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WELCOME

I am delighted to be writing this from our new offices! After more than a decade at our former address, we are pleased to be settled into our new premises at: 5B Heienhaff, L-1736 Senningerberg, Luxembourg.

Aside from packing boxes and moving, Alzheimer Europe is pleased to be a co-author of two new research papers this month. The first is a European consensus for the diagnosis of Alzheimer's disease which was published in The Lancet Neurology by a working group of experts. I was pleased to be among them and to contribute to this important work. The second paper shares the perspectives of the European Working Group of People with Dementia and their supporters, regarding the definition of advance care planning. This paper was published in the journal Palliative Medicine and both Dianne Gove, Director for Public Involvement and Ethics and Ana Diaz, Public Involvement Lead, are co-authors, alongside researchers from Vrije Universiteit Brussel and the DISTINCT project.

We are also delighted to announce a special publication about the 33rd Alzheimer Europe Conference (33AEC) which took place from 16 to 18 October 2023 in Helsinki, Finland, as well as online. If you were at the conference, we hope you enjoy looking back at some of the highlights from the event. If you were unable to join us, we hope that this publication gives you a real flavour of our conference and encourages you to join us for our upcoming 2024 conference (34AEC) taking place in Geneva, Switzerland, from 8 to 10 October under the banner "New horizons – Innovating for dementia". We have just launched the call for abstracts for the Geneva conference as well as opening registrations, with the reduced Early Bird fees being available until 15 July.

A new European research project called AI4HOPE has just kicked off and we are delighted to form part of the consortium. The new initiative is funded by Horizon Europe and aims to transform dementia care through cutting-edge digital health interventions.

Good news from Malta, where the National Dementia Strategy for the Maltese Islands 2024 – 2031, titled 'Reaching New Heights', has just been published. It aims to significantly improve the quality of services and the quality of life of persons living with dementia in the Maltese islands. This dementia strategy is a continuation of Malta's first national strategy and builds on progress made during its implementation. Congratulations to our Maltese colleagues on this important milestone!

Finally, I am pleased to share the progress of our campaign prior to the European Parliament elections in June. The campaign, which aims to make dementia a priority issue for decision-makers at a European level, includes a public Call to Action for which we already have more than 500 signatories. Thank you to all of them for their support! If you have not yet signed, we invite you to do so today, via our website.

Jean Georges
 Executive Director

SPOTLIGHT ON EUROPEAN ELECTIONS

29 FEBRUARY

Thank you to Baluchon France and Fondation Médéric Alzheimer for supporting our Helsinki Manifesto!



The Helsinki Manifesto outlines the current situation in relation to dementia across Europe, detailing specific demands for the European Commission Institutions and national governments. We are grateful to the 50 organisations currently supporting our Manifesto, including two new endorsements during February:

- Baluchon France
- Fondation Médéric Alzheimer.

We invite others to do the same. See here for more information: <https://bit.ly/AEHelsinkiManifesto>

29 FEBRUARY

Over 500 people are already supporting our Call to Action demanding that European decision-makers prioritise dementia - join them today!

We are delighted to share the progress of our campaign, in the runup to the European Parliament elections this June. Our campaign began in mid-January and aims to make dementia a priority issue for decision-makers at a European level. As part of this campaign, we issued a public Call to Action demanding that European decision-makers prioritise dementia as a policy issue and implement the actions of our Helsinki Manifesto. We already have 549 signatories. Thanks to all of them for their support! You can see the list of signatories, here:

<https://www.alzheimer-europe.org/policy/campaign/alzheimer-europe-election-campaign-2024/call-to-action-signatories>

We invite you to sign our Call to Action today!

Click here: <https://bit.ly/AECallToAction2024>

29 FEBRUARY

Thank you to four new supporters of the Dementia Pledge 2024!



The Dementia Pledge 2024 is a commitment which candidates standing for the European Parliament elections are invited to make, pledging their support in prioritising dementia in the areas of health, research, disability policy and informal carers and pledging to join the European Alzheimer's Alliance, upon election.

We are delighted that four MEPs have signed our Dementia Pledge 2024, during February. This brings the current total to five:

France

Pierre Larrousurrou (Nouvelle Donne, PES)

Slovenia

Franč Bogovič (SLS, EPP)

Milan Brglez (Social Democrats, PES)

Klemen Groselj (Freedom Movement, ALDE)

Romana Tomc (SDS, EPP).

All candidates standing in the European Parliament elections are encouraged to sign the pledge, either via <https://bit.ly/DementiaPledge2024> or by posting their support on social media (Twitter/X, Facebook, LinkedIn) using the hashtag #DementiaPledge2024

ALZHEIMER EUROPE

15 FEBRUARY

We have moved!



The Alzheimer Europe team has moved to new offices!

We are now located at:
Alzheimer Europe
5B Heienhaff
L-1736 Senningerberg
Luxembourg.

21 FEBRUARY

European Working Group of People with Dementia and European Dementia Carers Working Group discuss exercise infographics



On 21 February, some members of the European Working Group of People with Dementia (EWGPWD), their supporters, and the European Dementia Carers Working Group (EDCWG) attended an online consultation. The consultation was also attended by Nicola Veronese (University of Palermo, Italy), Montserrat Montes de Oca Ibarra (University of Alberta, Canada), Soraya Moradi-Bachiller (Public Involvement Officer, Alzheimer Europe), and facilitated by Ana Diaz (Public Involvement Lead, Alzheimer Europe).

During the meeting, the attendees provided their feedback on three infographics developed to inform about the effects that physical activity and exercise can have in delaying the onset and progression of Mild Cognitive Impairment and dementia due to different neurodegenerative diseases.

All the attendees who participated provided insightful feedback on the design and content of the infographics, which will help the research team develop a new and improved version.

27 FEBRUARY

We hope you enjoy our special new publication looking back at the 33rd Alzheimer Europe Conference in Helsinki!

We are delighted to announce a special publication about the 33rd Alzheimer Europe Conference (33AEC) which took place from 16 to 18 October 2023 in Helsinki, Finland, as well as

online. If you were at the conference, we hope you enjoy looking back at some of the highlights from the event. If you were unable to join us in Helsinki (or online), we hope that this publication gives you a real flavour of our conference and encourages you to join us for a future event.

This new publication, which is a supplement to the 44th edition of our "Dementia in Europe" magazine, is currently available in an electronic format (see download link at the end of this article) and printed copies will be sent out together with the magazine during the month of March.

The conference supplement includes a "Warmup" section, where you will find coverage of a number of important pre-conference meetings. We then take a look at all of the conference plenary sessions (Opening Ceremony, Plenaries 1 to 5, Closing Ceremony).

On top of coverage of the ancillary meetings and plenary sessions in Helsinki, we are pleased to share some other aspects of the event, including: a special symposium presenting the work of ten early-stage researchers, who were selected by our jury to benefit from attendance bursaries provided by the Alzheimer Europe Foundation; a special award ceremony for the winners of our 2023 Anti-Stigma Award, held during the Networking Dinner; some thoughts from our conference co-hosts, the Alzheimer Society of Finland (Muistiliitto), about the conference and about some of the sessions they organised; some highlights from social media; and a few facts and figures surrounding the event.

Photos and videos of 33AEC

Throughout the publication, we include links to [videos of our recorded sessions](#), so you can revisit them or view them for the first time, if you did not attend 33AEC. There are many photos from the event in the publication, including, among others, shots of the many and varied poster presentations and of the Networking Dinner held at Helsinki's beautiful "Old Student House". We have also shared links within the publication to the page on our website where you can view the [conference photo gallery page](#).

We hope you enjoy this very special conference publication! Download it here: https://bit.ly/33AEC_Highlights_Supplement



1 MARCH

Call for abstracts opens for 34th Alzheimer Europe Conference in Geneva



We are delighted to invite you to submit abstracts for the upcoming 34th Alzheimer Europe Conference #34AEC, which will take place in Geneva, Switzerland, under the banner "New horizons - Innovating for dementia". We look forward to welcoming delegates and speakers to our 34th Annual Conference from 8 to 10 October 2024.

Alzheimer Europe and Alzheimer Schweiz Suisse Svizzera are calling for abstracts for oral and poster presentations on the following subjects:

- Innovation in care and research
 - Artificial intelligence
 - Assistive technologies
 - Dementia registries
 - Preparing for new AD treatments
 - Telehealth and remote care
 - Clinical trial recruitment and retention
- Living with dementia
 - People living with dementia
 - Housing and neighbourhoods
 - Art and dementia
 - Empowerment and sexuality
 - Stigma and discrimination
- Patient pathways
 - Brain health and prevention
 - Detection and diagnosis
 - Treatment and medical management
 - Psycho-social interventions
 - Hospital care
 - End-of-life care

- Policy
 - Dementia strategies
 - New funding models for dementia care and research
 - Legal and ethical issues
 - National Alzheimer's associations
 - Campaigning for change
 - Dementia work force
- Inclusion and discrimination
 - Gender
 - Minority ethnic groups
 - LGBTQ+
 - Intellectual disability and Down syndrome
 - Public involvement in dementia research
 - Young onset dementia.

