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WELCOME



I would like to start off by welcoming our new colleague, Sébastien Libert, Public

Involvement Officer, to the Alzheimer Europe team, and by congratulating our colleague Lukas Duffner, Project Officer, on achieving his doctorate this month!

I would also like to warmly congratulate our members for all their hard work this September, also known as "World Alzheimer's Month", in particular on World Alzheimer's Day (21 September), a day dedicated to raising awareness as well as challenging the stigma that surrounds dementia. It never ceases to amaze me just how hard-working and creative our members are, with their many and varied new initiatives marking this important day in the dementia calendar. It is also fantastic to see many wonderful traditions being upheld, such as the important "Memory Walks" organised in so many countries. One such event takes place each year in Luxembourg, where we are based, and members of the team were delighted to attend and support this event, organised by Association Luxembourg Alzheimer (ALA). We were also excited to be joined by "Rolling for Dementia" campaigner Golnaz Atefi, who has skated over 1,000 km during September, promoting inclusivity and diversity in dementia care and research; meeting and interviewing researchers, healthcare professionals, and others along the way. Passing through Luxembourg for World Alzheimer's

Jean Georges, Executive Director

Day, she met with Alzheimer Europe, the ALA and the Info-Zenter Demenz. Since departing Luxembourg, Golnaz has achieved the World Record for the farthest distance ever skated by a female. Congratulations to her and her team for achieving this truly impressive goal. We look forward to welcoming Golnaz, who will be among the 950+ attendees at the 34th Alzheimer Europe Conference next week in Geneva, the final destination on her skating journey.

Also on World Alzheimer's Day, we were proud to re-launch the European Alzheimer's Alliance (EAA) with 75 MEPs from 21 countries and seven political groups. The EAA is a non-exclusive, multinational and cross-party group that brings together MEPs supporting the campaign of Alzheimer Europe and its members to make dementia a public health and research priority in Europe. I would like to particularly thank the group's four new Co-Chairs for their willingness to take on this important role, showing their dedication to our cause. They are: Nina Carberry MEP (Ireland, European People's Party), Romana Jerković (S&D, Croatia), Tilly Metz MEP (Luxembourg, Greens/European Free Alliance), and Hilde Vautmans MEP (Renew, Belgium).

In other important policy news, the EU4Health Civil Society Alliance, which includes Alzheimer Europe, has published an open letter to European Commission President, Ursula von der Leyen, expressing concern regarding the position of health within the priorities of the EU, following the announcement of the Commissioners-designate.

I look forward to seeing many of our readers in Geneva next week, for #34AEC!

Alzheimer Europe Board

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

Alzheimer Europe Staff

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

ALZHEIMER EUROPE

1 SEPTEMBER

Alzheimer Europe welcomes new colleague Sébastien Libert



Alzheimer Europe is pleased to welcome a new colleague, Sébastien Libert, who joined the team on 1 September 2024, as a Public Involvement Officer.

Prior to his role at Alzheimer Europe, Sébastien completed a PhD in Anthropology of Health and Ageing at University College London, in 2021. His doctoral research focused on social exclusion in later life and dementia. Following his

PhD, he worked as a Consultant with the World Health Organization Western Pacific Regional Office from 2021 to 2024. In this role, he supported Member States in addressing the challenges of population ageing and social determinants of health. At Alzheimer Europe, Sébastien supports the involvement of people with dementia in EU-funded research projects and programmes. He actively supports the European Working Group of People with Dementia and the European Dementia Carers Working Group.

You can see a list of all our staff at: <https://www.alzheimer-europe.org/about-us/who-we-are/staff>

13 SEPTEMBER

Three finalists selected for Alzheimer Europe's Anti-Stigma Award 2024 and winner to be announced at special ceremony in Brussels in December



Alzheimer Europe and the Alzheimer Europe Foundation are delighted to announce the finalists for the 2024 edition of their Anti-Stigma Award.

Following the great success of the initiative over the past two years, the 2024 edition was launched, with the aim

of recognising a European journalist for an article, news story or documentary which has contributed to combating stigma

and promoting a positive image of dementia and people living with dementia.

This year's Anti-Stigma Award will consist of a cash prize of EUR 5,000 for first place, a cash prize of EUR 2,500 for second place and a cash prize of EUR 1,250 for third place, each of which will be accompanied by a trophy. At a recent meeting of the Anti-Stigma Award committee, 11 shortlisted journalists presented their work and the top three were chosen among them.

The finalists are (in alphabetical order by surname):

- Ofelya Kamavosyan
- Andreas Kriemaier
- Magnus Renggli.

The winner will be announced during a special award ceremony as part of the European Parliament Dementia Day, taking place on 10 December 2024, in Brussels (Belgium).

More information can be found at: <https://www.alzheimer-europe.org/our-work/anti-stigma-award/anti-stigma-award-2024> Alzheimer Europe gratefully acknowledges the support of the sponsors of the Alzheimer Europe Anti-Stigma Award: Alzheimer Europe Foundation, C2N Diagnostics, Lilly and Roche.

Pictured: Finalists at the 2023 Anti-Stigma Award ceremony in Helsinki (Finland).

17 SEPTEMBER

Alzheimer Europe hosts online Alzheimer's Association Academy on anti-amyloid treatments for early Alzheimer's disease



On 17 September 2024, Alzheimer Europe held a session of its popular online Alzheimer's Association Academy, with presentations from European and US experts, as well as questions from our member organisations. The session provided a detailed update on the current landscape of these therapies and their integration into clinical practice.

Angela Bradshaw, Director for Research at Alzheimer Europe, outlined recent regulatory developments and Alzheimer Europe's position, emphasising the need for clear communication of risks and benefits to support informed decision-making

by patients and families. She highlighted the importance of investment in healthcare infrastructure to ensure access to these therapies. Read the Alzheimer Europe position paper here:

<https://www.alzheimer-europe.org/resources/publications/anti-amyloid-therapies-alzheimers-disease-alzheimer-europe-position-paper>

Frank Jessen from the University Clinic Cologne (Germany), presented the position of the European Alzheimer's Disease Consortium (EADC) following the recent announcement that the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency (EMA) had issued a negative opinion on the marketing authorisation for lecanemab. This negative opinion was issued in July 2024, due to concerns that the observed benefits did not outweigh the risks, particularly due to serious adverse events like amyloid-related imaging abnormalities (ARIA). However, Frank Jessen emphasised that lecanemab and donanemab are significant milestones in Alzheimer's research, as the first antibodies to show clinical efficacy in early-stage Alzheimer's disease. He noted that these treatments are part of a broader Alzheimer treatment pipeline, which will likely evolve to focus on combination therapies and precision medicine. He also called for mandatory real-world data registries to monitor treatments and ensure the collection of comprehensive safety data. Read the EADC position statement here:

<https://link.springer.com/article/10.14283/jpad.2024.153>

Jason Karlawish from the Penn Memory Center, University of Pennsylvania (US), shared his experience in integrating anti-amyloid therapies into clinical care in the US. He stressed the importance of patient-centred approaches and rigorous monitoring of side effects, especially considering the risks associated with ARIA. He and his colleagues at the Penn Memory Center have established specialised teams to ensure that patients are carefully evaluated and supported during treatment. Jason Karlawish also emphasised the need for the US Food and Drug Administration (FDA) to develop a Risk Evaluation and Mitigation Strategy (REMS) for lecanemab, which would address safety concerns by establishing strict protocols for patient monitoring and care. Read more on the REMS discussion here:

<https://www.statnews.com/2023/06/16/the-fda-needs-a-risk-evaluation-and-mitigation-strategy-for-alzheimers-drug-lecanemab/>

These developments are particularly relevant for the European dementia community and patient associations, as equitable access to future therapies and a focus on precision medicine become critical priorities. Alzheimer Europe's next Academy session is scheduled to take place on 19 November 2024.

17 SEPTEMBER

European Working Group of People with Dementia welcomes new members and contributes to research initiatives



The European Working Group of People with Dementia (EWGPWD) convened its first meeting online on 12 September 2024, following membership renewals at the Alzheimer Europe (AE) Annual General Meeting on 18 June 2024. Ten returning members warmly welcomed four newcomers: Minna Kinnunen (Finland), Jan Runar Eliassen (Norway), Kjell Ehn (Sweden), and Gerda Van Tongerloo (The Netherlands). The new Chairperson, Kevin Quaid (Ireland) opened the meeting with a round of introductions.

The meeting focused on two key topics. First, the group provided feedback on the further development of the lay glossary for the European Platform for Neurodegenerative Diseases project (EPND). Some of the members of the EWGPWD had contributed towards the development of this extensive glossary which contains over 200 definitions of terms mainly related to data sharing/reuse, biomedical and psycho-social research methodology and neurodegenerative diseases and symptoms. The aim of the glossary is to help lay people understand information they receive or access when considering participating in research or consenting to the sharing/re-use of their data. Dianne Gove (Alzheimer Europe) asked the current members of the group for their views on the best way to involve them in the finalisation of the glossary, the future management and updating of the glossary and its possible translation into other languages.

Next, the group shared their perspectives on palliative care for dementia, contributing to the AI4HOPE project. This project focuses on improving palliative care delivery for people with dementia through digital health interventions for pain management, care planning, and education. Discussions covered various topics, including end-of-life care, emotional support and carer support. Alzheimer Europe staff members Ana Diaz, Dianne Gove and Sébastien Libert facilitated the discussion, while Sarah Campill and Soraya Bachiller documented key

points. These insights will inform an information sheet outlining recommendations, challenges and opportunities in palliative care interventions for dementia stakeholders.

Ana Diaz also briefed the group on their participation in the upcoming **Alzheimer Europe Annual Conference** in Geneva, scheduled for 8-10 October 2024. This conference presents a valuable opportunity for members of the EWGPWD to contribute further to dementia research and policy discussions. The new Vice-Chairperson, Lieselotte Klotz (Germany), concluded the meeting with closing remarks.

Overall, the first meeting marked a successful start, welcoming new members, contributing to research initiatives, and promoting active participation for the benefit of all people with dementia. The EWGPWD looks forward to continuing their mission at the AE conference in Geneva.

18 SEPTEMBER

Alzheimer Europe hosts online Company Round Table meeting

At its 18 September online Company Round Table (CRT) meeting, Alzheimer Europe welcomed industry representatives from Acument, Alzheon, BioArctic, Biogen, Bristol Myers Squibb, C2N Diagnostics, Eisai, Eli Lilly, MSD, Novo-Nordisk, TauRX and Terumbo BCT along with Alzheimer Europe (AE) staff and the chairs of both the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG).

Cindy Birck began with an update on the Clinical trial watch, a dementia-friendly online resource. She spoke about the 20 active phase II trials, 13 phase III trials in the CRT, plus 4 new studies, all of which are happening in at least one EU country. She then shared about the upcoming CRT supplement which will accompany the October newsletter.

Angela Bradshaw then presented the regulatory developments in anti-amyloid treatments, discussing the European Medicines Agency (EMA) and the UK's Medicines and Healthcare products Regulatory Agency (MHRA) decisions and shared AE's three priorities for the new position paper being drafted for the EMA Committee for Medicinal Products for Human Use (CHMP). She also shared highlights from the Academy meeting on 17 September where issues surrounding anti-amyloid treatments were discussed.

Jean Georges provided an update on Alzheimer Europe activities, projects and staffing changes, sharing the list of current research projects including new projects launched in 2024 AD-RIDDLE and A14Hope as well as three new projects beginning in 2025 - DORIAN GRAY, FluiDx-AD and PREDICTFTD. Jean Georges then continued with an overview of the 2025 Work Plan and AE's core activities, finishing off by presenting AE's sponsorship opportunities and corporate activities.

Owen Miller was up next to share EU policy developments and an overview of AE's European Parliament election campaign and its key components: the Helsinki Manifesto, 2024 Call to

Action, and the European Dementia Pledge, going on to share the re-establishment of the European Alzheimer's Alliance (EAA) which he said would launch on World Alzheimer Day on 21 September.

Ana Diaz then presented AE's work in public involvement in research and the opportunities for companies to work with the Public involvement pool that has been created. She explained the benefits of involving people with dementia and their caregivers in research and the role of the working groups in research. The meeting was moderated by Jean Georges, who thanked everyone for their contributions.

30 SEPTEMBER

940 delegates already registered for the 34th Alzheimer Europe Conference in Geneva!



We are very pleased to announce that we already have 940 registered delegates for the 34th Alzheimer Europe Conference (#34AEC), taking place in Geneva (Switzerland) next week. 34AEC will take place from 8 to 10 October, under the banner "New horizons - Innovating for dementia" and is a collaboration between Alzheimer Europe, Alzheimer Schweiz Suisse Svizzera and Alzheimer Genève. The closing date for late registrations is today, 30 September 2024. You can register, here: <https://www.alzheimer-europe.org/conferences/2024-geneva/online-conference-registration>

Meet the speakers

Find out who our keynote speakers are: <https://www.alzheimer-europe.org/conferences/2024-geneva/2024-keynote-speakers>

Check out our detailed programme: <https://www.alzheimer-europe.org/conferences/2024-geneva/detailed-programme>

Follow the event and engage on social media

Our event hashtag is #34AEC. You can use this hashtag in any posts about the event or to search for an engage with our posts and other social media users' posts before, during and after the conference.

