Working Group member and The Alzheimer Society of Ireland ambassador Bryan Murray receives IFTA Lifetime Achievement**



Renowned Irish actor Bryan Murray received the Irish Film & Television Academy (IFTA) Lifetime Achievement Award on Wednesday 13 December at a special Reception at the Shelbourne Hotel in Dublin. The award is in recognition of his outstanding contribution to the world of film and television.

On receiving the award, Mr Murray, a member of The Irish Dementia Working Group (IDWG) and an ambassador for The Alzheimer Society of Ireland (ASI) said:

"I cannot begin to tell you how honoured I feel to be getting this award and to see everybody here tonight. I've always just loved what I do as an actor."

Mr Murray has been widely praised in recent years for his candid public speaking on his diagnosis of Alzheimer's, while continuing to star in Irish soap Fair City, in which he appears alongside his off-screen wife and ASI ambassador Una Crawford O'Brien.

From stage to screen performances, Bryan Murray is one of the most respected actors in Ireland, with an illustrious career that spans over five decades.

### **14 December: The Alzheimer Society of Ireland holds Christmas jumper fundraiser with Irish Parliament**

The Alzheimer Society of Ireland (ASI) held their annual Christmas Jumper Fundraiser and brought the event to the Irish Parliament.

There was an excellent turnout at Leinster House Dublin as Chair of the All-Party Oireachtas Group on Dementia Senator Fiona O'Loughlin raised awareness of dementia with a Christmas Jumper photoshoot.

Minister for Mental Health and Older People Mary Butler TD met with The ASI team at the event and took the opportunity to update on dementia policy developments.



### **15 December: Alzheimer Suisse announces joint project with Swiss Memory Clinics to improve current standards of care and support during dementia diagnosis in Switzerland**

In a press release on 15 December 2023, Alzheimer Switzerland announced their joint project with Swiss Memory



Clinics to implement minimum standards of care and support during the diagnosis of Alzheimer's disease and related dementias, to ensure a timely diagnosis combined with information that leaves the newly diagnosed individual with a sense of agency in spite of the diagnosis. These two organisations have been working together since 2021 to promote the early detection of Alzheimer's and related dementias and to tailor the information and advice given to people who are diagnosed. Though Alzheimer's is not yet curable, those benefiting from an early diagnosis and the right care and support can slow the progression of the disease and improve their quality of life. People often wait years for a definitive diagnosis, during which time they lack both the support they need and the access to precious resources that an early diagnosis can bring them. But receiving the diagnosis, even when it is expected, can be devastating to the person and their family, leaving them sitting with a multitude of questions and a feeling of hopelessness, and unless the practitioner giving them the diagnosis is aware of the resources available and how to adequately support people, they can walk away from a diagnosis feeling shocked or hopeless. Improving this process is the goal of both organisations.

The diagnostic tools used to reach a diagnosis, the way in which practitioners relay the diagnosis, and the information and support they offer post-diagnosis all contribute to the trajectory of the disease. When this process is informed and timely, it can guide the person through the many decisions they have to make by providing psychological support, facilitating easier access to healthcare, assistance with administrative, financial and legal matters and ultimately improve their quality of life and prolong independent living, delaying or even avoiding entry into nursing homes or hospitals.

## LIVING WITH DEMENTIA

**15 December: Member of the European Dementia Carers Working Group Zornitsa Karagyozyova writes about Alzheimer Bulgaria's 20th anniversary celebratory conference**



Hello, my name is Zornitsa Karagyozyova. I am a member of the EDCWG and represent the Alzheimer Bulgaria Civic Association (Алцхаймер България).

It is with great joy that I share that in 2023, the civil association Alzheimer Bulgaria celebrated its 20th anniversary. In honour of this unique anniversary, a national conference was organised, entitled "And now where? Providing care for Bulgaria's aging population". The event took place on 6 October 2023 in Sofia with approximately 80 people present. A live broadcast was provided for those who were not able to attend the conference, and the recording of the conference is available on the Alzheimer Bulgaria YouTube channel (<https://www.youtube.com/@alzheimerbulgaria7534>), or click on these links to see [part 1](#) and [part 2](#).

The chairman of Alzheimer Bulgaria opened the conference, followed by a congratulatory speech from Ivan Karagyozyov, a person with dementia and member of the association who spoke about his experience with the diagnosis and the support he received from Alzheimer Bulgaria. Congratulations on the occasion of the anniversary were also sent by representatives of various institutions in Bulgaria - the Deputy Minister of Health, the Chairman of the Economic and Social Council of the Republic of Bulgaria, and the Bulgarian member of the European Parliament.

The official opening was followed by four panels/sessions dedicated to different aspects of elderly care in Bulgaria. In the first part of the conference, the focus was on European policies and practices for the elderly in Bulgaria. Many experts participated and talked about their activities in this field. Jean Georges, Executive Director of Alzheimer Europe, joined the conference online and gave a presentation on European policies for people with dementia.

The theme of the second panel of the conference was caring for people with dementia and their relatives and carers. A representative of the Bulgarian Red Cross, representatives of one of the private homes for the elderly in Sofia, and also a psychologist who volunteers for the Alzheimer Bulgaria Association shared their experience in this area and spoke about the activities of the association such as the "Alzheimer's Café".

