

ALZHEIMER EUROPE NEWSLETTER

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WELCOME



It is with a heavy heart that I share the sad news that Marie-Odile Desana has passed away. She served on the Board of Alzheimer Europe from 2014 to 2018 and was President of France Alzheimer from 2010 to 2015. I will remember

her with great fondness from the many times shared with her at our meetings and conferences throughout the years, and I offer my deepest condolences to her partner Michel Palesi, to her family, friends and to her colleagues at France Alzheimer Bouches-du-Rhône.

September

In happier news, I would like to congratulate all our members for their hard work this September, also known as World Alzheimer's Month, particularly around World Alzheimer's Day (21 September). It never ceases to amaze me just how hard-working, dedicated and creative all our member organisations are and each year we read of so many exciting new activities marking World Alzheimer's Day. It is also fantastic to see many wonderful traditions being maintained, such as the important awareness and fundraising "Memory Walks" organised in so many countries. Find out more about just some of our members' great initiatives, in our special "World Alzheimer's Day" section.

For our part, we marked this important day with a flurry of social media activity, inviting people from the general public, with an interest in dementia and brain health, to join

our new European Public Involvement Pool. Members of the European Public Involvement Pool will have opportunities to participate in consultations, focus groups, written discussions and brief surveys. You can find out more about this in the Alzheimer Europe news section.

We were pleased to hear that the European Commission has published a proposal introducing a standardised European Disability Card and enhancing the current European Parking Card for persons with disabilities. Both cards will be recognised throughout the European Union. The European Disability Card will serve as proof of disability throughout the EU, granting equal access to special conditions and preferential treatment in public and private services. It will be issued by the national competent authorities and will complement existing national cards or certificates.

The Alzheimer Europe team and I are looking forward to welcoming all of you to Helsinki, for our 33rd Annual Conference, in just a few days! If you have not yet registered, please do so right away, as late registrations will close on 8 October. Our Networking Dinner and Award Ceremony, taking place on 17 October in Helsinki's Old Student House, has just a few seats remaining, so please register now, to avoid missing what promises to be a wonderful evening of great food and even greater company, as well as music and dancing. Our Anti-Stigma Award, now in its second year, will be presented during this event. See you there!

Jean Georges
Executive Director

IN MEMORIAM

25 September: In memoriam Marie-Odile Desana

We were deeply saddened to learn of the passing of Marie-Odile Desana, on 25 September 2023. Marie-Odile served on the Board of Alzheimer Europe from 2014 to 2018. She was President of France Alzheimer from 2010 to 2015, where she had also been Vice President (2008) and Administrator (2006). As a former carer for her mother, who lived with Alzheimer's disease, she created an association of family caregivers of people with Alzheimer's disease in Aix-en-Provence in France. She joined France Alzheimer's Bouches-du-Rhône chapter in 2003 and became the chapter President in 2004, a position she held for many years. She worked hard to improve support for families and to make France Alzheimer a key player in many national bodies, particularly during the roll-out of the 2008-2012 Alzheimer's Plan and the launch of the 2014-2019 neurodegenerative diseases plan. Her commitment was recognised nationally in 2011 when she became a "Chevalier de la Légion d'honneur" (Knight of the Legion of Honour).

Marie-Odile Desana's funeral will take place in Var, a region of Provence-Alpes-Côte d'Azur in France, on 7 October 2023. We will remember her with great fondness from the many times shared with her at our meetings and conferences throughout the years, and we offer our deepest condolences to Marie-Odile's partner Michel Palesi, to her family, friends and to her colleagues at France Alzheimer Bouches-du-Rhône.



Help us give a voice to people with dementia

[Donate](#)



ALZHEIMER EUROPE

14 September: The EWGPWD meets online to discuss inclusive meetings



On 14 September, members of the EWGPWD met online to discuss the topic of inclusive meetings. The meetings were organised and

facilitated by Project Officers Soraya, Ana and Daphné and Director for Projects, Dianne.

During the consultation, the members of the EWGPWD were asked to reflect on their previous experience specifically regarding participating in meetings, expressing opinions and being able to follow a meeting. They provided their views about situations where they felt like a meeting did not work out well or did not meet their expectations and why this was the case. They also talked about positive experiences of meetings and what was helpful to them in that regard. The discussions first centred on face-to-face meetings and then the group moved on to elaborate on issues specifically relating to online meetings.

All members participated very actively, providing useful feedback and examples that will serve to inform Alzheimer Europe's 2023 short report and recommendations about inclusive meetings and travelling. This topic will be explored further by the group in the next meeting of the EWGPWD in Helsinki.

18 September: Late registrations close on 8 October for the 33rd Alzheimer Europe Conference!

We are very pleased to invite you to join us at the 33rd Alzheimer Europe Conference (#33AEC) which will take place in Helsinki from 16 to 18 October 2023, under the banner "New opportunities in dementia care, policy and research". The event is a collaboration between Alzheimer Europe and Muistiliitto (Alzheimer Society of Finland).

These are exciting times for the European dementia movement with research on new treatments and improved diagnostics making progress. In parallel, we are also delighted to see a greater focus being given to making our societies more dementia-inclusive and ensuring that the views and voices of people with dementia are fully included in care, policy and research. With this in mind, we are truly excited to announce

that our first plenary session is being organised by members of the European Working Group of People with Dementia, all of whom have lived experience of dementia.

Our conference is sure to be a great networking opportunity, bringing together people from all areas of the dementia field, from across Europe and beyond. While the event will be mainly in-person, it will also include some broadcast elements such as plenary sessions, and other carefully selected parallel sessions and symposia to allow those unable to travel to participate from the comfort of their home or office. You can see our [detailed programme](#) and find out who our [keynote speakers](#) are, on our website.



Register now!

33rd Alzheimer Europe
Conference

New opportunities in
dementia care, policy
and research

Helsinki, Finland
16 - 18 October 2023
#33AEC



Register now, to avoid missing out!

You can take advantage of the late registration fees until 8 October 2023 to attend in-person in Helsinki or to follow our event via our virtual conference platform. Our late registration fee for in-person attendance is EUR 500 (instead of EUR 600 for last-minute registration fees, after 8 October). A 30% discount is available for participants from low and middle income countries. Special rates are also available for people with dementia, students and member associations of Alzheimer Europe. [Click here for more information.](#)

The full registration fee includes:

- Admission to all in person and online sessions
- Access to on-demand videos and posters after the conference until 31 January 2024
- Delegate bag and final programme
- Opening ceremony
- Welcome reception at Helsinki City Hall and transfer to the venue
- Scheduled coffee breaks and lunches on 16, 17 and 18 October
- Networking opportunities
- Access to the exhibition hall.

Alzheimer Europe and Muistiliitto gratefully acknowledge the support of all conference sponsors.

Click here to [register for 33AEC!](#)

Follow the event on Twitter: [#33AEC](#)

Join us for our Welcome Reception at Helsinki City Hall!

Already registered for #33AEC? Then you can also join our Welcome Reception for free. You need to register separately (at no extra cost). The Welcome Reception will take place in Helsinki's City Hall, thanks to the generous support of the Mayor of Helsinki, Juhana Vartiainen. We are deeply grateful for his support. For more information click [here](#).

Conference delegates interested in attending will need to register (for free) separately, via the following link: <https://www.lyyti.fi/reg/receptionoctober16>

Networking dinner and Award ceremony

Together with our co-hosts, we are proud to invite you to join a Networking dinner and the Award ceremony for the 2023 edition of our Anti-Stigma Award sponsored by the Alzheimer Europe Foundation. The dinner and ceremony will take place at the Old Student House in the heart of Helsinki, on Tuesday 17 October at 19:30.

Tickets are now available for sale via our online registration system. Register before 8 October to benefit from the late registration fee of EUR 100, instead of the last-minute fee of EUR 120.

Get your ticket now and join us for good food, good company and an evening of entertainment and even some dancing if you feel brave enough!

To add your Networking dinner and Award ceremony ticket to your existing conference registration, use our online registration system and select "Add another attendee", then select the ticket type "Networking dinner" and fill in your details. For more information click [here](#).

Accessibility information for people with limited mobility attending the Networking Dinner

For those of you who have registered for the Networking Dinner and Award Ceremony that will take place on 17 October 2023, there is some important information for you to bear in mind, if you have limited mobility:

While the dinner itself will take place in the ballroom of the Old Student House, which is on the ground floor, the welcome drink (from 7.30-8pm approx.) will take place on the upper floor, where access will be more difficult for people with limited mobility.

The venue (Old Student House) is a very old building and although it does have a lift, the lift is rather small and is located at the back of the building, through a door which can only be accessed from the outside (there is a ramp to gain access to this door). The subsequent pathway through the building, to reach

the area where the welcome drink is being served is long and complicated, through several doors and along several corridors. There are two winding staircases leading from the main entrance hall on the ground floor to the welcome drink area upstairs. These are quite old and are therefore slightly worn in places. Alzheimer Europe would ideally want to make these stairs more accessible for people with visual impairments or those who have difficulties with depth perception, by marking the edges clearly, with tape, but we are not allowed to do so (apart from the first few steps), due to the listed status of the building.

For those who are not able to navigate the stairwells, our staff will be on hand to help, in whatever way delegates feel most comfortable.

We of course want to cater for everyone's needs as best we can, to ensure that everyone can participate and in order to achieve this, we would kindly ask anyone with limited mobility who is registered for the Networking Dinner to contact us in advance and inform us of their needs, so that we can propose the best way to ensure that access goes as smoothly as possible.

21 September: This World Alzheimer's Day we invite you to help shape European brain health and dementia-related research



On the occasion of World Alzheimer's Day, 21 September, Alzheimer Europe is focusing on the importance of Public Involvement (PI) in dementia research and would like to invite individuals from the general public who are interested in dementia and brain health to join its new European Public Involvement Pool.

The platform allows members of the public (excluding health and social care professionals, students and service providers) to share their views on various research-related topics and projects. Members of the PI Pool will get access to opportunities to participate in consultations, focus groups, written discussions and brief surveys.

What is Public Involvement?

To ensure that research accurately reflects the preferences, needs and priorities of members of the public, their perspectives need to be included in different aspects of research processes and outputs/results. PI has been shown to

improve the quality of research. Also, it helps ensure that research is ethical, transparent and reflects the principle of "nothing about us without us".

What can people expect from joining?

By joining, members of the PI Pool will have the opportunity to provide input on different aspects of ongoing European research initiatives. Examples of topics include new technologies and Artificial Intelligence-based approaches to dementia prevention, screening, diagnosis or management and dementia risk prediction models etc. The main activities will be in English but there will be opportunities for specific activities in other languages (e.g. French, German, Italian or Spanish).