The call for abstracts will close on **15 May 2024**.

Click here for more information: <https://www.alzheimer-europe.org/conferences/2024-geneva/call-abstracts>

1 MARCH

Registrations are open for the 34th Alzheimer Europe Conference #34AEC!

We are delighted to invite you to register for the upcoming 34th Alzheimer Europe Conference (#34AEC), which will take place in Geneva, Switzerland from 8 to 10 October 2024, under the banner "New horizons - Innovating for dementia" and in collaboration with Alzheimer Schweiz Suisse Svizzera.

Take advantage of the early bird registration fees until **15 July 2024** and benefit from the reduced registration fee of EUR 400 instead of EUR 500.

The full registration fee includes:

- Admission to all sessions
- Delegate bag and final programme
- Opening ceremony and welcome reception
- Scheduled coffee breaks and lunches on 8, 9 and 10 October
- Networking opportunities
- Access to the exhibition hall and poster presentations.

A 25% discount is available for participants from low and middle income countries. Special rates are also available for people with dementia, students and member associations of Alzheimer Europe. Click here for more information:

<https://www.alzheimer-europe.org/conferences/2024-geneva/registration-fees>

“50 shades of Memory Work”

WEBINAR

Intergenerational activities
with foreign-born older people



On 12 March 2024, there is a rare opportunity to participate in an international webinar combining three topics that have been little discussed, let alone together. We combine research and practice in the fields of older minorities, memory-related challenges, and intergenerational work.

MUKES webinar “50 Shades of Memory Work” presents guest speakers from all over the world, including the key speaker Dr Alexandra Withnall (UK).

www.mukes.fi/news

AE NETWORKING

2 FEBRUARY	Gwladys met with The International Conference Center Geneva (CICG) to discuss the 34 th Alzheimer Europe Conference (34AEC).
5 FEBRUARY	Ange and Ana participated in a Strategic Planning meeting for the AD-RIDDLE project.
15 FEBRUARY	Gwladys participate in an All Things Events meeting.
15 FEBRUARY	Ange and Daphné participated in a consultation with the PROMINENT Public Involvement Board.
19 FEBRUARY	Jean met with representatives of Janssen.
20 FEBRUARY	Ana and Soraya participated in a consultation with the LETHE Advisory Board.
20 FEBRUARY	Alzheimer Europe organised an Alzheimer’s Association Academy on “Modifiable risk factors for dementia”.
21 FEBRUARY	Jean and Ana met with the Chairpersons of the European Working Group of People with Dementia and the European Dementia Carers Working Group.
21 FEBRUARY	Ana and Soraya participated in a consultation with some members of the European Working Group of People with Dementia and the European Dementia Carers Working Group.
21 FEBRUARY	Jean and Gwladys met with Stefanie Becker from Alzheimer Schweiz Suisse Svizzera regarding the 34 th Alzheimer Europe Conference (34AEC).
22 FEBRUARY	Owen attended The Good Lobby’s webinar “How can civil society can influence the EU institutions?”

23 FEBRUARY	Jean had a meeting with the European Public Health Alliance.
26 FEBRUARY	Alzheimer Europe held a Board meeting.
26 FEBRUARY	Ange and Ana organised a meeting with the World Young Leaders in Dementia (WYLD) network.
26 FEBRUARY	Ange and Daphné attended an AI4Hope project General Assembly meeting.
27 FEBRUARY	Soraya participated in a consultation with the ADIS Advisory Board.
28 FEBRUARY	Jean had a meeting with Essity.
28 FEBRUARY	Jean had a meeting with Roche.
29 FEBRUARY	Jean attended the EU4Health Civil Society Alliance.
29 FEBRUARY	Jean attended the Management Group of the Dementia Panel of the European Academy of Neurology.
29 FEBRUARY	Ana attended a meeting of the INTEREST project (Dublin, Ireland).



EU PROJECTS

13 FEBRUARY

LETHE project updates on its Brain Health Literacy Portal (BHelp)



LETHE (A personalised prediction and intervention model for early detection and reduction of risk factors causing dementia, based on AI and distributed Machine Learning) is in the process of releasing a digital platform to deliver a lifestyle intervention "BHelp" that aims to help users to improve

their brain health.

BHelp will be one of the main outcomes of the European Horizon 2020 funded project, LETHE. The platform combines personalised content and engagement with lifestyle professionals. The portal aims to adopt a multidisciplinary approach to support users with knowledge, tailored to their individual needs and preferences.

Upon registration, users access a profiling tool asking them to respond to a series of questions related to their personal profile and media content preferences. This data will serve to tailor and personalise the media content to each user profile. The contents on the portal include infographics, long and short videos, podcasts, but also other formats, providing an "Netflix-like" experience when it comes to learning about how brain health can be improved.

To enrich the portal's media content and ensure its ongoing relevance, the team behind BHelp plans to engage with lifestyle professionals across various domains, including nutrition, exercise and cognition. It is planned, that these experts will contribute with insights and expertise, creating content that aligns with the latest advancements in brain health research. The platform is initially developed to support the pilot activities within the LETHE clinical trial, therefore the portal will be initially available in the four languages of the pilot site included in the project: Italian, German, Swedish and Finnish. It is planned to employ an automatic translation tool that uses text-to-speech and speech-to-text functionalities to adapt the same content across other languages in future.

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

15 FEBRUARY

The PROMINENT Public Involvement Board gathers online for its second consultation about the project



On 15 February, members of the PROMINENT Public Involvement Board met online. Also participating in this meeting were partners of the PROMINENT project: Jyrki Lötjönen (Combinostics), Lena Sannemann (University of Cologne), Ange Bradshaw and Daphné Lamirel (Alzheimer Europe).

Attendees discussed the 'patient reports', that are part of the Clinical Decision Support System developed in PROMINENT. These reports are aimed at patients and those accompanying them to memory clinics (e.g. a partner or relative). They present, in an accessible format, information about a patient's diagnosis, exam results, eligibility for new disease-modifying therapies and other avenues to find support. The memory specialists will provide these reports, in printed form, to their patients to take home after an in-person appointment.

The members of the PROMINENT Public Involvement Board include people with different types of dementia, with MCI as well as relatives and carers of people with dementia. During the meeting, they gave very insightful feedback on the design, layout and content of the reports and on how to make these more understandable and helpful to people. New versions of the patient reports will be developed based on the group's input.

20 FEBRUARY

The LETHE Advisory Board meets online after using cognitive training app for three weeks

On 20 February, members of the LETHE Advisory Board gathered online. The meeting was also attended by partners of the LETHE project: Jyrki Lötjönen (Combinostics), Anna Rosenberg (THL), Anna Giulia Guazzarini (University of Perugia), Alara Abaci (Karolinska Institutet), Helena Untersteiner (Medical University of Vienna) and Konsta Valkonen (THL), Soraya



Moradi-Bachiller (Public Involvement Officer, Alzheimer Europe), and facilitated by Ana Diaz (Public Involvement Lead, Alzheimer Europe).

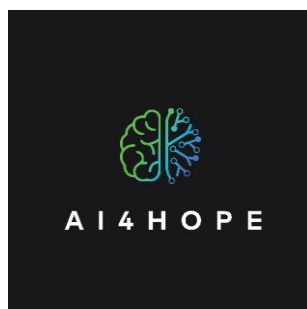
During the three weeks before the consultation, members of the LETHE Advisory Board were given access and were able to test a cognitive training programme, which contains six games that target different cognitive abilities. After these three weeks of using the programme, members of the LETHE Advisory Board provided their opinions about the games, the instructions to play them, the programme's design, and their experiences using it.

All the members participated actively and provided valuable feedback that will be used by the LETHE research team to improve the cognitive training programme and the games. Find out more about the LETHE project, here:

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

20 FEBRUARY

AI4HOPE aims to transform dementia care through digital health interventions



AI4HOPE, a new initiative funded by Horizon Europe, aims to transform dementia care through cutting-edge digital health interventions. With a mission to revolutionise support for people with dementia and their carers/supporters, AI4HOPE aims to reduce distress and anxiety while enhancing the overall quality of life.

Recognising dementia as a critical public health concern, AI4HOPE leverages its Horizon Europe funding to develop culturally sensitive palliative care solutions within a comprehensive digital ecosystem. By prioritising holistic support and sustainability, the project addresses the pressing need for innovative approaches to dementia care.