See you in Geneva!

30 SEPTEMBER

Alzheimer Europe Board meets online



The Alzheimer Europe Board gathered for a meeting online, on 30 September 2024. Board members reviewed the association’s finances and welcomed the positive forecast for the 2024 accounts ending with a small surplus. They also reviewed financial regulations and the 2025 work plan,

and received an update on preparations for next week’s 34th Alzheimer Europe Conference, as well as other upcoming meetings.

Following the recent negative opinion on the marketing authorisation application for lecanemab given by the Committee for Medicinal Products for Human use of the European Medicines Agency, the Board has adopted a position paper written by Alzheimer Europe Director for Research Angela Bradshaw and Executive Director Jean Georges. The position will soon be published by the organisation.

Other items adopted by the Board include the sponsorship opportunities for 2025 and a memorandum of understanding with the European Alzheimer’s Disease Consortium. The next meeting of the Alzheimer Europe Board is scheduled to take place in Brussels on 9-10 December.

SPONSORS OF THE MONTH

Alzheimer Europe would like to express its gratitude to the following sponsors for its 2024 and 2025 activities:



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

AE NETWORKING

3 SEPTEMBER	Jean met with the EFPIA AD Platform
3 SEPTEMBER	Dianne attended the Urge to Act kick-off meeting
4 SEPTEMBER	Jean met with representatives of the US Alzheimer’s Association
6 SEPTEMBER	Lukas attended a meeting of the WHO European Region aiming at the implementation of the WHO Framework for Action on Health and Care Workforce
6-7 SEPTEMBER	Jean attended the 20 th Anniversary Conference of the Malta Dementia Society (St. Julian’s, Malta)
10 SEPTEMBER	Jean and Ana met with representatives of Fundació Pasqual Maragall
12 SEPTEMBER	The Alzheimer Europe Public Involvement team organised a consultation with the EWGPWD for AI4Hope and EPND
13 SEPTEMBER	The Alzheimer Europe Anti-Stigma Award Committee met
13 SEPTEMBER	Dianne and Sarah hosted the bi-monthly PREDICTOM WP6 meeting
16 SEPTEMBER	Jean met with the European Academy of Neurology
17 SEPTEMBER	Alzheimer Europe organised an Alzheimer’s Association Academy on “Anti-amyloid treatments – Approaches in Europe and the US”

17 SEPTEMBER	Jean met with Merck Sharp & Dohme
18 SEPTEMBER	Alzheimer Europe organised a company round table meeting with its industry sponsors
18 SEPTEMBER	Dianne and Sebastien met with the HOMEDEM Doctoral Network
18 SEPTEMBER	Sarah attended the monthly PREDICTOM WP1 meeting
19 SEPTEMBER	Owen attended the EU4Health Civil Society Alliance catch-up meeting
20 SEPTEMBER	Jean met with Grifols
20 SEPTEMBER	Dianne and Cindy attended the AI-Mind WP7 meeting on exploitation advances
21 SEPTEMBER	Alzheimer Europe Chairperson Rosário Zincke dos Reis gave a presentation at the International Congress on Neurodegenerative Diseases, about “People living with Alzheimer and Parkinson diseases: The patient at the centre of care and their involvement in research” (Lisbon, Portugal)
23 SEPTEMBER	Angela participated in an EC review meeting for the RECOGNISED project
23 SEPTEMBER	Sebastien attended the AI4HOPE WP2-3 joint meeting
24 SEPTEMBER	Jean, Angela and Ana met with Petra Ritter to discuss AE’s involvement in TEF Health
24-25 SEPTEMBER	Angela participated in an IHI interim review meeting for the EPND project
24-25 SEPTEMBER	Cindy attended the TClock4AD NT-3 Summer School on Public Engagement and dissemination (Milan, Italy)
26 SEPTEMBER	Angela participated in an interview with the Dutch Medicines Evaluation Board for a research project on biomarkers
26 SEPTEMBER	The Alzheimer Europe Public Involvement team organised an informative meeting with members of the EDCWG
26 SEPTEMBER	Lukas and Chris attended the SciCom Luxembourg 2024 event
27 SEPTEMBER	Jean and Gwladys met with The Alzheimer Society of Ireland to discuss the 2026 AE Conference
30 SEPTEMBER	The Alzheimer Europe Board met
30 SEPTEMBER	Owen attended a WHO Europe pre-RC74 side event “Harnessing the power of digital transformation for better mental health”
30 SEPTEMBER	Soraya attended the PANEUCARE consortium meeting
30 SEPTEMBER-1 OCTOBER	Dianne and Sarah attended the PREDICTOM consortium meeting (Erlangen, Germany)

Help us give a voice to people with dementia

Donate





EU PROJECTS

1 SEPTEMBER

eBRAIN-Health project convenes a virtual General Assembly meeting, with updates on technical developments, brain modelling and public outreach activities



eBRAIN-Health

Last month, the eBRAIN-Health project hosted one of its quarterly General Assembly meetings, which was attended by Angela Bradshaw (Director for Research) and Daphné Lamirel (Public Involvement Officer). These meetings, which bring together representatives of the 20 partner organisations in eBRAIN-Health, act as a forum for high-level updates from the various eBRAIN-Health workstreams.

The eBRAIN-Health project aims to create an infrastructure for the lawful and transparent sharing of brain data, with the goal of building virtual representations of the brain to improve research and clinical management for brain conditions such as Alzheimer's disease. AE is involved in several work packages of the project, conducting activities related to communication and dissemination, public involvement, and ethics.

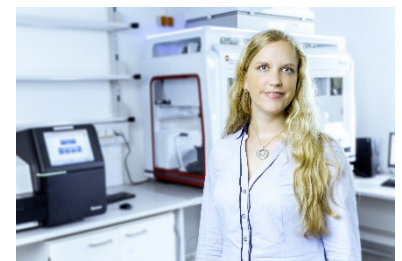
The Coordinator of the eBRAIN-Health project, Prof. Petra Ritter, started the meeting by presenting an overview of project progress. The leading partners of each work package presented updates on their activities, which encompass technical development of the eBRAIN-Health research platform, contracting and GDPR compliance work for clinical research data, and work on public outreach and involvement. Angela outlined

plans to present the eBRAIN-health project at the upcoming AE conference in Geneva, and Daphné detailed recent discussions from the eBRAIN-Health Patient and Public Advisory Group, which addressed the topics of consent and risk communication. Drawing the meeting to a close, Prof. Ritter thanked attendees for their active engagement and discussions. Learn more about the eBRAIN-Health project: <https://ebrain-health.eu/home.html>

3 SEPTEMBER

ADIS project shines a spotlight on early career researchers in an interview with Sarah Hücker

In this spotlight on early career researchers interview we talk with Sarah Hücker, Postdoc at the Fraunhofer ITEM-R Division Personalized Tumor Therapy in Regensburg, Germany.



She develops and automates methods that allow the **sequencing** of different nucleic acids (DNA, mRNA, miRNA, etc.) of single cells. In the ADIS project specifically, they search the transcriptome of peripheral blood immune cells for potential biomarkers of Alzheimer's disease.

Watch the recording here:

<https://vimeo.com/1005749830?share=copy>

11 SEPTEMBER

PROMINENT bridges European research communities to advance AI solutions tackling dementia



In a recent opinion piece published in “Dagens Medisin”, Hanneke Rhodius-Meester, a senior researcher at the Memory Clinic of Oslo University Hospital and Amsterdam UMC as well as PROMINENT project partner,

stressed that the necessary tools for improving dementia diagnosis are already here. While some suggest waiting for further technological advancements, such as AI-based solutions in development, Rhodius-Meester highlights that many advanced diagnostic tools are already being used in Europe.

Examples include tools like NeuroQuant, which automatically analyses brain MRI scans and has been used for years in Norwegian clinics, as well as ADappt and cNeuro, which have been successfully implemented in memory clinics across Europe. These tools predict the progression of dementia and differentiate between various types of the disease. cNeuro, in particular, has been integrated into global healthcare services and is now being implemented in Norway through the PROMINENT project.

Rhodius-Meester emphasises that instead of waiting for new technologies, Norway should connect more closely with larger European research communities, leveraging existing solutions to address dementia now. This approach will not only avoid delays but also ensure that healthcare practices align with cutting-edge developments across Europe.

The article is publicly accessible (in Norwegian), here: <https://www.dagensmedisin.no/vi-trenger-ikke-vente-to-ar-pa-en-norsk-ki-losning/651190>

18 SEPTEMBER

HOMEDEM students meet online with Alzheimer Europe to prepare their first consultation with the EWGPWD and the EDCWG



The HOMEDEM Doctoral Network, focused on optimising home environments for people with dementia, convened online on 18 September to prepare for their upcoming consultation with the Euro-

pean Working Group of People With Dementia (EWGPWD)

and the European Dementia Carers Working Group (EDCWG).

During this meeting, Dianne Gove, Director for Public Involvement and Ethics and Sebastien Libert, Public Involvement Officer from Alzheimer Europe met with HOMEDEM's PhD students to provide personalised feedback on their research projects. The students presented diverse topics, ranging from economic analyses of improving care autonomy to understanding feelings of home among people with dementia.

Based on the expert guidance, the students will develop consultation guides and methodologies to effectively engage EWGPWD and EDCWG members during the inaugural consultation in Brussels on 11 December 2024.

30 SEPTEMBER

Members of the Lethe Advisory Board met twice during September

The Lethe Advisory Board resumed its activities after the summer break and members met twice during the month of September. The first meeting took place on 19 September.

During this meeting, members received an update on the progress of the Lethe study at each clinical site (Austria, Finland, Italy, and Sweden). Participants also discussed how the feedback provided by members of the Lethe Advisory Board, over several meetings in the last years, has been used and has impacted different aspects and activities of the project. All the researchers present at the meeting reiterated the very valuable role of the Advisory Board in the project.

The second meeting took place on 30 September and during this meeting members provided feedback on the Brain Health Literacy Portal that the project is currently developing. Alzheimer Europe was represented at these meetings by Ana Diaz, Public Involvement Lead and Sébastien Libert, Public Involvement Officer.

Find out more about the project: <https://www.lethe-project.eu/>



EU project acknowledgements



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

The projects in this newsletter are:

eBRAIN-Health - grant agreement 101058516 (<https://www.ebrain-health.eu/>)

LETHE - grant agreement 101017405 (<https://www.lethe-project.eu/>)

Prominent - grant agreement 101112145 (<https://www.ih-prominent.eu/>)



The **ADIS** 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

MEMBERS OF THE EUROPEAN ALZHEIMER'S ALLIANCE

Currently, the total number of MEPs in the European Alzheimer's Alliance (EAA) stands at **75**, 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) and Hilde Vautmans MEP (Belgium, Renew Europe), 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:** Tomáš Zdechovský (EPP). **Denmark:** Kira Marie Peter-Hansen (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe). **Finland:** Merja Kyllönen (GUE/NGL). **France:** François-Xavier Bellamy (EPP); Mélissa Camara (Greens/EFA); Laurent Castillo (EPP); David Cormand (Greens/EFA); Marie Dauchy (PFE); Christophe Gomart (EPP); Catherine Griset (PFE); Céline Imart (EPP); Isabelle Le Callennec (EPP); Nadine Morano (EPP); Philippe Olivier (PFE); Mounir Satouri (Greens/EFA); Majdouline Sbai (Greens/EFA); Marie Toussaint (Greens/EFA). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Manuela Ripa (Greens/EFA); Terry Reintke (Greens/EFA). **Greece:** Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (PFE); Enikő Győri (PFE); Kinga Gál (PFE); György Hölvényi (EPP). **Ireland:** Barry Andrews (Renew Europe); Lynn Boylan (GUE/NGL); Nina Carberry (EPP); Luke 'Ming' Flanagan (NI); Billy Kelleher (Renew Europe); Aodhán Ó Riordáin; Maria Walsh (EPP). **Italy:**

Brando Benifei (S&D); Caterine Chinnici (EPP); Carlo Fidanza (ECR); Aldo Patriciello (PFE). **Lithuania:** Petras Auštrevičius (Renew); Vilija Blinkėvičiūtė (S&D); Dainius Žalimas (Renew). **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 (GUE/NGL). **Slovenia:** Matjaž Nemeč (S&D); Irena Joveva (Renew Europe); Vladimir Prebilič (Greens/EFA); Marjan Šarec (Renew); Milan Zver (EPP). **Spain:** Rosa Estaràs 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

21 SEPTEMBER

This World Alzheimer's Day, Alzheimer Europe is proud to relaunch the European Alzheimer's Alliance for the 2024-2029 term of the European Parliament

Alzheimer's and other types of dementia, as well as challenging the stigma that surrounds dementia, Alzheimer Europe is proud to relaunch the European Alzheimer's Alliance (EAA) bringing together 75 Members of the European Parliament (MEPs) from 21 countries and seven political groups.