In the past, Alzheimer Europe's focus has been on involving people with dementia and carers in research and the organisation is now seeking to broaden its Public Involvement activities to include people who do not have dementia but are interested in the topic, particularly people with no cognitive or memory problems, people who feel concerned about their memory and people with Mild Cognitive Impairment. Alzheimer Europe is also very keen to ensure a diversity of perspectives in its Public Involvement activities by including the perspectives of people from different minority and marginalised groups.

We therefore particularly welcome:

- Older people with no memory or cognitive problems, interested in brain health and dementia research.
- People at higher risk of dementia or with memory or other cognitive problems (e.g. Mild Cognitive Impairment).
- Additionally, we are keen to include the perspectives of members of minority and marginalised groups and cultures (with or without cognitive problems), such as people from minority ethnic groups, the LGBTQ+ community or those living in rural areas or residential care settings.

Find out more here: [Alzheimer Europe Public Involvement Pool | Alzheimer Europe \(alzheimer-europe.org\)](https://www.alzheimer-europe.org/public-involvement) or get in touch for more information at: Daphne.lamirel@alzheimer-europe.org or Dianne.gove@alzheimer-europe.org

28 September: Alzheimer Europe co-authors collaborative international guidelines on physical activity and exercise for prevention and management of mild cognitive impairment and dementia

Physical activity and exercise have been suggested as effective interventions for the prevention and management of mild cognitive impairment (MCI) and dementia, but with no international guidelines in existence, an international group of experts including Jean Georges, Executive Director,



Alzheimer Europe decided to author a set of international evidence- and expert consensus-based prevention and management recommendations. Their collaborative effort has resulted in these new guidelines, which are applicable to a range of individuals from healthy older adults to those with MCI/dementia, being published in the journal European Geriatric Medicine on 28 September 2023.

Physical activity is defined as any bodily movement produced by skeletal muscles that results in energy expenditure, while exercise is a subset of physical activity that is planned, structured and repetitive.

The guideline content was developed with input from several scientific and lay representatives' societies. A systematic search across multidisciplinary databases was carried out until October 2021. Recommendations for prevention and management were developed according to the GRADE and complemented by consensus statements from the expert panels.

Although the scientific evidence on the beneficial role of physical activity and exercise in preserving cognitive functions in subjects with normal cognition, MCI or dementia is inconclusive, this panel, composed of scientific societies and other stakeholders, recommends their implementation based on their beneficial effects on almost all facets of health.

The article is available (open access), here:

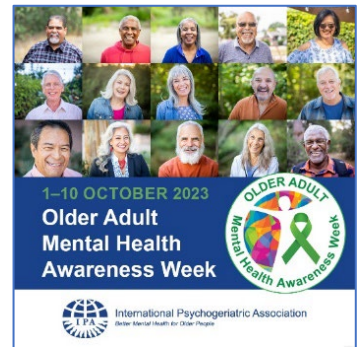
<https://link.springer.com/article/10.1007/s41999-023-00858-y>

1 October: Alzheimer Europe officially endorses Older Adults Mental Health Awareness Week

Alzheimer Europe is pleased to again be an Endorsing Partner of the International Psychogeriatric Association's Older Adults Mental Health Awareness Week. Now in its third year, the event runs from 1 October, the United Nations' International Day of Older Persons, until 10 October, World Mental Health Day.

Hosted by the International Psychogeriatric Association (IPA), Older Adults Mental Health Awareness Week focuses on raising awareness of the importance of Better Mental Health for Older People and of the impact of ageism on health outcomes. It also aims to highlight the importance of respecting the human rights of older persons with mental health conditions.

<https://awarenessweek.ipa-online.org/>



Sponsor of the month

Alzheimer Europe would like to express its gratitude to its first sponsor for 2024!

Read more about sponsorship opportunities here:

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



ALZHEIMER EUROPE NETWORKING

On 1 September, Ana and Dianne participated in a consultation with a few members of the European Dementia Carers Working group (EDCWG) and Evidera.

On 4 September, Ana participated in the INTERDEM Task Force Inequalities in Dementia Care.

On 6 September, Owen attended the Patient Think Tank meeting hosted by EFPIA.

On 6 and 26 September, Ana and Dianne participated in a meeting to prepare the plenary of the European Working Group of People with Dementia (EWGPWD) session at the Alzheimer Europe Conference.

On 11 September, Jean met with Alector.

On 12 September, Jean met with Bristol Myers Squibb.

On 12 September, Gwladys met with the Geneva Convention Bureau.

On 12 September, Dianne took part in the INTERDEM taskforce meeting on technology.

On 13 September, the Board of the Alzheimer Europe Foundation met.

On 13 September, Ana and Angela participated in the Evidera Advisory Group meeting with members of the EWGPWD and EDCWG.

On 14 September, Dianne, Soraya, Daphne and Ana participated in the meeting of the EWGPWD.

On 18 September, Angela participated in the RECOGNISED General Assembly.

On 19 September, Owen attended a European Disability Forum briefing session on the European Disability Card.

On 19 and 20 September, Ange participated in meetings of the Patients' and Consumers' and Healthcare Professionals' Working Parties (PCWP and HCPWP) of the European Medicines Agency.

On 21 September, Owen attended a meeting of the EU4Health Civil Society Alliance.

On 21 September, Dianne and Daphné participated in an online consultation of the eBRAIN-Health project's Public and Patient Advisory Group.

On 25 September, the Alzheimer Europe (AE) Board met.

On 27 September, Jean, Cristina and Gwladys met with the 33AEC committee.

On 27 September, Daphné and Soraya participated in a meeting about the AAIC Participant Inclusion Project Debrief.

On 28 September, Chris attended the SciCom Luxembourg 2023 event.

On 29 September, Angela participated in a DataSavesLives Core Group meeting.

On 29 September, Soraya, Daphné and Ana participated in an Information Session about the AE Public Involvement Pool.



Follow us on Twitter

EU PROJECTS

6 September LETHE Project Releases Tutorial Videos for User-Friendly App Navigation



The LETHE project, is committed to improving dementia risk reduction and early intervention. With its core mission of providing a user-friendly digital tool for individuals at risk of cognitive decline, LETHE has taken a significant step toward its goal. On September 6,

2023, the project unveiled a series of explanatory videos on its YouTube channel. These videos aim to guide users on how to navigate the LETHE app effectively.

The release of these explanatory videos is a milestone in LETHE's outreach efforts. These videos focus solely on guiding users through the LETHE app's functionalities. They cover essential topics such as how to use the app, input data, and interpret their weekly score.

The LETHE project represents a collaborative effort among European clinical centres, poised to make a significant impact on dementia risk reduction. By equipping users with the knowledge to navigate the app effortlessly, LETHE enhances the quality of life for older populations and reduces the dementia burden on society.

These tutorial videos serve as a testament to LETHE's commitment to user support and ease of use. As we address the challenges of an aging population, initiatives like LETHE play a vital role in simplifying cognitive health management.

To explore the tutorial videos and learn more about the LETHE project's work, visit the project's YouTube channel at:

<https://www.youtube.com/@LetheProject>

18 September: RECOGNISED convenes all project partners for its annual General Assembly meeting

On 18 September, partners working on the EU-funded RECOGNISED project met during a General Assembly meeting, held online and in-person in Barcelona, co-Chaired by Prof.

Rafael Simo (Vall d'Hebron University Hospital) and Prof. Noemi Lois (Queen's University, Belfast), the co-Leads of the project. Attended by representatives of the 21 Institutions participating in RECOGNISED, including academic institutions, SMEs and patient organisations, the General Assembly (GA) meeting summarised recent project developments and provided a forum for discussing upcoming plans. Alzheimer Europe was represented by Angela Bradshaw.

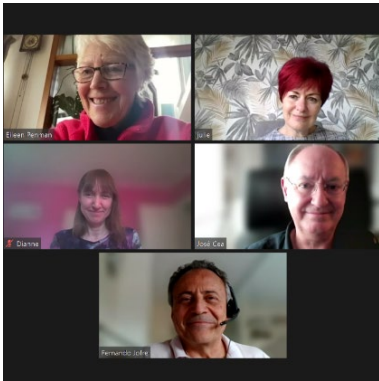
RECOGNISED is studying the biological mechanisms that cause changes in the retina in people with type 2 diabetes, to determine whether these mechanisms play a role in the development of cognitive impairment and dementia. Importantly, RECOGNISED is assessing whether evaluating the retina, easily accessible with non-invasive tests, could help in identifying earlier cognitive impairment in people with T2D, so that appropriate support can be given. At the General Assembly meeting, consortium members presented and discussed their preliminary results and future perspectives. A particular highlight was the cross-sectional clinical study, which has successfully recruited almost 250 participants with excellent retention at the 12-month mark. Leaders of the work packages focusing on preclinical research also showcased several recent publications looking at the biological changes underlying retinal and cognitive dysfunction in diabetes.

The afternoon sessions of the GA were focused on exploitation, dissemination and communications, highlighting some of the considerations for business development and underlining the importance of disseminating RECOGNISED outputs to relevant stakeholders. Prof. Lois and Simo closed the General Assembly



meeting by thanking all attendees for their valuable input, and continued efforts on behalf of the project.

21 September: The eBRAIN-Health Public and Patient Advisory Group members gather online for another consultation about the project!



On 21 September, members of the eBRAIN-Health Public and Patient Advisory Group, José (Spain), Fernando (Spain), Eileen (UK) and Julie (UK), met online for a consultation about the project. The meeting was facilitated by Daphné Lamirel (Project Officer) and also attended by

Dianne Gove (Director for Projects). The discussions centred around discussing various ethical concerns about the eBRAIN-Health project, namely the issue of what qualities may make digital brain twins more or less human-like, and the potential use of digital brain twins in situations where people may lack decision-making capacity. The second part of the session was dedicated to the issues related to privacy and how group members feel about sharing their data in the context of AI-related research.

The discussions were very active – members provided a range of different perspectives and interesting examples. We look forward to meeting in person in Luxembourg in November to continue discussing the eBRAIN-Health project.

21 September: AI-Mind launches study newsletter



The AI-Mind project aiming to provide better and personalised diagnoses for future patients is a 5-year EU-funded project. The members of the AI-Mind consortium are glad to announce the launch of its study newsletter, providing valuable updates on the latest

advancements in dementia research and the AI-Mind project’s progress.

The first issue expresses heartfelt gratitude to all study participants, whose contributions have been instrumental in advancing AI-Mind researchers’ understanding of the brain. The inaugural issue of the newsletter includes information about the goals of the project, the team of researchers working on it and the methodologies and procedures of the AI-Mind study. In addition, you can find out more about the various risk factors associated with dementia and gain a deeper understanding of

how these factors contribute to the onset and progression of dementia.

