

ALZHEIMER EUROPE NEWSLETTER

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WELCOME



Alzheimer Europe was delighted to host a Public Involvement event in Luxembourg this month, bringing together six European research projects for a series of consultations focusing on dementia and brain health

research. It was the first event of its kind to take place in Luxembourg and the first attended by the Advisory Boards of six EU-funded projects (EU-FINGERS, LETHE, Multi-MeMo, eBRAIN-Health, EPND and ADIS) all of which focus on different aspects of brain health and dementia research. The event was funded through the Joint Programme on Neurodegenerative Diseases, Innovative Medicines Initiative, and Horizon Europe. It was an important opportunity for all projects represented to share knowledge, experience, insights and ideas, with the aim of helping to move research forward, together.

We are proud to take part in these and other European projects, together with members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG), all of whom contribute to the progress of research through their Public Involvement work.

Members of both the EWGPWD and the EDCWG also took part in a series of interviews recorded during the 33rd Alzheimer Europe Conference in Helsinki. These videos, made in concert with the Dementia Researcher network led by Adam

Smith, are now available on our YouTube channel. Many thanks to Adam Smith and to the members from both working groups who gave their time to discuss their experiences of our conference, both as speakers and as delegates, and their Public Involvement work with Alzheimer Europe.

The EDCWG, as well as our national member organisations, also contributed to a newly-published position statement, in which we call for open, honest, empathetic and compassionate disclosure of dementia risk in both research and clinical practice. You can find out more about this position and the recommendations for health care professionals involved in risk disclosure in the Alzheimer Europe news section.

We are pleased to announce the launch of a new European project, PREDICTOM, in which we are excited to be involved and which aims to develop an Artificial Intelligence screening platform that can identify individuals at risk of developing dementia, even before symptoms manifest. Find out more in our EU Projects news section.

And finally, I would like to personally welcome Matjaž Nemeč MEP (S&D, Slovenia) to the European Alzheimer's Alliance, following an approach by Spominčiča – Alzheimer Slovenija. Mr Nemeč has been a member of the European Parliament since May 2022.

I hope you enjoy our newsletter and wish you all the best for the coming festive season!

Jean Georges
Executive Director

ALZHEIMER EUROPE

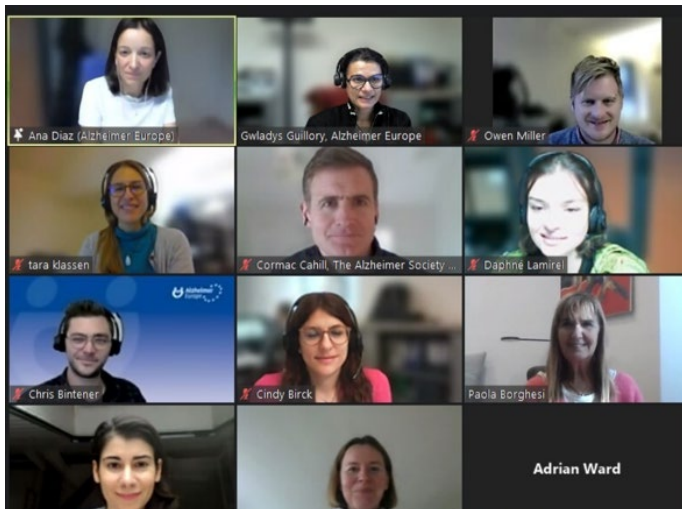
1 November: Alzheimer Europe signs Memorandum of Understanding with International Psychogeriatric Association



On 1 November 2023, Alzheimer Europe and the International Psychogeriatric Association (IPA) signed a Memorandum of Understanding, to provide the basis for future collaboration. Both Alzheimer Europe and the IPA share a common vision of

promoting the quality of life and wellbeing of people with dementia and their carers through education, research and advocacy.

13 November: Autumn Alzheimer’s Association Academy addresses the topic of legal capacity and decision-making



Legal capacity refers to the right that individuals have to make decisions for themselves within the constraints of the law – and which must then be recognised as being legal. Legal capacity and decision-making are important topics in the dementia field, as they affect the wellbeing and autonomy of people with dementia. At our November Alzheimer’s Association Academy meeting, four experts shared recent reviews, advances and initiatives addressing legal capacity and decision-making with colleagues from our member organisations. The meeting was moderated by Ana Diaz, Public Involvement Lead at Alzheimer Europe, who co-developed our 2016 Yearbook on legal capacity and decision-making.

The first speaker at the Academy meeting was our Policy Officer, Owen Miller. Owen has spent the last year working on an update to our 2016 Yearbook, which will be published in the coming weeks. The 2023 Yearbook reviews European, national and international legislation on legal capacity and decision-making, describing how different policies and strategies address aspects such as testamentary capacity, civil responsibility,

consent for medical treatment and research, powers of attorney and substitute/supported decision making. In his talk, Owen provided a detailed overview of the Yearbook, noting that while there are some commonalities in countries across Europe (e.g. limiting the ability to marry to those who have legal or decision-making capacity), certain countries are more progressive when it comes to laws regarding proxies or guardianship. There is still a lot more work needed to ensure the rights of people with dementia are respected, Owen explained, describing the key recommendations from the Yearbook. These include specific calls to action, such as the reform of laws that deny some people with dementia the right to vote, as well as the need for training and resources for supported decision-making.

Next, Lenka Vysoka (European Commission) spoke about new proposals for reform of cross-border arrangements for adults in need of support. These draft proposals from the European Commission are particularly relevant in situations where caregivers, families or friends of people with dementia live in different countries, and were developed in response to the growing number of people in need of support on cross-border issues. Lenka explained that 27.4 million adults in Europe are in situations of vulnerability, and that between 150,000-780,000 of them are at risk of cross-border issues. The 2000 Hague Convention on the Protection of Adults entered into force in 2009, she said, but compliance is slow and only 12 EU countries are contracting parties to the Convention. One of the aims of the proposals is to oblige Member States to sign, ratify and accede to the Convention, providing greater clarity and harmonisation on applicable laws and recognition of measures, as well as improved cooperation among competent authorities. Harmonisation also extends to registers of vulnerable persons, enabling data sharing between countries and competent authorities to increase the assurance of protection and respect of measures whilst abroad.

The third speaker, Adrian Ward (European Law Institute/ELI), gave a presentation of a newly-launched ELI project on decision-making, which is focusing on advance choices for future disablement. The term “advance choices” over “advance directives” was carefully chosen, hoping to prompt a shift from the mental health focus of advance directives, to a more holistic model of recording preferences and wishes, rather than instructions. The ELI project aims to develop model laws with practical guidance, with a view to encouraging the adoption of advance choices and supporting people in making use of them. Adrian spoke about the potential value of advance choices in the context of dementia, which can help provide support for peoples’ right to autonomy and self-determination. In doing so, he explained, people with dementia, their families and carers would have greater clarity and reassurance about their rights being respected now, and in the future.

The final speaker of the Alzheimer’s Association Academy meeting was Áine Flynn, Director of the Decision Support Service (Mental Health Commission, Ireland). Áine’s presentation on the adaptation of Irish legislation to the

requirements of the UN Convention for the Rights of People with Disabilities (UNCRPD) provided a valuable case study in the national context, compared to the EU context that was discussed by Adrian and Lenka. Áine explained that an overhaul to the Irish legislation was long overdue, with the Marriage of Lunatics Act dating back to 1811, and the Lunacy Regulation dating back to 1871. These statutory arrangements were blunt instruments, aiming to protect people lacking capacity, but infringing on their human rights. She then outlined the new reforms that were implemented in 2022, noting that there is now a presumption of capacity and that people must be supported in making their own decisions as far as possible, maintaining their dignity and autonomy. These reforms are operationalised through a new Decision Support Service, Áine explained, which provides a three-tier framework for supported decision-making, ranging from a decision-making assistant (appointed by the patient as a supporter, with no power to make decisions on behalf of the patient), to a co-decision maker and, at the highest level of support, a decision-making representative (appointed through Court application, for a limited time and with a limited scope).

14-16 November: Alzheimer Europe brings together multiple EU projects at first collaborative event for Public Involvement in European brain health research in Luxembourg



From 14 to 16 November 2023, Alzheimer Europe brought together six European research projects for an unprecedented series of consultations focusing on Public Involvement in dementia and brain health research.

At this unprecedented event, which took place in Luxembourg, 44 members of the Advisory Boards of six EU-funded projects (EU-FINGERS, LETHE, Multi-MeMo, eBRAIN-Health, EPND and ADIS) all of which are working on different aspects of brain health and dementia research, collaborated in a series of multi-project consultations. Members of these Advisory Boards, which are convened and moderated by Public Involvement leads at Alzheimer Europe, are people at a higher risk of, or living with, dementia, carers and supporters of people with

dementia and other lay people with an interest in brain health and dementia prevention.

This was the first collaborative meeting of this type and scale, uniting projects working on different aspects of brain health and dementia research, funded through the three largest research and innovation programmes in Europe: The Joint Programme on Neurodegenerative Diseases, Innovative Medicines Initiative, and Horizon Europe. The event promoted a collaborative approach to research and Public Involvement and was an important opportunity for all of the projects represented to share knowledge, experience, insights and ideas, with the aim of helping to move research forward, together.

The European Working Group of People with Dementia (EWGPWD) is involved in a number of projects through its work with Alzheimer Europe. Several members of the EWGPWD travelled to Luxembourg to participate in the event. Some of them are also members of the Advisory Boards of these projects.