The EAA, which has been active in the European Parliament since 2007, is a non-exclusive, multinational and cross-party group that brings together MEPs supporting the campaign of Alzheimer Europe and its members to make dementia a public health and research priority in Europe.

Alzheimer Europe is delighted to announce that Nina Carberry, MEP, (Ireland, European People's Party) and Tilly Metz, MEP, (Luxembourg, Greens/European Free Alliance) have agreed to become co-Chairs of the EAA. As Alzheimer Europe launches the new EAA for the 2024-2029 parliamentary term, we would like to say a huge thank you to all former members of the EAA for their support. See who they are:

<https://www.alzheimer-europe.org/policy/european-alzheimers-alliance/supporters>

For more information about the European Alzheimer's Alliance, including the names of the 75 MEPs who have joined so far, see the Alzheimer Europe website: <https://www.alzheimer-europe.org/policy/european-alzheimers-alliance/members>

European Parliament Dementia Day

Alzheimer Europe will organise the first edition of its European Parliament Dementia Day on 10 December 2024. On that day, representatives of national Alzheimer's associations and members of both the European Working Group of People with Dementia and European Dementia Carers Working Group will meet with their MEPs to give an update on the context of dementia at a national level and present Alzheimer Europe's call to see dementia recognised as a priority in the European Union health and research programmes, as well as in European social and disability policies.

At a lunch debate hosted by Tilly Metz, MEP on the same day, Alzheimer Europe will be providing an update for EU policy makers and civil servants on recent advances in the diagnosis and treatment of Alzheimer's disease. The association will also announce the winners of its third Anti-Stigma Award which will go to European journalists for news stories or documentaries addressing the stigma attached to dementia.

EU DEVELOPMENTS

1 SEPTEMBER

European Medicines Agency addresses patient engagement and clinical trial conduct at PCWP and HCPWP meetings



During the summer, Angela Bradshaw (Director for Research) joined a virtual meeting of the EMA Patients' and Consumers' Working Party (PCWP) and the Healthcare Professionals' Working Party (HCPWP). The first day was kicked off by Juan Burgos (EMA) and Marko Korenjak (European Liver Patients' Association),

co-Chairs of the PCWP, who welcomed online and in-person attendees to the meeting. Kaisa Immonen and Maria Mavris (EMA) started the meeting by providing an update on patient involvement in scientific advice procedures, and during the evaluation phase of medicines, with the CHMP. Kaisa outlined the methodologies that have been put in place to ensure that the patient voice is captured during the 'evaluation' phase of the medicine regulatory pathway. After a brief discussion on how experts are remunerated for their involvement in EMA activities, the agenda moved on to a presentation of how the EMA interacts with other regulatory agencies, focusing on the US FDA and the African Medicines Agency. Forums set up by the EMA to enable these interactions include the EMA-FDA patient engagement cluster and PCWP and FDA-CTTI Patient Engagement Collaborative (PEC), Maria Mavris explained. The final section of the PCWP meeting focused on the 2022-

2025 workplan for the Working Party, which has been refined following a survey addressed to the PCWP members.

The next day, a joint meeting of the PCWP and the Healthcare Professionals' Working Party was convened, by co-Chairs Juan Burgos, Marko Korenjak and Rosa Giuliani (European Society for Molecular Oncology). This joint meeting focuses on topics of particular relevance to both stakeholder groups, with a series of detailed, informative presentations from EMA colleagues. The first topic, which was presented by Melanie Carr (EMA), addressed the European Medicines Agency Network Strategy. This strategy, which has been extended to 2028 (from 2025), identifies shared goals, priorities and challenges for the Heads of Medicines Agencies (HMA; a network of national regulatory agencies) and EMA, guiding their collaborative work. Next came the member's voice section, where Francois Houyez of EURORDIS shared their analysis of medicines overviews from 179 CHMP opinions on medicines for rare diseases (issued between 2019-2023). Next, Mary McCarthy of the European Union of General Practitioners (UEMO) highlighted challenges for prescribing, and explained how more multidisciplinary collaboration could facilitate more effective prescribing of medicines by GPs.

After a short coffee break, the meeting reconvened with an EMA-led session on clinical trial activities, with presentations on the Clinical trials raw data pilot (by Frank Pétavy) and updates on the ACT EU and multi-stakeholder platform (Ana Zanoletty). Angela is a member of the Network Advisory Group on Raw Data, and provided brief reflections on stakeholder involvement through her work as part of this group. Dina Duarte (EMA) then spoke about an ongoing revision of the EMA guideline on Risk Assessment of Medicines on Reproduction and Lactation, presenting a concept paper that has recently been published. The final third of the meeting was dedicated to transparency activities and biosimilars. Francesca Scotti (EMA) presented the revised transparency rules for the Clinical Trials Information System (CTIS), which became available on 18 June 2024 with the launch of a new version of the CTIS public portal. Closing the meeting, Juan, Marko and Rosa thanked all attendees for their contributions and presentations, reminding attendees that the next meeting will be held in November. Access the agenda, meeting summary and presentations: <https://www.ema.europa.eu/en/events/european-medicines-agency-ema-patients-consumers-pcwp-healthcare-professionals-hcpwp-working-parties-joint-meeting-1>

13 SEPTEMBER

European Economic and Social Committee publishes social integration opinion

The European Economic and Social Committee (EESC) has published an Exploratory Opinion: "Promoting the social integration of persons with disabilities and persons with changed working capacity". The Opinion focuses on ways to help persons with disabilities enter the open labour market and better

implement the aims of the Disability Employment Package, published by the European Commission in 2022. Specifically, the EESC Opinion focuses on two topics:

- The social integration, complex rehabilitation and occupational rehabilitation of persons with disabilities and changed working capacity
- Launching an EU-level reflection around the need for reasonable accommodation.

The topic is in line with the priorities of the Hungarian Presidency in the social field, as the issue will be explored both through Council conclusions and during high level events. The exploratory opinion aligns with activities planned during the Hungarian Presidency and with the overarching presidency priority of addressing demographic challenges. The full opinion is available at: <https://www.eesc.europa.eu/en/news-media/press-summaries/promoting-social-integration-persons-disabilities-and-persons-changed-working-capacity>

16 SEPTEMBER

Civil society organisations sign open letter to EU leaders

Alzheimer Europe has joined with 415 other civil society organisations in signing an open letter, coordinated by Civil Society Europe, to key EU leaders, calling on them to commit to support and defend civil society organisations in the coming term.



The open letter is addressed to:

- Donald Tusk, for the upcoming Polish Presidency of the Council of the European Union
- Mette Frederiksen, for the upcoming Danish Presidency of the Council of the European Union
- Nikos Christodoulides, for the upcoming Cypriot Presidency of the Council of the European Union
- Roberta Metsola, President of the European Parliament
- Ursula Von der Leyen, President Elect of the European Commission.

The letter states that all European laws and policies should facilitate the actions of civil society without negative side effects. This involves conducting ex-ante fundamental rights impact assessments of all EU policies, incorporating intersectional evidence from diverse civil society to ensure policies support the exercise of fundamental rights.

Specifically, the signatories call for the following priorities for the next five years:

- A European Civil Society Strategy
- A strong mandate for a Commission Vice President responsible for democracy, civic space and dialogue with civil society
- Reinforcing intermediary bodies and adopting a Civil Dialogue Agreement
- Empowering Funding Policies

- A European Democracy Semester
- A stronger role of the Fundamental Rights Agency (FRA) as the European human rights institution.

The full letter is available at:

<https://civilsocietyeurope.eu/open-letter-ensuring-a-vibrant-civic-space-in-the-european-union-civil-societys-expectations-for-the-next-five-years/>

17 SEPTEMBER

European Commissioners-designate announced

President of the European Commission, Ursula von der Leyen, has announced the composition and structure of the College of Commissioners for the next five-year term. Of particular relevance for policy areas related to dementia are:

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

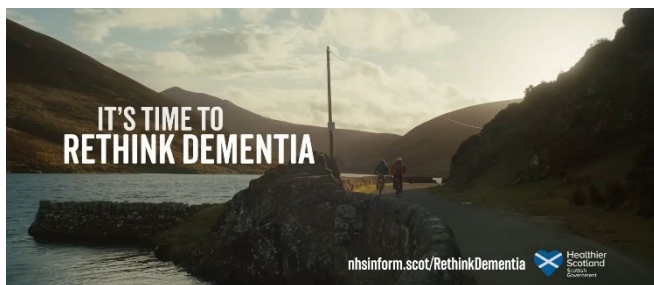
Each Commissioner-designate has also been given a Mission Letter, outlining the scope of the portfolio allocated to them. The Commissioners-designate will now undergo hearings, conducted by the European Parliament (EP), before a vote on the full College of Commissioners takes place at a future Plenary session of the EP.

The full list of Commissioners-designate and Mission Letters, are available at: https://commission.europa.eu/about-european-commission/towards-new-commission-2024-2029/commissioners-designate-2024-2029_en

POLICY WATCH

4 SEPTEMBER

Scottish Government launches national dementia campaign



The Scottish Government, in collaboration with the Convention of Scottish Local Authorities (COSLA), has launched a new campaign aimed at the public, encouraging people to

25 SEPTEMBER

EU4Health Civil Society Alliance publishes open letter to European Commission President Ursula von der Leyen

The EU4Health Civil Society Alliance (CSA) has published an open letter to European Commission President, Ursula



von der Leyen, expressing concern regarding the position of health within the priorities of the EU, following the announcement of the Commissioners-designate.

The letter notes that for health to be adequately addressed as a policy area, it requires a nominee with a relevant and appropriate background. Additionally, it stresses that the importance of health as a portfolio within the Commission, means that it must be approached in a manner which reflects the values of the EU.

Furthermore, the letter highlights that civil society organisations in the field of health play an important role in relation to the development and implementation of healthcare policy, which requires sustainable funding opportunities under the EU4Health programme, noting with concern, the lack of acknowledgement of these aspects within the Mission Letter to the proposed Commissioner for Health and Animal Welfare. As such, the EU4Health CSA demands a meeting with President von der Leyen to discuss these matters. The full letter is available at: <https://eu4health.eu/letter-to-ursula-von-der-leyen-on-the-appointment-of-a-health-commissioner/>

challenge their pre-conceived view of dementia. The “Rethink Dementia” campaign was launched on 4 September 2024, across TV, cinema, radio, press and digital media, supported by a PR campaign. The campaign aims to address the stigma around the illness, encouraging people to continue doing everyday activities with friends or relatives diagnosed with dementia. In addition, it highlights that research shows that including people with dementia in social activities can help them stay well for longer, as well as alleviating symptoms such as depression, anxiety and apathy. The film for the campaign can be viewed at: <https://www.youtube.com/watch?v=82cLVZaoskl&feature=youtu.be>

SCIENCE WATCH

16 AUGUST

Suicide risk in people with dementia: findings from a systematic review and meta-analysis

On 16 August, researchers from the UK published a systematic review and meta-analysis of prevalence and risk factors for suicide and dementia in the journal *Ageing Research Reviews*. The study highlights a significant concern for the mental health and well-being of people living with dementia, emphasising the need for tailored and targeted mental health as well as suicide prevention strategies.

The publication, which analyses 54 studies, found that people with dementia are at a higher risk of experiencing suicidal ideation, with a prevalence rate of 10%. The authors note that this is significantly higher than in the general population. However, the study found no significant difference in the risk of suicide attempts or deaths by suicide between those with and without dementia.

Furthermore, the researchers found that individuals with moderate dementia are more likely to experience suicidal ideation than those with mild dementia. In addition, younger people living with dementia were at an increased risk of death by suicide compared to older individuals. Also, men with dementia were found to be more likely to attempt and die by suicide than women.

Risk factors for suicide among people living with dementia include the stage of the disease, age as well as sex. These findings underscore the importance of integrating mental health support into dementia care, with particular attention to the unique risk factors that were identified. The scientists call for heightened vigilance and tailored interventions to mitigate the risk of suicide among people living with dementia.

The publication is open access and can be read here: <https://doi.org/10.1016/j.arr.2024.102445>

23 AUGUST

New study investigates the long-term effects of cholinesterase inhibitors in people with DLB



A new study, published in *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, suggests that cholinesterase inhibitors are beneficial for people with dementia with Lewy bodies (DLB). DLB is one of

the most common types of dementia. There is currently no

cure for DLB but there are treatments that can help control some of the symptoms such as cholinesterase inhibitors.

In the published study, the research team from the Karolinska Institutet in Sweden conducted an observational study aiming to investigate the long-term effects of cholinesterase inhibitors and memantine, assessing their impact on cognition, major adverse cardiovascular events and mortality in people with DLB. The study used data from 1.095 people with DLB from the Swedish Registry on cognitive/dementia disorders.

Findings showed that the use of cholinesterase inhibitors, particularly two types called donepezil and galantamine, significantly slowed cognitive decline over a 5-year follow-up period when compared to both memantine treatment or no treatment. No difference in major adverse cardiovascular events was seen for the treatment groups. There was also an association observed for cholinesterase inhibitors use with a lower risk for death in the first year after DLB diagnosis, but this effect was not sustained after 1 year in people with DLB.