You can read the newsletter here: https://www.ai-mind.eu/wp-content/uploads/sites/39/2023/07/AI-Mind_Study_Newsletter_issue1_EN.pdf

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

If you are planning to attend the 33rd Alzheimer Europe Conference (#33AEC) in Helsinki, join us for a special session dedicated to the AI-Mind project on 17 October at 14:00-15:15 (local time) titled “The potential of artificial intelligence for dementia risk prediction”. The AI-Mind team is looking forward to welcoming you to this enlightening session. For more information about the session and the speakers, visit: <https://www.ai-mind.eu/event/ai-mind-session-at-alzheimer-europe-conference/>

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 964220.

27 September: IDoService project receives Healthy Ageing Challenge Award ensuring follow-on funding for its I-Can-Do app

The IDoService project is delighted to announce that it has received a Healthy Ageing Challenge Award as follow-on funding to develop its I-Can-Do app further and to help realise it for public use.



With rising numbers of people with dementia, support at the early stages is important to help people maintain their health and wellbeing as long as possible. The challenge for supporting people at the early stages of dementia is in providing an individualised and tailored offer of activities in their local community that meets their interests and needs, that is not perceived as stigmatising, and that allows them to make a contribution for which they feel valued, states the project coordinator.

IDoService offers a novel and innovative programme with the service focusing on older people with a recent diagnosis of dementia and supporting them in identifying, participating in and contributing to social activities in their community by connecting them to local volunteer services. The Service is built around a core three-session plan, delivered by the wellbeing mentor, which allows people to explore their strengths and interests, get to know what is available locally and to decide what they want to do in a safe and convivial way. The IDoService team has successfully trialled the service with Age UK Salford during 2022. This resulted in the recommendation to provide a digital version of the service to allow sharing information between the wellbeing mentor, people with dementia, their care partners and volunteer service staff.

For this next phase, the team will now work with people with dementia, their care partners, dementia and volunteer organisations through co-design workshops to develop the I-Can-Do app prototype and extend the trial in Greater Manchester to make the Service more user-friendly and easily scalable. The project aims to have a wide impact on how to improve the wellbeing of people living with dementia and recognition of the value people with dementia can bring to society and to reduce stigma.

The project is funded through the UK Research and Innovation (UKRI) as part of the Healthy Ageing Challenge, delivered by Innovate UK and ESRC. The UKRI Healthy Ageing Challenge Catalyst Awards – Round 4 is delivered in partnership with Zinc.

This project built on the work done in the MinD project, in which Alzheimer Europe was involved.

For any questions or suggestions about access to meaningful activities, please do not hesitate to contact the research team on: mk.niedderer@mmu.ac.uk

For more information about the IDoService project, visit: www.idoservice.org



EU project acknowledgements



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

AI-MIND – grant agreement 964220
eBRAIN-Health – grant agreement 101058516

LETHE - grant agreement 101017405
Recognised - grant agreement 847749

Members of the European Alzheimer's Alliance



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

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

EU DEVELOPMENTS

6 September: European Commission publishes Disability Card proposal



The European Commission has published a legislative proposal that aims to facilitate access to the right to free movement for persons with disabilities by ensuring access to special

conditions, preferential treatment and parking rights when visiting another Member State.

The Commission's proposal introduces a standardised European Disability Card and enhances the current European Parking Card for persons with disabilities. Both cards will be recognised throughout the EU.

The European Disability Card will serve as proof of disability throughout the EU, granting equal access to special conditions and preferential treatment in public and private services. It will be issued by the national competent authorities and complement existing national cards or certificates.

The Commission's proposal also includes changes to the operation of the current European Parking Card, which will allow persons with disabilities to access the same parking rights available in another Member State. It will have a binding common format that will replace national parking cards for persons with disabilities and will be recognised throughout the EU.

To promote ease of use and reduce administrative burden, the proposed Directive will require Member States to:

- Provide the cards in both physical and digital versions.
- Make conditions and rules for issuing or withdrawing the cards publicly available in accessible formats.
- Ensure service providers offer information on special conditions and preferential treatment for persons with disabilities in accessible formats.

The Commission's proposal will be discussed by the European Parliament and the Council. Once adopted, Member States will have 18 months to incorporate the provisions of the Directive into national law.

Further information on the proposals is available at: https://ec.europa.eu/commission/presscorner/detail/en/ip_23_4331

7 September: United Kingdom to re-join Horizon Europe research programme

The European Commission and the United Kingdom have reached a political agreement on the UK's participation in Horizon Europe, the EU's research and innovation programme.

As of 1 January 2024, researchers and organisations in the UK will be able to participate in Horizon Europe on par with their counterparts in EU Member States and will have access to Horizon Europe funding. This will provide the opportunity for researchers to be part of a global network of researchers addressing a broad range of topics including health, mobility, digital etc.

The UK will be required to contribute financially to the budget and is subject to all the safeguards of the Trade and Cooperation Agreement. Overall, it is estimated that the UK will contribute almost EUR 2.6 billion per year on average for its participation in both the Horizon Europe and the Copernicus component of the Space programme.

More information on the agreement is available at: https://ec.europa.eu/commission/presscorner/detail/en/ip_23_4374

7 September: EU4Health Civil Society Alliance issue statement on sustainable financing

In a joint statement, the EU4Health Civil Society Alliance (CSA) has called for stronger and more sustainable funding mechanisms for health-focused non-governmental organisation (NGOs).



This call comes after a campaign from the EU4Health CSA to guarantee the continuation of operating grants for health NGOs, following on from an event organised in the European Parliament in June with the support of István Ujhelyi MEP.

The joint statement calls for:

DG SANTE to reinstate a multiannual framework for Operating Grants for health NGOs to correct the current imbalance compared to other sectors.

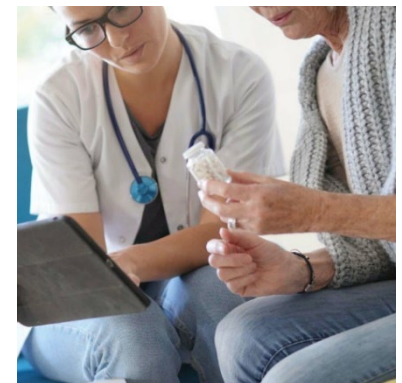
The European Commission to take clearer and more coherent action to support civil society in accessing sustainable funding, and to protect civil society from existing threats.

The European Commission to organise a dialogue between different DGs, the European Parliament and civil society to discuss and review the funding programmes, with the aim of breaking silos and supporting NGOs with more sustainable funding. The full statement can be read at:

<https://eu4health.eu/joint-statement-on-sustainable-funding-for-health-civil-society-organisations-csos/>

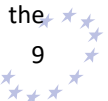
19 September: The ACT EU initiative has launched its website

The Accelerating Clinical Trials in the EU (ACT EU) initiative was launched in January 2022 by the European Commission, the European Medicines Agency (EMA) and the Heads of Medicines Agencies (HMA). ACT EU is a multi-annual programme aiming to create a favourable



environment for research and development in life sciences, through harmonisation, innovation and collaboration with stakeholders.

ACT EU builds on momentum of the Clinical Trials Regulation (CTR) and the launch of the Clinical Trials Information System (CTIS) on 31 January 2022. The initiative will deliver on the



clinical trial innovation recommendations of the EMA network strategy and the European Commission's Pharmaceutical strategy for Europe. The vision is to transform the EU into a region that supports clinical trial development and enables collaboration and innovation at all stages of the clinical research lifecycle. Seamless coordination among stakeholders, regulators and ethics committees will lead to more cross-border collaboration.

The website for the ACT EU initiative has been launched and contains updates on the progress of ACT EU priority actions. Key resources include latest information on the multi-stakeholder platform; the implementation of the Clinical Trials Regulation; voluntary procedures in scientific advice and the Simultaneous national scientific advice (SNSA) pilot. The website also includes news and events on clinical trials related to ongoing activities of the European Medicines Regulatory Network. The website is available at: <https://accelerating-clinical-trials.europa.eu/>

POLICY WATCH

1 September: Scottish Dementia Working Group and National Dementia Carers Action Network participate in consultation on proposal for a Commissioner for Older People in Scotland



Dementia does not discriminate between young and old, however, the members of the Scottish Dementia Working Group (SDWG) and of the National Dementia Carers Action Network (NDCAN) recognise that a significant number of people living with dementia, and dementia carers, are older. That's why they welcomed the opportunity to meet recently with Colin Smyth MSP (pictured, fifth from left, wearing a black blazer), to find out more about his proposal to establish an independent commissioner to promote and safeguard the rights and interests of older people.

Mr Smyth outlined the background to his proposal explaining that support for an independent champion for people in later life is increasing, particularly as a result of the many challenges older people faced during the COVID pandemic. He advised that Wales and Northern Ireland already have commissioners and expressed concern that Scotland is in danger of falling behind when it comes to an independent advocate championing the interests and amplifying the voices of older people.

The meeting heard about the way in which Children's Commissioners in the four nations of the UK have successfully championed the cause of children and considered how having a similar, independent, powerful voice speaking up for older

people could help deliver change for them in Scotland. Mr Smyth explained that the role of the Commissioner would be:

- Raising awareness of the interests of older people in Scotland and of the need to safeguard those interests
- Promoting the provision of opportunities for, and the elimination of discrimination against, older people in Scotland
- Encouraging best practice in the treatment of older people in Scotland.
- Keeping under review the adequacy and effectiveness of law affecting the interests of older people in Scotland
- Undertaking investigations into how service providers take account of the rights, interests, and views of older people in the decisions they take and the work they do.

Mr Smyth advised that his proposal would include a legal duty on the Commissioner to consult regularly with organisations who work with older people, such as Alzheimer Scotland, in order to ensure that the issues they are taking forward are those that matter to older people.

The members of the SDWG and NDCAN who met with him, explored a range of issues in relation to the proposal, including specific aspects of the role and functions of the Commissioner, particularly around conducting investigations and making recommendations; the cost of a Commissioner and the benefits and savings that could be derived from having one; the age of those that would fall within the remit of the Commissioner; the human rights challenges and issues faced by older people and carers; and, the appointment, term length and accountability of the Commissioner.

The discussion was extremely valuable in allowing the members of the two groups present to consider the proposal prior to responding to the consultation, which is open until 23 October 2023. More information on the proposal is available on the Scottish Parliament website:

<https://www.parliament.scot/bills-and-laws/proposals-for-bills/proposed-commissioner-for-older-people-scotland-bill>

21 September: Final policy roundtable discussion of dementia project in Montenegro is held on World Alzheimer's Day and emphasises the importance of building stronger networks

Within the framework of the project "Protecting of the right to dignified aging and dementia preventing", Institute Circle from Slovenia and NVU Impuls from Montenegro organised a fourth and final round table, with the aim of connecting important actors in the field of social care and local decision-makers. The project is supported by the European Union, Ministry of Foreign and



European Affairs of the Republic of Slovenia and Ministry of Public Administration of Montenegro.