What is Public Involvement?

To ensure that research accurately reflects the preferences, needs and priorities of members of the public, their perspectives - including experiences and concerns - need to be included in different aspects of research processes and outputs/results. Public Involvement has been shown to improve the quality of research by enabling researchers to benefit from the lived experience of people with dementia but also other lay people (for example, people with Mild Cognitive Impairment (MCI), people at risk of developing MCI or dementia, carers/supporters of people with dementia). Public Involvement work helps ensure that research is ethical, transparent and gives people with dementia and other stakeholders with an interest in dementia research a voice, reflecting the principle of “nothing about us without us”.

What are Advisory Boards?

Advisory Boards are made up of lay people including, for example, people with Alzheimer’s disease or dementia, people with MCI, carers, and people at risk of developing MCI or dementia. These groups meet regularly to provide feedback and advice to researchers about various topics and issues linked to the research activities conducted by the project consortium.

What happened at this event?

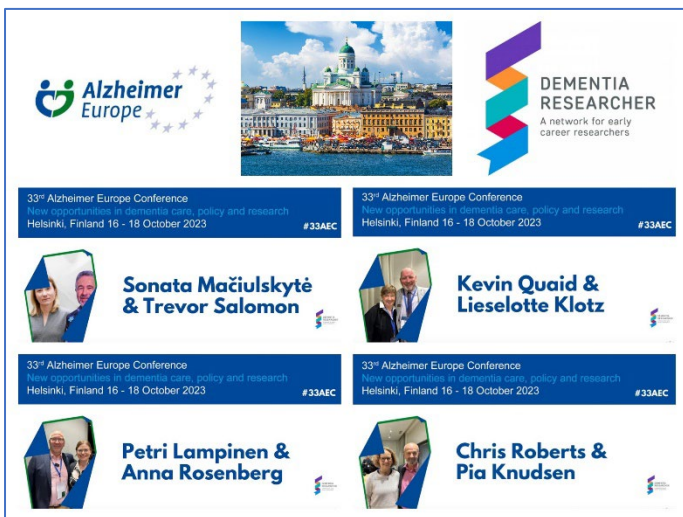
On 14 November, members of the Advisory Boards from the EU-FINGERS, LETHE and Multi-MeMo projects held a consultation, discussing topics around multidomain interventions to reduce dementia risk and communication tools for discussing risk of dementia with patients.

On 15 November, members of the EWGPWD provided advice to the ADIS and EPND projects on matters related to consent and data-sharing in dementia research. The same topics were addressed in Spanish with members of the ADIS Advisory Board on 16 November.

On 15 November, members of the eBRAIN-Health Advisory Boards met to test and provide their feedback on an app developed as part of the project and used for cognitive training and rehabilitation. They also shared their perspectives on the use of virtual reality tools in the context of brain health and dementia.

The event was funded by the Luxembourg National Research Fund (FNR) under the aegis of the EU Joint Programme – Neurodegenerative Disease Research (JPND), the European Union’s Horizon 2020 research and Innovation and the Innovative Medicines Initiative 2 Joint Undertaking (JU). The JU receives support from the European Union’s Horizon2020 research and innovation programme and the European Federation of Pharmaceutical Industries and Associations (EFPIA).

22 November: We present a series of interviews with members of the European Working Group of People with Dementia and European Dementia Carers Working Group from our conference in Helsinki



During the 33rd Alzheimer Europe Conference (33AEC) “New opportunities in dementia care, policy and research”, which took place between 16 and 18 October 2023 in Helsinki, we were delighted to work with Adam Smith, Programme Director for Dementia Researcher, to produce a series of four interviews. These four interviews are with members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) and focus on their experiences of the conference and on the vital contributions of both groups to the work of Alzheimer Europe and its conferences.

Interview 1

EDCWG Chairperson Sonata Mačiulskytė and Vice-chairperson Trevor Salomon discuss the group and its work, as well as their experiences of and contributions to the conference:

https://www.youtube.com/watch?v=43b6N9p54e4&list=PLO-PgQHI1WQU2y0vmGZMLG_hdmsCEZW40&index=1

Interview 2

In this interview, with EWGPWD Vice-chairperson Kevin Quaid and group member Lieselotte (Lilo) Klotz, discussions revolve around what they enjoyed most about the event and how they and the whole group were involved in different aspects of 33AEC:

https://www.youtube.com/watch?v=AWTuajbH3bY&list=PLO-PgQHI1WQU2y0vmGZMLG_hdmsCEZW40&index=2

Interview 3

Chris Roberts, Chairperson of the EWGPWD and group member Pia Knudsen focus on the importance of Alzheimer Europe's first ever conference plenary session organised and delivered entirely by people living with dementia (Chris chaired the plenary session and Pia was one of four speakers):

https://www.youtube.com/watch?v=RlxR8vzoSZA&list=PLO-PgQHI1WQU2y0vmGZMLG_hdmsCEZW40&index=3

Interview 4

The last of our 33AEC interviews is with EWGPWD member Petri Lampinen, who reflects on the event being hosted in his home country of Finland and on his active involvement. He also shares some of his highlights from the conference. Many thanks to Finnish researcher Anna Rosenberg for translating Petri's words into English:

https://www.youtube.com/watch?v=kcOvlg-DgW0&list=PLO-PgQHI1WQU2y0vmGZMLG_hdmsCEZW40&index=4



30 November: Alzheimer Europe calls for urgent action to disclose dementia risk in an open, honest, empathetic and compassionate way

In a new position statement published on 30 November 2023, and following engagement with its national members and the European Dementia Carers Working Group (EDCWG), Alzheimer Europe calls for open, honest, empathetic and compassionate disclosure of dementia risk in both research and clinical practice.

Alzheimer’s disease (AD) research has recently shifted its focus towards the development of diagnostic tools for earlier detection and risk prediction of dementia. There has also been increased attention on strategies to keep the brain healthy and reduce modifiable risk factors contributing to the disease's onset and progression. This shift would allow dementia researchers to recruit more suitable participants for clinical trials testing new AD treatments that would hopefully benefit more than just those in the latest stages of the disease.

Within this context, people with no known cognitive problems or in the early stage of AD (i.e. Mild Cognitive Impairment (MCI) due to AD), could have their risk of developing cognitive problems or progressing to AD dementia predicted and estimated as part of the research study in which they

participate. These risk assessment tools could be ultimately implemented in clinical practice, where people could be tested for their risk of developing dementia.

Alzheimer Europe notes that although dementia risk prediction is happening in research and may be happening in clinical practice in the near future, very little focus has been on the disclosure of such risk. To address this lack of focus on risk disclosure, Alzheimer Europe developed general and specific recommendations, developed in collaboration with Alzheimer Europe’s national members and the EDCWG. They are grouped as follows:

- General recommendations when disclosing risk for cognitive impairment to cognitively healthy people, or disclosing risk for AD dementia to people with MCI due to AD.
- Specific recommendations when disclosing risk for cognitive impairment to cognitively healthy people.
- Specific recommendations when disclosing the risk for AD dementia to people with a diagnosis of MCI due to AD.

The recommendations are aimed at both clinicians and researchers, as the risk disclosure may happen during someone’s participation in research or as part of a person’s proactive search for their risk status in a clinical practice. Recommendations include:

- Clinicians should be transparent about the capacity of current therapies and interventions have to create beneficial change and about their limitations. When recommending the adoption of healthy lifestyle choices, clinicians should clarify that the healthiest of lifestyles cannot, unfortunately, guarantee that someone will not experience cognitive impairment or AD dementia.
- Clinicians should also be transparent about the uncertainty of the clinical progression toward cognitive impairment or AD dementia. Risk prediction for cognitive impairment or AD dementia does not bring certainty or information about the likely course or progression of the disease
- Clinicians, researchers or counsellors should guide and inform the person on positive actions they can take upon receipt of results, such as positive lifestyle changes, support groups they can join and clinical trials from which they might benefit. Regular appointments should be offered to both monitor the person’s clinical progression and support the person.
- Clinicians should consider the personal utility that risk prediction for cognitive impairment may have for the individual. Some people may want to use this information to participate in a dementia prevention clinical trial, and/or to prepare themselves and their families for a possible future with AD.
- Clinicians should also consider personal factors such as age, employment status and their views about available drugs

to prevent the development of AD. These factors may contribute to the impact that risk prediction will have on a person’s personal and working life, and how they plan to approach life such as accelerating travel plans, taking on new challenges, or devoting more time to voluntary work

- If different factors such as time constraints make it unrealistic for clinicians to manage the disclosure process, then other professionals like counsellors should be involved in this process.

Commenting on the position statement, Alzheimer Europe’s Executive Director Jean Georges stated:

“In the last years, there has been a shift in dementia research, from only focusing on finding a cure towards exploring how to improve brain health and reduce risk. Alzheimer Europe is involved in several dementia research projects with a primary focus on risk prediction and reduction, and we hope that this shift will ultimately benefit not only people in the early stages of Alzheimer’s disease, but also people with no known cognitive problems. Although this is an exciting era in dementia research, clinicians must acknowledge that dementia risk prediction comes with a number of ethical, legal and social implications, and that disclosure should always be approached in an open, honest, empathetic and compassionate manner.”