The third part of the conference was a panel discussion about the prevention, early diagnosis and follow-up of dementias. Practitioners from leading hospitals and scientific researchers shared their experience as well as the latest developments in the field.

In the fourth and final panel of the conference, we looked towards the future, and the role of new technologies in the care of the elderly. Volunteers for the engineering-oriented association spoke about the latest participation of Alzheimer Bulgaria in – 'Social Store', an online platform designed to support the elderly in their quest for a dignified life.

The conference concluded with another important step in the association's advocacy for the rights of people with dementia and Alzheimer's disease. An open letter was sent to the National Assembly and the Council of Ministers of the Republic of Bulgaria, calling on the legislative and executive authorities to develop a comprehensive national strategy and plan for the early diagnosis, follow-up and care of people with dementia and support for their families.

The very fact that we held this conference, as well as being able to celebrate 20 years of the Alzheimer Bulgaria association and its active work to help people with various types of dementia and their families in a country where there is still no active state policy in their support can in itself be considered an important achievement. I am proud and happy to be a volunteer and member of this association!

**18 December: The first year of European Dementia Carers Working Group is finished! Let's wrap it up: (some) numbers, testimonials, tributes and wishes for 2024, writes group Chairperson, Sonata Mačiulskytė**

Along with 2023, the first year of the EDCWG comes to an end. On this occasion, we share what the year was like for us. We'll start with some numbers:

The EDCWG is a group of 13 active members involved in advisory boards of at least 5 projects. We:

- provided insights and contributed 3 testimonials for AE's 2023 Yearbook.
- We consulted on the recently published Position Paper on Risk Disclosure



- contributed 12 testimonials to the AE Newsletter
- recorded 2 video testimonials
- made 10 Call for Action videos for the upcoming European Parliament elections
- participated as a group in the 33<sup>rd</sup> AE Conference in Helsinki, where we were involved in 1 podcast, 1 panel session, 1 conference workshop and moderated 4 sessions. Pretty well done, isn't it?

#### **Testimonials: How do we rate our involvement in the group?**

„Loving it!“ says Barry Northedge from Scotland, and we all agree with him! It was an extremely enriching experience to work together with such a talented, caring, multinational group of people who still had time for socialising and a lot of laughter despite the challenges. The discussions were incredibly interesting and stimulating as well as relevant to the up-to-date issues of Alzheimer's disease and other dementias. Being involved in the group was therapeutic for many of us, helping to partially reconcile our past or present (sometimes tough) relationships with our own loved ones with dementia. Being involved in different activities also allowed us insight to the depth and range of work and research that is underway, giving us hope for the future diagnosis and treatment of AD and other dementias.

#### **Tributes and wishes**

We sincerely thank Alzheimer Europe (AE) for this extraordinary EDCWG journey together this year, and the opportunity to contribute our life experiences. Thank you to our national associations for nominating us to this group. We wish for the AE community to keep up the great work in 2024, keep the faith that early diagnosis and treatment will be possible, keep creating a more supportive, informed, and compassionate environment for people with dementia and carers, and maintain dementia at the forefront of the minds of all of Europe's decision makers.



## **DEMENTIA IN SOCIETY**

### **13 December: Bob & Diane Fund awards Visual Storytelling Grant to Helen Rimell for her project "No longer her(e)" - an intimate portrait of her mother's dementia and her family's support**



"No longer her(e)", Helen Rimell's stirring visual storytelling project about her mother (and family's) experience with Alzheimer's Dementia, has won this year's Bob and Diane Fund grant.

The title itself evokes a sense of loss; her mother's loss of capacity and all that entails, and the artist's loss of the woman her mother once was. Deeply intimate moments captured of her mother at home reveal the heart-breaking reality of living with dementia, both as the person living with it and as the

carers and family members. Helen left her former life to move home, along with her family, to become her mother's carer in 2021. One photo shows a tender moment caught as her young daughter helps her grandmother to eat and another of the pair on the sofa, eyes fixed upon one another, reminding the viewer of the humanity behind the disease.

This is the 8<sup>th</sup> year that the Bob and Diane Fund had offered this grant, with the aim of increasing awareness and support for Alzheimer's and dementia through visual storytelling of the lives of people living with dementia. You can view "No Longer Her(e)" by Helen Rimell here:

<http://www.bobanddianefund.org/2023-grantee>

## **NEW PUBLICATIONS AND RESOURCES**

### **1 December: New peer-reviewed resource "Flipping Stigma on its Ear Toolkit" was co-created with people with dementia working alongside academic researchers**

The Flipping Stigma on its Ear Toolkit is the direct outcome of a four-year Canadian research project called PAR (Participatory Action Research Study) where academic researchers worked alongside people with dementia (as co-researchers) with the aim of helping people recognise and respond to dementia-related stigma and discrimination ([flippingstigma.com](http://flippingstigma.com)). This peer-reviewed resource, developed during the COVID-19



pandemic, has been recognised by the WHO on their [Global Dementia Observatory Knowledge exchange platform](#) where it is one of the top 10 tools listed for awareness and inclusion.