The round table was held on 21 September 2023, in Nikšić (Montenegro), meaningfully on World Alzheimer's Day, aimed at raising awareness of dementia, reducing stigma, and educating about risk factors and prevention.

The meeting brought together key actors in the field of protection of elderly citizens and was focused on the topic "The importance of building a support network for people with dementia and their caregivers". It represented a significant step towards improving the care of people with dementia and their caregivers who, due to the need for constant care, are themselves at high risk of burnout. The goal of this round table was to emphasise the importance of creating a support network for these people and to provide guidelines to local governments and institutions for the improvement of social and child protection plans at the local level.

The round table was attended by representatives of local self-governments of Nikšić and Plužine, centres for social work in Nikšić and Podgorica, Red Cross Nikšić, Institute for Social and Child Protection, mentors, and volunteers on the project, as well as representatives of other relevant institutions. The discussions were inspiring, and the exchange of experiences and ideas among the participants contributed to a deeper understanding of the challenges faced by people with dementia and their caregivers.

During the meeting the Strategic Guidelines designed within the project were presented, with the aim of improving social protection plans of local governments and institutions, by prioritising older people and people with dementia, as well as therefore contributing to their improved quality of life.

The round table that was held on 21 September was a good example of how joint work and cooperation can bring about positive changes in society. The project "Protecting of the right to dignified aging and dementia preventing" continues the dedicated work to achieve its goals for the highest benefit of its target groups and beneficiaries, and looks forward to future innovations and achievements in the field of protection of senior citizens and prevention of dementia.

27 September: Roundtable event "Dementia – no one's business: are we ready for a dementia strategy?" held at Lithuanian Parliament

A roundtable discussion "Dementia - nobody's question: is it time for a national dementia strategy?" was organised by the association Dementia Lithuania, at the Seimas of the Republic of Lithuania (Lithuanian Parliament). The patron of the event was Monika Ošmianskienė, a Member of the Seimas of the Republic of Lithuania.

The roundtable was attended by guardians and representatives of persons living with dementia, members of the Seimas, representatives of ministries, the academic community and the providers of social and health services. The purpose of the event was to discuss dementia management in Lithuania, the current situation and the direction in which Lithuania needs to go regarding the formation of dementia policy and practice, in

order to manage the challenges posed by a rapidly-ageing society.

The vision of the association Dementia Lithuania is one where citizens of Lithuania are protected from dementia and those who have dementia are supported and valued. "In order to achieve this, we must first see things as they are, remove prejudices, dysfunctional systems," said event organiser Ieva Petkutė, head of Dementia Lithuania. She also noted that there are a lot of "invisible" components in the topic of dementia, such as the actual number of people living with dementia, dementia mortality, the cost of the informal care, etc.

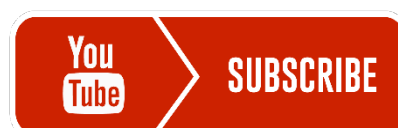
Jolita Švatiėnė, who shared her personal story of coming back to Lithuania after 12 years spent in Norway to take care of her mother, offered a space to explore a complexity of challenges that have to be taken into account, when creating the supportive and person-centred systems: the questions of social security, employment, women's rights and the need to support families are just a few.

Ministries acknowledged that close collaboration in dementia management is critical, but that the process is complex. The patron of the event Monika Ošmianskienė, noted that part of the challenges are related to organised efforts to encourage society to see that dementia is an important issue for all citizens: "We have to educate the public not only about ways to protect ourselves, but also to be less stigmatised - to involve the people around us and our loved ones to learn about dementia in order to contribute to the creation of an inclusive society."



The event was part of the project "Towards a Dementia Strategy: Situation Analysis and Public Awareness" which benefits from a grant under The Active Citizens Fund from Iceland, Liechtenstein and Norway, through the EEA Grants.

Sonata Mačiulskytė, Chairperson of European Dementia Carers Working Group, took part in this discussion. You can read her perspective in our "Living with dementia" news section.



SCIENCE WATCH

11 September: People with FTD from different ethnic backgrounds exhibit varying symptoms, according to a new study in JAMA Neurology

According to a new study published in the JAMA Neurology journal, people with frontotemporal dementia (FTD) from different ethnic backgrounds exhibit varying symptoms. These findings underline the risk of misdiagnosis for people from certain ethnic backgrounds, and the need for efforts to promote equitable access to an accurate, timely diagnosis for all.

FTD, like Alzheimer's disease, is a progressive, neurodegenerative disease that affects the way people think, function and behave. Caused by damage to brain cells in the frontal and temporal lobes, FTD causes particular symptoms such as loss of empathy and foresight, and issues with speaking or moving. Most people are diagnosed with FTD earlier in life (in their 50's and 60's), usually based on a clinical evaluation by doctors. However diagnosis of FTD is challenging, as people are often younger and symptoms can overlap with neuropsychiatric disorders. The goal of the new study, led by Lauren Massimo at the University of Pennsylvania, was to examine differences in clinical disease severity, function, and neuropsychiatric symptoms and at initial presentation comparing people with Caucasian, Asian or African-American backgrounds, with a diagnosis of FTD. To do this, they used National Alzheimer's Coordinating Center (NACC) data to determine whether clinical disease severity and neuropsychiatric symptoms differ between ethnic groups.

In their study, the researchers observed that African-American individuals had a greater frequency of delusions, agitation, and depression compared to Caucasian individuals. Individuals with an Asian background had a greater frequency of apathy, night-time disturbances, and appetite/eating changes compared to Caucasian individuals. The study also found that African-American people with FTD had higher levels of clinical disease severity and functional impairment at initial visit compared to other ethnic groups, even though they did not differ in symptom duration. These preliminary findings suggest that there are differences in neuropsychiatric symptoms and the extent of functional impairment between different ethnic groups. Considering the diagnosis of FTD is based on clinical symptoms, the existence of these ethnic disparities is concerning as certain patients with FTD may be at particular risk for misdiagnosis if their symptom profile does not fit within the current clinical criteria. Further research on facilitators and barriers to FTD diagnosis for different ethnic groups is required, to help researchers develop more effective strategies for engaging currently underrepresented individuals.

Read the article:

<https://jamanetwork.com/journals/jamaneurology/fullarticle/280945>

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12 September: ADNI aims to increase diversity in clinical trials

The Alzheimer's Disease Neuroimaging Initiative (ADNI) was launched in 2004 with USD 40 million in initial funding from the National Institutes of Health (NIH). Its primary aim is to improve Alzheimer's disease (AD) clinical trials, with this expected to translate into improved patient care. Since 2006, ADNI has shared clinical, neuroimaging and cognitive data and biofluid samples.

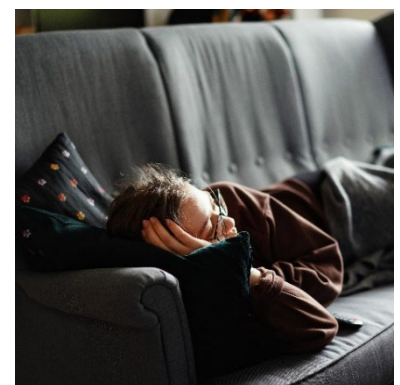
ADNI investigators led by Michael Weiner, MD, of the University of California, San Francisco, recently reviewed the initiative's sponsored trials from 2021 to 2022. Authors identified 1,459 publications from 2021 to 2022 that used ADNI data/samples and then reviewed the impact of 291 of these studies. The review published in the journal Alzheimer's and Dementia, details how ADNI studies improved disease progression understanding and clinical trial efficiency.

ADNI samples contributed to the development of plasma biomarkers such as phosphorylated tau for clinical use, and described prognostic abilities of amyloid beta, tau, neurodegeneration and inflammation biomarkers. Studies supported the amyloid cascade and detailed how genetic and vascular risk, co-pathologies, sex and resilience contribute to heterogeneity and biological subtypes of the disease. However, authors noted that the results may not be generalisable due to the limited cohort diversity. The ADNI-3 study recently drawn to a close and ADNI launched its latest study, ADNI-4, with an increased commitment to enrol participants from underrepresented populations in clinical trials.

<https://pubmed.ncbi.nlm.nih.gov/37698424/>

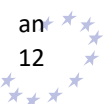
12 September: Study suggests that sedentary behaviour could be a potential risk factor for incident dementia

Sedentary behaviours, such as sitting while watching television or using a computer, have become increasingly common among the population. Previous studies have shown that sedentary-type activities are linked to various health problems (e.g. cardiovascular problems).



However, the association between sedentary behaviour and the risk of different subtypes of dementia (i.e. all-cause dementia) in older adults remains unclear.

In a new study published in JAMA, a team of researchers led by Dr David A. Raichlen from the University of Southern California (Los Angeles, US) gathered data from the UK Biobank and collected, using an accelerometer, measurements associated with body movements from 49,841 adults residing in Wales, Scotland, or England, aged 60 years or older, and who did not have a dementia diagnosis when they first wore the accelerometer. All the participants agreed to wear an



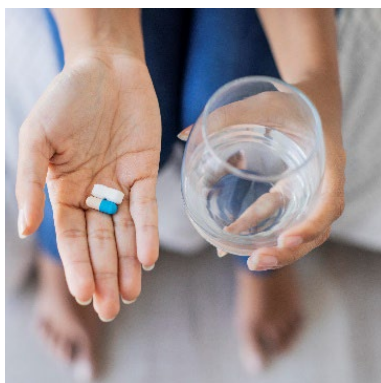
accelerometer for 24 hours per day for seven days on their dominant wrist. All of them were also followed up from the time the accelerometer was first worn (from 2013 to 2015) until they were either diagnosed with dementia, died, were lost to follow-up or until the last date of hospital admission (2021 in England and Scotland, and 2018 in Wales).

After collecting seven days of wrist accelerometer information, the team of researchers analysed the daily average duration of sedentary behaviour (hours per day), the average length and the maximal length of daily sedentary bouts, and the mean number of sedentary bouts per day (sedentary bouts were described as more than two consecutive 30-second epochs categorised as waking sedentary behaviours). During the time participants were followed up (almost seven years), 414 cases of incident all-cause dementia were identified. During this time, the team of researchers also found that there is a significantly positive association between the duration of sedentary behaviour (an average of 10 hours per day or more) and incident all-cause dementia in adults aged 60 years or older.

The study findings are in line with previous research and indicate that increased time spent on sedentary-type activities may be linked to lower cognitive performance and increased dementia risk. However, more research is needed to investigate whether this link is causal.

