

#### **HIGHLIGHTS**

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#### **WELCOME**



I am pleased to share the news that, following a re-examination of its ini-

tial, negative opinion, the Committee for Medicinal Products for Human use (CHMP) of the European Medicines Agency (EMA) has now issued a positive opinion on lecanemab for the treatment of early Alzheimer's disease (AD). The CHMP found that the benefits for a restricted population outweighed the risks, and therefore recommended approval of Eisai's marketing authorisation application. We welcome this news, enabling patients to make informed decisions based on their own circumstances. preferences and values, including the acceptability of risk and anticipated benefits, and I was personally delighted to be invited by Luxembourg radio station 100,7 to discuss what this news means for people with early AD in Europe.

In other important research news, revised diagnostic criteria for AD were presented on behalf of the International Working Group (IWG) during the 17th annual Clinical Trials on Alzheimer's Disease (CTAD) Conference. The IWG is led by Bruno Dubois, Nicolas Villain, Howard Feldman and Giovanni Frisoni, and comprises 46 international experts from 17 countries, including myself on behalf of Alzheimer Europe. The group reviewed the available evidence on the role and influence of biomarkers on the diagnosis and definition of AD, proposing a number of recommendations, which were published in the journal JAMA

Jean Georges, Executive Director

Neurology, in parallel to CTAD. Other highlights from CTAD can be found in our special "CTAD watch" section.

Another new scientific paper to which Alzheimer Europe contributed has been published by researchers from the LETHE project, in the journal of Alzheimer's Research & Therapy. It describes the LETHE study design, progress and first results. Congratulations to the authors, including our Public Involvement Lead Ana Diaz.

I am also pleased to announce that we continue to make great headway in our work engaging with Members of the European Parliament (MEPs) and working with them to prioritise dementia at a European level. Three more MEPs joined the European Alzheimer's Alliance (EAA) this month, bringing the total to 79 members and I would like to extend a warm welcome to Vytenis Andriukaitis MEP (Lithuania), Ondřej Dostál MEP (Czechia) and Dimitris Tsiodras MEP (Greece). We very much look forward to working with them and to meeting members of the EAA in Brussels on "European Parliament Dementia Day", which we are organising on 10 December. Photos from the 34th Alzheimer Europe Conference (#34AEC) are now available online, as are videos of the plenary presentations. I invite you to access the photos via our website and watch the videos (available in English, French and German), on our YouTube channel.

In closing, I would like to say congratulations on behalf of all of us at Alzheimer Europe, to Sabine Henry, who has received the title of Baroness from King Philippe of the Belgians, for her outstanding work for people affected by dementia as President of the Belgian Ligue Alzheimer.



#### **ALZHEIMER EUROPE**

#### 4 NOVEMBER:

Access videos and photos from our conference in Geneva!



We are pleased to share the professional photographs from the 34<sup>th</sup> Alzheimer Europe Conference (#34AEC), as well as the videos of the plenary presentations from the event, all of which have now been published online.

You can access the photos via our website, here (scroll to the bottom, below the list of media and social media links, to see the full gallery): https://www.alzheimer-europe.org/conferences/past-conferences/2024-geneva/news-and-media-34aec

You can watch the plenary videos in a specially-created playlist (available in English, German and French), on Alzheimer Europe's YouTube channel:

- English: https://www.youtube.com/watch?v=EqoBJv3copE&list=P LO-PgQHI1WQWj8qdGJSymWwmAuBj7ooev
- German: https://www.youtube.com/watch?v=rZWMC5SA4S0&list =PLO-PgQHI1WQUQP9taeGYGzqbcQLQND7UU
- French: https://www.youtube.com/watch?v=Wh0rExOzspl&list=P LO-PgQHI1WQU-amLKJjE\_aQPWA4bX\_fch

#### 12 NOVEMBER:

## Alzheimer Europe writes to WHO Europe Regional Director

Following the re-election of Hans Kluge as Regional Director for the World Health Organization's Regional Office for Europe (WHO Europe), Alzheimer Europe has written to the Regional Director asking for dementia to be prioritised in WHO Europe's policies.

In the letter, Alzheimer Europe highlights the that the number of people affected by these conditions is expected to rise drastically in the coming decades, including our estimates that that the number of people living with dementia across Europe will nearly double by 2050 compared to 2018.

The letter also expresses concern that the current approach to noncommunicable diseases (NCDs) does not providing sufficient attention to dementia. Specifically, "we highlight that while cardiovascular diseases and cancer are appropriately highlighted in the 'Race to the Finish' within the WHO's Special Initiative on NCDs and Innovation, there is a lack of a similar focus on neurodegenerative diseases.

We therefore urge the WHO Regional Office for Europe to ensure that neurodegenerative diseases receive the attention they deserve in its policy recommendations and ask for neurodegenerative diseases, including dementia, to be included as priority topics for the upcoming 4<sup>th</sup> High-level Meeting of the United Nations General Assembly on the Prevention and Control of NCDs."

#### 12 NOVEMBER:

Jan Runar Eliassen from the European Working Group of People with Dementia is interviewed by EURACTIV for special report on "Alzheimer's Disease: detection, diagnosis, treatment"

Runar Eliassen was interviewed **EURACTIV** for an article forming part of a report special "Alzheimer's Disease: detection, diagnosis, treatment". Jan Runar is from Norway and is a member Working European Group of People with

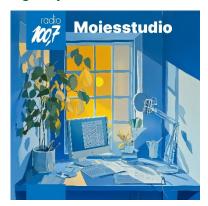


Dementia. The article for which he was interviewed by journalist Christoph Schwaiger is titled "'It's a very individual disease', Alzheimer's activist urges policymakers to boost understanding" and was published online on 12 November 2024. It can be read in English, here:

https://www.euractiv.com/section/health-consumers/news/its-a-very-individual-disease-alzheimers-activist-urges-policymakers-to-boost-understanding/



Luxembourg radio station 100,7 invites
Alzheimer Europe Director Jean Georges on
air to discuss lecanemab after drug receives
positive opinion from European Medicines
Agency



On 22 November 2024, Jean Georges, the Executive Director at Alzheimer Europe, was interviewed on Luxembourg radio station 100,7. He was invited to discuss the news that the Committee for Medicinal Products for Human use (CHMP) of the Euro-

pean Medicines Agency has re-evaluated its negative opinion on the treatment and gave a positive opinion on the drug, on 14 November 2024.

You can listen to the full interview (in Luxembourgish) here: https://www.100komma7.lu/show/Moiesstu-dio/202411220822/episode/Hellef-bei-Alzheimer-am-Ufankstadium?pd=radio

#### SPONSOR OF THE MONTH

Alzheimer Europe would like to express its gratitude to a new silver sponsor for its 2025 activities:



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

#### **AE NETWORKING**

5 NOVEMBER	Jean met with András Kulja, MEP (Hungary) and Romana Jerković, MEP (Croatia) (Brussels, Belgium)
6 NOVEMBER	Sarah attended the Fundamental Rights Platform webinar on EU LGBTIQ Survey III
7 NOVEMBER	Ana and Sarah met with the Swedish AD-RIDDLE project Advisory Board
8 NOVEMBER	Jean met with representatives of Johnson & Johnson
12 NOVEMBER	Angela participated in the 2024 IHI Brokerage event (Brussels, Belgium)
12 NOVEMBER	Dianne and Ana attended a meeting to discuss involvement in the INTERDEM working group on technology and White Paper
13 NOVEMBER	Angela participated in a panel for the PRIME project at Brain Innovation Days 2024 (Brussels, Belgium)
13 NOVEMBER	Jean met with representatives of Fourtold
15 NOVEMBER	Angela and Lukas visited the study site of the Luxembourg Programme for Dementia Prevention (pdp) (Luxembourg, Luxembourg)
18 NOVEMBER	Jean met with Boris Brzezinski, assistant of Adam Jarubas, MEP (Poland)
19 NOVEMBER	Sarah and Dianne met with the Public Ambassador Group for the PREDICTOM project
19 NOVEMBER	Ana and Angela organised a meeting with Evidera and representatives of the EWGPWD and EDCWG



20 NOVEMBER	Angela joined a meeting of the EMA's Patients' and Consumers' Working Party		
21 NOVEMBER	Owen attended a World Health Organization webinar on Science-Based Policymaking: Actions with Impact		
21 NOVEMBER	Lukas spoke at the dementia prevention conference of the Alzheimer Liga Vlaanderen (Antwerp, Belgium)		
21 NOVEMBER	Cindy attended an EFPIA Patient Think Tank meeting		
21-22 NOVEMBER	Jean, Chris and Sébastien attended the 2 <sup>nd</sup> PROMINENT Consortium meeting (Barcelona, Spain)		
22 NOVEMBER	Owen attended a DG EMPL civil dialogue on access to quality social and essential services		
22 NOVEMBER	Kate attended a European Disability Forum (EDF) event on "Influencing the media"		
25 NOVEMBER	Jean met with the EFPIA AD Platform		
26-27 NOVEMBER	Angela attended the 5 <sup>th</sup> anniversary meeting of the DataSavesLives initiative (Brussels, Belgium)		
28 NOVEMBER	Angela participated in a panel of the HMA/EMA Big Data Stakeholder Forum (Amsterdam, Netherlands)		
28 NOVEMBER	Owen and Jean attended the EU4Health Civil Society Alliance meeting		
28 NOVEMBER	Ana attended an INTEREST project meeting (Amsterdam, Netherlands)		
28-29 NOVEMBER	Sarah and Sébastien participated in the European Day of Persons with Disabilities together with the Chair and Vice-Chair of the EWGPWD (Brussels, Belgium)		
29 NOVEMBER	Angela attended a General Assembly meeting of the eBRAIN-Health project		
	<del></del>		







#### **EU PROJECTS**

#### 16 OCTOBER:

## ABOARD Fall Meeting 2024 takes place in Leiden



On 16 October, nearly 100 colleagues from the ABOARD consortium gathered at Zilveren Kruis in Leiden (Netherlands) for the ABOARD Fall Meeting 2024. The theme of the meeting was "The perspective of the health insurer".

The day started with a warm welcome from Jeroen Kemperman of Zilveren Kruis. Then, Wout Adema, director of Zorgverzekeraars Nederland, gave an inspiring keynote. He spoke about the challenges faced in healthcare, such as ensuring sustainable care for elderly people.

After this opening from the perspective of health insurers, several ABOARD partners discussed their projects. For instance, Argonde van Harten (Alzheimer Centrum Amsterdam) and Koen Dewaele (ADx NeuroSciences) talked about their work with new blood tests for dementia. Harry Post (Vektis) shared how data from health insurers provides insight into care use and costs in dementia. Marjolein de Vugt (Alzheimer Centrum Limburg) talked about healthy lifestyle interventions, and Jort Vijverberg (Alzheimer Centre Amsterdam) shared the latest developments in medication.

In the afternoon, four sessions took place under the heading "Public-private in practice". In each session, a young researcher spoke from a scientific perspective with an expert from the public or private sector. Together with the audience, a discussion ensued about how research results find their way into education, healthcare, or business. Many new ideas emerged and it was clear that there are more possibilities than it might seem at first glance. During a panel discussion, led by Sven van der Lee (Alzheimercentrum Amsterdam), experts from different backgrounds discussed how living and care are connected and can contribute to better care for people with dementia.

As a traditional finale, the "ABOARD shorts" shared news and plans from the breadth of the consortium. For instance, there were ideas about organising a bus tour of the country with the junior researchers, to share results with the public, whilst Janna Dijkstra, together with patient representative Robert Loose, talked about the successful "Eb and Tide" sailing week-

end they organised for young people with a parent with dementia. Alzheimer Europe Director Jean Georges is a member of the ABOARD project Advisory Board.

You can read the full meeting report (in Dutch) here: https://www.alzheimer-nederland.nl/onderzoek/projecten/aboard/nieuws/aboard-fall-meeting-samen-werkenaan-de-zorg-van-morgen

You can find more information about the ABOARD project here:

https://www.alzheimer-nederland.nl/onderzoek/projecten/aboard/

#### 28 OCTOBER:

## The Al-Mind 9<sup>th</sup> General Assembly gathers experts in Madrid



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On 28-29 October, partners from the Al-Mind project convened in Madrid, Spain, for the 9<sup>th</sup> General Assembly, hosted by the Complutense University of Madrid (UCM). The event brought together over 50 in-person participants and around 20 online attendees, offering an invaluable platform to review project progress, tackle challenges, and outline the next steps toward bringing Artificial Intelligence (AI)-based dementia risk prediction tools into clinical practice.