Our full position statement can be accessed on the Alzheimer Europe website:

<https://www.alzheimer-europe.org/policy/positions/alzheimer-europe-calls-urgent-action-disclose-dementia-risk-open-honest-empathetic>



ALZHEIMER EUROPE NETWORKING

- On 7 November (Brussels, Belgium) Angela participated in an EFPIA roundtable on timely detection and care.
- On 7 November, Ana participated in a consultation with members of the PREDICTOM Advisory Board.
- On 9-10 November (Stockholm, Sweden), Angela, Daphné and Chris attended the Prominent General Assembly Meeting.
- On 9-11 November (Gijón, Spain), Soraya attended the X CEAFA conference.
- On 14 November, Owen attended a consultation on a WHO Europe Framework.
- On 14 November, Angela attended the EMA Patients' and Consumers' Working Party meeting.
- On 14-16 November (Luxembourg, Luxembourg), Daphné, Ana, Chris, Cindy, Ange and Soraya participated in the Alzheimer Europe Public Involvement event.
- On 20 November, Jean met with Essity.
- On 21 November, Jean met with Novo Nordisk.
- On 22 November, Owen attended an EFPIA Patient Think Tank.
- On 28 November, Ana, Daphné and Soraya participated in an online consultation with the EDCWG.
- On 28-30 November (Athens, Greece), Angela attended the EPND Annual Meeting.
- On 29 November-1 December (Brussels, Belgium), Daphné attended the European Day of Persons with Disabilities conference.

Sponsors of the month

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

Read more about sponsorship opportunities here:

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



EU PROJECTS

17 October: AI-Mind project featured at 33rd Alzheimer Europe Conference in Helsinki



The AI-Mind project was well-represented at the 33rd Alzheimer Europe conference in Helsinki in October 2023, with an exhibition stand, a dedicated AI-Mind session and several presentations. In a dedicated session entitled "The potential of artificial intelligence for

dementia risk prediction", four panellists presented insights from the AI-Mind project. The AI-Mind expert speakers spoke about screening methods and opportunities created by using Artificial Intelligence (AI) for the prediction, research and diagnosis of dementia as well as Health Technology Assessment. First, the project coordinator, Dr Ira Haraldsen from Oslo University Hospital introduced the project with its key aim of developing AI-based tools for better dementia risk estimation. Then, Ainar Drews from University of Oslo demystified AI and elaborated on the opportunities created by AI in dementia research. The third speaker was Robin Vermeulen from Radboud University Medical Center who presented her early Health Technology Assessment work aiming to assess the potential (cost-)effectiveness of the AI-Mind tool for people with Mild Cognitive Impairment compared to current practice. Finally, Eugenio Di Brino from Università Cattolica del Sacro Cuore talked about the Health Technology Assessment approach and shared insights from the patient perspectives on AI technologies. The session attracted over 70 participants and ended with a lot of questions from the audience.

Furthermore, PhD students involved in AI-Mind showcased their work during the conference through oral and poster presentations, fostering lively discussions. Visit the AI-Mind YouTube channel to watch the presentations from the AI-Mind session https://www.youtube.com/@AIMind_eu/ and visit the project's website to learn more about AI-Mind: <https://www.ai-mind.eu/>



10 November 2023: PROMINENT Consortium Meeting Advances Collaborative Efforts in Neurodegenerative Disease Research



The PROMINENT Consortium recently convened for a General Assembly meeting from 9 to 10 November in Stockholm, Sweden, gathering representatives from 14 partner organisations. The two-day event, led by Project Coordinator Linus Jönsson from Karolinska Institutet, was a deep dive into the advancements of the project’s digital platforms and real-world evidence collection for the management of neurodegenerative disease.

Day 1 Highlights: Implementation, Evaluation, and Data Management

The day session started with an introduction of the 14 consortium partners, bringing together experts in neurodegenerative diseases and clinical neuroscience, Artificial Intelligence, Health Economics, Patient Advocacy with some of Europe’s leading medical centres for the diagnosis and treatment of cognitive disorders.

Linus Jönsson opened the meeting with a review of the consortium’s strategic goals and an outlook to the two-day meeting. Following this, Project Co-Coordinator Jyrki Lötjönen from Combinostics outlined the status of the project’s digital platform and the clinical decision support systems (CDSS), to be further developed within Work Package 2, by showcasing mock-ups also to be discussed during the workshop 1 (CDSS platform) on the second day.

Next, a member of Linus Jönsson’s Health economics of Alzheimer disease and other dementias group, at Karolinska Institutet, presented the results of an evaluation survey on CDSS across Europe that collected clinicians’ feedback in the European Alzheimer’s Disease Consortium, and project clinical Principal Investigators (PI)’s. The purpose of the survey was to create tools that support clinicians in optimizing the use of novel disease-modifying therapies for Alzheimer’s disease and set the stage for a discussion on how to manage and share clinical data within the project, led by Ferran Lugo of the BarcelonaBeta Alzheimer’s Research Center (BBRC). This is a critical step for PROMINENT, which will apply data from several studies across Europe to train and validate Alzheimer’s disease prediction models and diagnostic algorithms. This presentation

also introduced the workshop 2 (Data Management) on day two.

Plans to leverage the expertise and knowledge of Health Technology Assessment bodies regarding the use and collection of real-world evidence was presented by Sofie Persson from IHE, the Swedish Institute for Health Economics. Next, followed an investigation into the PROMINENT clinical study outcome measures, and their operationalization and implementation strategies, by Lena Sannemann from University Hospital Cologne.

This was followed by an overview of established communication materials and future plans, which included the launch of the ihi-prominent.eu website by Chris Bintener, an introduction to the Stakeholder Engagement and mapping work by Angela Bradshaw, and an introduction to the plans for Public Involvement by Daphné Lamirel, all of whom are partners from Alzheimer Europe.

The session was rounded off with an Innovative Health Initiative (IHI) overview by PROMINENT’s Project Officer, John Clifford, and a detailed account of project management by Audrey Niemann-Jönsson and Anna Hansson (Karolinska Institutet), and Montse Camprubi (SYNAPSE Research Management Partners).

Day 2: Fostering Future Collaboration and Study Insights

The second day of the PROMINENT Consortium Meeting was equally engaging, opening with a workshop on digital platform functionality led by Jyrki Lötjönen. In workshop 2, discussions were spearheaded by Ferran Lugo delving into the nuances of data sharing. Lena Sannemann led workshop 3, which provided opportunity to discuss clinical research priorities concerning outcome measures and timeframes within the clinical studies. The workshops were strong and gave important feedback to key questions relevant to critical cross-work package collaborative work.

Presentations of two new IHI projects within Alzheimer’s research was next on the agenda: PREDICTOM, by project PI Dag Aarsland of King’s College London, and AD-RIDDLE by project PI Miia Kivipelto of Karolinska Institutet. Highlighting the interconnected nature of the consortium, these presentations on IHI sister projects facilitated a broader discussion on future collaborative research, shared goals, and potential areas for future collaborations.

The meeting concluded with Linus Jönsson summarizing the key points and setting the stage for the consortium’s future, emphasizing the importance of continued innovation and collaboration.

Looking Ahead with Optimism

The PROMINENT Consortium Meeting proves our shared commitment to advancing the field of neurodegenerative disease research. Following half a year of remarkable progress, the consortium looks ahead to a future where its combined efforts can lead to advances in the diagnosis, treatment, and management of dementia and cognitive disorders.

We extend our gratitude to all partner organisations and attendees for their invaluable contributions and look forward to continued progress and success in the coming year.

Stay informed about the latest developments in the PROMINENT Consortium by subscribing to the project [newsletter](#)

Learn more about the project: <https://www.ih-prominent.eu>

14 November: Members of the EU-FINGERS, LETHE and Multi-MeMo Advisory Boards participate in a face-to-face consultation



From 14 to 16 November, an impactful face-to-face event for Public Involvement was organised by Alzheimer Europe in Luxembourg. The collaborative event brought together the members of six EU-funded projects, all of which are working on different aspects of brain health and dementia research, to collaborate in a series of multi-project consultations.

The first consultation held in 14 November gathered 17 members of the EU-FINGERS, LETHE and Multi-MeMo Advisory Boards who met for the very first time in person. Members came from nine European countries (Austria, Finland, Hungary, Italy, Luxembourg, Netherlands, Spain, Sweden, UK) to discuss topics around multidomain interventions to reduce dementia risk and communication tools for discussing risk of dementia with patients. AE Project Officer Ana Diaz extended a warm welcome to all delegates, emphasised the importance of their presence and the pleasant spirit driving the meeting. Then, Sean Sapcaru provided valuable insights into the Luxembourg National Research Fund (FNR), the main funder of research activities in Luxembourg. Next, Francesca Mangialasche and Anna Rosenberg took the floor to provide a comprehensive update on the EU-FINGERS and LETHE projects. They reminded the aims and mission of each project and both emphasised the pivotal role of the Advisory Board members as essential partners to guide and influence relevant decisions on how the research activities are conducted.

The heart of the consultation unfolded through four workshops in small groups, facilitated by Anna Rosenberg, Leonie Visser, Tanja de Rijke and Heleen Hendriksen and co-facilitated by Francesca Mangialasche, Ana Diaz, Cindy Birck and Mariagnese

Barbera. Members were engaged in dynamic discussions, exchanging thoughts and ideas on: 1) social activities in digital multi-domain interventions; 2) information needs on future Alzheimer’s disease medication; 3) a new tool to help patients and supporters to share personal information and 4) the implementation of tools to support preparation for memory clinic consultations.