[Sedentary Behavior and Incident Dementia Among Older Adults | Dementia and Cognitive Impairment | JAMA | JAMA Network](#)

13 September: Alzheon reports positive findings from its Phase II trial of ALZ-801 for early AD



On 13 September, Alzheon, Inc., a clinical-stage biopharmaceutical company focused on developing new medicines for neurodegenerative disorders such as Alzheimer’s disease (AD), reported two-year findings from its Phase II trial evaluating ALZ-801 in

people with early AD.

ALZ-801 is an oral small molecule that works to inhibit the formation of amyloid-beta oligomers or toxic clumps. The open-label, multicentre and single-arm Phase II biomarker trial evaluated biomarker effects, clinical efficacy and safety of ALZ-801 tablet in 84 participants with early AD, who carry either one or two copies of apolipoprotein ε4 allele (APOE4) and showed positivity for amyloid and tau biomarkers in cerebrospinal fluid (CSF). Participants received ALZ-801 (265 mg) tablet once daily for two weeks and twice daily thereafter over a 104-week treatment period.

A total of 75 participants completed one year of treatment and 70 of them continued treatment for another year. 68 participants provided evaluable plasma for biomarker assays and were included in the primary analysis. In this population, ALZ-801 achieved a statistically significant reduction in plasma

p-tau₁₈₁, a key biomarker of neurodegeneration, reaching 45% at one year and 31% at two years. Moreover, participants receiving ALZ-801 demonstrated a statistically significant 28% reduction in hippocampus volume at two years, when compared with an external group of early AD patients from the Alzheimer’s Disease Neuroimaging Initiative (ADNI), a longitudinal observational multicentre study. On the cognitive scale, as assessed with the Rey Auditory Verbal Learning Test (RAVLT) and the Digit Symbol Substitution Test, participants treated with ALZ-801 demonstrated a consistent improvement after 6 months of treatment and remained stable and above levels at study’s start through two years. Finally, the safety profile of ALZ-801 remains favourable and consistent with the prior safety database of over 2,800 people with AD, with no increased risk of vasogenic brain oedema (Amyloid-Related Imaging Abnormalities, or ARIA). Common adverse events experienced in more than 10% of participants were COVID infection, mild nausea and decreased appetite.

ALZ-801 is in Phase 3 development for the treatment of early AD. The APOLLOE4 study fully enrolled 325 participants and topline data is expected in the third quarter of 2024.

<https://alzheon.com/alzheon-reports-industry-leading-biomarker-brain-preservation-and-clinical-benefits-following-24-months-of-treatment-in-phase-2-trial-of-oral-alz-801-valiltramiprosate-in-patients-with-early-alzhei/>

14 September: Anavex reports follow-on analysis data from its Phase IIb/III study of blarcamesine in early AD

On 14 September, Anavex Life Sciences Corp., a clinical-stage biopharmaceutical company developing therapeutics for the treatment of neurodegenerative and neurodevelopmental disorders including Alzheimer’s disease (AD), announced findings from a follow-up analysis to its Phase IIb/III study investigating blarcamesine in people with early AD.



The trial was a randomised, double-blind and placebo-controlled study that enrolled 508 participants with early symptomatic AD in Australia, Canada, Germany, Netherlands and UK. Participants received blarcamesine (n = 338) or placebo (n = 170) oral capsules once daily for 48 weeks. The Alzheimer’s Disease Assessment Scale-Cognitive (ADAS-Cog) and Alzheimer’s Disease Cooperative Study-Activities of Daily Living (ADCS-ADL) subscales were used as primary end points to assess the cognitive and functional efficacy of blarcamesine. The trial was successful in meeting the co-primary endpoints.

The company bolstered these clinical findings with two independent biomarkers data. The follow-up analysis demonstrated a significant reduction in pathological amyloid-β



levels in plasma, as well as a significant slowing in brain volume loss, when blarcamesine was compared with placebo.

When it came to safety, the most common treatment-emergent adverse event was dizziness, which was transient and mostly mild to moderate in severity. Participants who completed the trial were able to enrol in an ongoing open-label extension study, called ATTENTION-AD, where they all receive blarcamesine for about two years. The study is expected to finish next year.

<https://www.anavex.com/post/anavex-sphase2b-3trialofblarcamesine-anavex-2-73-inpatientswithalzheimer-sdisease>

21 September: Alzheimer’s Disease Data Initiative announces its inaugural cohort of William H. Gates Sr. Fellows



On 21 September, World Alzheimer’s Day, the Alzheimer’s Disease Data Initiative (ADDI) announced its inaugural cohort of William H. Gates Sr. Fellows.

The William H. Gates Sr. Fellowship is named after the father of Bill Gates, who passed away from Alzheimer’s Disease in 2020. The Fellowship is a two-year programme that provides researchers a USD 100,000 financial award, mentoring and network opportunities, and other supports such as publication assistance and conference attendance.

The first cohort of Fellows was selected following a competitive application process, and have a broad range of research interests ranging from artificial intelligence to genomics and epidemiology. They also span a wide geographical range, with Fellows based in the US, Australia, Asia and Europe – including Dr Natalia Vilor-Tejedor at Barcelona Beta Brain Research Center, Spain. For the next two years, Fellows will use data from clinical studies and novel statistical approaches to advance their research programmes and make new discoveries on Alzheimer’s disease and related dementias. Read more about the Fellows, here:

<https://www.alzheimersdata.org/fellows/2023>

25 September: Anti-amyloid drug lecanemab is granted regulatory approval in Japan

Yesterday, Eisai and Biogen announced that Japanese regulators had approved their anti-amyloid drug, lecanemab, for the treatment of mild cognitive impairment or mild dementia due to Alzheimer’s disease. Lecanemab, which is marketed under the Leqembi® brand name, was approved by the US Food and Drug Administration in July. The drug was granted priority review status by the Japanese Ministry of Health, Labour and Welfare (MHLW) in January, with a review panel greenlighting its approval in August.

Lecanemab is one of the first approved disease-modifying therapies for Alzheimer’s disease (AD). As a monoclonal

antibody therapy, lecanemab targets and clears amyloid plaques that build up in the brain during the development of AD. Approval by Japanese regulators was based on the results of CLARITY-AD, a Phase 3, confirmatory trial which enrolled 1,795 participants who received either lecanemab (10mg/kg) or a placebo biweekly via intravenous infusion. This study met all its primary and secondary endpoints, demonstrating a 27% reduction in clinical decline after 18 months of lecanemab treatment on the global cognitive and functional scale, CDR-SB. In their press release, Eisai and Biogen highlighted results on a caregiver-reported assessment scale (the ADCS MCI-ADL) which showed a 37% benefit compared to placebo. The most common side-effects caused by lecanemab included amyloid-related imaging abnormalities (termed ARIA), which are linked to swelling or small bleeds in the brain. While most cases of ARIA in the CLARITY-AD trial were mild or asymptomatic, 0.7% caused seizures and other severe symptoms.

In accordance with an approval condition imposed by the MHLW, the companies will conduct a post-marketing surveillance study in all patients who receive lecanemab, until data from a certain number of patients are accumulated following market launch of the drug. Lecanemab is currently under review at the European Medicines Agency, with an outcome expected later this year or in early 2024.

Read the full press release, here:

<https://www.eisai.com/news/2023/news202359.html>

27 September: Ionis Pharmaceuticals and Roche enter new partnership for two novel programmes for Alzheimer’s and Huntington’s diseases

On 27 September, Ionis Pharmaceuticals announced that it has entered in a new collaboration agreement with the pharmaceutical company Roche for two early-stage programmes for Alzheimer’s disease (AD) and Huntington’s disease (HD). The new deal covers two undisclosed early-stage programmes for investigational RNA-targeting medicines.

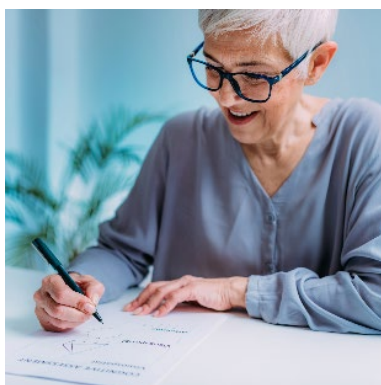


Under the terms of the partnership, Ionis will be responsible for progressing the two programmes through pre-clinical studies. Roche gains exclusive worldwide rights and will be responsible for clinical development, production and commercialisation activities of the medicines if they receive regulatory approval. The alliance will leverage Ionis’ expertise discovering medicines that target the root cause of the two central nervous system diseases and Roche’s global experience developing and commercialising therapies for nervous system disorders. Ionis will receive a USD 60 million upfront payment from Roche and is eligible to receive development, regulatory and commercial milestone payments, and tiered royalties.

This new agreement extends previous agreements over the past decade, starting with their collaboration in 2013 for tominersen, an Ionis-discovered investigational medicine for HD. Tominersen is currently being evaluated by Roche in a Phase II proof of concept study, named GENERATION HD2, in people with prodromal or early manifest HD.

<https://www.prnewswire.com/news-releases/ionis-enters-agreement-with-roche-for-two-novel-rna-targeted-programs-for-alzheimers-disease-and-huntingtons-disease-301939627.html>

28 September: New study suggests there may be a link between concussion early in life and cognitive decline in later life



A recent study was published in the online issue of *Neurology*, the medical journal of the American Academy of Neurology, and looked at identical twins who share the same genes and similar childhood experiences. The study demonstrated that having a concussion early in life is

linked to having lower scores on tests of thinking and memory skills years later as well as having a more rapid decline in those areas.

The participants of the study were 8,662 men who served in World War II. They took a test of thinking skills at an average age of 67 and then again up to three more times over 12 years. A total of 25% of the participants had experienced a concussion in their life. The researchers found that each twin who had had a concussion was more likely to have a lower level of cognition (measured on a test score) and cognitive decline, than his twin without concussion, although the effects were modest. In particular, a twin who had experienced concussion was more likely to have a lower test score at age 70, than his twin without concussion, especially if either the concussion had led to a loss of consciousness because of a head injury, or if they were 25 or older when the injury happened.

It is worth highlighting that the study did not account for the effects of other factors that can be linked to cognition such as high blood pressure, alcohol use, smoking status, education, hearing loss or physical activity. Another limitation of the study was also that the participants self-reported whether they had suffered a traumatic brain injury so it is possible that some had forgotten whether they had experienced traumatic injury.

<https://n.neurology.org/content/early/2023/09/06/WNL.000000000207819>



WORLD ALZHEIMER'S DAY

5 September: Austria runs a World Alzheimer's Month awareness campaign called "Self-help works"

In September 2023, World Alzheimer's Month, the non-profit association Dachverband Demenz Selbsthilfe Austria (of the umbrella organisation Dementia Selbsthilfe Austria) launched a nationwide campaign entitled "Selbsthilfe wirkt" (self-help works). In this campaign, affected persons and relatives share their personal experiences in dealing with dementia and offer personal insights into their thoughts, experiences and emotions. The campaign aims to educate, to sensitise the public to the issue of dementia and raise awareness of the positive impact of self-help in dealing with dementia-related changes.