Work package leaders presented updates on recent achievements including preliminary analysis of data collected within the study. The assembly also served as an excellent platform for a workshop on the Collective Evaluation of Experience, Explainability, and Practices in Al-Mind, facilitating collaborative discussions on refining Al-Mind tools to meet real-world clinical needs.



Discussions of the 9th GA focused on:

- Collaboration with European and global projects that is vital for the sustainability and future adoption of our comprehensive project data.
- Stakeholder involvement and preparing European health systems and legislation for the integration of Al-based dementia tools as well as dementia risk management.
- Clinical relevance and positioning Al-Mind in dementia and mild cognitive impairment (MCI) diagnostic pathways.
- Diversity within AI-Mind harnesses the project's heterogeneity to strengthen outcomes and broaden impact.

The assembly also featured insightful guest lectures from leading experts. Paolo Maria Rossini (IRCCS San Raffaele) delivered an insightful talk on "Why and where neurophysiological approaches are more informative than 'traditional' neuroimaging," emphasising the diagnostic potential of advanced neurophysiological methods. Giovanni Frisoni (Hôpitaux Universitaires de Genève) discussed the evolving landscape of Alzheimer's disease treatment and prevention, including the current practices of the memory clinics and the need to focus on risk assessment, communication and reduction.

https://www.ai-mind.eu/blog/reporting-from-ai-mind-9th-general-assembly/

#### 28-29 OCTOBER:

#### The European Platform for Neurodegenerative Diseases project convenes its third Annual Meeting in Madrid



On 28-29 October, the 3<sup>rd</sup> Annual Meeting of the European Platform for Neurodegenerative Diseases (EPND) convened in Madrid, gathering over 70 representatives from 29 private and public partners. Led by Pieter Jelle Visser (University of Maastricht), Niranjan

Bose (Gates Ventures), Tony Brookes (University of Leicester), and Phil Scordis (UCB), the meeting reviewed significant milestones and outlined strategies for the platform's next phase. Dianne Gove (Director for Public Involvement and Ethics) and Angela Bradshaw (Director for Research) represented Alzheimer Europe at the meeting.

Highlights from EPND's third year included the expanded EPND Catalogue, which now encompasses 85 neurodegeneration research studies. This resource offers comprehensive

metadata on clinical variables, biosamples, and datasets, empowering researchers to accelerate biomarker discovery. Updates on biomarker analyses revealed novel insights into mixed pathologies underlying Alzheimer's, Parkinson's, and related diseases.

Platform development updates from Gates Ventures introduced planned enhancements to the EPND Hub, including advanced biobank discovery tools and catalogue syndication, set to launch in December. These functionalities aim to streamline access to biosample and dataset information. Discussions emphasised biosample quality standards, with cohorts like gMAD-COSCODE achieving ISO certification for biobanking processes, ensuring data reliability. Looking ahead, sustainability and cross-sector collaboration remain priorities. Strategic planning efforts, led by Gates Ventures and Synapse, aim to secure EPND's long-term role in advancing neurodegeneration research.

Learn more about EPND: https://epnd.org/

#### 29 OCTOBER:

# AD-RIDDLE project brings clinical and workstream leads together for a Steering Committee meeting

On 29 October, our Director for Research, Angela Bradshaw, participated in a Steering Committee meeting for the Innovative Health Initiativefunded AD-RIDDLE project in



Madrid, Spain. On the margins of the Clinical Trials in Alzheimer's Disease conference, project and workstream leads met to share updates on progress and plan upcoming activities in the project.

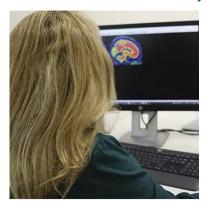
Following a warm welcome by project co-Leads Miia Kivipelto and Niranjan Bose, partners and PIs of clinical sites discussed the design and initiation of the AD-RIDDLE study. Involving eight sites in six European countries, the study will test and refine the AD-RIDDLE modular toolbox platform, which comprises an array of tools including digital cognitive assessments and blood-based biomarkers. Running alongside, the AD-RID-DLE implementation study will assess the adoption and use of these innovative tests in the real-world setting. Workstream leads have been organising clinical site visits, to understand the context for implementation and establish an evaluation plan for 2025 onwards. We also heard about advances in designing predictive algorithms for early risk and disease detection, supported by data mapping work to facilitate the provision of analysis-ready datasets - enabled by the European Platform for Neurodegenerative Diseases (EPND). Angela presented an update for the two work packages that AE is leading, which are addressing communications, public involvement, stakeholder engagement, ethics and policy.

Learn more about AD-RIDDLE: https://www.ad-riddle.org/



#### 29 OCTOBER:

# AMYPAD researchers demonstrate the reliability of the centiloid metric as a reliable measure of AD-related amyloid plaques



On 29 October, the Barcelonaβeta Brain Research Center (BBRC), the research centre of the Pasqual Maragall Foundation, issued a press release, announcing a significant milestone in Alzheimer's disease (AD) research.

The Neuroimaging Re-

search Group of the BBRC in collaboration with the AMYPAD (Amyloid Imaging to Prevent Alzheimer's Disease) Consortium, has demonstrated the reliability of the Centiloid metric for measuring amyloid plaques, one of the main hallmarks of AD. The work, published in Alzheimer's and Dementia and conducted across multiple clinical sites, improves diagnostic accuracy, particularly when assessing equivocal cases. The study has provided the basis for the European Medicines Agency (EMA) to consider this scale as a valid and robust biomarker of the accumulation of amyloid protein in the brain. The BBRC team has played a key role in this evaluation. Dr

The BBRC team has played a key role in this evaluation. Dr Mahnaz Shekari, first author of the publication and researcher at the Neuroimaging Research Group at the centre, explains that "we have demonstrated the precision of the Centiloid metric in memory clinic patients, establishing it as a reliable biomarker for diagnosing and tracking Alzheimer's disease. Furthermore, we offer a comprehensive, easy-to-follow guideline for using the Centiloid metric in amyloid PET quantification, making it accessible to both clinicians and researchers."

The EMA's Committee for Medicinal Products for Human Use (CHMP) has recognized the Centiloid Unit as a sensitive and robust universal measure for global amyloid load in the brain when used in clinical trials, provided that appropriate quality control procedures are followed. This allows for consistent comparisons of amyloid-PET scans across different tracers and procedures, supporting AD clinical trials.

With the anticipated rise in anti-amyloid drugs and their broader clinical use, the Centiloid metric will be crucial for evaluating drug efficacy and managing dosing effectively. According to EMA's Qualified Opinion, "the use of the Centiloid scale can provide a potential baseline measure for future therapy monitoring/follow up scanning".

https://amypad.eu/news/recent-news/validation-of-centiloid-metric-as-a-reliable-measure-of-alzheimers-related-amyloid-plaques/

#### 14 NOVEMBER:

# PROMINENT project supports Alzheimer's disease diagnosis amid recommendation of first disease-modifying treatment

The recommendation of lecanemab, the first disease-modifying therapy (DMT) for Alzheimer's disease (AD), by the European Medicines
Agency consti-



tutes a major breakthrough for the dementia community. However, several steps still remain before patients can access these new treatments, which are bound to challenge European healthcare systems. A major remaining hurdle is overcoming pricing and reimbursement discussions which will take place within each individual country. Further, health care systems will need to address limited capacity of specialist services for diagnosis and treatment. Supporting clinicians with tools to help them identify the patients most likely to benefit from these new therapies is therefore vital to improve health systems readiness and ensure quality care for people with AD. Diagnosis and management of AD are challenging due to the high incidence of comorbidities, such as cardiovascular and psychiatric conditions. By considering individual differences in patients' genetic makeup, lifestyles and clinical parameters, precision medicine has the potential to dramatically improve diagnosis, prognosis and treatment of AD. Considering these individual differences may help identify patients who may encounter adverse effects.

Last year, PROMINENT partners asked members of the European Alzheimer's Disease Consortium (EADC) of memory clinics about challenges in determining a diagnosis and managing patient care. Their responses underscored the need for decision support systems in clinical practice. Only 5% of respondents had previously used such a system, but 60% believed they will use it in the future, and 80% thought support with assessing eligibility for DMTs would be useful or very useful.

The PROMINENT project, a collaborative, pan-European public-private partnership funded through the Innovative Health Initiative (IHI) for five years, sets out to address challenges around diagnosis and treatment pathways. Find out more: https://www.ihi-prominent.eu/prominent-project-supports-alz-heimers-disease-diagnosis-amid-recommendation-of-first-disease-modifying-treatment/



And listen to Hanneke Rhodius-Meester, clinical Geriatrician at Amsterdam UMC & Oslo University Hospital about the development and use of our clinical decision support tool to improve diagnosis, communication, and shared decision-making for patients with memory-related issues.

https://vimeo.com/1029939059

#### 19 NOVEMBER:

## PREDICTOM Public Ambassador Group meets online



On Tuesday, 19 November several of the members of the Public Ambassador Group (PAG) for the PREDICTOM project met online together with research partners from the University of Exeter (UK) and Kings College London (UK) to discuss the first part of the partici-

pant journey on the PREDICTOM platform. The meeting started with a presentation by Jack Lewis from the University of Exeter, followed by a very fruitful discussion about the user-friendliness of the PREDICTOM platform so far. This discussion was led by Sarah Campill, Public Involvement Officer at Alzheimer Europe.

The meeting ended with a preview of the topic of the next meeting, given by Zunera Khan, and with praise from the PAG members for the joint efforts of the PREDICTOM partners and their goal to make early detection of dementia more accessible. They highlighted how this use of technology and biomarkers, accessible from the comfort of your own home, is almost futuristic. "This is fantastic! This is like science-fiction.", they commented.

#### 21 NOVEMBER:

## PROMINENT consortium meets in Barcelona for second annual meeting

On 20-21 November, the PROMINENT consortium held its second annual meeting in Barcelona, hosted by Fundación Pasqual Maragall. Representatives from all 18 partner organisations reviewed progress and planned next steps for advancing precision medicine in neurodegenerative diseases.

Project co-coordinator Linus Jönsson (Karolinska Institutet) opened with highlights from the past year, including the European Medicines Agency's recommendation for Lecanemab and the addition of three partners, who followed with presentations on their contributions.

Xin Xia (Karolinska Institutet) and Ferran Lugo (Barcelona-Beta Brain Research Center) shared updates on prediction



models and diagnostic algorithms. Jyrki Lötjönen (Combinostics) showcased progress on PROMINENT's digital platform, incorporating feedback from the Advisory Board to align with clinician and patient needs.

Day one concluded with presentations by Frank Jessen (Uniklinik Köln) on anti-amyloid therapies and Sandar Aye (Karolinska Institutet) on a dashboard to visualise the number of eligible patients for amyloid-targeting therapies across Europe.

Day two featured Sofie Persson (IHE) on real-world evidence in health technology evaluation and Lena Sannemann (Uniklinik Köln) on validating the digital platform for specialists and patients. Lennart Thurfjell (Combinostics) outlined private sector contributions, while Christophe Bintener (Alzheimer Europe) and Sébastien Libert (Alzheimer Europe) presented on communication activities and Public Involvement, respectively.

Andrea Martí del Rio (SYNAPSE) and Anna Hansson (Karolinska Institutet) concluded with updates on project management, confirming milestones are on track. Linus Jönsson formally closed the meeting, thanking attendees and wishing them safe travels.

Find out more about the project: www.ihi-prominent.eu

#### 21 NOVEMBER:

#### A new article about the Lethe study published

Researchers from the Lethe project have published a new article in the journal of Alzheimer's Research & Therapy. The article is entitled "A digitally supported multimodal lifestyle program to promote brain health among older adults (the LETHE ran-



domized controlled feasibility trial)" and describes the Lethe



study design, progress and first results. The Lethe study will last two years and will evaluate the feasibility of a digitally supported, adapted FINGER intervention among older adults atrisk, in four European countries (Austria, Finland, Italy, Sweden). In the trial, technology will be used to complement inperson activities, personalise recommendations, and collect digital biomarkers. The trial started in September 2022 and after the first six months, its first results show a good retention rate (over 98%). The article also includes a section about the Public Involvement activities which have been organised in this project by Alzheimer Europe. Ana Diaz, Public Involvement Lead at Alzheimer Europe is one of the co-authors of the article. The article is open access and can be accessed here: https://link.springer.com/article/10.1186/s13195-024-01615-4?utm source=rct congratemailt&utm medium=email&utm campaign=oa 20241121&utm content=10.1186%2Fs13195-024-01615-4

#### 22 NOVEMBER:

## New PREDICTOM project website and Data Catalogue launched



The PREDICTOM project recently announced the launch of their Data Catalogue, accessible on the new project website (www.predictom.eu). The website offers a wide range of infor-

mation and resources, which are interesting for people from the general public as well as for members of the research community.