Their user-friendly website offers guidance for three distinct groups:

- Persons living with dementia,
- family/friends/care providers of the person with dementia and
- researchers.

The toolkit aims to empower and enable the user with the following tools:

- 'Recognise' instances of stigma,
- 'Respond' to stigma and discrimination in a more effective way and
- 'Educate/advocate'.

As you scroll through the Toolkit, you can hear or watch touching stories told by people with Alzheimer's and/or dementia via audio and video clips.

The site provides links to resources for people in Canada, both for those with dementia and their loved ones. It provides [tips](#) for healthcare providers on how to communicate in an



empowering way with people with dementia. There is also an [action guide](#) created by people with dementia to aid people or groups looking to become advocates. It lays out the steps towards starting your own advocacy group in your community.

## 15 December: Experts in neurology, geriatrics and neuroradiology at World Congress of Neurology 2023 highlight importance of timely and accurate biological diagnosis of Alzheimer's disease



touchNEUROLOGY has a new learning activity available on its website, in which leading experts in neurology, geriatrics and

neuroradiology come together at the World Congress of Neurology (WCN) 2023 to highlight the importance of a timely and accurate biological diagnosis of Alzheimer's disease and provide practical insights into current and emerging diagnostic tools. The expert panel goes on to discuss the importance of patient-centred care and explore the role of the dementia care team in supporting the patient along the AD continuum. Dr Sharon Cohen chairs the session. She is a behavioural neurologist and the medical director of the Toronto Memory Program, a community-based medical facility, which she established in 1996 for the purpose of enhancing the diagnosis and treatment for individuals with Alzheimer's disease and related disorders. There are two other speakers in the session:

- Prof. Sven Haller, a neuroradiologist specialised in advanced neuroimaging for neurodegenerative diseases, who provides practical insights into current and emerging diagnostic tools for AD and how to utilize them to achieve an early and accurate diagnosis.
- Dr Ronan Factora, a geriatrician with a special interest in dementia and related disorders, who highlights the importance of collaborative patient-centred care and the role of the multidisciplinary dementia care team in supporting patients along the AD continuum.

This activity is jointly provided by USF Health and touchIME.

For more details and to watch the videos, see: [Clinical care pathway for Alzheimer's disease: Driving improvements in diagnosis - touchNEUROLOGY \(touchneurology.me.org\)](#)

## 18 December: New Oruen CNS Journal is published, featuring report on 33<sup>rd</sup> Alzheimer Europe Conference

ORUEN, a leading CNS medical publication and multimedia platform committed to improving international communication and medical education for physicians with clinical interests in CNS medicine, has published its report on the 33<sup>rd</sup> Alzheimer Europe Conference in Helsinki on 16-18 October. In addition to reporting on each of the plenary sessions, the welcome reception, the networking dinner and the winners of the Anti-Stigma Award for 2023, they also wrote about the Helsinki Manifesto, which was adopted by Alzheimer Europe and its members on 16 October, prior to the Conference's commencement.

You can find the article on pages 18-30 of Volume 9, Issue 2: <https://www.oruen.com/Journal/OruenCNSJ-Volume9Issue2/>

Click here to subscribe to [Oruen - The CNS Journal](#)



### Contact Alzheimer Europe:

Alzheimer Europe: 14, rue Dicks (L-1417), Luxembourg; [info@alzheimer-europe.org](mailto:info@alzheimer-europe.org); [www.alzheimer-europe.org](http://www.alzheimer-europe.org)

### Alzheimer Europe Board:

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

## AE CALENDAR 2024

Date	Meeting	AE representative
<b>9 January</b>	Meeting with Lilly	Jean and Angela
<b>11 January</b>	GSK Health Advisory Board (London, United Kingdom)	Jean
<b>12 January</b>	36AEC Organising Committee meeting with The Alzheimer Society of Ireland	Jean, Gwladys and Kate
<b>15 January</b>	Consultation with PROMINENT Public Involvement Board	Daphné and Angela
<b>17-18 January</b>	ADIS General Assembly Meeting (Barcelona, Spain)	Chris and Soraya
<b>22 January</b>	OECD High-Level Policy Forum (Paris, France)	Jean
<b>23 January</b>	Alzheimer's Association Academy on "Artificial intelligence in dementia research"	AE members and staff
<b>25-26 January</b>	ACT EU – Clinical Trials Data Analytics Workshop (Amsterdam, Netherlands)	Cindy
<b>31 January</b>	Consultation with the EWGPWD	Ana, Daphné and Soraya

## CONFERENCES 2024

Date	Meeting	Place
<b>8-10 October 2024</b>	34 <sup>th</sup> Alzheimer Europe Conference: "New horizons – Innovating for dementia"	Geneva, Switzerland

34<sup>th</sup> Alzheimer Europe Conference  
New horizons –  
Innovating for dementia  
Geneva, Switzerland  
8 - 10 October 2024 #34AEC  
[www.alzheimer-europe.org/conferences](http://www.alzheimer-europe.org/conferences)