According to our Dementia in Europe Yearbook 2019 and our updated 2021-2025 Strategic Plan, the prevalence of dementia is about 2% of the total population (over 10 million) of Europe and non-EU countries. It is estimated that this ratio will

climb to 3% or higher by 2050. With dementia prevalence increasing, AI4HOPE aims to deliver patient-centred digital health interventions that improve access to care and quality of life for those affected by the condition. The project aims to provide invaluable support to people with dementia and their carers/supporters through advanced care planning systems and emotion-regulation techniques.

Reminiscence therapy, one of the critical components of AI4HOPE's approach, has shown promising results in improving quality of life and reducing depression among people with dementia. The project aims to expand access to these vital support services by harnessing technology. AI4HOPE's innovative digital interventions span various technologies, including mobile applications, virtual reality, robotics, and gaming platforms. These tools are used to enhance communication, improve health outcomes, and promote overall well-being for people with dementia and their carers/supporters.

"Our Horizon Europe-funded project is dedicated to empowering patients and caregivers with cost-effective digital health interventions," said Associate Professor Riku Klén, AI4HOPE Project Coordinator.

AI4HOPE is a four-year Horizon Europe Research and Innovation Action and its consortium is composed of 16 partners, including Alzheimer Europe. The partners met online, for the project's kick-off meeting, on 30 January 2024 and Alzheimer Europe was represented by Angela Bradshaw, Director for Research, and Daphné Lamirel, Public Involvement Officer.

27 FEBRUARY

The ADIS Advisory Board meets online to discuss the terminology of a brain health campaign for young adults



On 27 February, members of the ADIS Advisory Board gathered online. The meeting was also attended by Andrea del Val (Hospital Clínic de Barcelona) and Ainhoa Etayo (Confederación Española de Alzheimer, CEAFA), and facilitated by Soraya Moradi-Bachiller (Public Involvement Officer at Alzheimer Europe, AE).

During the consultation, members of the ADIS Advisory Board and their supporters provided their views and opinions regarding the terminology to develop brain health campaigns, and the challenges people may face when taking care of their brain.

All the members and supporters participated actively and provided insightful feedback that will help AE to develop a brain

health campaign for young adults. Find out more about the ADIS project and its advisory board, here:

<https://www.adis-project.eu>

1 MARCH

BarcelonaBeta Brain Research Center reports on its involvement in the PROMINENT project



The PROMINENT project aims to improve the diagnosis and treatment of neurodegenerative diseases through precision medicine, amongst others, by leveraging the expertise at the BarcelonaBeta Brain Research Center (BBRC). In this post, we highlight contributions and insights from Ferran Lugo and Oriol Grau regarding their work as well as PROMINENT's potential.

Ferran Lugo discusses his work as a biotechnologist and data manager, focusing on developing a platform that uses predictive modelling to aid clinicians in diagnosing and managing neurodegenerative diseases. He highlights the necessity of a strategic data sharing approach to build this platform, incorporating patient data from across Europe.

"Predictive modelling (...) is really useful for research, because with already known data, we can predict different features, behaviours and even the results of certain experiments with a particular accuracy." - Ferran Lugo

<https://vimeo.com/918350209>

Ferran explains considerations for data sharing, contrasting centralised and federated approaches as well as the potential use cases of predictive models.

Oriol Grau, neurologist and researcher at BBRC, emphasises the role of AI-based predictive models in improving the prognosis and treatment of neurodegenerative disorders. He underscores the importance of collaborative efforts across disciplines to achieve the project's objectives.

"AI-based predictive models will have an important role in the clinical assessment of neurodegenerative disorders." - Oriol Grau

<https://vimeo.com/919068329>

Oriol points to the need for collaboration between public and private partners, involving experts from various backgrounds, such as clinicians, data managers, and engineers.

EU project acknowledgements



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

AI4Hope – grant agreement 101136769

LETHE – grant agreement 101017405

Prominent – grant agreement 101112145



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



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SPONSOR OF THE MONTH

Alzheimer Europe would like to express its gratitude to a new sponsor for its 2024 activities.

Read more about sponsorship opportunities here:

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



MEMBERS OF THE EUROPEAN ALZHEIMER'S ALLIANCE



Currently, the total number of MEPs in the Alliance stands at **86**, representing **26** Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance (EAA):

Austria: Claudia Gamon (Renew Europe); Monika Vana (Greens/EFA). **Belgium:** Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D). **Cyprus:** Costas Mavrides (S&D). **Czech Republic:** Tomáš Zdechovský (EPP). **Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe); **Finland:** Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France:** François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Pierre Larrourou (S&D); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). **Greece:** Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE-NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraiki (EPP); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland:** Barry Andrews (Renew Europe); Deirdre Clune (NI); Ciarán Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke 'Ming' Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Grace O'Sullivan (Greens/EFA). **Italy:** Isabella Adinolfi (NI); Brando Benifei (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:** Vilija Blinkeviciute (S&D). **Luxembourg:** Marc Angel (S&D); Charles Goerens (Renew Europe); Tilly Metz (Greens, EFA); Isabel Wiseler-Lima (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). **Poland:** Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP). **Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP). **Romania:** Cristian-Silviu Busoi (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Klemens Grošelj (Renew Europe); Irena Joveva (Renew Europe); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estaràs Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA). **Sweden:** Peter Lundgren (ECR).

EU DEVELOPMENTS

30 JANUARY

Alzheimer Europe responds to Council of Europe consultation

COUNCIL OF EUROPE



CONSEIL DE L'EUROPE

Alzheimer Europe has submitted a response to the Steering committee for human rights in the fields of biomedicine and health (CDBIO) of the Council of Europe, following its consultation on a Draft Recommendation on respect for autonomy in

mental healthcare. The Recommendation aims to provide common principles to promote a human rights-based approach in mental healthcare, safeguarding the rights and self-determination of persons with mental health problems.

Alzheimer Europe welcomed the opportunity to comment on these recommendations and raised concerns with the approach taken, specifically, the broadness of the recommendations and the separate Explanatory Memorandum (EM), which was not included as part of the consultation.

We expressed concern that the recommendations were not accessible as the need to refer to footnotes/the EM, may deter people from using them. Alternatively, we noted that if applied without reference to these additional documents, the Articles may not be applied in the way intended by the CDBIO. As such, we strongly urged the CDBIO to revise the Articles so that there is greater detail and specificity for each Article, without the need to refer to an EM or another document.

Alzheimer Europe also noted the difficulty in providing feedback on the Articles and the document as a whole, as many of the Articles are dependent on the clarification or further detail which is anticipated to be in the EM. These details were crucial to the understanding of both the intention behind, and the application of, the Articles, in relation to policy and practice. As such, we urged the CDBIO to put the EM out for consultation, so that stakeholders have the opportunity to comment on both documents. Alzheimer Europe's full response is available at:

<https://www.alzheimer-europe.org/policy/positions/council-europe-cdbio-recommendation-autonomy-mental-healthcare>

6 FEBRUARY

Political agreement reached on mid-term review of EU budget

On 6 February, the European Parliament and Council of the EU reached an agreement on the revision of the long-term budget of the EU.

This update reflects aspects of the Parliament's position adopted in December 2022, which called for a response to

evolving needs and unforeseen circumstances, as well as a stable financing solution for Ukraine, as well as the decision of the European Council on 1 February 2024. However, the revised funding package includes redeployment of funds from other programmes, including:

- EUR 1 billion will be taken from the EU4Health programme
- EUR 2.1 billion will be taken from the Horizon Europe research programme.

More details on the budget revision are available at:

<https://www.europarl.europa.eu/news/en/press-room/20240205IPR17408/deal-on-mid-term-revision-of-eu-s-long-term-budget>

12 FEBRUARY

Political agreement reached on European Disability and Parking Cards

The European Parliament and the Council of the EU have reached a political agreement on a Directive establishing the European Disability Card and the European Parking Card for persons with disabilities.



The European Disability Card and revised European Parking Card aim to ensure easier recognition of disability status and equal access to special conditions and preferential treatment across the EU. The main elements of the Directive include:

- Recognising the European Disability Card as proof of disability across the EU.
- Providing European Parking Card holders with the same parking rights across the EU.
- Requiring Member States to issue and renew the European Disability Card free of charge, in both physical format (with digital features) and in digital format.
- Requiring Member States to issue and renew the European Parking Card free of charge, or for a small fee to cover the administrative costs, in a physical format with digital features.
- Ensuring publicly accessible information on the conditions and procedures for obtaining these cards, as well as general information about the special conditions and preferential treatment offered to persons with disabilities.
- Guaranteeing enforcement and compliance by empowering persons with disabilities and their representatives to take legal action under national law.