A particular section that may be of interest for members of the public might be the "Public and Participant" section, which provides essential information on Public Involvement and Participant Recruitment. This includes details about various Public Involvement groups, such as Alzheimer Europe's Public Involvement Pool (PI Pool). The PI Pool is an online community of individuals from across Europe and by joining the mailing list, members can get informed about opportunities for involvement in European research projects focused on dementia and brain health. Moreover, people with a keen interest in joining the PREDICTOM study as participants can check their eligibility by reviewing the participation criteria on the website and finding out more about how to become a participant.

The Data Catalogue (https://www.predictom.eu/resources) will be especially useful for researchers. The catalogue was designed based on the FAIR principles:

- Findable
- Accessible
- Interoperable
- Reusable.

The PREDICTOM team aims to ensure that everyone who could benefit from this open resource can easily find it, explore the datasets, and build upon the research. Collaborative research environments like this one hold great value, as they can lead to discoveries that might otherwise go unnoticed.

#### EU project acknowledgements



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

AD-RIDDLE – grant agreement 101132933 (https://ad-riddle.org/)
Al-Mind - grant agreement 964220 (https://www.ai-mind.eu/)
EPND - grant agreement 101034344 (https://epnd.org/)
LETHE - grant agreement 101017405 (https://www.lethe-project.eu/)
PREDICTOM - grant agreement 101132356 (https://www.predictom.eu/)
Prominent - grant agreement 101112145 (https://www.ihi-prominent.eu/)



#### MEMBERS OF THE EUROPEAN ALZHEIMER'S ALLIANCE

Currently, the total number of MEPs in the European Alzheimer's Alliance (EAA) stands at **79**, representing **21** Member States of the European Union and seven out of eight political groups in the European Parliament. Alzheimer Europe is grateful to the Co-Chairs of the EAA: Nina Carberry MEP (Ireland, EPP), Tilly Metz MEP (Luxembourg, Greens/EFA), Romana Jerković MEP (Croatia, S&D), Hilde Vautmans



MEP (Belgium, Renew Europe) and Dainius Žalimas (Renew Europe, Lithuania) for their leadership and for hosting the organisation's European Parliament lunch debates on dementia. Alzheimer Europe would also like to thank the following MEPs for their support of the EAA:

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

#### **EUROPEAN ALZHEIMER'S ALLIANCE**

#### 11 NOVEMBER:

## European Commission responds to Hilde Vautmans MEP written question



The European Commission has responded to a written question from Hilde Vautmans MEP (Renew, Belgium), who asked:

"According to WHO estimates, dementia will become the third most common cause of mortality in Europe next year. However, the mission letter from Commission President von der Leyen does not mention de-

mentia. Beyond the impact on patients and their families and friends, we must also consider the significant societal cost of inaction.

- In light of this, is there a commitment to developing a European action plan on dementia?
- 2. How will the Commission ensure that this action plan addresses the full spectrum of dementia, including prevention, diagnosis, treatment, and care?
- What steps does the Commission plan to take to coordinate efforts with national governments and motivate Member States to develop and implement their national dementia strategies?"

In its response, the European Commission does not commit to developing a European Action Plan on Dementia, whilst referring to existing work, for example the current Join Action on Dementia and the existing Steering Group on Health Promotion, Disease Prevention and *Management* of Non-Communicable Diseases.

The written question and answer are available at: https://www.europarl.europa.eu/doceo/document/E-10-2024-001905-ASW\_EN.html



## Three MEPs join the European Alzheimer's Alliance







Alzheimer Europe is delighted to announce that three Members of the European Parliament (MEPs) have joined the European Alzheimer's Alliance (EAA). The EAA is a non-exclusive, multinational and cross-party group, with two key objectives:

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

We are delighted to welcome new EAA members:

- Vytenis Andriukaitis MEP (S&D, Lithuania)
- Ondřej Dostál MEP (NI, Czech Republic)
- Dimitris Tsiodras MEP (EPP, Greece)

We very much look forward to working with them to prioritise dementia as a policy priority at a European level.

A full list of Co-Chairs and all 79 current members of the EAA is available at:

https://www.alzheimer-europe.org/policy/european-alzheimers-alliance/members

Pictured (left to right): Dimitris Tsiodras MEP, Ondřej Dostál MEP, Vytenis Andriukaitis MEP

#### **EU DEVELOPMENTS**

#### 4 NOVEMBER:

## European Economic and Social Committee adopts opinion on health



### European Economic and Social Committee

The European Economic and Social Committee (EESC) has issued an opinion "Devising a European flagship initiative for health", calling for a programme based on the principles of universality, quality, accessibility, solidarity and inclu-

sivity. The Opinion sets out strategic pillar for such in initiative which would, amongst other things:

- Establish a European care and healthcare guarantee
- Implementing the integrated One Health approach
- Harness the potential of digitalisation and artificial intelligence (AI) to modernise health systems
- Uphold European financial instruments to support national health initiatives and funding
- Prioritise social and health investments
- Promote an integrated scoreboard of socio-economic, health and environmental reforms, with a view to a strategy that goes beyond growth
- Develop a targeted investment plan to strengthen capacity and promote care professions and healthcare workers
- Undertake collaborations between the EU and WHO Europe to retain, attract and support care workers, including nursing staff

• Embed institutionalised involvement of civil society in defining, evaluating and monitoring health priorities.

The full opinion is available at: https://www.eesc.eu-ropa.eu/en/our-work/opinions-information-reports/opinions/devising-european-flagship-initiative-health#msdynttrid=A-DYL89WbP-

bUzqfiwn21VDRvIT\_tIUzZ9e57tik5kfE

#### 12 NOVEMBER:

## World Health Organization (WHO) Europe publishes care toolkit

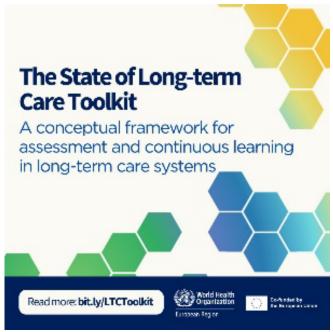
The WHO Regional Office for Europe has launched "State of Long-term Care (LTC) Toolkit", which aims to support policy-makers at regional, national and local level to reshape LTC systems to be more responsive, inclusive and sustainable. The toolkit has three main components:

- A conceptual framework that defines the broader components of LTC systems and mechanisms for LTC reform
- An implementation guide
- A detailed data-collection template.

The toolkit proposes a holistic approach to LTC system development, underpinned by a "results chain" structure. This approach brings together five key components: population care needs; system inputs; system outputs, system outcomes, and population-level impacts.

This model urges policy-makers to consider the resources available within the LTC system, both tangible (such as infrastructure and workforce) and intangible (such as funding mechanisms), and to evaluate how effectively these resources





are being used to deliver care services and meet the goals formulated in national policies.

As part of this work, three country-specific studies for Greece, Ireland and Lithuania, were launched, identifying challenges and priorities for progress in transforming their systems in line with national goals.

The work was supported with financial support from the European Commission's Directorate-General for Employment, Social Affairs and Inclusion, and is part of the European Care Strategy, contributing to the Council Recommendation on access to affordable high-quality LTC.

The toolkit and other resources, including the country-specific studies, are available at: https://www.who.int/europe/news/item/12-11-2024-who-europe-launches-a-newtoolkit-to-help-countries-to-transform-long-term-care-systems

#### 14 NOVEMBER:

## Discover the Citizen, Equality, Rights and Values (CERV) programme



The CERV Programme - 'Citizens, Equality, Rights and Values' - is funded by the European Commission's DG Justice and Consumers and has as its overall objective to protect and promote the rights and values enshrined in the EU Treaties and in the Charter of Fundamental Rights and international

human rights conventions, in order to support and contribute to the further development of open, democratic, fair and inclusive societies based on the rule of law. The CERV programme invests over EUR 1.5 billion available for entities that make Europe stronger by improving the quality of life of its citizens. Projects funded by the CERV programme are developed on four thematic strands:

- Union Values to safeguard and promote the values of the European Union.
- Equality, rights and gender equality that promote rights, non-discrimination and equality.
- Citizens' engagement and participation to promote citizens' involvement and participation.
- Daphne to combat violence, including genderbased violence.

#### Who can apply:

- Civil society organisations active at local, regional, national and transnational levels
- European networks
- Public authorities (including equality and human rights bodies)
- National, regional and local authorities
- Towns and municipalities
- Academia/research institutes
- Think tanks
- · The judiciary
- International organisations and other stakeholders active in promoting EU values and rights.

#### Campaign web page:

https://citizens-equality-rights-values.campaign.europa.eu/index\_en

Alzheimer Europe is hugely grateful to the CERV programme for supporting our work by providing us with vital funding in the shape of an Operating Grant.

#### 18 NOVEMBER:

#### EU Health at a Glance report published

The Organisation for Economic Cooperation and Development (OECD) has published Health at a Glance: Europe 2024, outlining the major challenges facing European health systems in the aftermath of the COVID-19 pandemic. The report focuses on two linked piv-



otal themes: addressing health workforce shortages and promoting healthy longevity. Five key messages were identified in the report:

- Urgent action is needed to address health workforce shortages in Europe
- Promoting healthy longevity can reduce the burden on health and long-term care systems
- Significant life expectancy gaps persist across countries and the health of young people is an enduring concern
- Progress in addressing lifestyle risk factors has stalled, with persistent socio-economic disparities



 EU countries have made gradual improvements in health crisis preparedness, but significant challenges remain in building public trust and combatting anti-microbial resistance.

The report notes that across the EU, nearly 8 million people have Alzheimer's disease or another dementia in 2021, according to the Global Burden of Disease study. It further highlights that for people aged over 70, over 9% of people have Alzheimer's disease or another dementia, being 3% among people aged 70-74 to 18% for people aged over 80.

The report notes that up to 45% of dementia cases could be avoided by addressing 14 modifiable risk factors, citing the 2024 Lancet Commission and its recommendations for actions to promote prevention.

Additionally, the report notes that dementia (including Alzheimer's disease) is the most important cause of healthy life years lost due to disability among older people in the EU. In addition, it notes that accidental falls account for a large number of years of life lost due to disability among older people.

The biennial Health at a Glance: Europe report is the first part of the European Commission's "State of Health in the EU". The second part is the Country Health Profiles, which is next expected in 2025. The full EU Health at a Glance report is available at:

https://www.oecd.org/en/publications/health-at-a-glance-europe-2024\_b3704e14-en/full-report.html

#### 20 NOVEMBER:

#### European Medicines Agency convenes an online meeting of its Working Parties for patients, consumers and healthcare professionals

On November 20, the European Medicines Agency (EMA) hosted its annual meeting for all members of the Patients' and Consumers' (PCWP) and Healthcare Professionals' Working Parties (HCPWP). The meeting began with an introduction by Juan Garcia Burgos (EMA), who welcomed the participants and the co-chairs of the Working Parties, Marko Korenjak (PCWP) and Rosa Giuliani (HCPWP). The meeting covered a variety of important topics related to medicines and medical devices, including regulatory science, digitalisation and AI, shortages, and communications, and kicked off with a recap of some 2024 patient and healthcare professional engagement highlights, delivered by the Head of EMA's Stakeholders and Communication Division, Melanie Carr.

After an update from Ana Zanoletty (EMA) on ongoing clinical trial activities in the EU, Denis Lacombe (EMA) shared key takeaways from the ACT (Accelerating Clinical Trials) EU Multi-stakeholder Platform Annual Meeting, which focused on fostering collaboration between different organisations. Participants were also encouraged to explore the Clinical Trial Infor-

mation System (CTIS) public portal, which has undergone recent improvements. Francesca Scotti (EMA) presented the updated portal, which features advanced search functionalities, a more user-friendly interface, and the ability to download search results and information on clinical trials. This update aims to make it easier for patients and healthcare professionals to access and navigate clinical trial information.

A new tool designed to help patients and healthcare professionals find clinical trials in the EU was also demonstrated by Ijsbrand van Rooijen (EMA). The tool, a trial map under development, was introduced in response to feedback from patient organisations seeking better access to trial data. The demo aimed to gather feedback before the tool's public launch in 2025. Participants were also informed about the planned 2025 relaunch of clinical data publication on the Clinical Data Portal, which will increase transparency and access to clinical data for research and regulatory purposes.

In the area of medical devices, attendees were updated on EMA's ongoing activities, including expert panel support for orphan medical devices. The meeting also covered the activities of the Big Data Steering Group and the progress of the Al multi-annual workplan (2023-2028), which focuses on the role of artificial intelligence in the medicinal product lifecycle. Luis Pinheiro (EMA) discussed the flexible nature of the workplan, which allows for annual revisions based on feedback and the rapid evolution of Al technologies.