Mariagnese Barbera concluded the event by presenting the overarching goals of the Multi-MeMo project and highlighting the continuity of Public Involvement work from EU-FINGERS to Multi-MeMo.

The project partners would like to extend their heartfelt gratitude to all members of the Advisory Boards for their engagement, commitment and invaluable contributions.

“I knew I was going to assist in an important event, but once I was in it, I realised that the meeting was far beyond my expectations. I think that this first experience of gathering Advisory Board members of different projects was a successful experiment of Public Involvement in research on brain health and hope that it will be repeated.”, said Miriam, member of the LETHE Advisory Board.

15 November: Consultations with the ADIS and EPND Advisory Boards focus on informed consent for primary research, and for data & sample sharing



Between 14 and 16 November, over 40 members of the Advisory Boards of six EU-funded dementia research projects collaborated in a series of multi-project consultations. These Advisory Boards are composed of people affected by dementia: people living with different types of dementia, individuals who are at risk of dementia or interested in brain health, and people who care for or support people with dementia. Convened and moderated by the Public Involvement team at Alzheimer Europe, the Advisory Boards provide valuable input and feedback to guide and improve research, ensuring the needs, perspectives and values of people affected by dementia are taken into account.

Consultations organised on 14 November focused on topics relating to brain health and dementia prevention, involving researchers from the EU-FINGERS, Lethe and Multi-MeMo projects. On 15 November it was the turn of EPND and ADIS, with consultations on consent – consent for primary research, and consent for data and sample sharing and reuse. These topics are particularly important for the two projects: EPND is an Innovative Medicines Initiative-funded project that is creating a platform for data and sample sharing from neurodegenerative disease research studies, while ADIS is a JPND (Joint Programme for Neurodegenerative Diseases)-funded project that is developing novel biomarkers for early detection and prediction of Alzheimer’s disease.

The consultations were moderated by AE team members Ana Diaz, Soraya Moradi-Bachiller, Cindy Birck and Angela Bradshaw, and organised with Daphne Lamirel - aiming to identify the views, concerns and preferences of people affected by dementia in relation to informed consent forms, processes and language. Advisory Board members underlined the importance of participating in research and data sharing, emphasising the need for greater awareness on the value of research participation and the need for data sharing and reuse to maximise the impact of research. Frank views were exchanged on terminology, process and design of informed consent forms, with a strong focus on using language that is precise and accurate but also understandable. Many thanks to all Advisory Board members for their active engagement and contributions!

Learn more about the ADIS project: <https://adis-project.eu/>

Learn more about the EPND project: <https://epnd.org/>

15 November: PREDICTOM project secures EUR 21 million investment to pioneer early Alzheimer’s detection



In 2023, more than 7 million people are living with dementia in the European Union. This number is projected to double, reaching 14 million in 2050. This will have a huge impact on healthcare systems, both in terms of human and financial resources. There is currently no cure for Alzheimer's disease (AD). Although the search for potential treatments is showing promise, it is anticipated that these medications will be most effective in early stages of the disease.

"Dementia affects all areas of life, e.g. in relation to health, employment, relationships and economic issues, impacting not

only the person who has dementia but also their families and informal carers. It is essential that people with dementia have access to timely diagnosis and treatment, particularly as significant progress is made in the development of disease modifying drugs" said Dianne Gove, Director for Public Involvement and Ethics, Alzheimer Europe.

PREDICTOM’S AI-platform

In light of this anticipation, PREDICTOM is developing an Artificial Intelligence (AI)-screening-platform that can identify individuals at risk of developing dementia, even before symptoms manifest.

Dag Aarsland, Professor of Old Age Psychiatry at King's College London and research lead at Stavanger University Hospital, is the driver behind the project.

"Detecting early signs of dementia is key to slowing its progression. Unfortunately, a majority of those at risk are not identified in time. Our platform seeks to change this by enabling early discovery, allowing timely intervention and preventative treatment", Dag Aarsland said.

Revolutionising screening, minimising healthcare strain

Another crucial aspect of PREDICTOM's project is that much of the screening can be performed by participants themselves in the comfort of their own homes.

By initiating the process at home, PREDICTOM aims to reduce strain on healthcare services and associated costs. Biomarkers, including saliva, stool, digital markers, and blood (via prick-tests), will be collected at participants' homes or GP offices, streamlining a process traditionally carried out in hospitals or specialised clinics.

More than 4,000 participants will partake in PREDICTOM’s trial project. The samples will be based on a pool of people from previous projects PROTECT UK, PROTECT Norway and Radar-AD, as well as people from the catchment area of other participating centres in Germany, France, Switzerland, Belgium, and Spain.

"If our project succeeds, there will be significant savings in both cost and time", Dag Aarsland said.

"The potential of this project to develop and test a novel approach to the collection of bio-samples, combined with the use of AI-based dementia risk prediction, will not only be beneficial to the effective management of dementia at national and European level, but also contribute toward making screening and diagnosis more accessible and tailored to the needs of individual patients", Dianne Gove said.

After the home collection, samples will be sent to PREDICTOM, where their platform will process the participant data, integrating blood, cerebrospinal fluid, imaging, electrophysiological, and digital biomarkers.

AI algorithms will then generate risk assessments, early diagnoses, and prognosis, which will lay the foundation for early intervention and treatment.

A Collaborative Effort Between Academia, Business, and Hospitals

A consortium of 30 partners from academia, business, civil society, and hospitals, backed by EUR 21 million in funding (EUR 8 million from the EU, EUR 9 million from industry and EUR 4 million from UKRI), is steering PREDICTOM. The consortium includes partners from 15 countries across Europe, Asia and America and is led by Stavanger University Hospital (Norway).

"GE HealthCare is honoured and thrilled to assume the leading industrial role in this vital undertaking, offering hope to those who might face an Alzheimer's disease diagnosis and providing innovative solutions along the patient's journey" said Timo Schirmer, Director, GE HealthCare MR Applied Science Lab Europe.

This project is part of the Innovative Health Initiative (IHI), a public-private partnership (PPP) between the European Union and the European life science industries. The EU funding is provided through Horizon Europe, while the remaining funding for this project comes from Novo Nordisk A/S, GN Hearing A/S, Pharmacoidea Hungary, GE HealthCare, Siemens Healthineers, Icometrix Nv Belgium, ALZpath Inc USA, University of Geneva, Altoida USA, BrainCheck Inc USA, Muhdo Health Ltd, and UK Research and Innovation (UKRI).

"We are very pleased to have such a robust team with top notch expertise spanning diverse fields, including IT, AI, medicine, aging research, and professionals from both small and large businesses", said Dag Aarsland. "Innovation thrives at the intersection of multiple disciplines, where the fusion of ideas and expertise sparks new and ground-breaking solutions", Timo Schirmer emphasised. The project runs from 1 November 2023.

For more information about the project, see: <https://www.helse-stavanger.no/en/predictom/>

20 November: "All ABOARD" - Dutch project celebrates halfway point by opening its doors to the general public at its "Midterm Meeting"



On 20 November 2023, two-and-a-half years after its launch, the five-year ABOARD project celebrated its midterm. Led by Wiesje van der Flier from Alzheimer Center Amsterdam, Amsterdam UMC, ABOARD is a public-private project which

aims to prepare for a future in which Alzheimer's disease (AD) is stopped before dementia has started. This is being done by: improving diagnosis, developing personal risk profiles, initiating nationwide data collection with a focus on patient-reported outcomes, and a focus on prevention strategies.

In the morning, over 80 consortium members joined together. Each work package organised their own networking activity, with a focus on cross-sectoral exchange of ideas. Work package one (diagnosis) harbours different topics of digital biomarkers, genetics, and proteomics. Yet, all share the same challenge of big data, which is why the Technical University Delft is also on board. Work package two (prediction) focused on how we can use information from general practitioners to learn about AD. The project attempts to link these (and other) data to the ABOARD-cohort, a national initiative to engage Dutch citizens in Alzheimer's research. ABOARD celebrated that the first 5,000 participants have signed up! Work package three (prevention) discussed the launch of Breinzorg.nl (braincare.nl). This online platform provides information to memory clinic patients regarding what they can do themselves to take care of their brain. Finally, Work package four (patient orchestrated care) shared learnings and results of the diverse studies gaining input from diverse project partners.

After lunch, the doors were opened for the general audience. An audience of care professionals, patients, families, research participants, and students excellently complemented the rest of the consortium, and gave new meaning to "all ABOARD". Work package leads presented where they envision the field is going. Next, junior researchers presented their results in parallel sessions. These interactive sessions were chaired by (private) consortium members, which fostered a lively discussion with the audience.

20 November was a day of celebration. The ABOARD project is thankful for what has been achieved so far and looks forward to delivering more results in the next project period. It is also, cautiously, already looking beyond 2026, because it seems that ABOARD is here to stay.