The Directive will enter into force 20 days following its publication in the Official Journal of the European Union. Within 30 months after the entry into force Member States will have to incorporate the provisions of the Directive into national law.

One year after this, the legislation will take effect, at which point persons with disabilities can apply for the cards. Details on the Cards are available at:

<https://ec.europa.eu/social/main.jsp?langId=en&catId=1139&furtherNews=yes&newsId=10763>

POLICY WATCH

19 FEBRUARY

Scottish Government publishes two-year delivery plan (2024 to 2026)



The Scottish Government
Riaghaltas na h-Alba

The Scottish Government has published an initial delivery plan for 2024-2026, setting out how it will work with local authorities to implement the commitments contained within Scotland's national dementia strategy. There are seven key deliverables, including:

- Creating a public-facing campaign that challenges the stigma associated with dementia, co-produced with the National Dementia Lived Experience Panel
- Commissioning an independent evaluation of the Aberdeen Brain Health Service, supported by a cross-governmental, cross-sectoral oversight group
- Working with Public Health Scotland, and local and academic partners, to add to the data collected and published on diagnosis and Post-Diagnostic Support
- Establishing a short-life working group to further develop current understanding of the workforces supporting people living with dementia to identify any gaps
- Commissioning an independent evaluation of Scotland's Post-Diagnostic Support policy and delivery, including the perspective of people living with dementia and care partners/unpaid carers and those living in care homes
- Establishing a Resilient Communities Programme Board tasked with identifying priorities and allocating dedicated Scottish Government funding to grass-roots and community organisations
- Establishing a cross-governmental, cross-sectoral steering group to help shape the Scottish Government's role in contributing to the research and understanding around risk, identification, diagnosis, and treatment.

The full delivery plan is available at:

<https://www.gov.scot/publications/new-dementia-strategy-scotland-initial-2-year-delivery-plan-2024-2026/documents/>

22 FEBRUARY

Malta launches its new dementia strategy for 2024-2031

The National Dementia Strategy for the Maltese Islands 2024 – 2031, titled 'Reaching New Heights', aims to significantly improve the quality of services and the quality of life of persons living with the condition in the Maltese islands. This dementia strategy is a continuation of the Maltese Islands' first national strategy and it builds on the sound progress made during its implementation.

A review of the objectives implemented was carried out and new evidence-based practices were sought. Based on this assessment, various action areas were identified in the strategy to address what Malta needs to reach new heights in this care sector.

This plan spans over the period of the next seven years. It lays out a vision for how people with dementia might live their lives as well as the necessary societal, policy, and service adjustments needed to facilitate this. The policy identifies priority areas that will help people with the condition and those who help them advance through dementia. The objectives to be achieved through the action areas include:

- Increase awareness and understanding of dementia by improving inclusivity and accessibility in community settings that maximise the opportunities for health, involvement, and security for everyone
- Reduce the risk of developing dementia by taking precautionary measures, such as increasing physical activity, preventing and reducing obesity, promoting balanced and healthy diets, quitting smoking and alcohol use, encouraging social engagement, promoting cognitively stimulating activities, preventing and managing diabetes, hypertension, and depression
- Obtain an early diagnosis to enable individuals to make advance care and legal planning while they are still able to make important decisions
- Instil a positive approach and empowerment, focused on helping persons with dementia and their families to live well with the condition



- Improve education and training to develop a dementia-capable workforce with skills to deliver high-quality services and support
- Strengthen seamless integrated person-centred care across all settings
- Advance towards better dementia prevention, diagnosis, treatment, and care by implementing dementia research.

An Inter-Ministerial Committee, led by the Ministry for Active Ageing, will be set-up to coordinate and oversee the imple-

mentation of the strategy. This will ensure that the actions outlined in the seven sections of the policy are implemented in an effective and efficient manner. It will also ensure that people with dementia, caregivers, and family members are included in the implementation process. The National Strategy document can be accessed via: <https://aacc.gov.mt/wp-content/uploads/2024/02/Final-Version-Dementia-Strategy-06-Feb-2024-1.pdf>

SCIENCE WATCH

31 JANUARY

Alzheimer Europe co-authors paper on perspectives of European Working Group of People with Dementia and their supporters on definition of advance care planning



A recent paper highlights the need to adapt the definition of advance care planning (ACP) to be inclusive of those with dementia and to emphasise the vital role of families in the process. It also advocates for a broader approach encompassing preferences for social aspects of care. The paper, entitled "The perspectives of people with dementia and their supporters on advance care planning: A qualitative study with the European Working Group of People with Dementia" and authored by researchers from Vrije Universiteit Brussel (VUB) and the DISTINCT project and co-authored by Alzheimer Europe Director for Public Involvement and Ethics Dianne Gove and Public Involvement Lead Ana Diaz, was published in the journal Palliative Medicine on 31 January 2024.

ACP is a process enabling individuals with decisional capacity to define goals and preferences for future medical treatment and care, discuss these with family and healthcare providers, and record and review them if appropriate. There are concerns that this definition may not apply to ACP in the context of dementia. This study aimed to gather the perspectives of the European Working Group of People with Dementia (EWGPWD) regarding the ACP definition. Three online focus groups and additional individual interviews were conducted.

The EWGPWD members expressed support for several aspects of the current ACP definition which they considered essential, such as that ACP should be a process and be regularly reviewed, that it should encourage communication and documentation of decisions about future care, and should not be limited to the completion of advance directives. However, the EWGPWD disliked that the current ACP definition explicitly targets 'individuals with decisional capacity', thereby excluding people with dementia who have less or lack capacity. Rather than advocating for a separate definition, the EWGPWD proposed adapting the existing definition to be more inclusive of those with dementia. They emphasised the importance of a relational approach to ACP, stressing the significant role of families and trusted relationships in decision-making processes. Moreover, they highlighted the need for the ACP definition to encompass broader aspects of care beyond medical treatment, including social care and meaningful activities. Recommendations for future adaptations to the definition were provided based on these findings.

The researchers from Vrije Universiteit Brussel (VUB) and the DISTINCT project who led this paper would like to thank the EWGPWD and their supporters for their valuable contributions.

The paper, which will soon be available in open access, can be found here: <https://doi.org/10.1177/02692163231219915>

31 JANUARY

Biogen discontinues development and sales of aducanumab for AD

On 31 January, the global biotechnology company Biogen announced its decision to discontinue development and commercialisation of aducanumab for early Alzheimer's disease (AD). Aducanumab received accelerated approval from the US Food and Drug Administration



(FDA) in June 2021. The company noted that this decision is not related to any safety or efficacy concerns. The plan is to reprioritise the resources in AD. Biogen, along with partner Eisai, will focus on advancing lecanemab, the first anti-amyloid beta treatment for AD to be granted traditional approval by the FDA. The drugmaker will also accelerate development of two experimental treatments, including its ASO targeting tau (BIIB080) and an oral small molecule inhibitor of tau aggregation (BIIB113).

Biogen will terminate the ENVISION clinical study, a Phase 4 post-marketing study aiming to confirm the benefit of aducanumab as required by the FDA under its accelerated approval. Biogen licensed aducanumab from Neurimmune and has terminated that license. Biogen will hand back the rights to Neurimmune.

<https://investors.biogen.com/news-releases/news-release-details/biogen-realign-resources-alzheimers-disease-franchise>

8 FEBRUARY

GSK and Alector initiate Phase II trial for AL101 in early AD



On 8 February, GSK and Alector announced the initiation of the global PROGRESS-AD Phase II clinical trial of AL101 (also named GSK4527226) in people with early Alzheimer's disease (AD) including mild cognitive impairment and mild dementia due to AD. The first

participant has been dosed in the trial, which is expected to enrol approximately 280 participants in US, Canada and Europe.

PROGRESS-AD is a 76-week randomised, double-blind and placebo-controlled Phase II clinical trial evaluating the efficacy and safety of two doses of AL101 in early AD. Participants will receive either the experimental drug or placebo via an intravenous infusion. The primary endpoint of the study is the progression of cognitive impairment as measured by the Clinical Dementia Rating Sum of Boxes (CDR-SB). The trial also evaluates other clinical and functional outcome assessments such as cognition, memory and activities of daily living.

AL101 has been shown to be generally well tolerated and elevated progranulin levels in healthy volunteers. Alector and GSK are co-developing and will be co-commercialising AL101 for the potential treatment of more prevalent neurodegenerative diseases, including AD and Parkinson's disease.

<https://investors.alector.com/news-releases/news-release-details/alector-announces-first-patient-dosed-progress-ad-phase-2>

12 FEBRUARY

New analysis of blood proteins identifies biomarkers as predictors of dementia in healthy individuals

In a recent study published in Nature Ageing, scientists from the Fudan University in Shanghai shown how profiles of protein in the blood could predict dementia prior to clinical diagnosis. These are known as biomarkers, which are molecules found in blood, other body fluids, or tissues that indicate a normal or abnormal process or a condition or disease.