Dementia often brings great changes and challenges. In addition to cognitive impairments, social and psychological problems often arise. Stigmatisation and the fear of losing memories and important skills affect life. Without support and social networks, those affected risk losing their independence early on, accompanied by feelings of being overwhelmed, of dependence and of loneliness.

Self-help (Selbsthilfe) is a main pillar in the health care system and provides decisive help in coping with the disease - also in the area of cognitive impairments such as dementia.

Active exchange and confidentiality during group meetings help protect against isolation, provide comfort, promote autonomy and expand skills in dealing with disease-related changes. Mutual understanding of the individual situation relieves and encourages both the person with the dementia and their family and friends.

Angela Pototschnigg (70 years old) has been living with cognitive changes for 10 years. She emphasised, "I am proud that I have learned to deal with my illness. My dignity has remained untouched by it." From her own experience, she knows the impact of the diagnosis and what it means for the lives of those affected and their families. Angela, who is also a member of the European Working Group of People with Dementia, is one of seven people who lend their voice and face to the campaign "Selbsthilfe wirkt".

The central element of the campaign is composed of seven stories from affected persons and relatives who share their individual experiences and insights in short videos on social media and whose faces can be seen on approximately 8,000 posters in doctors' surgeries and health care facilities throughout Austria. These stories not only share hope that living well with dementia is possible, but they also emphasise

the importance of self-determination, self-worth, self-care and other key aspects that have an enormous impact on life.

You want to get in touch? Contact Johanna Püringer (Obfrau) via info@demenzselbsthilfe.at

<https://www.demenzselbsthilfeaustria.at/kampagne/>

<https://www.facebook.com/demenzselbsthilfeaustria>

12 September: Alzheimer Portugal launches World Alzheimer's Day campaign based on the song "Every note brings a story" by well-known Portuguese songwriter João Só



Inclusion is the keyword of the Alzheimer Portugal campaign that was launched for World Alzheimer's Day, with the support of Roche, aiming to raise awareness among the Portuguese population about the role that each one can play in fighting stigma and promoting wellbeing, quality of life and social participation of people living with dementia and their families.

The campaign is based on the song "Every note brings a story" which the famous Portuguese songwriter, João Só (pictured, third from left), specially created for this occasion.

It's a beautiful melody that wants, through notes and chords, to remind us that we are all the same, in a message which draws attention to the need to promote a more inclusive society.

After the campaign launch event on 12 September, the initiative and the song were disseminated on Alzheimer Portugal's social media channels and generated the opportunity to talk about dementia on Portuguese television and radio and in the newspapers.

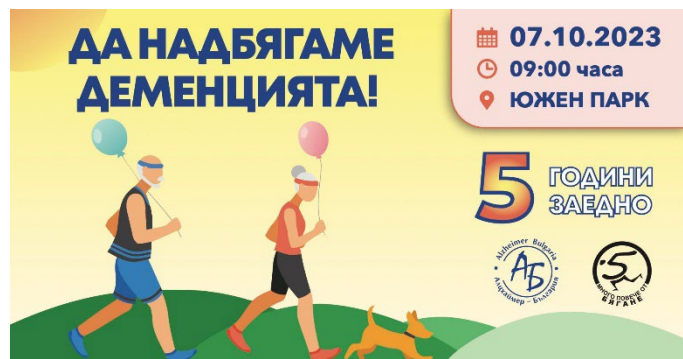
Despite the intense and long-term work that the organisation has been developing, it remains a great challenge to raise awareness in the community about what it is like to live with Alzheimer's disease or another form of dementia and Alzheimer Portugal believes that through music, a universal language that has the power to unite us, "we can reach people's hearts and achieve positive social change."

As the songs says: "Some more remembered, others less", we are equal, "in search of the right tone / Equally, looking for affection / Equal, in the desire to be close" to each other.

Watch the video:

<https://www.youtube.com/watch?v=xsBzRGIPc8>

21 September: Alzheimer Bulgaria focuses on the message "Health prevention through sport" this World Alzheimer's Day and will participate in the fifth edition of "Let's Outrun Dementia Together"



Alzheimer Bulgaria will take part, for the fifth consecutive year, in the regular Saturday 5 km run organised by "5krun", on 7 October at 09.00 in the South Park in Sofia. The run, with the cause "Let's outrun dementia together" has already become a tradition for the association and is charged with the message "health prevention through sport". This initiative aims to encourage regular amateur runs in the park to help people with dementia and their families, in their role as carers in several ways:

- prevention through sport
- slowing down the rate at which the disease progresses
- social interaction.

"Health prevention through sport" is the message with which Alzheimer Bulgaria marked World Alzheimer's Day this year, on 21 September, followed by two other days dedicated by the international community to physical and mental health - International Day of Older Persons (1 October) and World Mental Health Day (10 October).

Each year, more and more people participate in the run, wearing stamped T-shirts with the slogan. They enjoy the time together and the opportunity to be active.

21 September: Czech Alzheimer's Society marks World Alzheimer's Day with a series of "Memory Week" activities across the country

World Alzheimer's Day is commemorated every year in the Czech Republic as "Memory Week". This year, Memory Week lasted 21 days and during those days, the Czech Alzheimer Society (ČALS) organised several traditional events.

The mobile counselling centre in the Westfield Chodov shopping centre was again a success, open to the public for three days at the beginning of September.

Many people also came to the memory screening, which took place in the building of the public Czech Radio in the third week



of September. During this week, the issue of living with dementia was more widely covered by the media. Czech Radio invited Věra Ryšavá, member of the European Working Group of People with Dementia and ČALS consultant Eva Jarolímová for the main interview of the day. Věra can tell her story so well that life with dementia is suddenly very understandable even to people who do not pay attention to media reports featuring experts.

The contact points of the ČALS also joined the celebration of World Alzheimer's Day and one example of a very successful event was the mobile counselling organised by the Centre for Social Assistance and Services in Hradec Králové. Similarly successful were a series of lectures held in Naděje in Zlín.

Next year, Memory Week will most likely become Memory Month, and ČALS is looking forward to it!

21 September: Memory Walk highlights aspects of care in Lithuania



Dementia Lithuania organised a Memory Walk this year, marking World Alzheimer's Day. The programme was organised in collaboration with the Lithuanian Sports University and touched upon the theme of World Alzheimer's Month 2023, which was "never too early, never too late".

Jolita Švatiėnė, who is the carer for her mother who has Pick's disease, led the practice to reflect on the inner resources that people might have, when facing a challenging situation. "Finding what brings us joy, focusing on what things are in our control rather than what isn't – that's what the best we can do for ourselves".

Professionals working in the field of dementia, including psychologist Solveiga Žukauskienė and Gintarė Žičkevičienė invited the participants to explore how to extend the years of quality life for a person living with dementia, and examined the aspects of quality of communication in a care relationship. Associate Professor Vida Česnaitienė from the Lithuanian Sports University led physical activity practices that everyone could integrate in their daily life to support their wellbeing.

People not only from Kaunas, but from all around the Lithuania came to take part. The event was a manifestation of the community that is touched by dementia. Around 50 people who are caring after their relatives and people who work in the field of dementia gathered for the Memory Walk.

According to Ieva Petkutė, lead of "Dementia Lithuania" and curator of the event: "The event had a symbolic meaning of not only sharing the path, the pace and the experience with each other. It is also a manifestation that the people are living with dementia do lack visibility."

The organisers of the event collected feedback from the participants, which highlighted the importance of making this event a tradition. Here are some of their words: "This is a wonderful way to inform society and also for the people, who are challenged by dementia to meet people who understand."

The event of such a framework attracts the people. The most important is that you can meet people, who also care for their loved ones – then you feel supported and feel visible".

Dementia Lithuania is committed to continuing to organise the Memory Walk, going forward.

23 September: Association Luxembourg Alzheimer organises 22nd edition of its annual Memory Walk marking World Alzheimer's Day



On Saturday 23 September 2023, the Association Luxembourg Alzheimer (ALA) organised its 22nd Memory Walk on the Place Clairefontaine in Luxembourg City. From 11am to 5pm, visitors were able to find out about ALA services, Alzheimer's disease and other forms of dementia at various information stands. In a relaxed atmosphere, they had the chance to meet new people and take part in a wide range of discussions.

Alongside the food and drink stalls, there was also a range of entertainment, including a concert by Serge Tonnar & Band and music by Les Brasseurs. The Memory Walk gave participants an opportunity to show their solidarity with people living with dementia. Accompanied by a tourist guide, the walk took participants to the Place de la Constitution, where they were given explanations about the Gëlle Fra, Claus Cito and the Plateau Bourbon.

The theme of this year's Memory Walk was "Dementia - the world is turned upside down", because a diagnosis of dementia can turn one's world upside down. Daily routines, interactions and perceptions of the environment change. It's all very unsettling for the people affected and those close to them. We can all do something to support them. People with dementia

and their families need to feel accepted and integrated into society despite their illness.

The Minister for Family Affairs, Max Hahn, also honoured the ALA with his presence.

24 September: The Alzheimer Society of Ireland celebrates Alzheimer’s Memory Walk 2023

World Alzheimer’s Month culminated across Ireland, in the annual Alzheimer’s Memory Walk, proudly supported by Payzone, which took place in over 30 locations nationwide on 24 September.

There was an incredible turnout at the family-friendly event, with 4,000 walkers - in Ireland and across the globe - coming together to honour, celebrate and help to raise vital funds and awareness for people living with dementia and their family carers. Communities walked in support of families affected by the condition, and to remember those who have passed away after living with dementia.

The Alzheimer Society of Ireland (ASI) staff, local champions, Board, volunteers, advocates, supporters and people living with dementia and their families all came together to support the 64,000 people living with dementia in Ireland and their family carers.

Funds raised will support vital services, such as The ASI’s National Helpline, Dementia Advisers, Family Carer Training, Care, and Support Groups.

The ASI Memory Walk garnered significant national and local media coverage. Kathleen Farrell, member of The Irish Dementia Working Group, Maeve Montgomery, ASI Dementia Adviser for Louth, Tony McIntyre, member of The Dementia Carers Campaign Network and Memory Walk ambassadors, former Justice Minister Nora Owen and entrepreneur Ellen Kavanagh Jones were interviewed live by Memory Walk Ambassador Martin King on national morning television show, Ireland AM.