Participants were also briefed on the progress of the Union List of Critical Medicines (ULCM), which will be published in December 2024. The list is vital for tracking the availability of critical medicines such as cancer treatments, antibiotics, and vaccines across the EU. João Ferreira provided an update on the ongoing work to assess the criticality of additional medicines and substances. The meeting also included discussions on medicine shortages and the new communication process for shortages unrelated to safety or efficacy issues. João Ferreira presented the streamlined Medicine Shortages Communication (MSC) template, which will help ensure better communication with healthcare professionals during critical supply shortages. The new MSC process will be piloted starting in October 2024 and is expected to be fully implemented by April-May 2025. EMA's communication efforts were also highlighted in the final section of the meeting, with Giulia Gabrielli and Laure Herold providing an overview of their work on communicating about medicine shortages. They introduced a new cocreated campaign focused on shortage management, as well as a pilot project on Respiratory Syncytial Virus (RSV) that aims to involve more patient and healthcare professional organisations.

https://www.ema.europa.eu/en/events/european-medicines-agency-ema-patients-consumers-pcwp-healthcare-professionals-hcpwp-working-parties-meeting-all-eligible-organisations-2024



## European Commission publishes independent living guidance



On 20 November 2024, the European Commission published a Notice on "Guidance on independent living and inclusion in the community of persons with disabilities in the context of EU

#### funding".

This fulfils the European Commission's "flagship initiatives" within the European Strategy on Rights of Persons with Disabilities" 201-2030.

The guidance provides recommendations to Member States on the use of EU funding to support the transition from institutional care to community-based services and independent living for people with disabilities. As well as highlighting the existing policy context for independent living, the Notice provides practical guidance on the use of EU funding to promote the realisation of the right of people with disabilities to live independently and be included within their communities.

The guidance also highlights examples of measures funded by the EU in Member States, which have fostered the development of community and family-based services, as well as support for independent living and the implementation of deinstitutionalisation strategies. Additionally, the Annex to the Notice provides a self-assessment tool for operations and projects, in the context of both the Charter of Fundamental Rights and the UNCRPD. The Notice can be is available at: https://ec.europa.eu/social/main.jsp?lan-

gld=en&catld=89&furtherNews=yes&newsld=10919

#### 27 NOVEMBER:

## European Parliament approves College of Commissioners

On 27 November, the European Parliament approved the College of Commissioners for the forthcoming term of the European Commission. The Col-



lege passed with 370 number in favour, 282 against, and 36 abstentions. Of particular interest for dementia policy are the following Commissioners and portfolios:

- Executive Vice-President for People, Skills and Preparedness Roxana Mînzatu
- Commissioner for Preparedness and Crisis Management; Equality Hadja Lahbib
- Commissioner for Health and Animal Welfare -Olivér Várhelyi
- Commissioner for Startups, Research and Innovation Ekaterina Zaharieva.

The new term of the European Commission will formally commence on 1 December 2024. Further information on the Commissioners and their portfolios are available at: https://commission.europa.eu/towards-new-european-commission-2024-2029 en

#### **POLICY WATCH**

#### 8 OCTOBER:

European Academy of Neurology organises G7 Health Ministers' Meeting Side Event on "Prioritising Brain Health: A Global Imperative for Public Health"



On 8 October, the European Academy of Neurology (EAN) organised a G7 Health Ministers' Meeting Side Event on "Prioritising Brain Health: A Global Imperative for Public Health", in collaboration with Italian Brain Health Strategy Partners and Italian Society of Neurology.

This event, held in Ancona (Italy) alongside the G7 Meeting of Health Ministers, aimed to spotlight the critical importance of brain health as a central component of public health strategies for all countries.

The event shone a spotlight on the critical importance of brain health as a central component of public health strategies for all countries, convening leading experts and policymakers to discuss innovative approaches, share best practices, and outline strategic frameworks for integrating brain health into national and global health policies.

Speakers included:

- Marco Battino, Ancona City Council
- Manuela Caucci, Ancona City Council
- Nicola Baiocchi, President Regional Commission on Health and Welfare of Regione Marche
- Elena Moro, President European Academy of Neurology
- Alessandro Padovani, President Italian Society of Neurology



- · Giovanni Leonardi, Italian Ministry of Health, Italy
- Vladimir Hachiniski, Robarts Research Institute;
   Western University, Canada
- Paul Boon, EAN Brain Health Mission Coordinator
- Daniele Silvetti, Mayor of Ancona
- Beatrice Lorenzin, Former Minister of Health (Italy).

For more information, the full programme, and to view a recording of this special event on "Prioritising Brain Health: A Global Imperative for Public Health", please visit the EAN website:

https://www.ean.org/ean/advocacy/brain-health/g7-health-ministers-meeting-side-event

#### 24 OCTOBER:

New "Dementia Trials Accelerator" launched in the UK with the aim of dramatically increasing the number of dementia trial participants





Dementia Trials Accelerator Working to increase the number of people participating in late-stage clinical trials for dementia.



A new "Dementia Trials Accelerator", backed by GBP 20 million (EUR 24 million) of UK Government funding, has been launched to increase the number of people participating in dementia clinical trials in the UK from just 61 in 2021-22 to "tens of thousands". Spearheaded by two national research institutes, the UK Dementia Research Institute and the Health Data Research UK, the Dementia Trials Accelerator will tackle the historically low numbers of people enrolled into dementia trials in the UK.

The initiative, which is supported by the Government's Dame Barbara Windsor Dementia Goals programme (formerly known as the Dame Barbara Windsor Dementia Mission), aims to rapidly identify a large group of people who are at risk of or diagnosed with early-stage dementia. The Dementia Trials Accelerator is still in development and is not yet recruiting participants.

You can read the full news story, here:

https://ukdri.ac.uk/news-and-events/new-20m-dementia-tri-als-accelerator-will-increase-number-of-dementia-trial-participants-to-tens-of-thousands

For updates about the Dementia Trials Accelerator, please visit: https://ukdri.ac.uk/dementia-trials-accelerator

#### 7 NOVEMBER:

The Alzheimer Society of Ireland welcomes Ireland's accession to the Optional Protocol to the UN Convention on the Rights of Persons with Disabilities

The Alzheimer Society of Ireland (The ASI) welcomes Ireland's long-awaited accession to the Optional Protocol to the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Ireland signed the UNCRPD in 2007 but did not ratify it until 2018. The ratification places Ireland on par with



international standards, ending its status as an outlier since 2018, when it ratified the UNCRPD but initially excluded the Optional Protocol.

This decision is a vital step forward for people with disabilities, including those living with dementia, in aligning Ireland's standards with international human rights commitments, says The ASI, noting that for people with dementia in Ireland, this development strengthens their pathways to justice and accountability on fundamental issues of dignity, equality, and autonomy. The Optional Protocol offers an independent UN mechanism that enables individuals to lodge complaints when their rights under the UNCRPD are violated and no effective remedy is available within Ireland. This is a significant step forward in ensuring accountability and underscores the urgent need for dementia-inclusive policies to be fully realised.

"Much remains to be done by the state towards the full implementation of the CRPD and we urge the government to continue building on this progress and make Ireland a place where every person with dementia is valued, empowered, and protected", said Cormac Cahill, Head of Advocacy, Research & Public Affairs at The ASI.

The ASI and the Irish Dementia Working Group published a Charter of Rights for People with Dementia in 2016. This charter outlines the rights of people living with dementia in relation to participation, accountability, non-discrimination, empowerment and equality.



#### **CTAD WATCH**



The 17<sup>th</sup> annual Clinical Trials on Alzheimer's Disease (CTAD) conference took place from 29 October to 1 November 2024, in Madrid (Spain). Here are some research highlights from the event:

#### 29 OCTOBER:

## Eli Lilly announces positive results from TRAILBLAZER-ALZ 6 Phase IIIb study

On 29 October, Eli Lilly and Company presented new results from the TRAILBLAZER-ALZ 6 Phase IIIb study, highlighting the use of a modified titration regimen for donanemab, a monoclonal antibody targeting amyloid plaques in early symptomatic Alzheimer's disease (AD). The results, presented at the 17th Clinical Trials on Alzheimer's Disease (CTAD) conference in Madrid (Spain), demonstrated that this modified titration not only achieved similar levels of amyloid plaque removal but also reduced the incidence of amyloid-related imaging abnormalities with oedema/effusion (ARIA-E).

The TRAILBLAZER-ALZ 6 trial is a multicentre, randomised and double-blind study designed to evaluate different dosing regimens of donanemab and their effect on ARIA-E in people with early symptomatic AD, including mild cognitive impairment (MCI) and the mild dementia stage of disease. The trial enrolled 843 participants aged 60-85, selected based on cognitive assessments in conjunction with amyloid plaque imaging by PET scan.

The study included four treatment arms, with one arm receiving the once-monthly standard dosing regimen used in the Phase III TRAILBLAZER-ALZ 2 trial, and the remaining three arms receiving modified dosing regimens that administered the same total dose of donanemab but with adjusted infusion schedules.

he modified titration regimen, which involved shifting one vial from the first to the third infusion, showed that the incidence of ARIA-E was 14% in participants receiving the modified titration compared with 24% for those receiving the standard dosing regimen, at 24 weeks. The largest ARIA-E reduction with this modified titration was seen in apolipoprotein E (APOE4) ho-

mozygotes, carriers of a known genetic risk factor for developing Alzheimer's disease. Both the modified titration and standard dosing regimens of donanemab led to comparable reductions in amyloid plaques and P-tau217 levels.

The TRAILBLAZER-ALZ 6 study is ongoing with additional data investigating the potential reduction of ARIA-E in people with early symptomatic AD at week 52 expected early 2025. The company is currently discussing with global regulators regarding the results from the TRAILBLAZER-ALZ 6 trial, with the aim of seeking an update to the label for Kisunla (the brand name for donanemab), which is already approved in the US, Japan, Great Britain and other countries.

https://investor.lilly.com/news-releases/news-release-details/modified-titration-donanemab-demonstrated-reductionaria-e-early

#### 30 OCTOBER:

#### Roche presents interim data from its Brainshuttle AD study

On 30 October, the biotechnology company Roche presented the latest results from its ongoing Phase Ib/IIa Brainshuttle study at the Clinical Trials in Alzheimer's Disease congress (CTAD) in Madrid, Spain.

The Brainshuttle trial is designed to assess the safety, tolerability, pharmacokinetics and pharmacodynamics of trontinemab in people with Mild Cognitive Impairment or mild to moderate Alzheimer's disease (AD), who are amyloid positive. The drug is administered via intravenous infusion every four 4 weeks.

The interim analysis presented at CTAD included data from 160 participants. The first part of the study, which is complete, enrolled 60 participants across four cohorts. These participants received either escalating doses of trontinemab or placebo. The second part of the study is ongoing and involved 100 participants who are being treated with either 1.8 mg/kg or 3.6 mg/kg of trontinemab or placebo.

Results from the completed Part 1 study demonstrated rapid and robust amyloid plaque depletion, after 12 to 28 weeks, in participants receiving 1.8 mg/kg and 3.6 mg/kg of trontinemab. After 28 weeks of treatment, most participants in the highest two dose groups were amyloid negative. In addition to amyloid plaque reduction, preliminary Part 1 data indicated that amyloid removal is accompanied by large magnitude changes in relevant AD biomarkers such as total tau, ptau181 and Neurogranin in cerebrospinal fluid (CSF).

Trontinemab had an overall favourable safety profile. According to Roche, a "very limited" number of amyloid-related imaging abnormalities-oedema/effusion (ARIA-E) cases was observed. However, Roche disclosed one participant (78 years-old) receiving treatment who experienced a brain bleed in her right front lobe and died on day 44 of the study. The company said this participant had a superficial siderosis, as well as ad-



ditional lesions, signifying a probable cerebral amyloid angiopathy. As a result, Roche implemented protocol amendments, excluding participants with superficial siderosis from the study going forward.

You can find the oral presentation on the Roche website: https://medically.roche.com/global/en/neuroscience/ctad-2024/medical-material/CTAD-2024-presentation-kulic-latest-interim-results-from-brainshuttle-ad-study-pdf.html

#### 31 OCTOBER:

## UCB presents phase II data on bepranemab in early AD

On 31 October, the global biopharmaceutical company UCB presented data from its Phase IIa TOGETHER study, evaluating bepranemab in people with prodromal to mild Alzheimer's disease (AD). The findings were shared during a late-breaking symposium at the 2024 Clinical Trials on Alzheimer's Disease (CTAD) meeting in Madrid, Spain.