In the published study, researchers analysed blood samples collected from 52,645 healthy volunteers (median age of 58) enrolled in a large cohort from the United Kingdom (UK) Biobank. Blood samples collected between 2006 and 2010 were frozen and then analysed 10–15 years later by the research team. Until March 2023, a total of 1,417 participants developed dementia, revealing dysregulation of protein biomarkers. Alzheimer's disease and vascular Alzheimer's disease were the most common diagnoses among these cases.

Using artificial intelligence, the researchers looked for connections between nearly 1,500 blood proteins and developing dementia years later. They found that high blood levels of four proteins (GFAP, NEFL, GDF15 and LTBP2) were strongly associated with dementia. For some participants who developed dementia, blood levels of these proteins were outside normal ranges more than ten years before symptom onset. Further analysis confirmed the prognostic value of these high baseline levels for increased dementia risk. Individuals with higher GFAP levels were 2.32 times more likely to develop dementia. Notably, GFAP and LTBP2 were highly specific for dementia prediction.

<https://doi.org/10.1038/s43587-023-00565-0>

13 FEBRUARY

Otsuka reports Phase III topline results of AVP-786 for AD agitation

On 13 February, the global healthcare company Otsuka Pharmaceutical, announced topline results of its phase III clinical trial of AVP-786 in the treatment of agitation associated with dementia due to Alzheimer's disease (AD).

The trial, known as 17-AVP-786-305, is a multicentre, randomised, double-blind and placebo-controlled study evaluating the efficacy, safety, and tolerability of AVP-786 compared to placebo, for the treatment of agitation in people with dementia of the Alzheimer's type. More than 600 participants were enrolled in US and Europe and received either AVP-786 (low or high dose) or placebo orally twice-daily during 12 weeks.

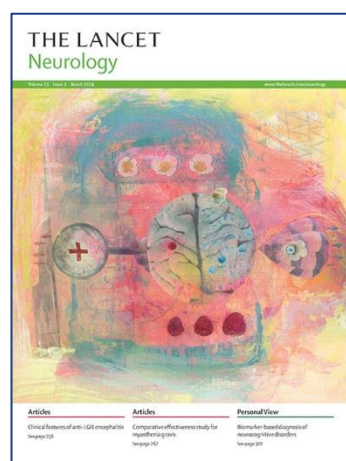
The experimental drug failed to meet the primary efficacy endpoint of the study, which is the change from baseline to week 12 in the Cohen-Mansfield Agitation Inventory (CMAI) total score between AVP-786 and placebo. During the trial, the incidence of falls was higher in participants receiving AVP-786,

with 8.6% in the high dose group and 9.1% in the low dose group, compared to 2.8% in the placebo group. The company said there were four deaths reported in the trial, including one in the low dose group and three in the placebo group. The full study results are not yet available. The company is planning to analyse the full data to determine the potential of AVP-786 and intends to submit the trial results for scientific publication at a later date.

https://www.otsuka.co.jp/en/company/news-releases/2024/20240213_1.html

15 FEBRUARY

European consensus for the diagnosis of Alzheimer's disease is published in The Lancet Neurology by a working group of experts including Alzheimer Europe



A multidisciplinary working group, consisting of 22 experts from 11 European scientific associations and Alzheimer Europe, has defined recommendations for the effective and individualised use of biomarkers for the diagnosis of Alzheimer's disease (AD) in memory clinics. Putting patients, instead of the disease or a test, at the centre of doctors' diagnostic considerations constitutes a turning point in the approaches currently applied. This work has been coordinated by a team from the University Hospital of Geneva (HUG), the University of Geneva (UNIGE) and the Fatebenefratelli of Brescia National Research Center for Alzheimer's Disease (IRCCS). Their consensus paper has been published in the March 2024 edition of The Lancet Neurology:

<https://www.sciencedirect.com/science/article/abs/pii/S1474442223004477>

[https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(24\)00041-3/fulltext](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(24)00041-3/fulltext)

The Lancet Neurology has published an editorial for its March 2024 journal, titled "Dementia diagnosis in the anti-amyloid era", which introduces the consensus paper:

[https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(24\)00041-3/fulltext](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(24)00041-3/fulltext)

Individualised diagnostic pathway

Experts from 11 European scientific associations and organisations, as well as Alzheimer Europe, have collaborated to define a diagnostic pathway focused on each individual case which enables the right tests to be identified according to the symptoms profile. The pathway is easy to use in memory clinics and enables a highly reliable diagnosis to be made.

This diagnostic pathway has been developed on the basis of the scientific literature and from the practical experience of the specialists. After having examined the individual's complaints, performed memory tests and conducted a brain MRI, the specialist can now take advantage of these recommendations to classify the case into one of the eleven defined phenotypes, then look for biomarkers using the tests recommended by the international experts, namely lumbar puncture, amyloid PET, glucose PET, ioflupane SPECT, MIBG SPECT and tau PET.

Moving beyond the biomarker-centric approach

The objective of the diagnostic pathway is to overcome the current limitations of the recommendations and guidance related to the diagnosis of AD. The latter focus mainly on the disease itself or on biomarkers, rather than on the person affected. Although they have been developed to help clinicians use the correct diagnostic tests, they reveal gaps when applied in clinical practice. Indeed, most of these recommendations do not take account of the many diagnostic options available nor of the existence of several tests that can be carried out simultaneously or sequentially. Moreover, those that do take these into account often only reflect the opinion of non-representative expert groups. As a result, in clinical practice biomarker choice is often influenced more by organizational and logistical considerations than by clinical factors.

"The diagnostic pathway we have developed will help clinicians define the most informative biomarker in the most frequent clinical case scenarios. It will promote consistency in the diagnosis of neurocognitive disorders in European countries, reduce the cost of analyses and identify those eligible for treatments with more precision," explains Prof. Giovanni Frisoni, head of the HUG Memory Center, Professor of Clinical Neuroscience at the University of Geneva and first author of the study.

Consensual method

To reach this consensus the 22 experts used the Delphi participatory approach to compare the difference in effectiveness of one test compared to another in various situations. This approach consists of measuring the specialists' opinion on the characteristics studied in order to retain only those opinions that achieve a consensus of over 70% and therefore considered highly probable.

Next steps

This pooling of expertise has enabled a reference standard to be established that will be useful to all doctors in Europe. It will now be incumbent on national services, healthcare providers, medical officials and insurance companies to implement it in each country.

As far as the study is concerned, the next step will be to integrate blood biomarkers into the decision tree. These are only available currently within the remit of research and are in the process of being approved for clinical use. In future they will avoid up to 70% of invasive tests such as lumbar punctures and PETs, helping to reduce costs and expand diagnoses in the general population.

20 FEBRUARY

New research from China Cognition and Aging Study detects biomarker changes 18 years before diagnosis of Alzheimer's disease



In a landmark paper published in the New England Journal of Medicine (NEJM), a team of Chinese researchers have mapped biomarker changes over time, identifying key signals that can precede a diagnosis of Alzheimer's disease by over 18 years.

There is a growing awareness that biological signs of Alzheimer's disease (AD) can be detected many years before a person develops cognitive changes and symptoms. However, the specific sequence of biological changes over time has not been conclusively established, in part due to challenges in performing longitudinal studies over extensive periods of time. To address this important issue, a team of researchers from the China Cognition and Aging Study (COAST) set out to map the biological changes that occur in the years and decades preceding AD diagnosis, by analysing samples of cerebrospinal fluid (CSF), brain imaging data, and cognitive test scores from COAST participants who were enrolled between the year 2000 and 2020.