There’s still time to support Memory Walk - visit [Memory Walk.ie](http://MemoryWalk.ie)



MEMBERS’ NEWS

16 September: Enduring love - couple affected by Alzheimer’s disease marks their 60th wedding anniversary while raising funds for The Alzheimer Society of Ireland



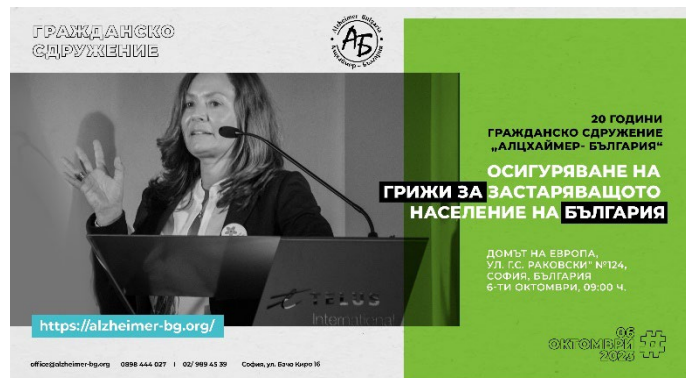
Brid Kelly, who lives with Alzheimer’s, and Vincent Kelly her husband and primary carer, celebrated 60 years of marriage with a vow renewal ceremony at The Alzheimer Society of Ireland’s (ASI) Curlew Road Day Care Centre in Dublin, garnering national media attention.

Brid and Vincent, a couple who navigate life with dementia, marked their 60th wedding anniversary with a special vow renewal ceremony at The ASI’s Curlew Road Day Care Centre in Drimnagh, Dublin on 15 September 2023.

The event - which honoured the past while embracing the present - took place ahead of World Alzheimer’s Day on 21 September, to raise funds for the Centre. Brid has attended Curlew Road for several years, and the Centre has greatly supported the couple throughout their journey with dementia. Family, friends, fellow Curlew Road Service users and their carers, and ASI Staff attended the ceremony.

The ceremony paid tribute to their original wedding day, which took place in Rathfarnham Church in Dublin on 16 September 1963. For Vincent, love means giving: “Love to me; love is giving. Bottom line.” Rather than wedding gifts, he encouraged well-wishers to donate to The ASI’s Curlew Road Day Care Centre in Dublin, which has made a significant difference in their lives. 64,000 people live with dementia in Ireland. Alzheimer’s is the most common type of dementia.

20 September: Alzheimer Bulgaria is hosting a conference to celebrate its 20th anniversary



This year, Alzheimer Bulgaria celebrates its 20th anniversary. The past two decades were dedicated to caring for the elderly and for people with dementia, improving their quality of life and that of their families and loved ones.

Alzheimer Bulgaria wants to celebrate this anniversary by not only looking back at all it has achieved, but also by thinking about what lies ahead. That is why the organisation will host a conference on 6 October, under the slogan “Where to now? Providing care for the aging Bulgarian population.”

The conference will be held on the 6 October from 9:00 AM at the House of Europe, 124 G.S. Rakovski street, Sofia, Bulgaria. There will be a livestream and a recording. The working language is Bulgarian, but most presentations will be translated into English.

The conference will look at different aspects of the topic of dementia and the work of Alzheimer Bulgaria. Different perspectives on the topic will be touched upon – on the part of politics, medicine, technology and care.

At the event, delegates will have the opportunity to hear the professional opinion of experts in the field of dementia research and care – representatives of national and international organisations and institutions, as well as the stories of people with dementia and their caregivers. Prominent speakers include Jean Georges, Executive Director, Alzheimer Europe, prof. doc. Liana Apostolova, scientists, IT specialists, administrative and care staff, etc., all of whom will share their experience and knowledge.

Alzheimer Bulgaria will be happy to share this moment with you! Sign up here, to attend the event live:

<https://forms.gle/d1QFgQWkzmSxMJK96>

27 September: Scottish Dementia Working Group members have their say on Scotland’s National Care Service

During 2022, members of the Scottish Dementia Working Group (SDWG) had their say on the Scottish Government’s proposals for a National Care Service for Scotland. You can read more about this in the [Active Voice Annual Report 2022](#)

This year, the members continue to engage with the National Care Service proposals as they proceed through the Scottish Parliament. The SDWG is keen to ensure people with personal experience continue to have their say, share their views, and

take the opportunity to play a part in creating something that will hopefully change things for the better for people with dementia. As such, the group was pleased to be able to participate in a recent National Care Service “Making Sure My Voice Is Heard” session in Strathpeffer in the Highlands, attended by SDWG member Margaret Northedge (pictured, right) and her husband Barry Northedge (pictured, left), who is a member of the European Dementia Carers Working Group (EDCWG).

The session, organised by the Scottish Government, explored issues around accessing social care support, eligibility for and being assessed for social care support. This was one of several co-design sessions taking place over the summer, and given the location of this session it had a particular focus on issues faced by people in rural and remote locations. Margaret and Barry live in a beautiful Highland village, so they are well acquainted with the issues faced by people living in these areas of Scotland.

The couple spoke about their own experiences and they, along with the Alzheimer Scotland Active Voice team members in attendance, highlighted what’s important to people living with dementia, their families and carers in relation to accessing social care support. The session explored what does and doesn’t work currently and discussed issues such as the importance of community link workers, and the possibility of ensuring people had a single point of contact to make it easier to access social care support.

The session considered the importance of providing support before a crisis point is reached; it looked at how best to deliver positive outcomes, involving family and friends and a “whole community” approach; as well as discussing the need to ensure self-directed support allows for greater flexibility, particularly in remote and rural areas where options for support may be limited.

The Scottish Government is still working towards 2026 for the introduction of the new National Care Service, and further co-design activities will take place over the next 18 months. The SDWG will continue to ensure the voice of those with personal experience is fed into the new National Care Service co-design process.



Pictured: Barry and Margaret Northedge, with Wendy Rankin-Smith (centre)

Barry Northedge commented:

"Margaret and I were extremely pleased to be encouraged by Wendy Rankin-Smith and Chris Kelly, Active Voice Team members of Alzheimer Scotland, to participate in the National Care Service consultations. We live in a very rural part of Scotland and the challenges that we face are distinctly different from some of our urban colleagues and for that very reason it is vitally important that we are given the chance to be heard in national consultations. Whatever structure is put in place for a National Care Service, it has to meet the needs of all parts of the country and all parts of society. There has to be an expectation of equality of service wherever you live and whoever you are and that can only be achieved if those minority and 'rural voices' are heard. The Active Voice Team supports and encourages people with lived experience, such as Margaret and I, to become involved, to be heard and to campaign for the services that we all deserve. We have opinions based on personal experience and those opinions matter!"

27 September: Dementia Lithuania gathers support on its petition for a dementia strategy in Lithuania



The association Dementia Lithuania launched a petition calling for a dementia strategy in Lithuania. The association stated: "In order to properly respond to the economic, social and health challenges related to dementia, Lithuania needs to have long-term, purposeful goals and an action plan. Dementia is

currently an incurable neurodegenerative syndrome that affects a person's cognitive functions and ability to take care of themselves. Dementia poses significant economic, health and social well-being difficulties for Lithuanian society, as well as throughout the entire world. With effective dementia management measures in the state, up to 40 percent of cases of dementia (Lancet, 2020) can be prevented or delayed, and those who already have dementia can be provided with adequate care."

The dementia situation in Lithuania is raising concerns:

- Currently about 42,000 people have dementia, and by 2050 this number will double.
- The public is not informed about effective strategies to reduce the risk of dementia.
- Dementia is usually diagnosed late: the public and specialists lack the knowledge to recognise the first signs and because of widespread negative attitudes related to dementia, people avoid seeking help in time.
- Health and social service systems are not ready to provide accessible, individualised and quality assistance to every citizen in a timely manner.
- There are many gaps in the training of specialists, in early diagnosis and post-diagnostic care.

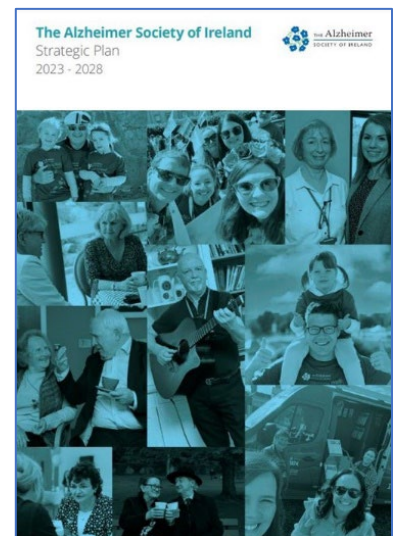
- Most people with dementia live at home, cared for by relatives without the necessary knowledge or skills. Without adequate support, such individuals face negative economic, health and social welfare consequences.

A national dementia strategy in Lithuania would help to prepare for dementia-related difficulties, reduce the risk of dementia, improve the quality and availability of services by providing assistance to persons with dementia and their relatives, stimulate innovations in the field and establish trustworthy monitoring of the key dementia indicators.

The petition, which was open for over a month, collected nearly 2,000 signatures from individuals who have personal experience of dementia or are working in the field. Support was also officially expressed by such organisations as the Association of Social Work Schools, the Association of Nursing Specialists, and the Association of Municipal Public Health Bureaus. The next step is for Dementia Lithuania to present its petition to the Parliament of the Republic of Lithuania.

27 September: The Alzheimer Society of Ireland is thrilled to present its new Strategic Plan 2023 – 2028

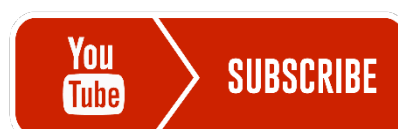
The Alzheimer Society of Ireland (ASI) has a new Strategic Plan 2023 – 2028, which outlines the organisation's crucial role in supporting people living with dementia, their family carers, and supporters in Ireland. It comes at a pivotal time in developing Ireland's understanding and response to dementia. This strategy is The ASI's blueprint for the next five years and builds on its past achievements



As part of The ASI's strategic process, the organisation talked with and listened to people living with dementia, carers of people living with dementia, its volunteers, staff, Board members and partner organisations.

The new strategy sets out an ambitious vision for equity of access to high-quality services and supports, improving the ability of people with dementia to live well at home and in their communities, for as long as possible.

For more information and to read the new strategy, please visit: <https://alzheimer.ie/about-us/our-strategy/>



LIVING WITH DEMENTIA

26 September: "Why am I here?" carer Carmel Geoghegan considers the purpose and importance of Public Involvement work



"Why am I here?" As someone who has been involved as a public/patient advocate for ten years, this is a question I ask myself on a regular basis.

Way back in 2013, I got involved in my first ever Public Patient Involvement (PPI) project. Of course it was all very new and mysterious as this was a new concept and also my life prior to 2010 had been on a very different path.