The TOGETHER study enrolled 466 participants, who were treated with either a low or high dose of bepranemab, or placebo, over a period of 80 weeks. The study aimed to assess the safety, efficacy and tolerability of bepranemab, an investigational anti-tau antibody targeting the mid-region of the tau protein. The majority of participants have now entered the 48-week open-label extension (OLE) period, where they receive bepranemab for 44 weeks, followed by a safety follow-up visit scheduled 20 weeks after the final infusion.

Findings demonstrated that the trial did not meet its primary endpoint, showing no beneficial effect of bepranemab compared to placebo on the Clinical Dementia Rating Scale Sum of Boxes (CDR-SB) total score at Week 80. However in key secondary endpoints, bepranemab slowed cognitive decline (ADAS-Cog14) and rate of tau accumulation versus placebo. In a deeper analysis of predefined subgroups, low tau burden at baseline and APO $\epsilon$ 4 non-carriers, consistent high-dose treatment benefit was shown across multiple primary and secondary outcome measures, including cognition and function. In contrast, in the subgroup comprising participants with high tau at baseline who were also APO $\epsilon$ 4 carriers, no significant benefit from high-dose bepranemab across almost all clinical endpoints was observed.

Bepranemab was generally well tolerated. Both the placebo and bepranemab treatment arms reported similar incidences of brain haemorrhagic events and inflammatory changes. https://www.ucb.com/stories-media/Press-Releases/article/UCB-Presents-Encouraging-Data-on-Bepranemab-in-Early-Alzheimer-s-Disease-in-Phase-2a-Study-at-CTAD-2024

#### 1 NOVEMBER:

## International Working Group publishes revised diagnostic criteria for Alzheimer's disease



On 1 November, Prof. Howard Feldman presented revised diagnostic criteria for Alzheimer's disease at the Clinical Trials on Alzheimer's Disease (CTAD) Conference in Madrid on behalf of the International Working Group (IWG).

The IWG, led by Professor Bruno Dubois and Dr Nicolas Villain (Hôpital Universitaire Pitié-Salpêtrière-Sorbonne Université, Paris, France), Professor Howard Feldman (University of California, San Diego, USA) and Professor Giovanni Frisoni (Hôpitaux universitaires de Genève, Geneva, Switzerland) and comprised of 46 International experts from 17 countries, including a representative of Alzheimer Europe, reviewed the available evidence on the role and influence of biomarkers on the diagnosis and definition of Alzheimer's disease.

The IWG proposed a number of important recommendations which were published today in parallel to this presentation in the Journal of the American Medical Association – Neurology (JAMA Neurology):

- Alzheimer's disease should be defined as a clinicalbiological entity where diagnosis is made in consideration of both a clinical disorder and the support of positive amyloid and tau biomarkers.
- This definition supports a diagnosis of Alzheimer's disease at an early prodromal stage once mild but definite clinical features are in place.
- For people who are cognitively normal with positive amyloid related biomarkers only, the IWG proposes the term "Asymptomatic at risk of Alzheimer's disease", since these individuals have an increased lifetime risk of developing symptomatic Alzheimer's disease.
- The IWG also proposes the category of "Presymptomatic Alzheimer's disease" for those people with autosomal dominant genetic mutations, with Down syndrome and with other distinct biomarker profiles



that put them at extremely high lifetime risk of expressing the clinical disorder (f.ex. combining amyloid positivity with tau accumulations in the neocortical regions).

When presenting these recommendations, Professor Feldman highlighted: "The recommendations of the IWG that are published today advocate for the diagnosis of Alzheimer's disease as being one that is established clinically with support from biomarkers which reflect disease pathology. We consider that on their own these biomarkers reflect varying levels of risk of developing disease in people without clinical symptoms." In its recommendations, the IWG also takes a position on the recently published "Revised criteria for diagnosis and staging of Alzheimer's disease" of the Alzheimer's Association Workgroup. The IWG highlights that a purely biological definition of Alzheimer's disease, which extends a diagnosis of Alzheimer's disease to cognitively normal people with one core biomarker, could lead to false positives and people potentially living with a label of Alzheimer's disease without ever developing any symptoms (patients-in-waiting) with large societal ramifications. Dr Nicolas Villain commented: "As our understanding of Alzheimer's disease evolves, the advancements in biomarkers are allowing for earlier diagnosis, even before symptoms appear. However, it's crucial to emphasise that our main focus should be on the potential future risks of cognitive decline associated with these biomarkers, rather than just the biological changes themselves."

Professor Dubois added: "These recommendations are the collaborative effort of 46 international experts who emphasise that diagnosing Alzheimer's disease should primarily rely on

clinical evaluation supported by biomarkers. Importantly, we are distinguishing between two groups: those who show typical Alzheimer's symptoms and have positive biomarkers are diagnosed with the disease, while those who have positive biomarkers but no typical Alzheimer's symptoms are considered at risk. This distinction is crucial as it paves the way for more targeted research, risk assessment, and the development of personalised treatments for those at risk."

The IWG also stressed the importance of continued research on asymptomatic people at risk of AD to better understand and measure individual risks. Professor Frisoni commented: "Further developing brain health services for the prevention of dementia could lead to better evaluation of risk, communication of risk and risk reduction strategies targeting modifiable risk factors."

Jean Georges, the Executive Director of Alzheimer Europe and one of the co-authors welcomed the recommendations: "The IWG recommendations are in line with Alzheimer Europe's current position against routine biomarker testing for diagnostic purposes in individuals without any cognitive symptoms. Labelling people who test positive for amyloid as having preclinical Alzheimer's disease may have significant negative psychological consequences. Instead, we would recommend disclosing an individual's risk, ensuring that appropriate support, counselling and tailored risk reduction plans are provided to help them process and manage this information." Read the JAMA Neurology article:

https://jamanetwork.com/journals/jamaneurology/fullarticle/2825806

#### **SCIENCE WATCH**

#### 22 OCTOBER:

Sex-specific dementia risk linked to obstructive sleep apnea in older adults: Findings from a 10-year study



On 22 October, researchers from USA published a study in the journal SLEEP Advances examining how obstructive sleep apnoea (OSA) may contribute to dementia risk,

focusing on sex-specific differences over a 10-year period. They analysed data from 18,815 adults aged 50 and older in the Health and Retirement Study (HRS) in the United States, all dementia-free at the study's start.

The findings revealed that OSA was more common in men (68%) than in women (31%). However, by age 80, women with OSA showed a 4.7% higher cumulative incidence of dementia

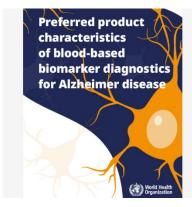
compared to those without OSA. For men, the increase was 2.5%. Even after adjusting for age-related factors, OSA was still significantly linked to dementia risk in both sexes, with the effect remaining stronger in women.

This study suggests that OSA, a potentially modifiable condition, could be an overlooked factor in dementia prevention, particularly in women. The study can be accessed here: https://doi.org/10.1093/sleepadvances/zpae077



#### 23 OCTOBER:

World Health Organisation launches its Preferred Product Characteristics of Blood-Based Biomarker Diagnostics for Alzheimer's Disease



On 23 October, the World Health Organisation (WHO) organised a webinar to celebrate the launch of its Preferred Product Characteristics (PPC) for Blood-Based Biomarker Diagnostics for Alzheimer's Disease. Chaired by Tarun Dua, Head of the

Brain Health Unit at the WHO, the webinar included short talks by expert panellists Oskar Hansson (Lund University, Sweden), Charlotte Teunissen (Amsterdam UMC, Netherlands), Momodou Cham (Richard Novati Catholic Hospital, Kenya), Suzanne Schindler (Washington University School of Medicine, USA) and Pedro Rosa-Neto (McGill University and University of Rio Grande Do Sul, Brazil). Together, they outlined the intended use of the PPC, the types of samples and tests that are covered, as well as key points of technical guidance and clinical performance.

PPCs are technical documents that define the preferred attributes of diagnostic products for regulatory purposes, policy, and implementation in healthcare systems worldwide. This PPC defines the preferred parameters of blood-based biomarker diagnostics for Alzheimer disease to ensure that these products will not only exhibit optimal clinical performance but are also relevant and accessible to different populations. During the webinar, panellists emphasised the importance of providing guidance on how to interpret results, which must consider factors such as age, sex, genetic mutations, medications, comorbidities, local/regional conditions and disease stage. Additionally, they highlighted key aspects that need to be considered, including accessibility, affordability, workforce capacity and training, requirements of technical support and equipment maintenance. Considerations for implementation included global access, post-diagnostic support and perspectives of people with lived experience.

Download the PPC: https://www.who.int/publications/i/item/9789240099067

#### 13 NOVEMBER:

## A new study suggests that age at diagnosis of type 2 diabetes is linked to dementia risk

Type 2 Diabetes Mellitus (T2DM) is a significant risk factor for developing dementia which has become incredibly prevalent among younger individuals. Obesity, on the other hand, is not a primary risk factor for impaired cognitive functioning, but it can exacerbate the effects of cardiovascular risk factors on cognition. However, the association between the age a person receives a T2DM diagnosis with their risk of developing dementia and whether obesity moderates that association is still unknown.

In a new study published in the journal PLOS ONE, a team of researchers led by Dr Bei Wu from New York University (US) investigated the link between age at T2DM diagnosis and dementia risk, and whether obesity moderates this relationship among adults aged 50 or over with previously diagnosed T2DM.

This research involved 1,213 Black and Hispanic adults recruited from the Health and Retirement Study. All of them were aged 50 and over without dementia upon joining the study and with T2DM confirmed by blood tests. The participants were followed for up to 14 years, after which the development of dementia was checked based on cognitive tests.

A total of 17.8% of the participants (216) developed dementia during a medium 10-year follow-up period. The researchers also found that adults diagnosed with T2DM at a younger age were at increased risk for developing dementia compared to those diagnosed at 70 or older. Specifically, individuals diagnosed with diabetes before the age of 50 were 1.9 times more likely to develop dementia, while those diagnosed between 50 and 59 were 1.72 times as likely, and those receiving the diagnosis between 60 and 69 years were 1.7 times as likely. In addition to these findings, the research team found that obesity influences the link between T2DM and dementia. Individuals with obesity who were diagnosed with T2DM before the age of 50 had the highest risk of dementia among all the participants.

Although this study has some limitations (e.g. measurement of dementia was based on cognitive tests only, T2DM was self-reported at baseline, etc.), it shows the link between the age of T2DM diagnosis and the risk for dementia, as well as the influence that obesity has on this association. More studies are needed to explore the mechanisms of the diabetes-dementia relationship, and interventions targeting obesity in dementia prevention for adults with T2DM, particularly for those receiving the diagnosis before the age of 50.

https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0310964



#### Alzheimer Europe welcomes the positive European Medicines Agency opinion on lecanemab



On 14 November 2024, following a re-examination of its initial, negative opinion, the Committee for Medicinal Products for Human use (CHMP) of the European Medicines Agency (EMA) issued a positive opinion on Eisai's marketing authorisation application for lecanemab for the treatment of early Alzheimer's disease (mild cognitive impairment and mild dementia due to Alzheimer's disease). In its opinion, the CHMP found that the benefits of lecanemab for a restricted population outweighed its risks, and therefore recommended approving the marketing authorisation application.

Alzheimer Europe welcomes the positive decision by the CHMP, which addresses many of the concerns highlighted in Alzheimer Europe's official response to the initial CHMP decision, enabling patients to engage in discussions with their physicians and make informed decisions based on their individual circumstances, preferences and values, including the acceptability of risk and anticipated benefits.

Alzheimer Europe appreciates and supports the considered approach that the EMA has taken to identify patients likely to benefit from treatment and exclude those at greatest risk of harmful side-effects. During the re-examination, the CHMP focused on participants with only one or no copies of the ApoE4 gene, assessing data from a subgroup of 1,521 individuals out of the 1,795 participants in the Clarity-AD trial of lecanemab. In this group, the risk of amyloid-related imaging abnormalities (ARIA) was generally lower than in the full trial population, which included people with two copies of the ApoE4 gene.

As a result, the indication for lecanemab has been narrowed, to exclude people carrying two copies of the ApoE4 gene, as well as individuals receiving anticoagulant therapy. The CHMP has also mandated additional measures to reduce risk, including a controlled access programme, regular MRI scans for safety monitoring, and a post-authorisation study to assess the effectiveness of these risk minimisation measures. These measures have improved the benefit-risk balance for lecanemab, protecting people at greatest risk of harmful side effects such as ARIA.