Alzheimer Europe Director Jean Georges is a member of the project's Advisory Board. More information about ABOARD, including an animation-video, can be found on the website: www.aboard-project.nl

28 November: Members of the Pattern-Cog Advisory Board gather online to discuss concerns and worries about the use of Artificial Intelligence in dementia research

On 28 November, Alzheimer Europe's European Dementia Carers Working Group (EDCWG), which serves as the Pattern-Cog project Advisory Board (Pattern-Cog AB), gathered online. The meeting was organised by Alzheimer Europe (AE), and facilitated by AE Public Involvement Officers Soraya Moradi-Bachiller and Daphné Lamirel and Public Involvement Lead Ana Diaz. This meeting aimed at gathering feedback from the members about the 33rd Alzheimer Europe Conference (33AEC) and discussing concerns and worries that people may have



several activities and consultations organised by AE. Soraya then followed by giving an overview of the use of AI by the dementia research projects in which AE is involved. Soraya explained that, in some projects, AI is used to develop tools to predict someone's risk of developing cognitive problems or progressing to Alzheimer's disease (AD) dementia, whereas in others, AI can help mimic and simulate some parts of the brain to understand better how it works.

The members of the Pattern-Cog AB were then asked to provide their views on concerns and worries raised by other Public Involvement advisory boards, mostly linked to the use of AI, e.g.: bias, discrimination, accountability, fear of AI replacing the doctor, data sharing and explainability. They were then asked what uses of AI in dementia research would concern and worry them most. The discussion was lively and all the members of the Pattern-Cog AB gave insightful and important contributions to the consultation.

about the use of Artificial Intelligence (AI) in dementia research projects.

Ana started the meeting by thanking all members of the EDCWG for their great participation at 33AEC and their involvement in

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:

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eBRAIN-Health – grant agreement 101058516
EPND– grant agreement 101034344

LETHE - grant agreement 101017405
PREDICTOM - grant agreement 101132356
Prominent - grant agreement 101112145



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

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

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

PatternCog - This project is supported by the Luxembourg National Research Fund (INTER/PerMed21/15748787/Pattern-Cog), under the frame of ERA PerMed

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

EUROPEAN ALZHEIMER’S ALLIANCE

1 November: Matjaž Nemec joins European Alzheimer’s Alliance



Matjaž Nemec (S&D, Slovenia) has joined the European Alzheimer’s Alliance, following an approach by Spominčica – Alzheimer Slovenija.

Mr Nemec has been a member of the European Parliament since May 2022. His European Parliament profile can be viewed at:

https://www.europarl.europa.eu/meps/en/233862/MATJAZ_NEMEC/home



EU DEVELOPMENTS

8 November: Alzheimer Europe supports manifesto for policy reform on Continenence Health in Europe launched during first Continenence Health Summit

On 8 November, Alzheimer Europe joined 22 scientific, professional, patient and non-profit organisations in launching a manifesto for policy reform on Continenence Health in Europe.



The manifesto was launched at the first Continenence Health Summit in Brussels and aims to raise awareness among EU and national policymakers of continence health problems and to instil the need for action.

The manifesto calls for concrete policy changes to face the challenges posed by the report and makes ten high-level recommendations to European and national policymakers to recognise the importance of patient-centred continence care. It also promotes a holistic understanding of the intricate links between continence health and healthy ageing, women’s health, as well as disease areas like cancer, mental health, neurological problems and several other comorbidities such as

obesity. This will require increased funding for continence health research.

The summit presents the results of a report commissioned by the European Association of Urology, and conducted by Triangulate Health Ltd, on the socio-economic and environmental costs of continence health problems. This research on the economic burden of urinary incontinence reveals that the cost of continence care will reach an estimated EUR 69.1 billion in 2023. These costs include the impact of incontinence on individuals' health, the costs of medical consultations and products such as continence pads, incontinence-related absenteeism at work, nursing home admissions, and the environmental impact of incontinence care.

If no action is taken to support continence health, the economic burden could rise by 25% in 2030, to EUR 86.7 billion. This economic burden becomes considerably higher when including caregiver costs.

Read the manifesto:

https://d56bochluxqnz.cloudfront.net/media/109857_EAU_Urge-To-Act_Manifesto_A5-folder.pdf

11 November: Parliament and Council agree 2024 EU budget

The European Parliament and the Council of the European Union have reached an agreement on the EU budget for 2024, which will ensure funding for the EU's priorities for next year. The agreement on the 2024 budget is for commitments of EUR 189.4 billion. Of particular relevance for policies relating to dementia:

- EUR 47.9 billion for regional development and cohesion to support economic, social and territorial cohesion
- EUR 13.6 billion for research and innovation, of which EUR 12.9 billion for Horizon Europe, EU's research programme
- EUR 21.9 billion for people, social cohesion, and values, of which EUR 16.8 billion is for the European Social Fund (ESF+) and EUR 261 million to promote justice, rights, and values
- EUR 754 million for EU4Health.

Full details of the agreement are available at:

https://ec.europa.eu/commission/presscorner/detail/en/ip_23_5685

14-15 November: European Medicines Agency hosts meetings of its Patients' and Consumers' & Healthcare Professionals' Working Parties



On 14-15 November, our Director of Research & Policy, Angela Bradshaw, attended meetings of the European Medicines Agency (EMA) Patients' and Consumers' and Healthcare Professionals

Working Parties (PCWP/HCPWP). Alzheimer Europe is a member of the PCWP, which includes over 40 civil society

organisations representing patients and consumers, and provides a platform for exchange of information and discussion of key topics for EMA, patients and the general public.

On 14 November, the PCWP meeting addressed the availability and accessibility of medicines, with presentations from EMA and European Commission experts on the interface between European regulators and health and technology assessment (HTA) bodies, the EMA critical medicines list, and updates on medicines repurposing activities. Bela Dajka (European Commission) provided an update on the European HTA Stakeholder Network, which is being established by the EMA as part of its responsibilities under the new HTA Regulation. This pan-European group are working on implementation of the HTA Regulation, Bela explained, with regular meetings planned in the coming year. Another topic was the COVID-19 pandemic, with a presentation from Melanie Carr of the EMA on lessons learned, and discussions on generating clinical evidence for treatment and prevention of Long COVID.

On 15 November, the PCWP and HCPWP met, bringing together both EMA Working Parties in a meeting co-Chaired by Juan Garcia Burgos (EMA), Marko Korenjak (PCWP co-Chair) and Rosa Giuliani (HCPWP co-Chair). This meeting was focused on updates from the different EMA committees; EMA data-related initiatives and digitalisation; regulatory science and innovation; and communications. EMA speakers representing the COMP, CAT, CHMP and PDCO Committees, which review orphan medicinal products, advanced therapies, human medicinal products, and medicines for children. Each Committee involves representatives of patients, consumers and healthcare professionals in their work, asking for their views on medicines in different disease areas. Moving on to data-related initiatives, EMA experts provided updates on the Big Data Steering Group, DARWIN initiative, patient experience data and AI-based methods for evidence generation.

Following an interactive discussion on accessible communications, members of the PCWP and HCPWP spoke about new initiatives from their organisations in the "Member's Voice" section. Francois Houyez of EURORDIS (European Organisation for Rare Diseases) presented new research on Goal Attainment Scaling, a new approach for identifying and measuring individualised, patient-centred outcomes. Finally, Marcin Rodzinka-Verhelle of the Standing Committee of European Doctors (CPME) presented a recent national survey that assessed antimicrobial resistance stewardship programmes, prescribing guidelines and awareness campaigns, concluding that more action is needed to coordinate, engage and educate stakeholders within and across countries. The next PCWP and joint PCWP/HCPWP meetings will be organised in March 2024.

27 November: European Parliament organises Disability Rights week

The European Parliament has organised a Disability Rights week between 27 November and 4 December, in order to raise awareness and enhance the public debate around disabilities rights and to support people to exercise their rights.



The week is organised to coincide with the International Day of Persons with Disabilities on 3 December 2023 and will see several parliamentary committees voting, debating and holding events regarding disability policies.

This includes the Petitions Committee hosting its annual workshop on the rights of persons of disabilities, with the Transport Committee due to discuss barriers in the fields of transport and tourism. Additionally, the Employment and Social Affairs Committee will hold several events, including an exchange of views on the European Disability Card and European Parking Card.

A joint hearing will also be held by the Women’s Rights and Gender Equality Committee on “Harmful practices in the EU towards women and girls with disabilities”, whilst a meeting with members of national parliaments on the participation of people with disabilities in the electoral process is also planned. Full details of activities and debates taking place as part of the week can be found at:

<https://www.europarl.europa.eu/committees/en/european-parliament-s-first-disability-r/product-details/20231121EOT08001>

POLICY WATCH

6 November: Ministry of Health announces completion of Psychiatric Reform in Greece including new institutional framework for treatment of dementia and Alzheimer's disease



The Panhellenic Federation of Alzheimer’s Disease and Related Disorders (Alzheimer Hellas) welcomes the press conference of the Ministry of Health, which took place on 6 November 2023, focusing on the completion of the Psychiatric Reform in Greece. During the press conference, the Deputy Minister of Health, responsible for Mental Health issues, Dimitris Vartzopoulos presented the upcoming bill for the reform, and the Minister of Health, Michalis Chrysochoidis (pictured), presented the new institutional framework for the treatment of dementia and Alzheimer's disease.

The Panhellenic Federation of Alzheimer’s Disease and Related Disorders (Alzheimer Hellas) welcomes the press conference

After years of continuous efforts by all stakeholders active in providing information, services and care for people with dementia and their families in Greece (Alzheimer Associations since 1995, Panhellenic Federation for Alzheimer’s Disease since 2007, National Observatory for Dementia since 2015, Hellenic Initiative Against Alzheimer’s disease since 2019, etc.) and always in collaboration with the Directorate of Mental Health of the Ministry of Health, Alzheimer Hellas expects that all procedures will take place much faster than in the past. Alzheimer Hellas also hopes that the new action plan, as well as the draft law on the rights, daily life and procedural matters governing the lives of people with dementia and their families, will be fully implemented to effectively help all those affected by the disease.