The authors discussed the potential cognitive benefits of cholinesterase inhibitors in people with DLB and noted that further research is necessary to better elucidate the underlying mechanisms and the long-term outcomes.

<https://doi.org/10.1002/alz.14118>

3 SEPTEMBER

Athira Pharma announces results from Phase 2/3 LIFT-AD trial for mild to moderate AD

On 3 September, Athira Pharma, a late clinical-stage biopharmaceutical company focused on developing small molecules to restore neuronal health and slow neurodegeneration, announced top-line results from its Phase 2/3 LIFT-AD clinical trial of fosgonimeton in people with mild-to-moderate Alzheimer's disease (AD). The LIFT-AD trial was a randomised, placebo-controlled and double-blind study that evaluated the efficacy and safety of fosgonimeton. 312 people with mild-to-moderate AD received once-daily subcutaneous injections of either fosgonimeton or placebo during 26 weeks.

The company reported that the study failed to meet its primary endpoint, which was the change from baseline after 26 weeks of treatment using the Global Statistical Test (GST), a combination of results from measures of cognition (ADAS-Cog11) and function (ADCS-ADL23). The topline results also showed that the trial did not meet its key secondary endpoints of cognition (ADAS-Cog11) and function (ADCS-ADL23). In a pre-specified subgroup analyses of participants with moderate AD



or who were APOE4 carriers, fosgonimeton showed a numerically greater treatment effect in clinical outcomes compared to placebo. In addition, data across biomarkers of protein pathology (A β 42/40, p-Tau181, and p-Tau217), inflammation (GFAP) and neurodegeneration (NfL) showed directional improvements with fosgonimeton treatment versus placebo after 26 weeks.

The drug was generally well tolerated, with a favourable safety profile. Full analysis of the results is planned to be presented at the 17th Annual Clinical Trials on Alzheimer's Disease (CTAD) taking place on 29 October-1 November, in Madrid, Spain.

<https://investors.athira.com/news-releases/news-release-details/athira-pharma-announces-topline-results-phase-23-lift-ad>

3 SEPTEMBER

Monitoring solution for Amyloid-Related Imaging Abnormalities in Alzheimer's disease approved for market



On 3 September, icometrix published information about the market approval of a monitoring solution for amyloid-related imaging abnormalities in Alzheimer's disease. The approval covers several regions, including Europe, Israel, Japan, Switzerland, and the United Kingdom.

The need for this monitoring solution comes from the potential side-effects of the novel disease-modifying therapies for Alzheimer's disease, which include specific brain abnormalities known as Amyloid-Related Imaging Abnormalities (ARIA). ARIA can lead to severe neurological complications. Although these abnormalities can be identified through brain MRI scans, detecting and assessing the severity of ARIA is a complex, time-consuming, and challenging process.

The approved solution utilises Artificial Intelligence-based algorithms to detect and measure ARIA on brain MRI scans. It provides assessments for both ARIA subtypes: ARIA-E (edema/oedema) and ARIA-H (haemorrhage).

Validation studies have demonstrated that the solution offers significant benefits for radiologists. It improves reading performance, reduces the time required to assess ARIA, enhances agreement between readers on ARIA severity, and increases diagnostic accuracy. These improvements are beneficial for both general and specialised radiologists, according to the company. Further information:

<https://icometrix.com/resources/icometrix-is-proud-to-announce-the-market-approval-of-icobrain-aria>

4 SEPTEMBER

New study explores the role of social contact for dementia risk

Contact with others has been proposed as protective against cognitive decline and dementia. This has also been underlined by the recently published report of the Lancet Commission on Dementia Prevention, Intervention and Care, suggesting that a substantial proportion of dementia cases can be attributed to social isolation. Social contact is complex and it is not yet clear, which aspect represent the most suitable targets for risk reduction.

A recent study by the Alzheimer Centrum Limburg published in the journal Psychological Medicine aimed to examine how different social contact factors are interrelated and which ones are most predictive of dementia risk. For this, the team of researchers analysed data of more than 7500 participants of the English Longitudinal Study of Ageing (ELSA), who were followed up between 2004 and 2019. Information regarding various aspects of social contact collected in 2004 was used to identify distinct social factors. This included information about the size of a person's social network, the frequency of engagement in social leisure activities, but also feelings of loneliness and perceived social support.

The authors found that higher frequency and quality of contact with the respondents' children (among those who have children) and more frequent social leisure activity engagement were associated with a lower risk of dementia. Conversely, those reporting more negative experiences of social support (e.g., frequently being disappointed by one's social network) and higher levels of loneliness had a higher risk of developing dementia. Additional analyses suggested that these factors may be linked to dementia through their connection with depressive symptoms.

Previous studies suggest that social contact may protect against dementia by building up cognitive reserve or buffering stress. Findings from this study suggest that symptoms of depression may represent an additional psychological link.

"Besides raising awareness and promoting social contact on an individual basis among the general public, we should also target external barriers keeping people from engaging in a socially active lifestyle" Lukas Duffner, lead author of the publication, says.

The full study can be read (open access) here:

<https://www.cambridge.org/core/journals/psychological-medicine/article/social-relationship-factors-depressive-symptoms-and-incident-dementia-a-prospective-cohort-study-into-their-interrelatedness/22F46E300ADBCF90361ED76B565619CA>

6 SEPTEMBER

Childhood dementia: A case study on the effect of psychosocial interventions on behaviour and psychological symptoms



In a recent paper, Mustafa Atee, Ineka Whiteman, Rebecca Lloyd and Thomas Morris look deeper into two cases of childhood dementia (Sanfilippo syndrome and CLN3 Batten disease), which are rare, fatal neurodegenerative disorders, that can develop in childhood or adolescence. With their paper, the research team aimed to address the gaps in the literature and clinical experience regarding psychosocial interventions for managing behaviours and psychological symptoms of dementia in childhood dementia.

In their study, the researchers describe the implementation of multimodal person-centred psychosocial interventions and their effectiveness in alleviating behaviours and psychological symptoms in childhood dementias based on two cases. The research team found that physical and verbal aggression, irritability, and lability seem to be primary behaviours and psychological symptoms of dementia in childhood dementia. Moreover, those behaviours and symptoms seem to be affected by factors such as pain, caregiver approach, and environmental stimuli. After the implementation of multimodal person-centred psychosocial interventions, such as sensory stimulation or structured routines, significant improvements in behaviours and psychological symptoms of dementia, as measured by the Neuropsychiatric Inventory-Questionnaire and qualitative feedback from caregivers, were observed. The interventions seem to be effective in reducing irritability and aggression, highlighting their potential benefits in managing behaviours and psychological symptoms of dementia.

The study was published in *Palliative Care & Social Practice*. To learn more about the paper follow the link: [Behaviours and psychological symptoms of childhood dementia: two cases of psychosocial interventions - Mustafa Atee, Ineka Whiteman, Rebecca Lloyd, Thomas Morris, 2024 \(sagepub.com\)](https://doi.org/10.1186/s40900-024-00623-w)

6 SEPTEMBER

Study explores family carers' motivation to join a Strategic Guiding Council in dementia research

On 6 September, a team of researchers published a study in *Research Involvement and Engagement*. The publication examines the involvement of family carers in dementia research through a



Strategic Guiding Council (SGC) created for a Family Carer Decision Support (FCDS) study. The SGC, which comprises of family carers from Canada, Ireland, the UK, the Netherlands, and the Czechia, was established to inform the design and implementation of the FCDS intervention. This intervention focuses on supporting family carers in making end-of-life care decisions for individuals with advanced dementia.

The team explored the motivation of ten family carers to participate in the SGC as advisors. For this, they conducted semi-structured interviews and did a thematic analysis of the transcripts. Key findings highlight three main themes: reciprocal learning, using lived experience to support other carers, and advocating for change in dementia care.

The study concludes that family carers were motivated to join the SGC to help others navigate the healthcare system, provide psychosocial support, and advocate for better access to end-of-life care. Their participation allowed them to share their experiences, engage in advocacy, and learn from health professionals as well as fellow carers. The article is open access and can be read here:

<https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-024-00623-w>

19 SEPTEMBER

New report from the STRAP consortium identifies priorities for research on the impact of COVID-19 restrictions on people affected by dementia



A new international report, funded by the Canadian Institute for Health Research (CIHR) through the European Commission's Joint Programme on Neurodegenerative Disease Research (JPND) funding scheme, has been released, outlining key research priorities

that address the impact of COVID-19 control measures on people with dementia and their care partners living at home. This 14-country perspective aims to define a comprehensive research strategy to improve policies and support systems in future crises, focusing on Europe and the Global South.

The report, entitled "Strategizing Transdisciplinary Research Priorities Around the Impact of COVID-19 Control Measures on People with Dementia and Care Partners Living at Home: A 14-Country Perspective", highlights the urgent need for research that informs how people with dementia and their care partners can be better supported during public health emergencies. The primary goal of the report was to identify research priorities in response to the challenges faced by people with dementia and their care partners due to COVID-19 restrictions. By involving stakeholders from 14 countries, the report defines a research strategy that can drive policy improvements and ensure appropriate support in future crises.

The report is based on findings from a systematic literature review, online survey and stakeholder consultation process. In total, 29 people with dementia, 110 care partners, and 117 healthcare professionals were involved in the survey, which was distributed across 14 countries in Europe, South America, Africa and Asia. The top 10 research priorities identified by stakeholders across all regions and groups clustered together in four themes, spanning physical health and daily routine; mental health; disease progression; and impact on carers. These priorities reveal common concerns about the worsening health and well-being of people with dementia during the pandemic and highlight the urgent need for better support structures and communication about available care resources. The

report also emphasises that future research is essential to prevent accelerated decline during public health crises, calling for improved strategies to ensure that people with dementia and their care partners are better informed, reducing stress, anxiety, and the care burden they experience.

Read the report, here: <https://www.gbhi.org/news-publications/strap-strategizing-transdisciplinary-research-priorities>

27 SEPTEMBER

A recent study suggests that cognitively stimulating leisure activities may slow cognitive decline in older adults with Mild Cognitive Impairment



Cognitive impairment is a common health problem with an increasing occurrence rate. People diagnosed with Mild Cognitive Impairment (MCI) are likely to progress to dementia and have a greater risk of decline in cognition than cognitively healthy individuals. Although research has shown that non-pharmacological interventions, including leisure activities (such as crosswords, puzzles, reading, playing a musical instrument and learning new skills), are associated with better cognitive function over time, the benefits of such activities in postponing or preventing cognitive decline among older adults with MCI based on different levels of participation are still unknown.

In a recent study published in the Journal of Cognitive Enhancement, a team of researchers led by Dr Jungjoo Lee from the University of Southern Mississippi, Texas A&M University and Indiana University (US), investigated the effects of different levels of cognitively stimulating leisure activities (CSLA) participation on three cognitive functions (i.e. memory, working memory, and attention and processing speed) among older adults with MCI. This longitudinal research used data from the Health and Retirement Study (HRS) core from 2012 to 2020. The HRS is a household-based survey, administered biennially, that contains information about aging among older adults aged 45 to 90 from the US. A total of 5,932 older adults with MCI with ages ranging from 50 to 109 years old (58.5%

females and 41.5% males) were included in this study which merged data from the 2012 to 2020 HRS to obtain CSLA participation over 8 years. Then, researchers subdivided the total amount of CSLA participation into three groups (i.e. the low, mid and high-level CSLA participation). The high-level CSLA participation group consisted of individuals who reported a higher frequency of CSLA participation compared to the other two groups.

Researchers found that the high-level CSLA participation group had the highest mean memory compared to the low and mid-level groups and had also the highest score in working memory over the period analysed. Regarding attention and processing speed, the gaps between the three groups were the largest and only the high CSLA participation group kept similar attention and processing speed levels consistently from 2012 to 2020.

Although this study shows some limitations, such as the lack of comparison between older adults with MCI and younger adults with MCI, or the lack of consideration of the different types of MCI, it seems that engagement in higher levels of CSLA (at least three to four times a week) increased memory, working memory, and attention and processing speed levels in older adults with MCI compared to the low and mid-level CSLA participation groups. More research is needed to design and implement effective CSLA programs for older adults with MCI and to overcome the barriers to CSLA participation among this population.

[A Longitudinal Analysis of the Relationship Between Different Levels of Cognitively Stimulating Leisure Activity and Cognitive Function Among Older Adults with MCI | Journal of Cognitive Enhancement \(springer.com\)](#)

SPOTLIGHT ON WORLD ALZHEIMER'S DAY / MONTH

12 SEPTEMBER

Confederación Española de Alzheimer y otras demencias (CEAFA) presents a set of demands agreed by its member organisations for World Alzheimer's Day



The Confederación Española de Alzheimer y otras demencias (CEAFA) produced a document of claims, i.e. a set of demands that have been agreed by the member organisations at a working meeting held earlier this year (in April) and that respond to the

global and shared approach of all the organisations that make up the Confederation.