Alzheimer Europe also welcomes the commitment from Eisai and Biogen to increase awareness of ARIA and ensure early management of side-effects, by providing guidance and training for healthcare professionals, as well as an alert card for patients. The companies will also set up an EU-wide registry study to estimate the incidence and severity of side effects and collect information about patients' progression to the next stages of Alzheimer's disease.

Jean Georges, the Executive Director of Alzheimer Europe, stated: "As with many other conditions, this first drug with a new mode of action constitutes an important advance for the Alzheimer's disease community in Europe. We therefore welcome the positive outcome from the CHMP's re-examination of lecanemab. In our position paper on anti-amyloid therapies, we called for timely, safe and equitable access to these medicines. We now look to companies to adopt reasonable and sustainable pricing policies and to payers to ensure lecanemab is covered by national reimbursement systems. Healthcare systems must also be adapted, so that people can receive an accurate, timely diagnosis with access to treatment and effective monitoring for potential side effects. The side effects and benefits of lecanemab will need to be communicated to people with early Alzheimer's disease in realistic terms, in order to allow informed decision-making."

Approval of the lecanemab marketing authorisation application by the EMA is a major step forward for Europeans affected by Alzheimer's disease. At the same time, Alzheimer Europe recognises that lecanemab will only benefit a small fraction of people with the disease. The organisation therefore reiterates its call for continued research into other treatment options, including symptomatic therapies, treatments for people in more advanced stages of the disease and with other types of dementia. In addition Alzheimer Europe remains committed to a holistic approach where treatments are included alongside counselling, support and care of people with dementia and their carers throughout the disease process. The full press release from the EMA can be accessed here:

https://www.ema.europa.eu/en/news/leqembi-recommended-treatment-early-alzheimers-disease

#### 14 NOVEMBER:

# Systematic review of decision-making processes for pain assessment and management for people living with dementia is published online

The recently published systematic review conducted by the research team around Lihui Pu Madushika highlights the decision-making process involved in pain assessment and management for people living with dementia. The team focused on the different steps to decision-making and the key decisions by people with dementia, and their informal and formal carers,



to create a model based on these results. Within the publication, the various steps of decision-making and the key choices made by both individuals with dementia and their formal and informal caregivers to develop a model based on their findings were examined.

The research team's main take-home message was the difference between pain assessment and pain management. While both represent complex, collaborative and dynamic decision-making processes between the person with dementia and their formal/informal carers, pain assessment seems to involve a certain degree of guesswork, while pain management is more a trial-and-error procedure of pain-relieving interventions. In both cases, decisions are based on the understanding of the person with dementia and go along with high uncertainty.

According to the authors, their findings emphasise the need for a pragmatic approach to overcome the challenges of effective pain management in people with dementia. Based on their findings, a model was developed to help guide future implementations of decision-making in pain assessment and management. Lihui Pu Madushika and colleagues concluded that more pragmatic approaches are required to overcome challenges, especially uncertainty and decisional conflicts.

Please follow the link to read the full paper: https://doi.org/10.1016/j.gerinurse.2024.10.047

#### 25 NOVEMBER:

#### Alector announces results from INVOKE-2 Phase 2 trial in early AD

On 25 November, Alector, a clinical-stage biotechnology company focused on developing therapies for the treatment of neurodegenerative diseases, announced results from its IN-VOKE-2 Phase 2 clinical trial, which evaluated the safety and efficacy of AL002 in people with early Alzheimer's disease (AD).

INVOKE-2 was a randomised, double-blind, placebo-controlled, dose-ranging and multi-centre trial conducted across 11 countries including several EU countries. The trial aimed to assess whether AL002 could slow disease progression in early AD, with participants receiving either AL002 or a placebo intravenously for up to 96 weeks.

The trial did not meet its primary endpoint of slowing disease progression, as measured by the Clinical Dementia Rating Sum of Boxes (CDR-SB). AL002 also showed no significant effects on secondary endpoints or biomarkers. Despite this, the treatment with AL002 demonstrated sustained target engagement and evidence of microglial activation. MRI scans indicated amyloid-related imaging abnormalities (ARIA) in some participants, particularly those treated with AL002. Additionally, infusion-related reactions were observed.

Following these results, Alector announced the termination of the long-term extension study for AL002. The company will now focus its efforts on other clinical trials, including the IN-FRONT-3 Phase 3 trial of latozinemab in frontotemporal dementia and the PROGRESS-AD Phase 2 trial of AL101/GSK4527226 in early AD. Topline data from IN-FRONT-3 is expected in late 2025 or early 2026.

https://investors.alector.com/news-releases/news-releasedetails/alector-announces-results-al002-invoke-2-phase-2-trial

#### 26 NOVEMBER:

## Anavex Life Sciences submits a marketing authorisation approval for Alzheimer's drug blarcamesine to the EMA

Anavex Life Sciences Corp., a clinical-stage biopharmaceutical company, has announced the submission of a Marketing Authorization Application (MAA) for its lead drug candidate, blarcamesine, to the European Medicines Agency (EMA) for the treatment of Alzheimer's disease (AD).



Blarcamesine is a small molecule administered orally once daily. It exerts its effects by targeting the Sigma-1 receptor (SIGMAR1) and muscarinic receptors in the brain. Results from the Phase 2/3 trial of blarcamesine were presented at the 2024 Clinical Trials in Alzheimer's Disease conference, outlining the findings from over 500 participants enrolled at sites in Australia, Canada and the UK. Participants received a daily dose of 30mg or 50mg blarcamesine, or a placebo, for a period of 48 weeks.

While no significant changes were observed on the functional ADCS-ADL scale, results presented at CTAD showed that participants receiving a 50mg daily dose of blarcamesine exhibited 38.5% slower clinical decline as measured on the ADAS-Cog13 scale of cognitive function. The drug also had a tolerable safety profile (mild dizziness and fatigue was reported by 13% of participants receiving the 30mg dose) and does not require routine MRI monitoring.

Read the company press release:

https://www.anavex.com/post/anavex-life-sciences-announces-submission-of-blarcamesine-maa-for-treatment-ofalzheimer-s-disease-t



## Cassava Sciences's experimental AD drug fails in Phase 3 study

On 26 November, Cassava Sciences, a clinical-stage biotechnology company focused on developing treatments for Alzheimer's disease (AD), announced that its experimental drug, simufilam, did not meet its pre-specified co-primary, secondary and exploratory endpoints in the Phase 3 ReThink-ALZ study.

The trial, which aimed to evaluate the safety and efficacy of simufilam in people with mild-to-moderate AD, was conducted across over 75 clinical sites in the US, Canada and Australia. The double-blind and placebo-controlled trial randomised 804 participants to receive either simufilam or a placebo twice daily for 52 weeks.

The results revealed that simufilam did not show a significant reduction in cognitive or functional decline compared to the placebo group. The co-primary endpoints were the change in cognition and function from baseline to the end of the double-blind treatment period at week 52, assessed by the ADAS-COG12 and ADCS-ADL scales. Additionally, secondary endpoints, which included well-established measures of neuropsychiatric symptoms and caregiver burden, also did not demonstrate significant improvements. Safety was evaluated through multiple measures, including adverse event monitoring.

In response to these findings, Cassava Sciences also announced the discontinuation of the open label extension study and another Phase 3 trial, ReFocus-ALZ, both evaluating simufilam in mild-to-moderate AD.

https://www.cassavasciences.com/news-releases/news-release-details/cassava-sciences-topline-phase-3-data-did-not-meet-co-primary

#### 27 NOVEMBER:

## MHRA approves new AD diagnostic imaging agent

On 27 November, the UK Medicines and Healthcare products Regulatory Agency (MHRA) announced the approval of flortaucipir, a diagnostic agent for adults with cognitive impairment who are being evaluated for Alzheimer's disease (AD). This



radiopharmaceutical product is used during a type of brain scan called positron-emission tomography (PET) to help detect abnormal forms of the tau protein, a key feature of AD. Developed by Eli Lilly subsidiary Avid Radiopharmaceuticals, flortaucipir received approval from the US Food and Drug Administration (FDA) in 2020 and the European Medicines Agency (EMA) in 2024. Flortaucipir is given by injection into a vein about 80 minutes before obtaining an image from a PET scan. The MHRA approval was based on a diagnostic performance study showing that flortaucipir PET scans had a sensitivity of 92% in the ability to detect significant build-up of abnormal tau protein in the brain. Flortaucipir PET had a specificity of 76% (76% of patients without significant tau protein build-up were correctly rated as negative). MHRA added that flortaucipir PET scan results alone cannot confirm or refute a diagnosis of AD in people with cognitive impairment and that doctors must use the scans alongside other available clinical evaluation and diagnostic tools. Full safety details are available through the MHRA.

For more details, you can read the press release: https://www.gov.uk/government/news/mhra-approves-new-diagnostic-agent-for-adult-patients-showing-signs-of-cognitive-impairment-for-alzheimers-disease

#### **MEMBERS' NEWS**



#### 24 OCTOBER:

Alzheimer
Association of
Larissa (Greece)
organises exhibition
visit called "Gratis
from the Front"

On 24 October, the scientific director of the Alzheimer Association of Larissa in Greece

(E.E.N.A.L.), Artemisia-Phoebe Niflis, along with a group of friends of the Association, visited the exhibition "Gratis from the Front", at the Guard Officers' Club in Larissa. The purpose of the visit was to inform the public about the Postal Corps' role during the Hellenic-Italian war of 1940. The tour was conducted by captain Lambrini Terzoudis, who vividly narrated the history and contribution of the Postal Corps during the war. In particular, what was highlighted was their role on emboldening the troops through letters, as well as on transporting food and clothing. At the same time, the equipment of the post offices was presented, and the methodology of managing letters and parcels.

Participants were excited, moved and travelled (metaphorically speaking) to the 'front line', while recalling their parents'



and relatives' stories. A discussion followed, about the brief information the soldiers had about the ways of writing and reading the letters, to keep their morale high. In addition, people admired the way the letters were written, as well as their content, which was full of hope, optimism, and love. Then, an experiential workshopwas given "gratis", by the women's team who wrote letters to the troops, relatives and friends, on cards chosen among the various Hellenic Army Corps. The visit ended with a photo shoot and with one wish: "we will never forget those who died fighting for national ideals."

#### 24-27 OCTOBER:

Serbian Alzheimer's Society and Pasqual Maragall Foundation from Spain establish a valuable collaboration and organise "Days of Catalan Film" together



On 24-27 October, an event called "Days of Catalan Film" was held in Belgrade. It was an opportunity for members of the Serbian Alzheimer's Society (SUAB) to watch a screening of the feature-length documentary "Bicycle, Spoon, Apple" (2010) by Charles Bosch, which was shown at the Museum of the Yugoslav Film Archive. This important film succeeded in uniting science and art into one informative, educational, and artistically cathartic symbiosis. While well-known scientists introduce the viewer to the world of proteins and dying brain cells, the human face from the screen smiles at the audience, at the beginning of the diagnosis. The viewer experiences and sees before their eyes the irrefutable transformation of a human being and the regression, despite the enormous family support and the vigour of a well-known politician to fight and be an active subject in his illness, becoming painful and unstoppable.

The day after the screening of the film, SUAB had the opportunity to meet and talk in more detail with Eva Nebot, Director of the area of advocacy and institutional relations, and Nina Gramunt, a Neuropsychologist leader for training and outreach at the Pasqual Maragall Foundation. Their presentations were on "Understanding Alzheimer's Disease: The example of Pasqual Maragall". On behalf of SUAB, the presenters were Nadežda Satarić, President of the association, and

Željka Cvjetan Gortinski, actress and drama therapy facilitator, who gives her time to the realisation of weekly Thursday day-care workshops for people living with dementia.

This event was a great opportunity to exchange useful information about the work of both organisations. Although the Pasqual Maragall Foundation is primarily focused on scientific research related to Alzheimer's disease, the common thread with SUAB is a commitment to the prevention of this disease, and a focus on the importance of increasing public awareness. "Days of Catalan Film" and other events are organised under the auspices of the Representation of the Government of Catalonia in Southeastern Europe, in cooperation with the Catalan Cinematheque and with the support of the Spanish Embassy in Serbia.

#### 7 NOVEMBER:

Four dementia associations in Sweden recently did a survey to "take the temperature" regarding lecanemab for the treatment of early Alzheimer's disease in their country

Four associations in Sweden, Alzheimerfonden, Alzheimerguiden, Demensförbundet, and Hjärnfonden carried out a survey to "take the temperature" regarding people's thoughts on lecanemab



for the treatment of early Alzheimer's disease in their country, as well as more generally about how people with dementia and their relatives viewed taking part in drug treatment research or taking treatments despite side effects. They carried out this survey because they had so many call in connection with the news during the summer that the Committee for Medicinal Products for Human use (CHMP) of the European Medicines Agency (EMA) had given a negative opinion on lecanemab. This survey was completed prior to the recent news that the CHMP at the EMA had re-evaluated its negative opinion on the treatment and has now given a positive opinion on lecanemab, on 14 November 2024.