Finally, the organisation welcomes the establishment of the National Council on Dementia and Alzheimer’s disease with the participation of representatives from four ministries (Health, Family, Labour and Finance).

10 November: Zavod Krog (Slovenia) and NVU Impuls (Montenegro) organise final event for project on dementia emphasising the continuation of good practices in the future



Zavod Krog from Slovenia and NVU Impuls from Montenegro successfully organized the final event of the project "Protecting of the right to dignified aging and dementia preventing", which runs from January 2022 to the end of December 2023, in the North of Montenegro. The event took place on 10 November 2023, in Tehnopolis in Nikšić and was aimed at sharing the experiences, presenting project results and good practices to important local decision-makers, experts, non-governmental organisations, relevant institutions and the general public.

The participants of the event, moderated by Marija Razić, learned about the key project activities through the presentation of Marina Doknić from NVU Impuls, including the first survey of the needs of the elderly, people with dementia, their families and caregivers, which was carried out as part of the project in 2022. It turned out that the concept of dementia in Montenegro is not well understood and is treated only as a symptom of ageing, and as such is not given enough attention. There is not a single strategic act in the country aimed at directly protecting people with dementia and supporting their families, who feel the greatest impact of care. The project partners believe that these important statistical and research data on dementia can serve as a basis for further research, and in the future also for laws and strategies at both national and local levels regarding the systemic care and support of people with dementia and their family members. The main project activities were also devoted to the training of volunteers to



work with people with dementia and their mentoring to offer lay psychosocial support to the aforementioned target groups. Within the project, an e-manual was created that enables the education of the next generations of volunteers, many activities were also aimed at actively raising awareness among the population about dementia, reducing stereotypes and prejudices that are still very present in society.

The event was attended by the president of the Nikšić Municipality, Marko Kovačević, who further emphasised the Municipality’s support for project activities, good practices, and the inclusion of volunteers in the provision of services for which they are qualified, as these are recognised as necessary and are well-received among the target groups. The address of the mayor of Plužine, another partner Municipality, Slobodan Delić, also recognised the importance of good cooperation in the future, as well as that of Igor Galić, the director of the Institute for Public Health, which is an important actor in the field of systemic changes for the benefit of the elderly, people with dementia and their families. The contribution and importance of the project for support in the field of elderly rights and dementia was also expressed by Mladenka Tešić, representative of the Delegation of the European Union in Montenegro, and Mirjana Vidaković, who, on behalf of the Embassy of the Republic of Slovenia in Podgorica, highlighted the many years of successful cooperation with Zavod Krog and emphasised support in the future as well. The project is supported by the European Union, the Ministry of Foreign and European Affairs of the Republic of Slovenia and the Ministry of Public Administration of Montenegro.

Volunteers gained a lot of theoretical and practical knowledge by participating in the project. Their feedback was presented by Lejla Srdanović and Radovan Suknović, leaving a special mark on the final event. All volunteers on the project and associated partners also received certificates of appreciation from Zavod Krog and NVU Impuls, as an expression of gratitude for good cooperation and successfully implemented project activities.

The participants of the final event also watched a project video, the purpose of which is to raise awareness about dementia, its signs, prevention, and how and where to seek help. An indispensable part of the final event was also the panel discussion, where experts in the field of health and social care Dr Damir Adrović, Zoran Vukićević and Marija Stanišić shared key information about dementia, what is essential when caring for the elderly, and also emphasised the importance of broader psychosocial support, which can be provided by the volunteers of this project as well.

The final event represented an excellent day of socialising, networking, and raising awareness among all participants, partners, decision-makers, and the general public about the importance of interdisciplinary and intergenerational cooperation to the greatest benefit for all stakeholders and society. Zavod Krog and NVU Impuls would like to thank everyone who made the success of this project possible, and emphasise their continued commitment to building a society that strives for well-being and the highest possible quality of life for all its people.

14 November: Dementia Awareness training delivered by The Alzheimer Society of Ireland at Irish Government Buildings



On 14 November 2023, The Alzheimer Society of Ireland (The ASI) delivered a Dementia Awareness ‘Learn, Listen, Link’ training in Leinster House at the Irish Government Buildings in Dublin. The session was hosted by Senator Fiona O’Loughlin, the Chair of the All-Party Oireachtas Group on Dementia.

Team ASI was pleased to join Minister of State Mary Butler TD to welcome TDs, Senators, and political staff to the training, which was delivered by The ASI’s External Learning & Development Manager Dr Fergus Timmons. Minister Mary Butler also addressed the audience in relation to ongoing support and funding for people living with dementia and the importance of building understanding and cross-party Oireachtas support for dementia.

During the session, advocates and couple Gerry and Nuala Paley, who were interviewed by The ASI’s Advocacy Manager Clodagh Whelan, highlighted the importance of having Dementia Inclusive Communities. Gerry, a member of The Irish Dementia Working Group, spoke about how his community plays a significant role as he navigates life with dementia. Nuala, a member of The Dementia Carers Campaign Network, discussed the needs of dementia carers in Ireland today.

The Dementia Awareness Training session saw wonderful collaboration between The ASI’s Advocacy, Research & Public Affairs team and colleagues from HR, Learning & Development, and Operations.

Pictured: Senator Fiona O’Loughlin, Team ASI and Advocates outside Leinster House

22 November: WHO and UN publishes Decade of Health Ageing report

The World Health Organization (WHO) and United Nations (UN) have launched the first UN Decade of Healthy Ageing (2021-2030) progress report, which examines efforts to improve the lives of older people since 2020, as well as highlighting activities in support of healthy ageing in nearly 50 countries.

The report features results from a survey of 136 countries, conducted between late 2022 and early 2023, with comparisons made with the survey from 2020. This comparison showed an increase in the number of countries with legislation



against ageism, support older people's access to assistive products and national policies on comprehensive assessments of health and social care needs.

Despite progress, further efforts are needed as the report highlights that less than a third of countries reported having adequate resources to deliver on the UN Decade's four areas of action:

- Changing how people think, feel and act about age and ageing
- Ensuring communities foster the abilities of older people
- Delivering person-centred, integrated care and primary health services responsive to older people
- Providing access to long-term care for older people in need.

The full report is available at:

<https://www.who.int/publications/i/item/9789240079694>



SCIENCE WATCH

26 October: A study by the Women's Brain Project and Framingham Heart Study Brain Aging Program shows gender differences in Alzheimer's disease diagnosis



The Women's Brain Project, an organisation dedicated to exploring sex and gender characteristics in brain diseases, has partnered with Framingham Heart Study Brain Aging Program at

Boston University to study sex-specific differences in Alzheimer's disease (AD) diagnosis. Their research demonstrates that sex differences in neuropsychological test performance may play an important role in the detection of AD in its preclinical stages. This new study, published in the journal *Alzheimer's & Dementia* on 26 October 2023, builds on prior work showing sex-specific differences in gender-specific brain function.

The study, which involved 1,787 men and 2,228 women without dementia at baseline and utilised neuropsychological assessment data analysed by machine learning, has delivered insights into how men and women differ in neuropsychological test performance. By considering both standard test scores and Boston Process Approach measures from Framingham Heart Study participants, the researchers employed linear regression,

Cox proportional hazards and Extreme Gradient Boosting models to discern these sex-specific distinctions. Overall, this study showed the significant differences in neuropsychological test scores between men and women. A notable finding was that the Boston Naming Test, which assesses language abilities, is proving to be more sensitive in detecting early cognitive changes in women than in men. In women, lower scores in specific memory tests correlated with a higher risk of AD.

These results, the researchers conclude, suggest that neuropsychological tests can be leveraged for developing more sensitive, sex-specific indices for the diagnosis of AD. Link to the publication:

<https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.13500>

3 November: T3D Therapeutics presents top-line results from its phase 2 PIONEER trial

Top-line results from the Phase II PIONEER trial of oral T3D-959 for the treatment of people with mild-to-moderate Alzheimer's disease (AD) were presented by T3D Therapeutics at this year's Clinical Trials in Alzheimer's Disease (CTAD) conference, held in October in Boston.

PIONEER was a Phase II randomised, placebo-controlled and multi-centre trial evaluating the efficacy and safety of T3D-959 in people with mild-to-moderate AD. 250 participants received either placebo or T3D-959 orally once a day for 24 weeks. Three doses of T3D-959 were tested (15, 30 and 45 mg).

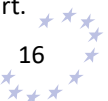
The Alzheimer's Disease Assessment Scale–Cognitive Subscale (ADAS-Cog11) and the Clinical Global Impressions of Change (CGIC) were the two primary endpoints of the study and they were not met in the overall population. Clinical evidence of improvement in cognition was shown in a sub-group of participants, those who had a high baseline pTau-217 ratio.

The secondary endpoint, plasma Ab42/40 ratio change, was met in the group receiving T3D-959 30mg. The effect was similar to lecanemab at 6-months. In the high pTau-217 ratio group the improvement of Ab42/40 ratio was nearly 2-fold greater than the overall group. T3D-959 30-mg treatment in the overall population significantly improved the neurodegeneration biomarker neurogranin, as well as biomarkers of inflammation and metabolism. In addition, the experimental drug was generally well tolerated.