COAST was a China-wide, prospective cohort study that enrolled participants aged 45-65 years in 2000 with no cognitive complaints. The primary analysis reported in the NEJM paper focused on 648 COAST participants who developed AD, matched with 648 participants with normal cognition, following them for almost 20 years. By comparing CSF biomarker and brain imaging datasets between the two groups, the researchers were able to track when biomarker and brain imaging changes first appeared during the development of AD. Levels of CSF amyloid beta (42) were the first to diverge, with changes detectable 18 years prior to diagnosis. Next, the ratio of CSF amyloid beta (42) to amyloid beta (40) was shown to be different 14 years prior to clinical signs of disease appearing, followed by changes in phosphorylated tau181 11 years before diagnosis. CSF levels of neurofilament light chain were altered 9 years before diagnosis, followed by hippocampal atrophy and cognitive decline a few years later. Together, these important results shine a light on the timing of biological events

in the years prior to diagnosis, which could help clinicians better understand when to initiate efforts for risk reduction, prevention and therapy.

https://www.nejm.org/doi/full/10.1056/NEJMoa2310168?query=featured_home

27 FEBRUARY 2024

Recent research indicates that being bilingual might reduce the risk of MCI and dementia

A recent study, published in the journal Alzheimer's & Dementia, delved into how speaking multiple languages might affect our brains as we get older. Researchers Aparna Venugopal and colleagues, looked at a large group of people living in an urban area in India and uncovered an interesting finding: those who spoke more than one language tended to have better memory and thinking skills in older age. They found that bilingual people – those who can speak two languages – were less likely to have Mild Cognitive Impairment (MCI) or dementia compared to those who only spoke one language. Even if someone only spoke a little of a second language, it still seemed to contribute to reducing the risk of cognitive decline. The study also showed that it did not matter if someone spoke two languages or more – there were no differences found between the prevalence of MCI and dementia in those who spoke two languages compared to those who spoke three languages or more.

The study authors explain that speaking more than one language might be beneficial for the brain particularly because switching between languages may keep people's brains active and more flexible, and thereby help increase 'neuronal plasticity'. This mental exercise could also help build a 'reserve' in our brains, which might protect from cognitive decline as people get older. Interestingly, this study was conducted in India, where many people naturally speak more than one language, suggesting that growing up in a bilingual environment could benefit our brains in the long run.

It is worth highlighting that the study has a few shortcomings. Firstly, people's rating of their language skills might not have been entirely accurate, because it was based on their own assessment. Additionally, the researchers only looked at one point in time when measuring cognitive health and bilingualism. For future research, the study authors therefore recommend using more objective measures of language proficiency and conducting longitudinal studies to better understand the long-term effects that speaking multiple languages may have on brain health.

See the study, here:

<https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.13702>

27 FEBRUARY 2024

New study evaluates the feasibility of a personalised dementia risk reduction programme in Luxembourg



The "Programme Dementia Prevention" (PDP) in Luxembourg is a nation-wide initiative designed to tackle cognitive decline and dementia risk among the population. The programme is open to people with either Mild Cognitive Impairment (MCI) or Subjective

Cognitive Decline (SCD). It is composed of a first stage where people get an initial referral, neuropsychological assessment and risk factor profiling. Subsequently, the results of assessments are provided to participants as well as vouchers for access to multi-domain interventions depending on people's preferences and specific risk factors. Individuals are then followed up over time. The PDP offers a diverse range of activities and services delivered by local partners across Luxembourg, ranging from cognitive training and physical activities to psychological and dietary counselling. These offerings are updated based on the latest scientific evidence and feedback from participants, ensuring relevance and accessibility. The present article, published in PubMed, was aimed at describing and evaluating the feasibility of the programme.

The programme enrolled 450 participants since its launch in February 2018, with an average age of 69.5 years. 87.1% of participants had MCI at baseline, while 7.3% had SCD and 4.7% were excluded due to suspected dementia. The programme received referrals from various medical professionals, with general practitioners being the most common (68.5%), leading to a steady increase in appointments over time. The average time between appointments was approximately 70 days and the programme offered regional consultation sites to improve accessibility, with about 18.9% of participants choosing this option. A survey conducted 11 months after the programme's launch showed positive feedback from referring physicians, indicating satisfaction with the programme's individualised approach and recommendations for patient care.

Despite its overall success, the PDP faces several challenges, including addressing mobility issues and navigating Luxembourg's linguistic diversity. Efforts to overcome these challenges include offering flexible recruitment locations and multilingual support for participants and staff. Looking ahead, the PDP aims to further expand its offerings and engage in outreach activities such as informative events. Find out more:

[Programme Dementia Prevention \(pdp\): A Nationwide Program for Personalized Prevention in Luxembourg - PubMed \(nih.gov\)](#)

MEMBERS' NEWS

25 JANUARY

New report highlights life-enhancing benefits of The Alzheimer Society of Ireland's Day Care at Home Service



On 25 January, The Alzheimer Society of Ireland (The ASI) launched the [evaluation of their Day Care at Home \(DCAH\) Service report](#) which highlights significant positive benefits for people living with dementia and their families.

In 2023, The ASI commissioned an [evaluation](#) of the impact and effectiveness of the DCAH Service. This evaluation – led by Dr Emma O'Shea at The Centre for Gerontology & Rehabilitation, University College Cork (UCC) – follows an analysis of feedback provided by DCAH service users, ASI staff, and external stakeholders. The Health Service Executive (HSE)'s National Dementia Services (NDS) provided funding for this research and supported The ASI to deliver this much-needed service.

The significant positive outcomes highlighted in this study reflect the commitment, dedication and care provided by staff in delivering the Day Care at Home Service. Tadhg and Marian Kelleher use the Day Care at Home Service in Co. Cork. Every week, Lizimani 'Lee' Milanzi, a carer at The ASI visits Tadhg and Marian's home and works with Tadhg who lives with dementia.

Tadhg says: "The Alzheimer Society of Ireland's Day Care at Home Service is a great help to myself and my wife Marian. I enjoy when Lee from The ASI visits, we do exercises and take walks in the forest close to my home. I like the fresh air and getting out and about."

The Day Care at Home Service allows relatives caring for loved ones some respite. Marian, Tadgh's wife said she is grateful for Lee's support which gives her a chance to take care of the farm or take time out for herself without worry. "Sometimes I'll go for a coffee or visit a friend and maybe do a bit of shopping. I have those hours for myself, some time out and I know Tadgh will be well supported at home."

15 FEBRUARY

President of the Slovenian Working Group for People with Dementia Tomaž Gržinič wins second place in doubles tennis tournament



Tomaž Gržinič, member of Spominčica – Alzheimer Slovenija, president of the Slovenian Working Group for People with Dementia and a former member of the European Working Group of People with Dementia, has won second place in a doubles tennis tournament organised by the AAB Sports Cultural Society Slovenia.

Tomaž actively participates in all activities that are taking place at the Memory Centre for Persons

with Dementia Spominčica. Spominčica commented:

"With Tomaž's smile, we get a dose of inspiration every day. He proves that people with dementia can also maintain activity and are an important part of society! Congratulations, Tomaž!"

Pictured: Tomaž Gržinič (right) with Štefanija L. Zlobec, President of Spominčica (left)

21 FEBRUARY

Fundación Alzheimer España welcomes the approval of the Royal Decree-Law reforming the patronage law in Spain



The recent approval of the Royal Decree-Law reforming the patronage law in Spain by the Council of Ministers is a milestone in the promotion of philanthropy, addressing challenges that remained unchanged for over two decades. This legislative renewal introduces significant improvements such as: encouragement of micro-patronage, tax deductions review to incentivise larger donations, and diversification in the forms of collaboration and donation. These

changes aim to boost participation by both citizens and entities in support of causes of general interest, covering key sectors such as education, culture and disease research.

The positive and enthusiastic response from the Third Sector, along with unanimous recognition of the reform, reflects broad consensus on its potential to strengthen the social fabric and welfare in Spain. These measures are designed not only to enhance active participation in philanthropy but also to increase the resources available for charitable causes, marking the beginning of a more inclusive and solidarity-based time in Spanish patronage. Undoubtedly, this reform represents a step forward towards a more dynamic, fair, and effective patronage system, aligned with the needs of the 21st century and the strengthening of social welfare and the associative fabric in the country. You can find additional information via this link (in Spanish):

<https://www.fundaciones.org/es/noticias-aef/aprobacion-reforma-mecenazgo-19122023>

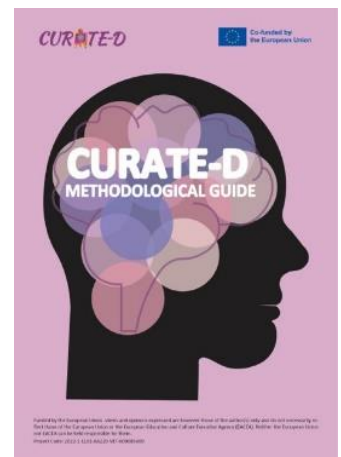
23 FEBRUARY

The Panhellenic Federation of AD & Related Disorders presents its CURATE-D project

The European Erasmus+ project 'A Game-based methodology for empowering dementia-friendly communities and equal access to Culture for people with Dementia (CURATE-D)', aiming to promote equal opportunities, accessibility and social inclusion for people with dementia in cultural experiences, has successfully concluded its first phase with the release of the 'CURATE-D Methodological Guide'.