Alzheimer Europe's member association Demensförbundet, which was one of the four survey organisers, has shared some information about the survey and its results:

The Swedish survey was a self-recruited web form, including both quantitative summaries and open-ended responses. It was open between 12 September and 2 October 2024 and the number of respondents totalled 295.

When respondents were asked to consider the risk-benefit profile of the treatment, more than 8 out of 10 (85 percent) said they believed the treatment should be approved. Nearly as



many (81 percent) said they would choose to undergo the treatment themselves if recommended by their doctor. Some of the key themes from open-ended responses were:

- Greater autonomy: Patients and their families
  wanted more opportunities to make informed decisions about whether to undergo treatment for Alzheimer's disease. Many wanted to choose for themselves whether to pursue a treatment, even with the potential risks of side effects.
- More time with better quality of life is worth the risk: Many were willing to take risks to slow the progression of the disease and gain more time with a better quality of life, even if the risks are known and the side effects potentially serious.
- Frustration over inequality: There was frustration among respondents over the EMA's restrictive judgment in this case, compared to other markets and therapeutic areas. Many believed the system should be more flexible, especially for fatal diseases like Alzheimer's.
- Support for research and development: Patients
  and their families emphasised the importance of
  continued research and the implementation of new
  treatments, which also form the foundation for future
  research. Many called for more opportunities to participate in clinical trials to help advance the development of future medications.

#### 11 NOVEMBER:

The Alzheimer Society of Ireland expands dementia services with new activity lodge



On 11 November, The Alzheimer Society of Ireland (The ASI) continued to strengthen its efforts in supporting people with young-onset dementia. Following the opening of an activity lodge in County Cork in May, the ASI officially opened its new activity lodge in County Wexford. This new lodge provides a safe, engaging, and inclusive space where people living with young-onset and early-stage dementia can participate in a variety of therapeutic activities designed to enhance their quality of life.

The lodge offers a range of programmes including art therapy, music sessions, cognitive exercises, gardening, and social events tailored specifically for individuals with dementia. It also provides a space for carers to connect with each other and access support, ensuring a holistic approach to dementia care.

Siobhan O'Connor, Head of Operations and Community Engagement at The ASI, said: "Our goal with the activity lodge is to create a space where people living with dementia can thrive. This is not just about care; it's about providing meaningful opportunities for social engagement, creativity, and joy." The opening of this lodge comes at a critical time, as the number of people living with dementia in Ireland is expected to rise significantly in the coming years.

#### 15 NOVEMBER:

Ágnes Egervári, President of Hungary's Social Cluster Association, receives "Families Award" at Generations Working Together for a Competitive Future" conference in Budapest



The "Generations Working Together for a Competitive Future" conference was held in Budapest, this year as part of the rotating EU Presidency. The event brought together high-ranking representatives from multiple countries, focusing on topics such as demographic challenges and the situation of the elderly.

On 15 November during the awards ceremony, the 2024 Age-Friendly Municipality Award, the Award for the Protection of Human Dignity, the Families Award, and the Sarolta Monspart Award for the elderly were presented. It was heart-warming to hear the commendations. This year, special emphasis was placed on recognising initiatives supporting people living with dementia, fostering dementia-friendly attitudes, building communities, and supporting caregiving families.

Dr Ágnes Egervári (pictured, centre), President of Alzheimer Europe's member in Hungary, the Social Cluster Association, received the Families Award. Huge congratulations to her and to the Social Cluster Association!



Alzheimer Poland discusses the country's upcoming Dementia Plan with Deputy Minister of Health Wojciech Konieczny



On 19 November, Edyta Ekwinska, Vice President of Alzheimer Poland, met with Deputy Minister of Health Wojciech Konieczny at the Polish Ministry of Health. The meeting took place as part of the newly established Brain Health Team operating at the Patient Rights Ombudsman. The topic of the conversation was, among others, the Dementia Plan currently being developed at the Ministry of Health.

#### 21 NOVEMBER:

Sabine Henry, President of Belgium's Alzheimer League, ennobled by King Philippe



On 21 November 2024, Sabine Henry, the President of Belgium's Alzheimer League, received the title of Baroness for her "nobility of heart and an exceptional career serving the Belgian population affected by dementia". The title was awarded to her by His Majesty, King Philippe of the Belgians. Congratulations to Baroness Sabine Henry, from all of us at Alzheimer Europe!

#### 22 NOVEMBER:

The Alzheimer Society of Ireland launches its general election manifesto "Make a pledge to keep dementia a priority"



With the general election in Ireland due to take place on 29 November, The Alzheimer Society of Ireland (The ASI) has launched its election campaign "Deliver on Dementia – Make a Pledge to Keep Dementia a Priority." The campaign urges election candidates and parties to sign the pledge at www.dementiapledge.ie

The initiative was officially unveiled with a photo-call in Dublin, attended by ASI staff, members of the Irish Dementia Working Group, and the Dementia Carers Campaign Network. With the growing need for dementia supports and services, it is crucial that the next Government builds on recent investments and continues to address the challenges faced by individuals affected by dementia across Ireland, particularly in rural areas. The actions outlined in The ASI's manifesto can make a significant difference in communities nationwide. The manifesto includes six key asks, such as: resourcing the model of care for dementia, making brain health a public health priority, and developing a national dementia registry. The ASI's Head of Advocacy, Research and Public Affairs, Cormac Cahill said: "In recent years, Ireland has made significant progress in supporting people with dementia and their carers. However, momentum is essential for the next Government to continue and expand these gains. The Alzheimer Society of Ireland is ambitious for the lives of those with dementia and those who care for and support them. We urge all candidates to recognise dementia care as a priority and integrate it into their election issues, manifestos and future Government programmes."

The ASI's 'dementia pledge' campaign is a collective effort, with staff, advocates, volunteers and supporters actively lobbying election candidates to ensure dementia remains a top priority. For more details, visit www.dementiapledge.ie



The results of the project 'Erasmus+ CURATE-D: A game-based methodology for empowering dementia-friendly communities and equal access to culture for people with dementia' are freely accessible online





The European project 'Erasmus+' CURATE-D, aiming to promote equal opportunities, accessibility and social inclusion for people with dementia in cultural experiences and training professionals using game-based learning, ends in December 2024 and presents its results.

The results were developed with the collaboration of all project partners: Challedu, coordinator; the Panhellenic Federation of Alzheimer's Disease and Related Disorders of Thessaloniki and the Herakleidon Museum of Athens (Greece); the Gaiety School of Acting - The National Theatre School of Dublin (Ireland) and the Association of Relatives of Alzheimer's of Valencia (AFAV, Spain).

The first result is the "CURATE-D Methodological Guide": the first part of the guide includes the definition of dementia, its main symptoms and tips on how to treat it. The second part is dedicated to mixed-methods research: literature research on dementia-friendly policy and cultural activities at international level as well as interviews with people working in dementia care or cultural settings about their needs. The third part includes the theoretical background on game-based learning and best practices for dementia caregivers using game-based approaches, as well as the presentation of the methodology of the CURATE-D project.

The second result is the "Educational Guide" for cultural staff, a detailed guide that can be used as an educational tool for cultural staff in various types of museums, art spaces and cultural organisations, in order to create spaces, exhibitions, events that are in line with the needs of people with dementia and their carers.

The third output is the "Educational Guide for dementia professionals", a detailed guide that can be used as an education tool for dementia professionals to support people with dementia in cultural activities to create and augment dementia-friendly environments and communities.

The fourth result is the "CURATE-D Educational serious game" which main purpose is to train staff of cultural organisations and dementia professionals on how to create dementia-friendly cultural experiences. While playing, learners can enrich their skills and develop knowledge in the field of accessibility and dementia-friendliness. The game is also a way of raising awareness on dementia.

The fifth output is the "Training of professionals and the CURATE-D conclusions report". After the implementation of pilot workshops using the tools produced during the project to 50 professionals in all countries, their feedback was collected and a report was developed on the final conclusions of the CURATE-D project methodology. This will be useful material for other organisations that want to implement the CURATE-D methodology and tools. All results are freely accessible and can be found on the CURATE-D project website: www.curate-

Stay tuned for project news on the website: curate-d.eu, Facebook, which you can find via the QR code:



#### 27 NOVEMBER:

Alzheimer Athens recently hosted the 2<sup>nd</sup> Alzheimer Festival under the banner "Let's Give the Right Stigma to Dementia"

In September 2024, Alzheimer Athens hosted the 2<sup>nd</sup> Alzheimer Festival at the Stavros Niarchos Cultural Center (SNFCC) Lighthouse, drawing more than 7,000 participants. Held on 14 and 15 September, under the theme "Let's Give the Right Stigma to Dementia," the festival aimed to inspire understanding and inclusivity.

Prominent figures, including Minister of Health Adonis



Georgiadis, attended the event. In a landmark moment, the Minister pledged to pass legislation on the rights of dementia patients and caregivers by the end of the year, signalling progress toward a more supportive framework.

The festival's programme included lectures by leading experts, such as Dr Paraskevi Sakka, President of Alzheimer Athens, who shared the latest advancements in dementia care and emphasised the importance of implementing the National Action Plan for Dementia. Engaging discussions allowed attendees to voice their concerns, while hands-on workshops covered essential topics like nutrition, physical activity, and innovative technologies for dementia diagnosis and management.



Alzheimer Athens recently organised the 1<sup>st</sup> Elderly Festival "A Celebration of the Elderly Community"



Building on the momentum of raising awareness, Alzheimer Athens, in partnership with the Region of Epirus and the Municipality of Arta, organised the 1st Elderly Festival from 4 to 6 October 2024. This three-day event celebrated older adults and their contributions to society.

Held in Arta, the festival featured cultural, educational, and entertainment activities aimed at enhancing well-being and promoting community engagement among older citizens. With support from local cultural clubs and authorities, the event attracted approximately 2,000 participants.

The Elderly Festival fostered a strong sense of belonging, encouraging active citizenship and intergenerational connection. It served as a reminder of the importance of valuing and empowering older members of the community.

Alzheimer Athens remains steadfast in its mission to address the challenges of dementia and foster a more inclusive society. Through year-round events, the organisation works tirelessly to promote awareness, advocate for policy changes, and provide support for patients and caregivers.

#### LIVING WITH DEMENTIA

#### 28 OCTOBER:

Pia Knudsen, former member of the European Working Group of People with Dementia, shares her experience of having coffee with Queen Silvia of Sweden



I have never received so many likes on Facebook... or so much interest from so many people, as when I shared this experience. Now, here it is, for you.

My name is Pia Knudsen, I am 61 years old and live in Aarhus, Denmark. I have had an Alzheimer's dementia diagnosis since 2019. I am still in the early stages of the disease and I use my fairly healthy brain to spread knowledge about my life with dementia, for better or for worse. This story is absolutely for the better. In September of this year, I was invited to a large Nordic health conference in Stockholm, Sweden, to share the knowledge I have about living with dementia. I contribute in many contexts with this knowledge, both nationally and internationally... but this was something special, because I noticed in the programme that Sweden's Queen Silvia would be giving the opening speech. She had eight minutes, I had 30. Wow!

So, when the organisers of the conference asked if there was anything I needed or would like during the day, I mentioned, mostly as a joke, that I would like to have a cup of coffee with the Queen, and thought no more of it, not really believing for a second that it was possible. I went on stage and delivered my speech, with the

Queen sitting in the front row, both smiling and with tears in her eyes, just like the other members of the audience. When the speech was delivered and the applause had stopped, two large men approached and escorted me off the stage and into another room next to the conference hall. There was Silvia, Queen of Sweden... I took a deep breath... Then she came over to me with a smile, and from that moment on, I felt at ease. We shook hands, sat down together, and then the conversation started... nonstop for half an hour. It felt so natural and cosy because we had so much in common to talk about. You might not think of a meeting like that because she is a queen, and I am a person with dementia, but believe me, she is a compassionate



and loving person. Silvia's mother died of dementia, and therefore she spends much of her life promoting knowledge and understanding of the disease, just like I do. Throughout our conversation, she kept her hand on top of mine on the table in front of us. When our time together was up, and her security people asked us to wrap up the meeting, I decided to ask her something I would never have done before I got a terminal illness, but I have nothing to lose anymore. I said: "Thank you so much for this wonderful conversation, Silvia", completely forgetting how to address a queen, but then she smiled, and I was sure she was okay with it. Then I told her that I wanted to give her a hug, but others had told me that you don't give hugs to royals. Then she smiled even more and said, "Then I would like to give you a hug," and boy, is she good at it!