These claims are as follows:

- The singularity and specificity of dementia should be recognised
- The right of people to receive early and accurate diagnosis should be recognised
- The right of access to current and future treatment should be recognised
- The Dependency Law must be deeply revised
- The network of associations that make up CEAFA should be considered a privileged ally in the fight against Alzheimer's and in promoting the quality of life of people affected by the disease.

The claims can be found in this [document](#) and also in a short [video](#)

On 12 September, the conference "Somos específico@s" (We are specific) was organised in the Municipal Auditorium of Guardo (Palencia), where the President of CEAFA, Maria Dolores Almagro, presented the main claims. This year the event was held in a small town of less than 6,000 inhabitants:

"The choice of this town is a recognition of the work of the association, but also of the people affected by Alzheimer's or other types of dementia who live in rural areas. This year, as we claim our specificity, we wanted to go a step further, not only to report these situations, but to come here to tell the country that rural areas also exist, that they want attention and that their inhabitants deserve access to the resources they need", said Maria Dolores Almagro.

The event was attended by experts from the health and social fields, as well as a member of CEAFA's Panel of Experts on People with Alzheimer's, who reflected on and discussed the importance of the specificity of the disease in order to guarantee the rights of people affected by Alzheimer's disease. For further information:

<https://www.ceafa.es/es/que-hacemos/dia-mundial-del-alzheimer/dia-mundial-del-alzheimer-2024>

17 SEPTEMBER

A debate on "Attitudes around dementia and human rights" was organised in Lithuania during World Alzheimer's Month to help draw attention to the stigma surrounding dementia

The discussion was organised as part of the World Alzheimer's Month programme and in connection with the photography exhibition "Step into my shoes". The event aimed to draw attention towards stigma that surrounds dementia in Lithuania. The discussion panel consisted of Monika Ošmianskienė, Member of the Lithuanian Parliament, Ingrida Žurlytė, Head of the World Health Organization (WHO) office in Lithuania, Ieva Petkutė, founder and head of Dementia Lithuania, Vida Stokienė and Viktorija Šimanauskienė, family carers, and Austėja Dapkutė, neurology resident. The moderator of the discussion was Žydrė Gedrimaitė.

The newest Alzheimer's Disease International (ADI) World Alzheimer Report, on attitudes around dementia, highlights the systemic gaps that have a direct impact on the health and well-being of people living with dementia and their carers in Lithuania. For example, the report highlighted that a mere 25% of the carers in Lithuania think that there is a sufficient amount of care services accessible to them in their community. This is among the lowest rate in Europe. In addition, the report revealed a worrisome tendency in attitudes considering the rights and the voice of people living with dementia, these are all some of the highest rates in Europe: 75% of carers (and over 80% of the general public) think that family responsibilities should be removed from the person living with dementia; 66% of carers feel that their loved one was ignored by health professionals; 35% of the public in Lithuania think that moving a family member with dementia into a care home, even against their wishes, would be the best option.



The participants of the discussion "Attitudes around dementia and human rights" shared insights about the current situation from different perspectives. Ieva Petkutė highlighted the need to develop cohesive and cross-sectorial systems to address the numerous challenges. Monika Ošmianskienė, stressed the responsibility of civil society to be vocal about the situation and the need for change before the upcoming Parliament elections in October. Vida Stokienė and Viktorija Šimanauskienė shared their experience of receiving services and the challenges caused by the prevalent attitudes among the public. Austėja Dapkutė shared her ideas and insights about the attitudes in the health care system and certain factors that enable these attitudes to prevail in the system, when training doctors. Finally, Ingrida Žurlytė reminded those present that Lithuania has been offered guidance by the WHO to create a dementia plan that would serve all: people living with dementia and their carers, family members, professionals and the wider public.

Pictured: Ieva Petkutė (Dementia Lithuania) takes part in the discussion. Photo by Dainius Stankus

20 SEPTEMBER

Alzheimer Poland co-organises annual conference on dementia and marks World Alzheimer's Month with several events



On 20 September, Alzheimer Polska (Alzheimer Poland) co-organised an annual conference on dementia, which took place at the Office of the Human Rights Commissioner. For the first time, the event was opened by a person living with Alzheimer's disease, called Jolanta. During three thematic panels the most important questions on carers' and medical support, available or needed, from the State were discussed. One of the panellists, Małgorzata Michalska, who represented the Ministry of Health, confirmed that the Polish Strategy for Dementia 2025-2030 has been prepared by the Ministry and would soon come into force.

This year, several events around World Alzheimer's Month took place in Poland. One of them was an exhibition of paintings by Anna Rendecka shown at the Zacheta Gallery in Warsaw. Her paintings were made in cooperation with the Warsaw Alzheimer's Centre, whose residents had been an inspiration to present faces of dementia on canvas. The exhibition entitled "Vanishing" is an attempt to express in an artistic way a process of memory impairment and to create space for discussion on the consequences.

20 SEPTEMBER

Serbian Society for Alzheimer's Disease (SUAB) hosts public forum on World Alzheimer's Day

On 20 September, in order to mark World Alzheimer's Day, the Serbian Society for Alzheimer Disease (SUAB), held a Public Forum with members of SUAB, professionals working with people with dementia and their families, and members of the general public. The event was opened by Nevena Dodić, Deputy President of the Stari Grad Municipality, who highlighted the efforts made to support senior citizens. The Deputy Ambassador of Spain, Darío Otero Castro, also attended the event to support SUAB's work, and Vera Kondev, a retired



journalist living with dementia, thanked him on behalf of those living with dementia.

Dr Aleksandra Miličević Kalašić from the Institute for Gerontology spoke about the importance of early diagnosis, recognising the symptoms and managing dementia risk factors. Slavica Stuparušić, a journalist from national newspaper "Politika" and daughter of a mother with dementia, shared her experience of her mother's early symptoms, family denial, and the negative effects of prescribed benzodiazepines. She emphasised the importance of early diagnosis and appropriate medication, also discussing the financial strain: "We spend 10,000 to 15,000 dinars monthly for diapers and medication, as my mother doesn't qualify for insurance-covered diapers because she's mobile."

Slavka Nikolić from the City Centre for Social Work discussed the rights on social protection, focusing on procedures for home assistance and placement in public old-age care homes. Ljiljana Nestorović from the association "Bread of Life" stressed the importance of their support programme for people living with dementia and their families. Nadežda Satarić, the president of SUAB, highlighted her organisation's advocacy efforts and the work of members of the "Network Humanus" to improve the position of people with dementia and their families, calling for a national strategy for dementia and urging local governments to provide support services. She also emphasised the need for dementia awareness and stigma reduction.

Family members shared their stories, emphasising challenges and lack of support from social services and sharing their experiences openly, which has previously been a rare occurrence in Serbia. Also at the event, findings from the World Alzheimer Report 2024 were shared by Alzheimer's Disease International (ADI). The event concluded with music from the "Bread of Life" association, to highlight the importance of social activities for dementia prevention.

21 SEPTEMBER

Association Luxembourg Alzheimer organises its 23rd Memory Walk on World Alzheimer's Day

On 21 September, on World Alzheimer's Day, the Luxembourg Alzheimer Association (ALA) organised its 23rd Memory Walk on Place Clairefontaine in Luxembourg City. From 11.00 to 17.00, visitors were able to find out about the ALA's services, Alzheimer's disease and other forms of dementia at the information stands. In a relaxed atmosphere, they had the opportunity to meet great people and take part in numerous discussions. In addition to the food stands, various activities took place, including a Jukebox concert, music with Les Brasseurs and a concert by MIL-Chouer, an inclusive choir bringing together people with and without dementia. The "walk" allowed participants to show their solidarity with people living with dementia. This walk, accompanied by a tour guide, took participants to Place Guillaume II, the Grand Ducal Palace and the Chamber of Deputies.

The theme of this year's Memory Walk was "A thought for those who forget". In the world of the ALA, "Conversations fragment, words escape, and memories fade... Dementia is a condition that slowly and silently erodes memories, altering the perception and personality of those affected. We must cultivate a society where people with dementia are not marginalised, but included and valued. To this end, the concept of the thought (the flower) was used in different forms: in the form of stickers with which people were able to show their solidarity with people with dementia, but also as decoration at the Memory Walk and as a small gift for visitors to our residential and care home in Erpeldange-sur-Sûre. Mr Max Hahn, Minister of Family, Solidarity, Living Together and Reception, and Mrs Martine Deprez, Minister of Health and Social Security also honoured us with their presence, as did our colleagues from Alzheimer Europe."



21 SEPTEMBER

Alzheimer Europe attends Association Luxembourg Alzheimer Memory Walk on World Alzheimer's Day



We were delighted to attend the 23rd annual Memory Walk organised by our colleagues at Association Luxembourg Alzheimer (ALA) on 21 September, marking World Alzheimer's Day. Alzheimer Europe was represented at the event by Jean Georges, Executive Director, Christophe Bintener, Project Communications Officer, Kate Boor Ellis, Director for Communication and Policy, Angela Bradshaw, Director for Research, Lukas Duffner, Project Officer, and Dianne Gove, Director for Public Involvement and Ethics.

21 SEPTEMBER

Alzheimer's and dementia associations in Montenegro join associations around the globe to raise awareness about dementia on World Alzheimer's Day



On World Alzheimer's Day, Alzheimer's and dementia associations raise awareness among citizens about dementia and the psychosocial support they can receive. They do this through public actions on the streets of cities and in institutions. Currently, in Montenegro, volunteers and psychologists are providing psychosocial support and counselling to individuals with dementia and their families aimed at improving the quality of life for those affected by the disease, in eight Montenegrin municipalities.

Each year in September, Alzheimer's and dementia associations, along with everyone involved in the treatment, care, and support of people living with dementia and their caregivers, unite around the world and become part of an international campaign to raise awareness about dementia and to challenge stigma. There are currently estimated to be over 55 million people worldwide living with dementia and the number of people affected is set to rise to 139 million by 2050, with the greatest increases in low and middle income countries, according to Alzheimer's Disease International (ADI). The Institute Circle (author of this article) and NGO Impuls are working to try to prevent dementia in Montenegro.

21 SEPTEMBER

Swedish award for "Dementia Team of the Year" goes to Demenscenter in Linköping, on World Alzheimer's Day



The Demenscenter in Linköping (Sweden) received Demensfondens new "Dementia Team of the Year" scholarship of SEK 50,000 (Swedish krona, equivalent to just over EUR 4,400) to be used for continued skills development. The scholarship aims to draw attention to a multi-professional dementia team/cognitive team and contribute to spreading good examples in Sweden. Demensfondens is very motivated because their multi-professional teamwork with collaboration in the municipality and region has shown that there are opportunities for working methods that provide good support to people with dementia and their relatives through the course of the disease. The Dementia Fund received 36 applications. Members of the association board with experience and skills such as dementia nurses and former Medically Responsible Nurses ("Medicinskt Ansvarig Sjuksköterska") have assessed all applications. "It was not easy to choose one of so many valuable initiatives and good working methods. Despite such different conditions that exist around the country, the teams have managed to find ways of working that provide good support for people with dementia and their relatives. It gives hope for the future," says

Liselotte Björk, Chairperson of Demensförbundet, the Swedish Dementia Association.

The scholarship will be used for continued skills development and will be used within one year. It was presented on World Alzheimer's Day on 21 September. Demensfonden is one of the most important research funds for research on nursing and dementia in Sweden. Since it was founded in 1994, Demensfonden has supported research projects at Swedish universities and colleges. Demensfonden is managed by Demensförbundet and controlled by the Swedish Fundraising Control.

21 SEPTEMBER

The Alzheimer Society of Ireland spotlights key research news during World Alzheimer's Month



As part of World Alzheimer's Month, The Alzheimer Society of Ireland (The ASI) co-hosted a public event with Dementia Research Network Ireland (DRNI), which aimed to break down the science of dementia. The ASI was blown away by the reaction to the 'Science of Dementia for the Non-Scientist' event. The day was packed with incredible speakers from several disciplines who shared their expertise in an accessible way, alongside a fantastic PPI (Patient and Public Involvement) panel who brought the lived experience of dementia to the fore.

The ASI commends the speakers, panellists and team behind the scenes for their hard work and effort as part of the event. The organisation also extends a special thank you to Keynote Speaker Professor Ian Robertson. A wonderful collaboration with the team at DRNI, The ASI looks forward to the next event. The 'Science of Dementia for the Non-Scientist' event was made possible with funding from Health Research Board Conference and Events Sponsorship Scheme.

Walking the Talk for Dementia

The ASI was proud to support John and Kathleen from its Research PPI Panel, The Dementia Research Advisory Team, to attend an immersive week-long conference 'Walking the Talk

for Dementia' set against the backdrop of El Camino de Santiago. John and Kathleen were joined by Dr Laura O'Philbin (Research & Policy Manager). This experience brought together over 70 walkers from 30 different countries living with or working in different aspects of dementia - all determined to make a positive difference by tackling the most challenging and inspiring topics. Since this experience, The ASI has been a proud collaborator on a global anti-stigma campaign that was launched on World Alzheimer's Day. You can view the campaign [here](#).

21 SEPTEMBER

The Serbian Association for Alzheimer's Disease declares that it is time to act on dementia in Serbia!