This document plays a pivotal role in implementing the project, showcasing the innovative methodology grounded in game-based learning to be applied across all activities. Moreover, it outlines the fundamental structure for the upcoming results, which includes two learning guides for the training of professional caregivers working with people with dementia and for cultural professionals. The guide not only encompasses good practices but also incorporates activities to advance the overall project objective. This guide is freely accessible and can be downloaded from the CURATE-D project website: <https://curate-d.eu/>

The methodological guide is the result of the work developed collaboratively since the beginning of the project by the partners: Challedu, the coordinator; Panhellenic Federation of Alzheimer Disease and Related Disorders, Thessaloniki and Herakleidon Museum of Athens (all three located in Greece); The Gaiety School of Acting (GSA) of The National Theatre School



of Dublin, Ireland and the Association of Relatives of Alzheimer (AFAV) of Valencia, Spain. The co-creation of the CURATE-D methodology will enable the transnational impact of the project and the direct connection with the needs of the target groups.

In short, the first part of the guide contains the definition of dementia, its main symptoms, and advice on how to cope with them. The second part is devoted to a mixed research methodology: desk research on dementia-friendly policies at EU level and partner countries, dementia-friendly cultural activities, along with interviews with people working in dementia care and cultural venues about their needs. This bridges gaps in knowledge regarding dementia-friendly activities and how to implement dementia-friendly initiatives in their organisations, respectively. The third part includes the basic theoretical background on game-based learning and best practices for dementia caregivers using a game-based approach as well as the presentation of the innovative CURATE-D project methodology.

23 FEBRUARY

Alzheimer Portugal signs public petition and draws up recommendations to improve response to disappearance of people with dementia in Portugal



Earlier this year, a civic movement launched a public petition (Direito previsto na Constituição da República Portuguesa e na Lei n.º 43/90) to improve the prevention and response to the disappearance of people with dementia, which Alzheimer Portugal has signed and publicised, and currently has reached over 7,800 signatures. In

this context, Alzheimer Portugal has drawn up recommendations to help searching for missing people with dementia, which have been publicised to the public, security forces and local authorities. This document includes a list of common behavioural patterns and strategies to be implemented, including filling in a form to describe the individual profile of the missing person with dementia.

This issue has never been systematically considered, and the Portuguese authorities still have no specific procedures for implementing prevention and response measures. The petition is addressed to the Portuguese Government and Parliament, the Health Regulatory Authority, the Ministry of Health and all public and private hospitals, as well as police authorities and local councils, and lists concrete measures to be urgently implemented.

The petition was prompted by a specific case that shook Portuguese society. On 12 December 2023, Avelina Ferreira, who

had been diagnosed with dementia, went with her husband to a Lisbon hospital to be seen in the emergency room. Despite alerting health professionals of his wife's condition, he was prevented from accompanying her and she ended up leaving the hospital alone. Despite the efforts of friends, colleagues and family, who carried out painstaking searches and widely publicised the situation in the media and on social networks, the woman is still missing.

Portuguese legislation has recognised the right of patients to be accompanied in health services for several years (Lei nº 15/2014). However, this law has been systematically disrespected. Alzheimer Portugal believes that the petition and the media attention that has been given to this issue represents an effective contribution to ensuring compliance with the law and the rights and safety of people with dementia. Alzheimer Portugal is committed to working with the organisations involved to ensure that these dramatic and unacceptable situations no longer occur in their country.

23 FEBRUARY

Alzheimer Hellas announces the official start of 2D-BioPAD: A new Horizon Europe project



Alzheimer Hellas is thrilled to announce the official start of 2D-BioPAD, a pioneering project funded by the European Union, under Grant Agreement No.101120706. With a budget of nearly EUR 6 million, this Horizon Europe Research and Innovation Action officially commenced in October 2023 and will last 48 months.

The project's kick-off meeting took place on 10-11 October 2023 in Thessaloniki (Greece) at the prestigious Center for Interdisciplinary Research and Innovation (CIRI) of the Aristotle University of Thessaloniki. The kick-off meeting saw all project partners converge to discuss their roles, responsibilities, and aspirations for the successful realisation of the project's specific objectives.

2D-BioPAD is developing a fast, reliable, cost-effective and digitally enabled Point-of-Care (PoC) In-Vitro Diagnostic (IVD) system for early Alzheimer's disease (AD) detection. The 2D-BioPAD system employs cutting-edge 2D materials (i.e., graphene), nanomaterials and aptamers, to enhance biocompatibility, sensitivity, and specificity for simultaneously detecting up to five AD biomarkers in blood. The device will be accompanied by a user-friendly mobile app that will give real-time access to quantified results to healthcare professionals in primary healthcare settings. Along the way, Artificial Intelligence

(AI) will be used for optimising the design and implementation of the 2D-BioPAD system.

Two clinical pilot studies will be conducted in three European clinical centres, in Germany, Greece and Finland, offering the necessary evidence for technical and clinical validation. Regulatory and ethical considerations will be included in 2D-BioPAD's design to allow faster and widespread adoption.

The 2D-BioPAD consortium, under the leadership of CATRIN-RCPTM at Palacky University Olomouc, is composed of 11 partners across eight European countries: Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, and Spain. The consortium members include: Palacky University Olomouc (UP), Q-Plan International, Catalan Institute of Science and Nanotechnology (ICN2), Grapheal, Aristotle University of Thessaloniki (AUTH), Novaptech, University of Eastern Finland (UEF), Greek Association of Alzheimer's Disease and Related Disorders (GAADRD), Envia, Central Institute of Mental Health in Mannheim (ZI), and University College Dublin/National University of Ireland (NUID UCD - CeADAR).

23 FEBRUARY

Alzheimer Larissa in Greece supports digital literacy of people with dementia-with creative session using 3D pens

From 2021, Alzheimer Larissa has been supporting the digital literacy of people with dementia by training them to use tablet

devices.

The aim of this programme is to increase cognitive empowerment, creativity, sociability and self-confidence. The topics of learning and skill development are varied, tailored to the beneficiaries' wishes and the current situation.

On the occasion of Christmas 2023, computer specialist Konstantina Bethava presented the 3D pen and its operation and gave a training. After the training, the participants were enthusiastic and agreed to use the 3D pen to create their own 3D Christmas decorations.

This experience highlighted and enhanced their technological skills, promoted creativity and helped to increase their confidence in using new technologies. Their 3D creations impressed the other beneficiaries, who expressed interest in participating in future activities.




Alzheimer's Society
Annual Conference
Making dementia a priority for all
 14 May 2024
 etc.venues, 155 Bishopsgate,
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Book your place

LIVING WITH DEMENTIA

22 FEBRUARY

Nigel Hullah, member of the European Working Group of People with Dementia, writes about Welsh "Museums Inspiring Memories" project



Funded by the National Lottery Community Fund, Museums Inspiring Memories is a three-year partnership project between Amgueddfa Cymru and Alzheimer's Society Cymru, exploring how we can use our seven museums, National Collections Centre and collections to improve the health and wellbeing of people affected by dementia.

Using information gathered at over 30 consultations and engagements between December 2022 and March this year, we and our Dementia Voices in Heritage Group (made up of people living with dementia, unpaid carers, care staff, heritage sector colleagues, and representative organisations) are currently focused on developing a dementia-awareness training package for the heritage sector.

In recent months, the team has been hosting pilot activities at several of our museums to gather participants' feedback on how we can make our 'offer' more accessible, welcoming, and supportive. These have included Curatorial-led talks in the community, a visit to the barracks and Roman garden at the National Roman Legion Museum, a seasonal Wellbeing Walk at St Fagans, a series of Dementia Friendly Underground Tours at Big Pit National Coal Museum, and others.

Over the coming nine months, we also look to develop, test, and launch:

- a package for paid and unpaid carers, family members, and loved ones of those living with dementia to support and encourage the use of heritage places, spaces, and resources with those they care for
- an 18-month programme of accessible activities to take place at all Amgueddfa Cymru museums and in the community.

To learn more, please get in touch by email on MIMs@museumwales.ac.uk or by phoning (+44) 02920 573 418.

More information can also be found on our webpage: [Museums Inspiring Memories](#)

Executive summary of our baseline report and a link to our first blog:

The project team has discovered that addressing the issue of people with dementia should not involve treating them as a problem that needs to be fixed. Instead, it requires working together, providing them with a voice, access to resources and facilities, and acknowledging them as valued and contributing members of society.

All the teams on the Museum estates have achieved this, resulting in a truly engaged project supported by everyone involved. Evidence suggests that museums can act as agents of social change for inclusion and participation. However, culture is often overlooked as a crucial component of social change initiatives.

This means that people who understand dementia must take a stand, even if they are excluded from conferences or undermined by others with 'higher titles'. Thankfully, leaders like Sharon, Gareth, and the teams from the Museum sites across Wales prioritise doing what is right, not just going through the motions.