<https://www.prnewswire.com/news-releases/t3d-therapeutics-announces-positive-top-line-results-from-the-phase-2-pioneer-trial-of-t3d-959-in-mild-to-moderate-alzheimers-disease-301976115.html>

7 November: New research suggests that PET scans of the heart may be able to detect very early signs of Parkinson's disease and dementia with Lewy bodies

Parkinson's disease (PD) and dementia with Lewy bodies (DLB) share a common biological feature: the abnormal accumulation of a protein called alpha-synuclein inside nerve cells. These proteins clump together in small structures called Lewy bodies – structures that give their name to DLB. In a new study published in the *Journal of Clinical Investigation*, a team of US-based researchers identify a very early hallmark of Lewy body diseases, which can be detected using PET scans of the heart.





Many researchers now believe that the biological processes that drive Alzheimer’s disease start many years before symptoms become apparent. The same is thought to be true of other neurodegenerative diseases like PD and DLB: scientists have shown that neurodegeneration – driven by the accumulation of abnormal proteins in nerve cells – starts many years before motor or cognitive symptoms occur. Aiming to find new ways to detect the very early stages of Lewy body diseases, researchers at the US National Institutes of Health analysed data from PDRisk, a prospective, longitudinal study in which 82 individuals at risk for Lewy body diseases (determined by genetic risk factors, olfactory and sleep issues, and orthostatic hypotension) underwent long-term follow up. Their analysis focused on 34 at-risk individuals who were followed for up to 7.5 years, undergoing regular clinical examinations as well as MRI and PET scans.

The PET scans measured the uptake of a protein called dopamine, which is negatively affected in Lewy body diseases. Rather than focusing entirely on the brain, researchers also studied PET scans of the heart, to understand whether altered dopamine uptake can predict the development of PD or DLB in later years. These analyses found that those who had low levels of ¹⁸F-dopamine in the heart were much more likely to develop PD or DLB: eight of nine people were later diagnosed with one of these diseases. Conversely, of the 25 participants with normal levels of dopamine uptake in the heart, only one of the 11 who completed 7 years of follow-up went on to develop a Lewy body disease. The researchers concluded that Cardiac ¹⁸F-dopamine PET can efficiently distinguish at-risk individuals who are diagnosed subsequently with a Lewy body disease, from those who are not.

16 November: Results from the two Phase 3 trials of Gantenerumab in early AD have been published

In November 2022, the pharmaceutical company Roche announced that its Phase III GRADUATE I and II studies of gantenerumab, an investigational anti-amyloid beta antibody, for the treatment of early Alzheimer’s disease (AD), did not meet their primary endpoint.

The GRADUATE studies were two global, double-blind, randomised and placebo-controlled clinical trials evaluating gantenerumab in people with mild cognitive impairment (MCI)

due to Alzheimer’s and mild Alzheimer’s dementia, collectively called early AD. In these two identically designed studies, 1,965 participants across 30 countries received either gantenerumab or placebo by subcutaneous injection every two weeks. The primary outcome was the change from baseline in the score on the Clinical Dementia Rating scale–Sum of Boxes at week 116.

The findings have been recently published in The New England Journal of Medicine. Authors concluded that among people with early AD, the use of gantenerumab led to a lower amyloid plaque burden than placebo at 116 weeks but was not associated with slower clinical decline.

<https://www.nejm.org/doi/full/10.1056/NEJMoa2304430>

21 November: Researchers examine the association between food insecurity and dementia

For older adults, food insecurity is associated with an increase estimated dementia risk, according to a study published on 21 November in the journal JAMA Network Open.



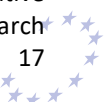
In the study, US researchers used data from the US Health and Retirement Study, a nationally representative, biennially fielded longitudinal survey of non-institutionalised individuals aged 50 years and older and their spouses. Analyses were conducted with data from people with food insecurity data in 2013 and cognitive outcome data between calendar years 2014 and 2018. Food insecurity status in 2013 was assessed using the validated US Department of Agriculture 6-item Household Food Security Module. Respondents were asked a series of questions related to food purchases and consumption over the past 12 months to determine food security status, such as whether they were able to afford the food they needed or whether they ate less due to financial constraints. Respondents were classified as being food secure, low food secure and very low food secure.

The sample included 7,012 participants with a mean age of 67.7 years. Overall, 18.4% of the analytic sample were food insecure: 10.3% experienced low food security and 8.1% experienced very low food security. Researchers found that participants experiencing low or very low food security had a higher probability of dementia, compared to food-secure older adults. Low and very low food security was also associated with lower memory levels and faster age-related memory decline.

<https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2812086>

24 November 2023: A recent study, using digital brain models, sheds light on the link between healthy ageing and cognitive decline

A study, conducted by researchers from Aix-Marseille University, Forschungszentrum Jülich and Heinrich-Heine University Düsseldorf, utilised virtual brain models to explore the connection between healthy brain ageing and cognitive decline. The study, made possible by the EBRAINS research



infrastructure, aimed to understand how structural changes in the brain are linked to variations in cognitive decline among individuals.

The study made use of a large dataset from the "1000BRAINS" cohort study, examining over 1,000 participants aged 55-85 through magnetic resonance imaging (MRI). Analysing this extensive dataset, the researchers identified specific structural changes associated with ageing.

Virtual brain models were created to simulate the functional consequences (i.e. the consequences on cognition) of these structural changes. By introducing degradation between the brain's hemispheres in the Virtual Brain Aging model, the researchers replicated the functional changes observed in the ageing process. This included simulating the "functional dedifferentiation" process, whereby the ageing process is associated with a decrease in the division and specialisation of different regions of the brain. The researchers extended their findings to the individual level by generating virtual brains for each participant in the 1000BRAINS study. They confirmed that specific individual structural changes (in particular a process called 'interhemispheric fibre tract decline' linked to white matter decline in the brain) predicted varying degrees of functional decline.

In summary, the study, enabled by EBRAINS, demonstrated that manipulating brain structure in through computer-derived models replicated observed trajectories of white matter decline and supported the dedifferentiation hypothesis. These findings provide mechanistic insights into how changes in the architecture of functional brain networks contribute to cognitive decline during ageing.

[The virtual aging brain: Causal inference supports interhemispheric dedifferentiation in healthy aging - ScienceDirect](#)

27 November: Personalised lifestyle changes improve cognition in older adults at risk for AD

A new study led by researchers at UC San Francisco and Kaiser Permanente Washington found that personalised health and lifestyle changes can delay or even prevent memory loss for higher-risk older adults. Findings were published in the journal JAMA Internal Medicine.

The study, known as SMARRT, for systematic multi-domain Alzheimer's risk reduction trial, was a randomised clinical trial with a 2-year personalised, risk-reduction intervention. A total of 172 participants at elevated risk for dementia (age 70-89 years and with ≥ 2 of 8 targeted risk factors) were recruited from primary care clinics associated with Kaiser Permanente Washington. Data were collected from August 2018 to August 2022 and analysed from October 2022 to September 2023.

82 participants were randomly assigned to the intervention group (personalised risk-reduction goals with health coaching and nurse visits) and 90 participants to the control group who were mailed education materials every three months. This study differed to others in providing personal coaching that was customised to each participant. After two years, results showed that the personalised and multidomain intervention demonstrated larger improvements in the composite cognitive

score, better composite risk factor score and improved quality of life compared with a health education control group.

<https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2811803>

29 November: Study finds link between early coronary heart disease and dementia

On 29 November, Chinese researchers published a paper in the Journal of the American Heart Association suggesting a link between early coronary heart disease (CHD) and dementia.



The aim of the study was to assess the potential relationship between age at CHD onset and the development of dementia. This study aimed to examine whether younger onset age of CHD is associated with a higher risk of incident dementia. Data were obtained from the UK Biobank, a large biomedical database and research resource with health records of about 500,000 adults. A total of 432,667 adults (mean age 57 years old) were included, of whom 11.7% had CHD. Compared with participants who did not have CHD, participants with CHD had higher risks of developing dementia from any cause, Alzheimer's disease and vascular dementia. Authors concluded that younger onset age of CHD is associated with higher risks of developing all cause of dementia, Alzheimer's disease and vascular dementia.

<https://www.ahajournals.org/doi/10.1161/JAHA.123.031407>

MEMBERS' NEWS

12 October: Alzheimer Larissa (Greece) organises multidisciplinary actions with rhythm and colour



Alzheimer Larissa (E.E.N.A.L.), GREECE, in the context of the celebration of World Mental Health Day, the implementation of the global message "our minds, our rights", and animation of the beneficiaries of the painful ordeal of Daniel and Elia, carried out multi-thematic actions. On the day of the event, E.E.N.A.L. President Eleni Nifli spoke to caregivers about the value of mental health, in terms of individual well-being, well-being and peoples' rights to mental health without discrimination. At the same time, psychologist Maria Manda presented the ways of strengthening mental resilience. This was followed by a dance-movement workshop, where people with dementia played with colours and implemented the tango of Nefeli, with a unique

dance under the guidance of the dance theatre teacher Maria Koutoula.