The Serbian Association for Alzheimer's Disease (SUAB), together with its members, people with dementia and their families, conducted a World Alzheimer's Day campaign, in



line with the campaign of Alzheimer's Disease International (ADI). They petitioned the Institute of Public Health of Serbia and the City Institute of Public Health Belgrade to include World Alzheimer's Day in their event calendars.

Additionally, they proposed to the mayors of major cities in Serbia to illuminate in purple public buildings, bridges, and fountains on the night between 21-22 September and the initiative was accepted. Many interviews and appearances in the national media (25 events) followed, along with posts on SUAB's social media and those of its members.

On 20 September, SUAB also published the following public statement: "We lack day care centres and respite accommodation, support groups, counselling, educational workshops for people with dementia and their families as well as systematic education for healthcare professionals."

A family member caring for a person with dementia cannot receive more than one week of sick leave per year in Serbia, nor does an employed family carer have the option of working part-time. Access to financial support for home care is difficult and there are no permanent or temporary vacancies available in public health care and old-age care institutions. Therefore, SUAB called on the Government of the Republic of Serbia, local governments, and individuals "to recognise the urgency of the situation and take decisive measures to raise aware-

ness and reduce stigma, which remains an obstacle to diagnosis, treatment, care, and support for people with dementia and their families.”

21-22 SEPTEMBER

France Alzheimer organised its second edition of MEMORUN to mark World Alzheimer’s Day

On World Alzheimer’s Day this year, France Alzheimer organised the 2nd edition of its MEMORUN, a race committed to supporting those living with dementia and their caregivers. This event was also an opportunity to promote the benefits of physical activity and to mobilise the general public around this major public issue, at a time of political uncertainty and clear political inertia concerning neurodegenerative diseases.



The Ambassador of the event, three-time Olympic gold medalist Marie-José Pérec (pictured), stayed the whole weekend to support the runners, give out the medals and raise awareness during this sportive and festive event. The participation more than doubled since last year, demonstrating a great enthusiasm for the event. Participants, who had the choice to walk or run (a race of 1 km for children, a race of 5 km or 10 km for adults, or a walk of 5 km), were very happy to support the cause, they took the time to talk to the volunteers and asked question about dementia.

The Alzheimer Village, on the race site in the park of Vincennes, also used the occasion to:

- welcome runners and the general public
- provide information about the disease, its risk factors and risk reduction
- enable people living with dementia and their caregivers to participate in a friendly event and share their experience
- allow everyone to try adapted physical activities, surrounded by volunteers and professionals.

More than 2,300 runners took part in the 10 km race and 15 companies registered teams to participate.

22 SEPTEMBER

The Alzheimer Society of Ireland raises vital funds and awareness with Memory Walk and special film screening



The Alzheimer Society of Ireland (The ASI) marked the culmination of World Alzheimer’s Month with significant fundraising and awareness efforts. On 22 September, communities across Ireland came together in 40 different locations to participate in The ASI’s 5th annual Memory Walk. This event honours and celebrates people living with dementia and their families. With over 4,000 participants, the 2024 Memory Walk became the biggest one yet. Malahide, Co. Dublin saw the largest turnout, with more than 300 walkers.

Speaking ahead of the event, Mairéad Dillon, Head of Fundraising for The ASI, said: “We are thrilled with the number of participants registered for this year’s Alzheimer’s Memory Walk. This is set to be our largest event yet, and the funds raised today will make a real difference in the lives of people living with dementia and their loved ones.”

World Alzheimer’s Day on 21 September saw the special screening of “Don’t Forget to Remember”, to raise funds for the ASI. Directed by Ross Kileen, this heartfelt documentary follows the artist Asbestos and his parents, Helena and Matt, as they navigate Helena’s dementia journey. Members of the Dementia Carers Campaign Network, an advocacy group supported by The ASI, shared their personal experiences during the early stages of the film’s creation.



World Alzheimer’s Month, and every month thereafter, serves as a reminder of the resilience and strength of those affected by dementia. The Alzheimer Society of Ireland remains committed to supporting them and their families in every possible way.

23 SEPTEMBER

PROMINENT launches World Alzheimer's Day campaign about enhancing dementia diagnosis with AI and patient-centred care

“I think individualised printouts are exceptionally helpful because when a person gets a diagnosis it can be a lot to take in and may be left wondering did they forget anything that the doctor said. This way they can read it back in their own time and it might give them the assurance that they need and make it easier on them to explain it to their loved ones.”

Kevin Quaid
Member of the PROMINENT
Public Involvement board

The Innovative Health Initiative-funded PROMINENT project is advancing the use of AI to assist clinicians in diagnosing cognitive impairments with greater precision, thereby improving care for patients. By focusing on patient-centred approaches, the project aims to provide clearer, personalised information to those affected by neurodegeneration.

Alzheimer Europe leads the communication, dissemination, and Public Involvement activities of the project and engaged members of the project's Public Involvement Board to learn about their thoughts about AI tools for dementia diagnosis and individualised printouts. These have been shared as part of a campaign during World Alzheimer's Day. Here is what they thought:

Alfred Wallace highlights the value of AI-based decision support: "AI-based tools are a valuable addition. I also believe that it helps patients and their families to receive printouts of their diagnosis and test results."

Kevin Quaid stresses the importance of using all available resources: "I do believe that every and all resources should be made available to doctors, AI-based clinical decision support will hopefully speed up diagnosis and doctors would hopefully be able to see comparisons between patients and get a better understanding of this disease."

Nigel Hullah discusses the integration of AI in clinical practice: "The integration of AI-based clinical decision support tools in diagnosing dementia could offer numerous benefits, enhancing the accuracy, efficiency and effectiveness of the diagnostic process. Individualised printouts from doctors can be highly beneficial for patients in understanding their diagnosis and test results."

Sonata Mačiulskytė reflects on how AI can ease the shock of a dementia diagnosis: "Whilst people may suspect they have dementia, the diagnosis is always a shock, both for them and their families. If AI can save time and enable more focused but understandable information, I'm all for it."

26 SEPTEMBER

Spominčica – Alzheimer Slovenia organised many activities during World Alzheimer's Month

As in previous years, this year Spominčica – Alzheimer Slovenia once again organised and participated in numerous activities during World Alzheimer's Month, aimed at raising awareness and providing information about dementia.

On 11 September, Spominčica was invited to the 18th Health in Eastern Europe & Central Asia meeting. During the online gathering of the Working Group on Health in Eastern Europe and Central Asia, current developments in the health sector across these regions were discussed. Štefanija L. Zlobec, President of Spominčica, presented the organisation's activities focused on improving dementia management at both the national and European levels.

On 17 September, Spominčica members also participated in the Public Forum on Alzheimer's disease as part of the 15th International Conference on Brain Energy Metabolism, titled "Brain Bioenergetics in Aging – Neurovascular and Neurometabolic Coupling and Fuels." Participants from Spominčica were:

- Štefanija L. Zlobec, president of Spominčica – Alzheimer Slovenia
- Dr Milica Gregorič Kramberger, MD, Specialist in Neurology
- Assist. dr Polona Rus Prelog, MD, Specialist in Psychiatry
- Božidar Voljč, MD, Specialist in Family Medicine, President of the Medical Ethics Commission of the Republic of Slovenia.

The forum was opened by dr Nataša Pirc Musar, President of the Republic of Slovenia, who also highlighted the good cooperation with Spominčica, which had trained the staff of the Office of the President of Slovenia. The office is also a Dementia-Friendly Point, established by Spominčica.



On 21 September, Spominčica organised the traditional Memory Walk in Ljubljana. The gathering took place at the National Gallery of Slovenia. Following the opening speech by Štefanija L. Zlobec, a cultural programme was held, featuring performances by members of the Fužine Activity Center. After

the cultural programme, Spominčica went to the City Hall, where they were welcomed by representatives of the City of Ljubljana. This year's Memory Walk in Ljubljana was again held under the honorary patronage of Zoran Janković, Mayor of Ljubljana.

On 25 September, the National Museum of Slovenia (Muzejska ulica) joined the Dementia-Friendly Points (DPT) network. The new Dementia Friendly Point was established at Muzejska ulica in Ljubljana and on this occasion, speeches were delivered by the museum's director, Mateja Kos Zabel, and Štefanija L. Zlobec. The event was enriched by a heart-warming cultural performance by children from the dr France Prešeren kindergarten. Representatives from the Ministry of Culture of the Republic of Slovenia, museum employees, and residents of the DEOS Senior Center in Notranje Gorice, which is also a Dementia Friendly Point, were among the attendees. Spominčica thanks the National Museum of Slovenia for opening its doors and increasing accessibility for people with dementia.

27 SEPTEMBER

The Czech Alzheimer Society organised many events during "Memory Week"



World Alzheimer's Day is commemorated by the Czech Alzheimer Society (ČALS) during the so-called "Memory Week". This year, ČALS organised tradi-

tional events during this period: a mobile counselling centre at the Westfield Chodov shopping centre and a memory testing session at the Czech Radio station. Both events were successful. Almost 1,000 people stopped by the mobile counselling spot in the shopping centre over three days, and ČALS provided more than a quarter of the visitors with in-depth counselling.

At the radio station, they tested the memory and other cognitive functions of 75 people. 13 of them, whose tests detected depression or anxiety, or who showed measurable memory problems, were referred to a specialist. According to updated prevalence estimates, which ČALS updates annually according to Alzheimer Europe's methodology and publishes in its annual report, 171,000 people in the Czech Republic are living with some form of dementia. Three quarters of them are being treated.

28 SEPTEMBER

Alzheimer's Care Armenia marks World Alzheimer's Month with two "Walks to End Alzheimer's"



This World Alzheimer's Month, Armenia joined the global effort to raise awareness about Alzheimer's disease with a series of events, including the highly anticipated "Walk to End Alzheimer's" in Yerevan and Gyumri. The first event took place on 28 September and the second is scheduled on 5 October. The Walk symbolises unity and hope for a future without Alzheimer's and aims to bring together individuals from all walks of life, including family members, caregivers, healthcare professionals, and students. The goal is to spotlight the growing challenges faced by those affected by Alzheimer disease and dementia, particularly in underserved regions in Armenia.

Speeches from key figures, including the president of Alzheimer's Care Armenia emphasised the importance of awareness and early intervention. The aim in hosting this event was to strengthen the community's understanding of Alzheimer's and its impact, while simultaneously creating a platform for open dialogue about dementia care in Armenia. This event is especially significant as Armenia is witnessing an increase in the ageing population and a subsequent rise in dementia-related conditions. Raising awareness and breaking the stigma around Alzheimer's in our society is vital for fostering more supportive and informed communities.

30 SEPTEMBER

Confederación Española de Alzheimer y otras demencias (CEAFA) organises many awareness events for World Alzheimer's Day

The promotional slogan chosen by the Confederación Española de Alzheimer y otras demencias (CEAFA), the Spanish Confederation of Alzheimer's and other dementias, for this year's World Alzheimer's Day was: "Somos específico@s" (We are specific). The aim was to raise awareness and then demand that the country's administrations take dementia into consideration, as it is a condition that must be specifically addressed and attended to.



This year's World Alzheimer's Day image consists of a puzzle with one of the pieces in a different colour that does not fit in

with the rest, representing the singularity and specificity of dementia. CEAFA wanted to fill social networks with puzzles to reach as many people as possible, so they created a protocol to collaborate in this action and provided all the material necessary to perform it. This campaign had great support on social networks and has become a highly shared initiative, showing support for their collective.

Adif (Railway Infrastructure Administrator) collaborated with CEAFA for World Alzheimer's Day by projecting a video "Somos específico@s" on the screens and digital supports of several main train stations all over Spain, during the week of 17-23 September.

Several public buildings in Spain (such as City Councils, Congress of Deputies, Senate, etc.) showed their support by illuminating their façades in green on World Alzheimer's Day. The president of CEAFA, Maria Dolores Almagro Cabrera, the executive director, Jesús Rodrigo Ramos, and the members of PEPA (Panel of Experts of People with Alzheimer's) were interviewed on television, radio and in the written press. For further information:

<https://www.ceafa.es/es/que-hacemos/dia-mundial-del-alzheimer/dia-mundial-del-alzheimer-2024>

30 SEPTEMBER

Rolling for Dementia campaigner Golnaz Atefi breaks World Record during World Alzheimer's Month while promoting inclusivity in dementia care on her way to 34th Alzheimer Europe Conference!

During World Alzheimer's Month this September, Golnaz Atefi skated 1,026 km, setting the Guinness World Record for the farthest distance ever skated by a female.

Golnaz said, of her campaign: "I'm honoured to have accomplished this as part of the Rolling for Dementia campaign, raising awareness about dementia. My mission was to engage with professionals and community members across Europe, finishing at the Alzheimer Europe conference, to highlight the critical need for inclusivity in dementia care and research."