I'm glad to say that the project is inspiring! It's always encouraging to know that actions can positively impact someone. I hope that the ideas presented in the text continue to inspire everyone to work towards creating a more inclusive and supportive society for people with dementia and other marginalised groups. Remember, even small actions can make a big difference!

[Our first blog: Museums Inspiring Memories – our first year!](#)

26 FEBRUARY

Trevor Salomon, Vice-Chairperson of the European Dementia Carers Working Group, writes about "A Chance Meeting"

Last September I was invited by Alzheimer's Society to participate in an event called Accessible Banking Forum, hosted by Ernst & Young at their London offices. All the main banks were in attendance together with representatives of various disabilities charities. Amongst the objectives of the Forum were the stated aims of discovering best practice for embedding accessibility in (banking) product design and aligning around key learnings and next steps needed to convert insights into action. I was asked to speak informally for just a couple of minutes, at the start of a group breakout session, to share some of my observations and reflections as my wife's carer about her challenges as a person living with dementia unable to remember or communicate her security details when engaging with her bank.



At the end of the Forum there was a networking/drinks reception where I had a brief but very enjoyable conversation with a lady, name of Sara Collis, who turned out to be Interim Payments Teams Manager for C. Hoare & Co. - <https://www.hoaresbank.co.uk/> - the UK's oldest private bank, owned continuously by the Hoare family for 12 generations. Sara asked me if I would be prepared to present to her colleagues at the bank about dementia, and dementia in the context of banking.

I of course agreed and in February this year found myself speaking to around 60 of Sara's co-workers. I confess I was really quite surprised when, on a show of hands, it appeared that by far the majority of the attendees had been touched by dementia in their personal lives. I talked about the most common types of dementia, how they manifest themselves in terms of the symptoms, and touched on the two **new drugs** that have been shown to slow down the progression of Alzheimer's disease, and hopefully which will mark a turning point in its treatment. I spoke in detail about the banking difficulties faced by people living with dementia, including remembering pin codes and passwords and the challenges of modern day online, mobile and telephone banking exacerbated by the closure of so many local branches.

C. Hoare & Co. puts customers at the very heart of its business, offering very personalised services, crafted to individual requirements, and in this regard, I reminded the audience of the importance of talking to customers about having Power of Attorney documents in place as well as up-to-date wills and how to engage with customers who may have dementia. The session concluded with a series of thoughtful questions from the audience, some related to banking but many to their own personal circumstances. I was very grateful to Sara to be afforded the opportunity to talk to her colleagues and with the next Accessible Banking Forum due to take place in March, I'm already wondering what may result from the next chance meeting.

DEMENTIA IN SOCIETY

11 FEBRUARY

James McKillop's song "Diff'rently The Same" features on BBC Radio Scotland



Dr James McKillop, DUni. MBE was diagnosed with dementia in 1999. He is a pioneer dementia advocate from Scotland and is also a poet and songwriter. He

wrote the recently-released song "Diff'rently The Same" and on 11 February 2024, the lyrics of the song were read out on

the Iain Anderson Show on BBC Radio Scotland. The song is about how Mr McKillop feels about his dementia diagnosis. You can listen to the song, here: <https://bold-scotland.org/james-mckillops-differently-the-same/>

You can listen to the reading on the Iain Anderson Show on BBC Radio Scotland (minutes 37.10 – 41.12), here: <https://www.bbc.co.uk/sounds/play/m001w78v>

EDUCATION

28 FEBRUARY

Registrations are open for KU Leuven 2024 Summer Course on Ethics in Dementia Care



The Centre for Biomedical Ethics and Law of the KU Leuven is organising the 10th edition of the Summer Course on Ethics in Dementia Care, taking place in Leuven, Belgium, from 2-5 July 2024. The language of instruction will be English. The objective of the course is to foster exchanges on foundational, clinical-ethical and organizational-ethical approaches to

dementia care practices. During the course, national and international experts will give presentations on various ethical topics in the domain of dementia care. There will be time for intensive discussions.

The course will be of interest to participants from diverse professional backgrounds, such as medicine, nursing, psychology, social work, gerontology, health care administration, philosophy and theology, and to PhD students undertaking courses of study in these areas. Detailed information on programme, funding opportunities, registration and payment can be found at:

<https://www.kuleuven.be/english/summer-schools/ethics-in-dementia-care-10th-edition-2024>

or you can download the brochure: <https://www.kuleuven.be/english/summer-schools/ethics-in-dementia-care-10th-edition-2024/ethics-in-dementia-care-booklet-2024.pdf>

The deadline for course registration is **15 June 2024**.

JOB OPPORTUNITIES

22 FEBRUARY

PhD position on Health and Economic Outcomes of Early Dementia Diagnosis available at Vrije Universiteit Amsterdam



A PhD candidate is sought for an open position at Vrije Universiteit Amsterdam, working on a project on Health and Economic Outcomes of Early Dementia Diagnosis. The PhD candidate will apply a wide range of methods to assess the association between the timing and quality of dementia

diagnosis and healthcare utilisation (quantitative registry-based analyses and decision analytic modelling), and explore preferences and needs of people with dementia and their caregivers regarding post-diagnostic support interventions (semi-structured interviews, discrete choice experiment). A group of co-researchers consisting of people living with dementia and their caregivers will collaborate with the researchers in the complete cycle of the project. The deadline for applications is **19 March 2024**.

Find out more and apply, via: <https://workingat.vu.nl/vacancies/phd-position-on-health-and-economic-outcomes-of-early-dementia-diagnosis-amsterdam-1056537>

AE CALENDAR 2024

DATE	MEETING	AE REPRESENTATIVE
4 March	Alzheimer Europe Foundation Board	AEF
5 March	Multi-MeMo General Assembly Meeting	Ana, Cindy
5-9 March	AD/PD 2024 Conference (Lisbon, Portugal)	Ange
7 March	Meeting with EU Brain Partnership	Jean
7 March	Consultation with the ADIS Young Adults Advisory Board (session 1)	Soraya
11 March	eBRAIN-Health Public and Patient Advisory Board Consultation - Daphné, Dianne and Sarah	Daphné, Dianne and Sarah
11-12 March	Al-Mind General Assembly Meeting (Amsterdam, Netherlands)	Cindy
14 March	Finding Alzheimer's Solutions Together (FAST) Council	Jean
14 March	Consultation with the ADIS Young Adults Advisory Board (session 2)	Soraya
15 March	Consultation with the ADIS Young Adults Advisory Board (session 3)	Soraya
18-19 March	Alzheimer Europe Board (Brussels, Belgium)	AE Board and staff
19 March	Company Round Table (Brussels, Belgium)	AE sponsors and staff
19 March	European Parliament Reception "Making dementia a European priority" (Brussels, Belgium)	AE members, sponsors and staff
19-20 March	Public Affairs Meeting (Brussels, Belgium)	AE members and staff
19-20 March	European Working Group of people with dementia (Brussels, Belgium)	EWGPWD members and staff
25 March	34 th Alzheimer Europe Conference committee meeting	Gwladys, Jean
26 March	World Dementia Council (London, UK)	Jean
27 March	Meeting with Roche	Jean
28 March	Meeting with Bristol Myers Squibb (BMS)	Jean

CONFERENCES 2024

DATE	MEETING	PLACE
5-9 March	AD/PD 2024 – Advances in science & Therapy, https://adpd.kenes.com/	Lisbon, Portugal
11-12 April	Genetically Determined Alzheimer Disease Cross-fertilization between Down Syndrome & Autosomal Dominant Alzheimer Disease, https://dsad-adad.com/	Barcelona, Spain

24-26 April	36 th Global conference of ADI - Dementia: Insights. Innovations. Inspirations, https://adiconference.org/	Krakow, Poland and online
14 May	Alzheimer's Society Annual Conference, Making dementia a priority for all https://www.alzheimers.org.uk/dementia-professionals/conferences-and-events/annual-conference	London, United Kingdom
28 July-1 August	AAIC 2024 – A global forum to advance dementia science, https://aaic.alz.org/	Philadelphia, USA and online
25-27 September	IPA 2024 International Congress - Crossing Oceans and Connecting People to Improve Mental Health for Older Adults, Buenos Aires (Argentina), https://www.ipa-online.org/events/2024-international-congress	Buenos Aires, Argentina
8-10 October	34 th Alzheimer Europe Conference – New horizons – Innovating for dementia	Geneva, Switzerland
20 October – 1 November	17 th Clinical trials on Alzheimer's Disease (CTAD), https://www.ctad-alzheimer.com/	Madrid, Spain



34th Alzheimer Europe Conference
New horizons –
Innovating for dementia
Geneva, Switzerland
8 - 10 October 2024 #34AEC
www.alzheimer-europe.org/conferences