I became my mum's primary carer overnight and lost my dad in a whirlwind battle with cancer. Life is precious and while we are all busy we need to live in the moment and make all our actions count.

My life changed dramatically. I returned to education so I could be a better advocate for my mum and, after she passed away, I decided to continue to try and highlight some of the flaws in our health system. Of course this is never easy as you are going up against "the System", which self protects at all costs.

My first encounters with researchers and the academic world were inevitably quite scary and it took some time to build my confidence and my ability to engage with all the various stakeholders round the table. It also took time to find my voice, as I had envisioned it.

Joining this new world of research is a great move to allow me to help make changes and to ensure that the most important voice at the table is heard, that of the lived experience, which no other person can represent. Everyone's experience is different and all are relevant, so when joining a PPI group, it is important to remember that you are there with your own experience but you are also there to represent those who have no voice at the table.

Over the past ten years, my life has become a kaleidoscope of experiences, feelings, emotions, learning, meeting amazing people and hopefully influencing some change. PPI work has many facets, depending on the project itself, the individuals involved, where the project is based – at national, European or global level - who the lead researcher/organisation/institution is and what their attitude and understanding is regarding the value of the voice of PPI representatives.

This engagement is very varied and, in my opinion, it is what constitutes good or bad research interactions, which are a vital element of the process. What are the key foundation stones that need to be addressed to secure a solid experience and an output of truly meaningful research?

- PPI representatives should be able to voice their opinions on all aspects of a project/piece of research.
- Engagement should be seen as a continuum of activities and outputs.
- Consistency and transparency should become standard practice in PPI.
- As PPI is the bridge between the researchers and the general public our involvement should be focused on tangible outputs that can enhance life in general.
- There are now a number of well-developed frameworks and guidelines available to use as a reference for building a solid understanding of a working relationship between all stake holders. Our input should include influencing and shaping outputs from the start to the finish, establishing and receiving updated reports on monitoring and evaluation, and holding stakeholders accountable for ensuring consistency in the delivery of outcomes.
- It is important to allocate adequate funding in the project budget for PPI. Though reimbursement for our time can come in many forms, not just monetary: We can be co-authors, co-researchers, co-facilitators, as we also want to be encouraged and facilitated to build our own capacity and to foster a culture of respect and equality so that we can be more effective collaborators.

26 September: Sonata Mačiulskytė, Chairperson of European Dementia Carers Working Group, takes part in World Alzheimer's Month panel discussion at Lithuanian Parliament focusing on the importance of a national dementia strategy

August and September were very intense months for the association Dementia Lithuania. Being a Board member of the association, I had the honour to be one of the speakers, representing people living with dementia and their carers in the panel discussion dedicated to World Alzheimer's Month and the end of a campaign calling for a national dementia strategy in the country. The panel discussion, titled "Is Dementia Nobody's Question: Is It Already Time for National Dementia Strategy?", was organised in the Parliament of the Republic of Lithuania, hosted by Monika Ošmianskienė, Member of the Lithuanian Parliament and Chairperson of the Disability Affairs Committee.

Parliament Members, representatives of the Ministries of Social Security and Labour and Health, representatives of the academic community, service providers, carers and representatives of people with dementia gathered in the Constitution Hall. The purpose of the event was to discuss the situation of dementia management in the country, the status quo and the direction in which dementia policy and practice should be directed to address the challenges of a rapidly ageing society.

Carers, doctors and service providers spoke out about the limitations of the national system: Uneven access to health services, late diagnosis, lack of inter-agency and cross-sectoral collaboration, as well as a lack of post-diagnostic support. Both Ministries acknowledged that close collaboration in dementia management is critical, but noted that the process is complex. The stalled tax reform is also holding back positive changes. Without inter-agency and cross-sectoral collaboration people with dementia and carers remain trapped by bureaucracy.

The symbolic handing over of the call for action wrapped up the panel discussion. Lithuanian residents were invited to speak out about the need to have a national dementia strategy, with around 2,000 people responding to this call. Supporting letters were received from the Lithuanian Union of Nurses, the Lithuanian Association of Social Work Schools and from the Association of Public Health Bureaus in Municipalities. A petition appeal will now be prepared and sent to the Parliamentary Petitions Committee.

Pictured: Sonata (right) taking part in the World Alzheimer's Month panel discussion



DEMENTIA IN SOCIETY

1 September: Janni Ahlgren receives Alzheimer Life Scholarship from HRH Queen Silvia of Sweden



Janni Ahlgren, daughter and supporter to her father Stefan Eriksson, who was until recently a member of the European Working Group of People with Dementia, has received an Alzheimer Life Scholarship from HRH Queen Silvia of Sweden. Janni and Stefan have been fighting to remove stigma and to increase knowledge about Alzheimer's disease and dementia for seven years and have been dementia ambassadors at national and European level, speaking to policymakers, researchers and students and participating in feasibility studies for various research projects, among others. Janni has edited films on their travels and tried to spread them to inspire people to continue living as well as possible for as long as possible.

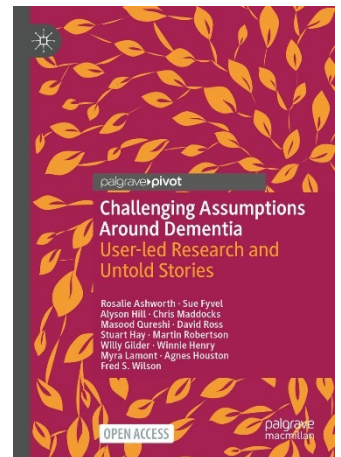
Janni is an ambassador for the Swedish Alzheimer's Foundation and continues to fight alongside them. "Being selected by a jury and being recognised in this way means so much to me and my family. Thank you so much to everyone involved", said Janni.

<https://alzheimerlife.se/eldsjalarna-som-bryter-stigmat-kring-alzheimer/>

NEW PUBLICATIONS AND RESOURCES

1 September: New book on challenging assumptions around dementia published in open access

On 1 September, a new book called "Challenging Assumptions Around Dementia: User-Led Research and Untold Stories" was published. The co-authors are people affected by different forms of dementia and members of the Patient and Public Involvement Group of NHS Scotland's Neuroprogressive and Dementia Network. Their book seeks to challenge



preconceived ideas that dementia only affects older people, that it's all about memory loss and that a dementia diagnosis represents the end of someone's active life.

Their work was brought together by research psychologist Dr Rosalie Ashworth who leads the Partners in Research initiative, focusing on getting those with lived experience to become more involved in informing research – and moving the focus of research from the illness to the people affected by it. Dr Ashworth said: "A huge part of what the co-authors are saying is that your life will be different - but that doesn't mean it's over. They want to encourage people to find what is meaningful to them and to create a new life with the diagnosis of dementia."

"The plan had been to focus on the different types of dementia and the different experiences people had. But when we all

came together, that became just one chapter and so many other things needed to be included.”

One of the twelve co-authors, Agnes Houston, former Vice-chair of the European Working Group of People with Dementia, said she hopes that every NHS professional will read the book. Her dementia affects her senses and, even after her diagnosis, professionals were telling her she couldn't possibly have dementia, forcing her to go through the process to have her diagnosis confirmed a second time: “I've never looked back. I decided – what do they know? It's my diagnosis. It's my life. I will live it the way I want to.”

You can find the book (open access), here: <https://link.springer.com/book/10.1007/978-3-031-27223-3>

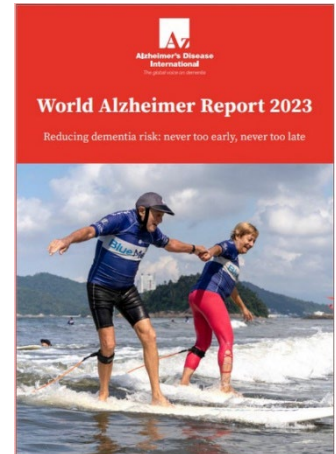
21 September: Alzheimer's Disease International publishes World Alzheimer Report 2023

On World Alzheimer's Day, 21 September, Alzheimer's Disease International published its World Alzheimer Report 2023. This year's report is called "Reducing Dementia Risk: Never too early, never too late".

The report, which is written in a journalistic style with key case studies, focuses on reducing the risk of dementia and offers global insights into the ways in which dementia risk factors are experienced around the world.

It examines the drivers behind risk reduction and provides an accessible overview of both modifiable and non-modifiable risk factors as well as the benefits of lifelong risk.

The report also highlights global disparities in individuals' ability and means to mitigate their risk of dementia, galvanising a call to action for governments to provide population-based systemic changes to promote risk reduction and the importance of dementia research. Read the report: <https://www.alzint.org/resource/world-alzheimer-report-2023/>



Contact Alzheimer Europe:

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Alzheimer Europe Board:

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

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AE CALENDAR 2023

Date	Meeting	AE representative
5 October	European Disability Forum ENGO meeting	Owen
5 October	EC review meeting for the VirtualBrainCloud project	Angela
9 October	EPND Workshop on biomarker best practices	Angela
10-11 October	WHO Europe Regional summit on policy innovation for healthy ageing in the WHO European Region (Lisbon, Portugal)	Owen
10-12 October	Lausanne X Workshop (Lausanne, Switzerland)	Angela
15-16 October	Meeting of the EWGPWD and of the EDCWG	Ana, Daphne, Soraya and Angela
16 October	Alzheimer Europe Annual General Meeting (Helsinki, Finland)	AE members, Board and staff
16-18 October	33 rd Alzheimer Europe Conference "New opportunities in dementia care, policy and research" (Helsinki, Finland)	AE members and supporters
18 October	AI-Mind Ethics workshop	Angela, Ana and Cindy
19 October	PatternCog General Assembly (Helsinki, Finland)	Jean, Cindy and Soraya
19-20 October	AI-Mind General Assembly (Helsinki, Finland)	Cindy
25 October	Liverpool Dementia Conference (Liverpool, United Kingdom)	Chris

CONFERENCES 2023

Date	Meeting	Place
15-19 October	WCN 2023 - The XXVI World Congress of Neurology, https://wcn-neurology.com/	Montreal, Canada
16-18 October	33 rd Alzheimer Europe Conference, "New opportunities in dementia care, policy and research", www.alzheimer-europe.org/conference Helsinki, Finland	Helsinki, Finland
25 October	Liverpool Dementia & Ageing Research Forum, https://www.alzheimer-europe.org/node/237018	Liverpool, UK
15-17 November	Université d'automne «Éthique et maladies neurologiques évolutives» 2023, https://www.espace-ethique.org/actualites/universite-dautomne-ethique-et-maladies-neurologiques-evolutives-2023	Marseille, France



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33rd Alzheimer Europe Conference

New opportunities in dementia
care, policy and research

Helsinki, Finland

16 - 18 October 2023 #33AEC

www.alzheimer-europe.org/conferences