As part of the campaign, she visited the Alzheimer Europe offices in Luxembourg where she discussed the importance of inclusivity in dementia care as part of her campaign. Together, with the Alzheimer Europe team, she participated in the annual Memory Walk organised by Association Luxembourg Alzheimer on World Alzheimer's Day, an inspiring event that brought together organizations, researchers, and the public for a fun, friendly, yet informative environment. "I hope more events like this are arranged regularly and in more places, as inclusive dementia care requires stronger connections between research and the community", she said.

As part of her research fellowship at University College London, Golnaz will be investigating attitudes toward dementia

prevention across diverse groups through a survey of 1,000 people in the UK.

Although the campaign was originally set to conclude in September, the overwhelming support, with more than 100 professionals and community members now involved to share their insights, has been incredibly encouraging. As a result, the "Rolling for Dementia" journey, both on and off skates, will continue and will run throughout Golnaz Atefi's fellowship, continuing to collect and share insights about dementia. "I'm incredibly grateful to Alzheimer Europe for promoting inclusive dementia care, and I'm looking forward to both learning from and sharing the latest advancements in research during the conference", she concluded.



Pictured: Members of the Alzheimer Europe team with Golnaz Atefi at the Memory Walk organised by Association Luxembourg Alzheimer on World Alzheimer's Day

30 SEPTEMBER

Alzheimer Switzerland supports communication with people living with dementia this World Alzheimer's Day and launches German version of Alzheimer Europe guidelines on respectful communication

Communication is much more than words, facial expressions, gestures, and body language play a crucial role. For those with Alzheimer's or other forms of dementia, communication evolves as language skills change. This year, on World Alzheimer's Day, Alzheimer Switzerland turned its focus to "Communication and Dementia" with resources in German, French, and Italian. The initiative included a landing page for an online campaign, prevalence figures, and additional materials like the



"auguste" magazine, a newsletter, and a flyer answering the ten most frequently asked questions on maintaining communication with people living with dementia.

The association's World Alzheimer's Day press release also served to raise awareness among media professionals about dementia-friendly reporting. The 2022 guidelines on respectful

communication, developed by the European Working Group of People with Dementia, were highlighted for this purpose. These guidelines are now also available in German, in addition to the existing versions in French, English, and Italian. You will find them under the keyword "Sprachleitfaden" in the "Media" section of the Alzheimer Switzerland website at www.alz.ch

You can also find this German version on the Alzheimer Europe website, here: <https://www.alzheimer-europe.org/resources/publications/leitlinien-fur-eine-ethische-und-inklusive-kommunikation-uber-alzheimer-und>

MEMBERS' NEWS

6 SEPTEMBER

The Malta Dementia Society organised an international one-day conference titled 'Dementia in Malta: Past, Present and Future'



On 6 September, the Malta Dementia Society organised an international one-day conference titled 'Dementia in Malta: Past, Present and Future'.

This event also marked the 20th anniversary since the launch of the Society. The extensive programme included a number of talks, demonstrations and workshops, with the latter showcasing various activities organised for community-dwelling individuals living with dementia in Malta, Denmark, Norway and the United Kingdom. Local and foreign dementia experts participated, with Alzheimer Europe being represented by its Executive Director, Jean Georges. In his speech, Jean gave a brief outline of how dementia is affecting societies in Europe and what Alzheimer Europe is doing in making dementia a European public health and research priority. He was also interviewed by Maltese television news channel TVM News, during the event: "Dementia needs to become a priority in Europe" - TVMnews.mt

The importance of giving a voice to people living with dementia was highlighted in the opening speech by Chris Roberts, an active member and former Chairperson of the European Working Group of People with Dementia. Subsequent interventions highlighted the significance of providing person-centred

care during admission to hospital, the pivotal role that outside places play in the overall wellbeing in dementia, how Malta is actively participating in transforming dementia care, the challenges that dementia in long-term care poses and how societies can influence policy and practice. Supporting these talks were two demonstrations that were very well received by the audience. The first was Dancing to Dementia, an activity that the Malta Dementia Society organises for people living with dementia in the community and residential homes where dance takes centre stage. The attendees were invited to participate and for a few minutes, the conference hall turned into a dancing showground to the pleasure of everyone. The other demonstration involved the use of physiotherapy as a means of enhancing mobility and overall quality of life. Again, there was great participation from the audience.

The conference also included six workshops that presented a number of activities that are designed for individuals living with dementia in a number of European countries. The Danish, Norwegian and one of the UK groups presented their Lifelong Learning Programme whereas the other UK group showcased its music sessions. Two Maltese groups presented their ongoing work on techniques that stimulate communication and the central role that psychotherapy plays in dementia care. In the afternoon, a panel discussion was held where a number of health and social care professionals working in the dementia field, including a dementia caregiver, discussed ways with which Malta can move forward in this sector.

The closing speech was delivered by Her Excellency, Marie-Louise Coleiro Preca, President Emeritus of the Republic of Malta. Her Excellency reiterated that although significant advancements have been made in Malta with respect to awareness and dementia management and care, a lot still needs to be done and it is our duty, as a society, to ensure that these individuals and those who care for them are provided with the best support services that meet their needs. A gala dinner to celebrate this anniversary milestone was organised the next

day. It was the perfect way to close a successful conference. For her constant work and dedication, Vinnie Catania was awarded the Malta Dementia Society Lifetime Achievement Award. A special thanks goes to all those who have participated and to the sponsors whose generosity and contributions made all of this possible.

Pictured: Charles Scerri giving Vinnie Catania the Malta Dementia Society Lifetime Achievement Award

17 SEPTEMBER

Dementia Lithuania organises exhibition to reflect on family carer experience



The exhibition “Step into my shoes” (original title in Lithuanian “Nepatyręs nesupras”) is a silent testimony of the caregivers of persons living with dementia that carries the purpose of raising awareness in the public about the carer experience today in Lithuania. “Current reality leveraging support systems in the health care, social care systems and communities, public awareness about dementia, the prevalence of dementia related stigma is the reason the family members draw the routine of caring in Lithuania today as a journey of loss, prolonged mourning, in the search for meaning and connectedness”, says the curator of the exhibition, art researcher, founder and head of the association Dementia Lithuania, Ieva Petkutė.

The exhibition was created through a participatory research process called “Photovoice”, where photography and text were used to capture different aspects of everyday experience. 10 participants that took part in the creative process of developing the exhibition came from different parts of the country - both from major cities (Vilnius, Kaunas) and from smaller towns and the countryside (districts of Trakai, Ignalina, Biržai districts, Vilkaviškis, Jonava). The collective process included discussions, photography workshops, individual work, etc. The group was closely involved in the whole process of the exhibition development, so the final result can be considered to be representative of the dominant experience of informal care in Lithuania.

The visitors of the exhibition shared different insights about the importance of such an exhibition, highlighting the potential of

creative methods to raise awareness in the public about dementia. People who have close or a more distant experience of “caring for someone” highlighted that the exhibition offered a powerful experience: “I have not personally experienced it, but only indirectly. My wife took care of her dad, I waited for her while she was at his place. She was always tense and tired. This exhibition reflects very well the experience we lived”, one visitor said.

Others emphasised the importance of informing the public, and of accelerating the development of support systems: “I am a mother, I have a little daughter. I have not encountered dementia either in my family or in my environment. The exhibition is really useful... To know how it can be. After all, we are not immune to it. So that we know how it can happen”, shared another visitor.

18 SEPTEMBER

Alliance of Age Sector NGOs pre-election briefing for Irish politicians



On 18 September, Ireland’s Alliance of Age Sector NGOs hosted a pre-election briefing event in Dublin to meet with Irish general election candidates to call for the establishment of an Independent Commissioner for Ageing and Older People.

The Alliance, representing seven leading older persons organisations, is calling on all Irish political parties to include a commitment in their manifestos, ahead of the next general election, to establish an Independent Commissioner for Ageing to ensure that Ireland’s various policy commitments relevant to older people are meaningfully monitored.

An Independent Commissioner would have a mandate which recognises the full capacity and potential of older people, covering their needs and rights across the spectrum, not just in terms of health, care, and vulnerability.

The Alliance is made up of seven leading older persons organisations - The Alzheimer Society of Ireland, Irish Senior Citizens Parliament, Alone, Age & Opportunity, Irish Hospice Foundation, Active Retirement Ireland, and Third Age - who are working collaboratively to combat ageism.

27 SEPTEMBER

Members of the Scottish Dementia Working Group and the National Dementia Carers' Action Network collaborate on two innovative projects



Involving the perspectives of those with lived experience is crucial, and the members of the Scottish Dementia Working Group (SDWG) and the National Dementia Carers' Action Network (NDCAN) are at the forefront of this philosophy.

Their active participation in many initiatives brings together a whole range of expertise and insights, which is so beneficial to the projects they champion. Two significant initiatives that SDWG and NDCAN members have been actively engaged with from the beginning are the 'NHS Education for Scotland (NES): New to Skilled Educational Programme'; and Alzheimer Scotland's innovative ADAM online portal. Recently, members from both groups dedicated a productive day to recording engaging content as part of their commitment to both these important projects.

NHS Education for Scotland (NES): New to Skilled Educational Programme

This programme has been developed in response to feedback from the NHS workforce which highlighted a need for dementia training at the informed and skilled levels of the Promoting Excellence Framework. Members of both campaigning groups

have been involved in this project from the outset and recently participated in a poignant 'in conversation' recording, which will serve as an integral part of the training programme. Acknowledging that members' perspectives can sometimes differ, the groups collaboratively opted to create two separate recordings, ensuring that all voices were heard.

The film recordings offered members the chance to share their experiences of living with dementia or caring for someone with the condition, discussing both positive experiences and negative impacts. They emphasised what is important for the health and social care workforce to know, and moreover, how they can contribute to making a positive difference. Once edited the recording will help 'bring to life' this vital education resource aimed at training the NHS professionals with the knowledge and understanding necessary to foster compassionate care and support.

Updating ADAM

ADAM (About Digital and Me) is an online platform created by Alzheimer Scotland which has been designed to support individuals living with dementia by connecting them with the right technology tools at the right moment. ADAM has been co-designed with the invaluable input of members from the SDWG and NDCAN groups. They have been involved since its inception to ensure the platform is dementia-friendly, accessible for everyone, and features products that are tailored to the needs of both those living with dementia and their carers. The online platform has recently gone through some updates, and once again the group members were on hand to assist in this process with Margaret from SDWG and Maureen from NDCAN only too pleased to narrate the introductory welcome message users receive when accessing the site.

Listen to the new welcome message, and explore ADAM to discover how it can help you navigate the world of technology with ease and confidence: <https://www.meetadam.org/>



DEMENTIA LAB ethics + aesthetics in design
2025

Call for participation is now open
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LIVING WITH DEMENTIA

3 SEPTEMBER

Hatice Sertaç Süslü, new member of the European Dementia Carers Working Group, attends an event on optimal medication use, organised by the European Geriatric Medicine Society



On 24-25 June, I had the honour of representing dementia caregivers and the Turkish Alzheimer's Association at an event organised by the European Geriatric Medicine Society (EuGMS). I was invited to participate in a roundtable discussion on the topic of optimal medication use. The purpose of the event was "to explore all possibilities for improving the benefit/risk ratio of medications through public health policies, education of physicians and other health professionals, and the empowerment of patients and caregivers."

As a caregiver for my mother, who has Alzheimer's and vascular dementia, I was relieved to see that the issues that had been confusing us about her medication regimen over the last four years were a primary concern for the geriatric specialists. This realisation was both a relief and a significant benefit for me, and I am truly grateful. During the meeting, a doctor remarked, "It is normal to have many complaints and use many medications at an advanced age, but using more than 5-6 medications raises suspicion of unnecessary medication." A Belgian doctor also noted, "An elderly

person should have his son or daughter with him when he goes to the doctor," explaining that the patient may not fully understand or may forget the doctor's recommendations - or worse, may not share them with their family at all. It was also highlighted that certain medications frequently prescribed by urology and cardiology could pose additional risks for older patients due to side effects, drug-drug interactions, or drug-disease interactions.

The importance of communication and collaboration between different medical specialties when treating older patients was emphasised, along with the need for electronic health records to flag risky drug combinations.

The abbreviations frequently used during the meeting - many of which were new to me - are a reflection of the common challenges faced in geriatrics:

- STOPP: Screening Tool of Older Peoples Prescriptions
- START: Screening Tool to Alert to the Right Treatment
- IMU: Inappropriate Medication Use
- FRID: Fall Risk Increasing Drugs.

The meeting was recorded, and videos are accessible on the EuGMS website www.eugms.org and on social media.

17 SEPTEMBER

Kjell Ehn, new member of the European Working Group of People with Dementia, shares his experience of hallucinations and what he has learned living well with his diagnosis

Since I got my diagnosis, three years ago, I have started to write about my daily situation as a form of therapy and it somehow helps me sort feelings and thoughts that come and go with my new life. I have noticed that I am really fond of my new hobby and it has also resulted in a "job" as a columnist in the Swedish "Demens magazin" that is issued four times a year. Here is a shorter and slightly modified version of a column that was issued a year ago in that magazine:

Late one evening I am standing in the shower, letting the warm rays wash over me and calm me down in a meditative way. I, who always have been good at orienteering, had just come back from a training in the forest where I had got lost and almost panicked. Immediately the thoughts had appeared...the doctor's words at the cognitive clinic a few months ago. "Kjell, you have amyloid clumps in your brain and in the stage where you are right now, we call it cognitive impairment, and yes, it is Alzheimer's, and you will gradually be getting worse...".