So the fairy-tale ended happily, with me receiving a loving and long hug from Silvia, who is the Queen of Sweden. This is one reason why I describe my life with dementia, for better and for worse, mostly for the better.

PS. I gave her my homemade business card, so I'm waiting for her to text me.

#### 29 OCTOBER:

## Trevor Salomon, Chairperson of the European Dementia Carers Working Group, shares his experience of meeting the UK Prime Minister Sir Keir Starmer

In October 2024, the UK Government launched a consultation and engagement process with members of the public, staff and patients to determine how it will set about delivering a modern National Health Service (NHS) fit for the future, to meet the changing needs of the UK's changing population.

I was lucky enough to be invited by Alzheimer's Society to attend the launch event in London. The invitation came in the form of a phone call, on a Friday morning, asking me if I was available the following Monday to represent dementia and dementia carers at the meeting. What puzzled me was that the venue was unknown and would not be communicated to me until all arrangements were in place. I should have put two and two together and figured out for myself that this was for security reasons, though I had no expectation that the Secretary of State for Health and Social Care, Wes Streeting, would attend and it absolutely did not occur to me the importance of this event was such that the Prime Minister, Sir Keir Starmer, would fit an appearance into his busy schedule.

I eventually received the logistics and made my way on the Monday morning to the 'secret venue' where I found myself amongst 100 specially invited attendees, mostly doctors, nurses, paramedics and staff working in Accident and Emergency departments at London hospitals. In addition to me representing dementia, others were there to speak for diabetes, multiple sclerosis, stroke, etc. The structured, facilitated discussion fell broadly into three main categories:

- moving more care from hospitals to communities
- making better use of technology in health and care
- focusing on preventing sickness, not just treating it.

It was fascinating and a privilege to be part of the conversation which all of a sudden came to a halt when the Secretary of State and the Prime Minister arrived to address the gathering. I found myself standing immediately behind the Prime Minister for his short speech until he swivelled round to meet and informally chat to us, at which point I took advantage of the time he gave me to talk about the clear need to increase dementia diagnosis rates, support the integration of health and social care systems with appropriate dementia training, and address the inequalities of care.

The UK Government has taken the view that this is a once in a generation opportunity to set the NHS on a path for the future and I was delighted that my voice was requested to be part of the fixing process.





European Working Group of People with Dementia Chairperson Kevin Quaid shares his joy as Irish Government ratifies Optional Protocol to the UN Convention on the Rights of Persons with Disabilities



The Irish Government finally approved the accession by Ireland to the Optional Protocol to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), on 8 October 2024. This is news that Irish people who have being given a diagnosis of dementia and are under the age of 65 will welcome, after waiting years for it. The Optional Protocol is an international agreement that complements the UNCRPD, which aims to promote, protect, and ensure that all persons with disabilities fully and equally enjoy all human rights and fundamental freedoms. Ireland ratified the Convention in March 2018, but had not ratified the Optional Protocol, until now.

The Optional Protocol itself introduces two key procedures. The first allows individuals or groups to file a complaint to the Committee on the Rights of Persons with Disabilities regarding violations of their rights, while the second empowers the Committee to investigate serious or systematic breaches of the Convention. By taking this step, Ireland has reaffirmed its dedication to creating an inclusive society where the voices of persons with disabilities are valued and respected. It not only strengthens our national framework for disability rights but also sends a clear message internationally of our commitment to justice and equality for all.

It has taken quite a while and a lot of advocacy work to get to this stage but we finally got there, with the help of some wonderful people and the voices of lived experience! There is nothing that people with dementia cannot achieve and hopefully for the people who are getting diagnosed each and every day and are under the age of 65, their

financial worries are a burden that can be eased a little. You can read the Alzheimer Society of Ireland's response to the news about the Optional Protocol, here:

https://www.alzheimer-europe.org/news/alzheimer-society-ireland-welcomes-irelands-accession-optional-protocol-un-convention-rights

You can read the Irish Government announcement about the Optional Protocol, here:

https://www.gov.ie/en/press-release/aa312-government-announces-decision-to-accede-to-the-optional-protocol-to-the-un-convention-on-the-rights-of-persons-with-disabilities/

#### **PUBLICATIONS AND RESOURCES**

#### 28 OCTOBER:

Luxembourg's Programme for Dementia Prevention launches "pdp Braincoach"



On 28 October 2024, the "pdp Braincoach" app was launched as

an addition to Luxembourg's national Programme for Dementia Prevention (*pdp*). With the introduction of the app, this initiative targets primary prevention, raising awareness about dementia risk reduction to Luxembourg's population and encouraging residents to take early and proactive steps toward brain health. *pdp* Braincoach is an adaptation of the Dutch MijnBreincoach app and is specifically tailored to Luxembourg's population. The app gives users insights into their personal risk profile for dementia and offers tailored feedback on

"room for improvement" incentivising lifestyle changes concerning twelve modifiable risk and protective factors. Based on scientific evidence, the following risk factors, if well addressed, can prevent a substantial proportion of dementia cases:

- Cardiovascular disease
- High blood pressure
- High cholesterol
- Diabetes
- Chronic kidney disease
- Obesity
- Diet
- Physical inactivity
- Mental stimulation
- Smoking
- High alcohol consumption
- Depression.

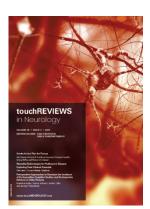


With the help of the *pdp* Braincoach app, users receive practical feedback on where they can make changes to support long-term brain health. Once a user selects one or more risk factor themes, the app sends notifications, offering tips, quizzes and challenges to help them work steadily toward these goals for only a few minutes daily. By addressing multiple aspects of lifestyle and health, the app provides a comprehensive approach with local resources to support users in lowering dementia risk, empowering individuals to take manageable steps to protect their cognitive health.

The Programme for Dementia Prevention is a collaborative effort between the Luxembourg Institute of Health, the University's Luxembourg Centre for Systems Biomedicine, and the Centre Hospitalier de Luxembourg. Initiated in 2018, the program's goal is to reduce dementia risk among individuals with subjective cognitive complaints or mild cognitive impairment living in Luxembourg. By offering in-depth neuropsychological assessments and receiving personalized health advice from 'memory coaches', the program provides specialized guidance to personalised reduction of dementia risk.

With the launch of *pdp* Braincoach, this initiative extends to a wider adult audience, including those aged 40 to 75 who may not have specific cognitive complaints but are interested in maintaining cognitive health. The app opens up preventive resources to a broader demographic, aiming to embed dementia prevention habits into everyday life.

pdp Braincoach is available for free on the Luxembourg Android and Apple app stores in English, French, and German. To access a web-based version or learn more about the app, visit www.pdp-app.lu. For more information regarding the Programme for Dementia Prevention, visit: www.pdp.lu



#### 12 NOVEMBER:

# TouchNEUROLOGY publishes new edition of its journal touchREVIEWS in Neurology

The latest edition of touchRE-VIEWS in Neurology is full of topical content that highlights the current landscape and future di-

rections in neurological research and treatment.

Explore touch REVIEWS in Neurology Volume 20, Issue 2, 2024, here:

https://touchneurology.com/journals/touchreviews-neurology/touchreviews-in-neurology-volume-20-issue-2-2024/

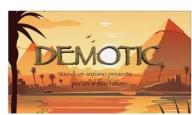
There is some specific content related to Alzheimer's disease, which may be of interest to our readers: "Psychosis in Alzheimer's Disease: A Review of Current and Prospective Therapeutic Strategies", which can be accessed, here:

https://touchneurology.com/alzheimers-disease-dementia/journal-articles/psychosis-in-alzheimers-disease-a-review-of-current-and-prospective-therapeutic-strategies/

#### 13 NOVEMBER:

## "DEMOTIC" dementia cartoon videos are now available to view online

At the recent 34th Alzheimer Europe Conference in Geneva, as part of the parallel session "P39. Campaigning for change", the concept of "DE-MOTIC" was presented by Filippo Bergamo (Italy). MOTIC" dementia cartoon videos were created un Italy, with the aim of providing con-





tent that is accessible to all ages, to help the public better understand dementia.

Two DEMOTIC cartoons have now been published online, created with the help of the same people living with dementia who voice the characters. People living with dementia were invited to be involved in the project, helping to write the scripts and doing voice recordings of the dialogues, leading to the creation of these two cartoons by a graphics studio.

With the cartoons now online, a study on the impact of the cartoons will be made after one year, by the Psychology faculty of the University of Bologna.

You can view the cartoons, here:

First episode: https://youtu.be/DSNmTb27uDI Second episode: https://youtu.be/Si2c5u9\_Gzl

Pictured: Filippo Bergamo (centre) together with co-authors

Andrea Fabbo and Rabih Chattat



#### **AE CALENDAR 2024**

DATE	MEETING	AE REPRESENTATIVE
3 December	Alzheimer's Association Academy: Independent living and dementia	AE team
4 December	PREDICTOM project Task 5.1 online meeting	Sarah/Dianne
4 December	PREDICTOM project PAG meeting	Sarah/Dianne
5 December	EuroPCom EU communications conference	Chris/Kate
5 December	LuxInnovation HealthTech Cluster and Horizon Europe day (Belval, Luxembourg)	Angela, Lukas, Soraya
5 December	Support role in EMA consultation	Dianne and Sarah
6 December	European Regional Disability Summit	Owen
9 December	Alzheimer Europe Board meeting (Brussels, Belgium)	AE Board and staff
10 December	Association of Association Executives "Building inclusive events"	Gwladys
10 December	Company round table meeting (Brussels, Belgium)	AE Board, members, sponsors and staff
10 December	European Parliament Lunch Debate "Inequalities in dementia care and treatment in Europe" (Brussels, Belgium)	AE supporters, members and staff
10 December	Alzheimer Europe Public Affairs Meeting (Brussels, Belgium)	AE members and staff
10 December	Alzheimer Europe Anti-Stigma Award Ceremony (Brussels, Belgium)	AE Foundation, AE supporters, members and staff
10-11 December	EWGPWD and EDCWG meeting (Brussels, Belgium)	PI team
11 December	Alzheimer Europe workshop on "Advocating with Impact" (Brussels, Belgium)	AE members and staff
12 December	Meeting with Biogen (Amsterdam, Netherlands)	Jean
12 December	Feedback session for HOMEDEM students	Dianne and Sébastien
12-13 December	Final General Assembly meeting of the PRIME project (Cologne, Germany)	Angela
13 December	Multi-MeMo project AB meeting	Ana, Cindy, Sarah
19 December	Brain Health Mission meeting	Jean



#### **CONFERENCES 2025**

DATE	MEETING	PLACE
13-16 February 2025	14 <sup>th</sup> Panhellenic Conference on Alzheimer's Disease and 6 <sup>th</sup> Mediterranean Conference on Neurodegenerative Diseases, https://www.alzheimer-conference.gr/index.php/en/	Thessaloniki, Greece
20-22 March	19 <sup>th</sup> World Congress on Controversies in Neurology (CONy), https://cony2025.comtecmed.com/	Prague, Czechia
1-5 April	International Conference on Alzheimer's and Parkinson's Diseases and Related Neurological Disorders (AD/PD™ 2025) https://adpd.kenes.com/partners-related-events/	Vienna, Austria
15-17 May	The 8 <sup>th</sup> Venusberg meeting on Neuroinflammation, https://neuroinflammation.uni.lu/	Belval, Luxembourg
3-6 June	15 <sup>th</sup> edition of the National Alzheimer Conference, http://www.alzcongres.ro	Bucharest, Romania
21-24 June	11th Congress of the European Academy of Neurology, Neurology within society, https://www.ean.org/	Helsinki, Finland
6-8 October	35 <sup>th</sup> Alzheimer Europe Conference, "Connecting science and communities: The future of dementia care", https://www.alzheimer-europe.org/conferences	Bologna, Italy
12-15 October	XXVII World Congress of Neurology, https://wcn-neurology.com/	Seoul, South Korea
4-5 February 2026	2 <sup>nd</sup> International Conference on the Prevention of Alzheimer's Disease (ICOPAD 2026), https://www.hug.ch/en/evenement/2nd-international-conference-prevention-alzheimers-disease-icopad-2026	Geneva, Switzerland



Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Commission. Neither the European Union nor the granting authority can be held responsible for them.



### 35<sup>th</sup> Alzheimer Europe Conference

Connecting science and communities:

The future of dementia care

Bologna, Italy
<u>6 - 8 October 202</u>5 #35AEC

www.alzheimer-europe.org/conferences