While the warm rays wash over me, "he" suddenly appears again. It's Tomás, my new friend. I don't really know who he is, or where he's coming from, but he has popped up every now and then since I was



diagnosed. He is currently halfway up the left side of the shower cubicle, but he is not visible, he just "is" there. He has no body and speaks only Spanish. "Mi hermano gemelo" (My twin brother) as he calls himself. I don't know why, but I feel safe with him. He gives me an outside perspective and he is also very different from me in his manner, much more spontaneous and does not take life so seriously..."don't worry", he normally says. "Kjell, see the diagnosis as a second chance, an adventure, life isn't over yet!".

After the shower, Tomás and I start sketching on a sheet of paper, the pieces of my new puzzle, my new life. He asks questions and I try to answer as well as I can. Sometimes he gets a little too pushy and I must ask him to calm down a bit, after all it's my life we're talking about. What I take with me, though, from what he says, is that there are positive things about the diagnosis...yes. I now know that I have a limited time left to live and function normally. This means that I must be clearer about how I want to live my life and with whom. I can't waste time on acquaintances and "friends" who don't bring anything to my life "just because".... Suddenly, in the mess of all ideas and sketches that we've made, I see the missing piece. You know, that redemptive piece that makes several odd pieces of the puzzle come together. With the "missing" piece in place the puzzle suddenly brings colour, shape and meaning to my new life.

I turn to Tomás and say: "Tomás! I realise now that I am not a diagnosis, I *have* a diagnosis and my focus going forward will be, to not let the diagnosis hinder me until it's due. Tomás, I want to be an adventurer and enjoy life fully!" Tomás looks at me, smiles and says in Spanish: "Adventurers don't get lost, they just discover new sides of life".

23 SEPTEMBER

Annick Germeys, member of the European Dementia Carers Working Group, shares the news that "Restaurant Misverstand" has been nominated for an International Emmy Award 2024!



In October 2022, my husband Geert received the diagnosis of young-onset dementia, a form of Alzheimer's, at just 53 years old. It was a tough time of mourning and acceptance, but Geert is an optimistic person. Together, we quickly found the drive to turn our lives in a positive direction. Our focus is on what can be done, rather than on what no longer can. We don't know what the future holds, but we're determined to make the best of it. This mindset has brought many wonderful opportunities our way, including an invitation from the production company Roses Are Blue to take part in the TV show Restaurant Misverstand (The restaurant that makes mistakes).

In this programme, host Dieter Coppens, along with chef Seppe Nobels, sous-chef Romina, and eight people with young-onset dementia, open a restaurant. The show, which airs on the national

channel VRT1, with the support of Alzheimer Liga Vlaanderen, aims to highlight what people with young-onset dementia are still capable of after their diagnosis, and that's a lot.

I look back on the filming with great joy; it was an unforgettable adventure, one that's hard to match. Television was completely new to me, but from the very first filming day - right in our home - I saw how the programme was made with so much calm, respect, and warmth. This gave both Geert and me a sense of peace, even though we were a bit nervous about the first filming days at the coast. The recordings took place in Ostend, along Belgium's coastline.

That first day of filming was intense. How would things unfold? But soon enough, not only did the participants bond, but the caregivers did too. The crew took great care of the participants, while we, the caregivers, had time and space to connect. It's hard to explain how, in just a few days, we formed such a strong bond with complete strangers. We quickly understood each other; few words were needed. Everyone had their own story, and we mainly listened.

I soon realised we all shared the same motivation: to explain to others what young-onset dementia is, and what it means for the loved ones of those diagnosed. We wanted to show that it's not just about dealing with the diagnosis but also about supporting our partners and families, navigating administrative challenges, and dealing with a life that has been completely turned upside down. But we've managed to find our footing again. There is life after this difficult diagnosis. While people with young-onset dementia may appear "normal," please understand they function differently. I'm incredibly thankful that the production company chose that unique approach, one that focused on each participant's personal story.

I truly hope this programme gets picked up in other countries and opens people's eyes. It's the ultimate anti-stigma show. After all, young-onset dementia can affect anyone. And those who face it deserve dignity, respect and understanding. I'm thrilled that the show has been nominated, and I'm crossing my fingers that the Emmy Award for 'Non-scripted Entertainment' goes to Belgium!

DEMENTIA IN SOCIETY

3 SEPTEMBER

Alzheimer Europe joins the European Association for Urology, associations, researchers and healthcare professionals in the Urge to Act Kick Off meeting

On 3 September, the further promotion of the “Transforming EU Continence Health: A Manifesto for Policy Reform” (of which Alzheimer Europe is a signatory) was discussed (https://d56bochluxqnz.cloudfront.net/media/109857_EAU_Urge-To-Act_Manifesto_A5-fo) as well as a

report commissioned by the European Association of Urology on the socio-economic and environmental costs of continence health problems, an Infographics sheet and preparations for the first EUrology Aperó around the Urge to Act Campaign on 25 September in Brussels. There are also plans to dress up the Manneken Pis for this occasion (pending approval from the City Council). Dianne represented Alzheimer Europe in this work.



PUBLICATIONS AND RESOURCES

10 SEPTEMBER

New Dementia Researcher Communities platform is launched



On 10 September, the brand new Dementia Researcher Communities platform was launched, extending the support already offered by Dementia Researcher (delivered by UCL/UCLH BRC). The new platform was made possible thanks to funding from the National Institute for Health and Care Research (NIHR), Alzheimer’s Association, Alzheimer’s Research UK, Alzheimer’s Society and Race Against Dementia.

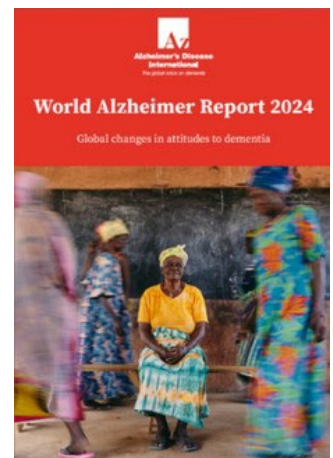
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20 SEPTEMBER

Alzheimer's Disease International publishes World Alzheimer Report 2024

On 20 September, Alzheimer’s Disease International published its World Alzheimer Report 2024. This year’s report is called “Global changes in attitudes to dementia” explores attitudes toward dementia, examining how the condition is perceived and understood by society and the stigma that still surrounds the condition, underpinned by a global survey of more than 40,000 individuals across 166 countries and territories, and 24 expert essays.

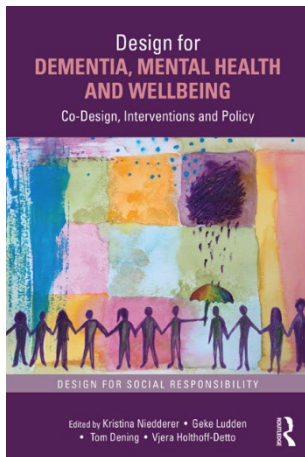
Read the report: <https://www.alzint.org/resource/world-alzheimer-report-2024/>



25 SEPTEMBER

Design for dementia, mental health and wellbeing book is launched

The online book launch of “Design for dementia, mental health and wellbeing: Co-design, Interventions and Policy” was held on 25 September 2024. The book explores the role of design in supporting mental health and wellbeing for people living with dementia, mental illness and neurodiverse conditions. It emphasises the need to recognise design as a powerful means for supporting people in their everyday lives at home, in the community with preventive and well-being-focused strategies.



The launch offered an inspiring evening of bite-size presentations and discussions by some of the book’s editors and contributors about its key topics. The evening was chaired by Dr Anna Bergqvist from Manchester Metropolitan University (UK). To begin, Professor Rachel Cooper, OBE, Series Editor of the Design for Social Responsibilities Series, of which the book is a part, spoke about the book in the context of the series.

Prof. Cooper explained that the series was developed to showcase the application and benefit of design in different areas.

The evening further followed the structure of the book with its three parts: co-design, interventions and policy. Each part was introduced by one of the editors, followed by vivid presentations by some of the contributors. The first part on co-design was introduced by Professor Kristina Niedderer, Manchester Metropolitan University (UK), followed by contributors Dr Rachel Losada, INTRAS (Spain), Dr Leigh-Anne Hepburn, University of Sydney (Australia), and Dr Laura Malinin, Nancy Richardson Design Center, Colorado State University (USA). They explored themes of ethics, citizenship, power relationships and empowerment in co-design, noting the importance for involving people with lived experience at all stages of the

process to provide an expert critical voice to counterbalance the clinical voice.

The second part, on interventions, was introduced by Professor Geke Ludden, University of Twente, The Netherlands, followed by Dr Jodi Sturge, University of Twente (Netherlands), and Dr Christian Wölfel, Technische Universität Dresden (Germany). It considered the culturally and value sensitive adaptation of design interventions and their applications. Dr Sturge provided an example with the comparison of dementia villages in the Netherlands and in Canada, and the differences in adapting this model to the two locations due to the need to cater for different national requirements and experiences.

The third part, on policy was introduced by Professor Tom Denning, Nottingham University (UK), followed by reflections by Dr Andy Bell, Centre for Mental Health, Dr Camilla Buchanan, PolicyLab (UK), Dr Elena Bellini, Duit (Italy). The discussion reflected on policy and related standards in and for design and mental health. It explored the design of policy, policy and regulations for design as well as the influence of design on shaping policy.

Being experienced designers and clinicians, the contributors to the book emphasised how design can be a collaborative, creative process as well as an outcome of this process. Speakers discussed different issues raised in the book and their relevance to advancing current policy and provision of mental health and wellbeing services internationally.

AE CALENDAR 2024

DATE	MEETING	AE REPRESENTATIVE
30 September-1 October	Annual PREDICTOM Consortium meeting (Erlangen, Germany)	Dianne, Sarah
1-2 October	International Conference on Dementia (Budapest, Hungary)	Jean
1-2 October	Conference of the Czech Gerontological Society and Czech Alzheimer Society (Prague, Czech Republic)	Angela
3 October	European Disability Forum – European NGO coordination meeting	Owen
7-8 October	European Group of Governmental Experts on Dementia (Geneva, Switzerland)	Jean, Owen, Tara, Lukas, Ana
7-8 October	INTERDEM Annual Meeting (Geneva, Switzerland)	Ana, Dianne, Lukas
7-8 October	European Alzheimer’s Disease Consortium (Geneva, Switzerland)	Angela
8 October	European Working Group of People with Dementia meeting (Geneva, Switzerland)	Dianne, Sarah
8 October	European Dementia Carers Working Group meeting (Geneva, Switzerland)	Ana, Soraya, Sébastien

8-10 October	34 th Alzheimer Europe Conference “New horizons – Innovating for dementia” (Geneva, Switzerland)	AE members and staff
17 October	European Patient Forum High-Level Policy Event (Brussels, Belgium)	Lukas, Sébastien
18 October	Meeting with Expertise Centrum Dementie	Jean
21 October	Pattern-Cog General Assembly meeting	Cindy, Soraya
22 October	AD-RIDDLE Advisory Board	Ana, Sarah
23 October	Multi-Memo & Lethe educational event	Ana, Sarah and Cindy
22-23 October	Assessing the capacity to consent project (Oslo, Norway)	Dianne
24 October	COFACE Roundtable discussion on family carers (Brussels, Belgium)	Sébastien
28-29 October	General Assembly of the EPND project (Madrid, Spain)	Dianne, Angela
28-29 October	General Assembly Meeting of the AI-Mind project (Madrid, Spain)	Cindy
29 October	AD-RIDDLE Steering Committee meeting (Madrid, Spain)	Angela
29 October-1 November	Clinical Trials in Dementia (CTAD) Conference (Madrid, Spain)	Angela, Jean

CONFERENCES 2024-2025

DATE	MEETING	PLACE
8-10 October	34 th Alzheimer Europe Conference – New horizons – Innovating for dementia, https://www.alzheimer-europe.org/	Geneva, Switzerland
29 October – 1 November	17 th Clinical Trials on Alzheimer’s Disease (CTAD), https://www.ctad-alzheimer.com/	Madrid, Spain
13-16 February 2025	14 th Panhellenic Conference on Alzheimer’s Disease and 6 th Mediterranean Conference on Neurodegenerative Diseases, https://www.alzheimer-conference.gr/index.php/en/	Thessaloniki, Greece
20-22 March 2025	19 th World Congress on Controversies in Neurology (CONy), https://cony2025.comtecmed.com/	Prague, Czechia
1-5 April	International Conference on Alzheimer’s and Parkinson’s Diseases and Related Neurological Disorders (AD/PD™ 2025) https://adpd.kenes.com/partners-related-events/	Vienna, Austria



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34th Alzheimer Europe Conference

New horizons – Innovating for dementia

Geneva, Switzerland

8 - 10 October 2024 #34AEC

www.alzheimer-europe.org/conferences