On 12 October, information material was distributed to the neighbouring school against discrimination and on 14 October the action entitled: "Put colour in your life" was done in collaboration with the group 'POSI AGAPI', which supports people with autism. The aim of this was to encourage the group, to strengthen human relations, to eliminate discrimination and stigmatisation. The president of the E.E.N.A.L. welcomed the group by staging the myth of Persephone. Volunteer Anna Garagouni, dressed in autumn colours, played the role of Persephone, causing excitement, smiles and interactive discussion. The team members were inspired by the branches and leaves that accentuated Persephone's wreath and asked to draw. Volunteers provided them with paper and paints in order to paint. They used a palette of dark green, brown and yellow to depict the branches and leaves of Persephone's wreath. Then, the volunteers and guests played with balloons, to the rhythm of green and purple. The actions concluded with a positive social impact and with multiple encouraging messages.

16-18 October: Flemish Working Group of People with Dementia launches call to action for respectful communication at 33rd Alzheimer Europe Conference



From 16 to 18 October, the 33rd Alzheimer Europe Conference (33AEC) took place in the Finnish capital Helsinki, where the Alzheimer Liga Vlaanderen (the Flemish Alzheimer's association) and the Flemish Working Group of People with

Dementia had the opportunity to present the mission and the recent campaign of the Flemish Working Group. The Working Group is supported by Alzheimer Liga Vlaanderen

Olivier Constant, Advocacy and Awareness Raising Officer Alzheimer Liga Vlaanderen and Coordinator of the Flemish Working Group of People with Dementia (pictured, right) and Réal Larnou (member of both the Flemish Working Group and the European Working Group of People with Dementia (EWGPWD) coordinated by Alzheimer Europe) had a clear message for delegates:

"Just like you and me, people with dementia still have big and small dreams. Giving them the opportunity to make them come true is not a luxury for the chosen few, but a basic human right. Treat people with dementia as the unique individuals that they are instead of patronising them!"

The call to action for respectful communication of the Flemish Working Group's media manifesto (which they also translated from Dutch to English for the Conference) and the accompanying "First Aid Kit" (verbanddoosje) received a lot of

support. From Estonia to Wales and from the Netherlands to Ireland, so many attendees from different countries were enthusiastic after the presentation. It certainly encourages the Flemish Working Group of People with Dementia to continue working on its mission!

In addition, as Chairman of the Flemish Alzheimer's Association, Jef Pelgrims participated on behalf of the Flemish association's national colleagues from LINAL in the Annual General Meeting of Alzheimer Europe, where all member organisations are represented at European level and Réal Larnou was also active in the session of the EWGPWD. A well-filled agenda! The Flemish delegation can look back on intense but inspiring days at the Alzheimer Europe Conference, which attracted more than 1,000 attendees this year! They left cold Finland with a suitcase full of warm memories.

8 November: Global collaboration in neurodegenerative disease and emergency preparedness: Turkish Alzheimer Association and Irish Civil Defence Workers Association foster international partnership



The Turkish Alzheimer Association is pleased to announce a significant development in its collaboration with the Irish Civil Defence Workers Association. The Executive Director of the Turkish Alzheimer Association, Füsün Kocaman has been honoured with an invitation to speak at the Annual Conference organised by the Civil Defence Workers Association in Cavan Town, Ireland on 8 November 2023.

This collaboration stems from the joint participation of the Association and Dublin Civil Defence in the Erasmus+ project, 2022-1-TR01-KA220-VET-000086566 named "YOU ARE ON OUR MINDS" with a mission aimed at addressing the multifaceted challenges posed by persons with dementia in crisis situations. Addressing these challenges requires tailored emergency preparedness plans that consider the specific needs and abilities of persons with dementia involving caregivers, healthcare professionals, and especially search and rescue staff in collaboration with dementia support organisations to develop strategies that prioritise the safety and well-being of individuals with dementia amidst catastrophic events.

The Annual Conference in Cavan Town serves as a hub for professionals and experts in civil defence, providing an ideal setting to discuss the vital intersection of dementia care and civil defence efforts. The Turkish Alzheimer Association has been a torchbearer in fostering awareness, with vast commitment in the field of Alzheimer's advocacy, supporting affected individuals and families and advancing research initiatives related to Alzheimer's disease. Hence, Ms Kocaman's participation in this international conference not only elevates the organisation's profile but also reinforces the importance of global collaboration in tackling the challenges posed by neurodegenerative diseases.

8-11 November: CEAFA organises the tenth edition of the National Alzheimer Conference under the slogan "Integrating innovation"



On 8-11 November (Gijón, Spain), the Confederación Española de Alzheimer y otras demencias (CEAFA), together with the Asociación Alzheimer Asturias as host, organised the tenth edition of the National Alzheimer Conference under the slogan "Integrating innovation". The conference was conceived and designed as a participatory event. For this reason, it involved the participation, as speakers, of people with neurodegenerative diseases leading to dementia, carers, supporters, professionals from Spanish associations of relatives of people with Alzheimer's disease and representatives from industry and academia.

During these four days, the speakers and the attendees addressed issues that have a direct impact on the care and support of people with dementia or people in the early stages of any neurodegenerative disease leading to dementia. The presentations also focused on the latest advances in dementia research, the current political situation and protection of people with dementia and their carers and supporters in Spain, and the experiences and good practices in care shared among healthcare professionals, family members, volunteers and people with dementia.

Soraya Moradi-Bachiller represented Alzheimer Europe at this event and presented the 2020 Alzheimer Europe guide on intercultural dementia care for health and social care providers.

10 November: Kevin Quaid awarded Honorary Doctorate from Longford College, reports The Alzheimer Society of Ireland

The Alzheimer Society of Ireland (The ASI) is thrilled that dementia advocacy champion Kevin Quaid, has been awarded an Honorary Doctorate of Business Administration from Longford College, at a prestigious ceremony on 10 November 2023. The Doctorate, awarded through Rushford Business School, acknowledges Kevin's outstanding contributions to the field of Lewy Body Dementia Advocacy, specifically through the values of innovation, leadership, and a commitment to public service.



Kevin Quaid was diagnosed with Lewy Body Dementia in 2017, after a previous diagnosis of Parkinson's disease. Since then, he has fearlessly campaigned to raise awareness and eliminate the stigma surrounding dementia. As an active advocate, he tirelessly works to promote awareness about the condition through speaking engagements and media appearances. Additionally, Kevin has channelled his experiences with dementia into writing two insightful books, titled "Lewy Body Dementia, Survival and Me" and "I am KEVIN not Lewy."

This Honorary Doctorate serves as a testament to Kevin's unwavering dedication and profound expertise in advocating for the rights and well-being of individuals with dementia. Kevin, who is from Co. Limerick and lives in Co. Cork, is the Chair of the Irish Dementia Working Group as well as Vice-Chair of the European Working Group of People with Dementia. He is also co-founder of Lewy Body Ireland.

27 November: A decade of hard work and dedication: The Irish Dementia Working Group celebrates ten years of impactful advocacy



During November, the Irish Dementia Working Group (IDWG) celebrated 10 years of influential and impactful work, at an event kindly hosted by the Irish Human Rights and Equality Commission (IHREC) at their premises in Co. Dublin. The advocacy group were joined by Minister of State for Mental Health and Older People Mary Butler TD, Irish TV presenter Miriam O'Callaghan and actors Bryan Murray and Una Crawford.



O'Brien. The Alzheimer Society of Ireland (The ASI) staff and supporters also attended the celebrations.

The gathering saw Minister Butler present the members of the IDWG who graduated from the 'Rights Made Real' course, which was commission-funded by IHREC. President of Ireland, Michael D. Higgins also sent a letter congratulating the IDWG on a decade of advocacy.

Established with the support of The ASI and initially made possible by The Atlantic Philanthropies, the IDWG is a group of people living with dementia who advocate for better services, supports, and policies in Ireland. Overseen by The ASI's Advocacy, Engagement and Participation Officer, Saoirse Kelly, the IDWG has become a powerful force for change, giving a voice to people living with dementia and fostering a more inclusive society.

In the past decade, the IDWG has made significant strides in amplifying the lived experience of people with dementia. Through their work, they have brought the voice of the person with dementia to the forefront, ensuring that people with dementia can continue to actively participate and contribute to society.

Pictured: TV's Bryan Murray and Miriam O'Callaghan with Members of the Irish Dementia Working Group

28 November: Interconnection Programme of day centre for patients living with Alzheimer's disease in Kozani (Greece) organises "Weaving friendships beyond age" event

The staff, together with the patients (older women), at the Day Centre for the Protection of the Elderly of the Municipality of Ptolemaida (KIFI) in Greece, decided to raise awareness about Alzheimer's disease through an event, inspired by the online community of "Random Acts of Crochet Kindness", whose main purpose is to share small acts of kindness daily by giving away

handmade gifts randomly (specifically, little figures called "worry dolls"). The concept possibly dates back to the traditions of the Mayans in Guatemala, where they used to weave dolls that would absorb negative energies and worries, providing peace and rest to their owners. The children especially would whisper their fears into their dolls' ears and place them underneath their pillows so that they may sleep peacefully and protected and leave their worries behind when they wake up the next day.

The event aimed to emphasise the significance of giving and to promote the intergenerational aspect of the centre, so the team and patients at KIFI decided to weave their very own "worry worms" which were gifted to the centre's friends at the PS14 Kindergarten of Ptolemaida. After the women attending KIFI had woven the worry worms, they decorated them and packaged them, along with a poem they had written as a group.

On 28 September, having finished with the preparations, the group visited the kindergarten, where they were welcomed with arms wide open. To start with, they introduced themselves to the children, who then wanted to know how the women spend their time at the KIFI day centre and how it was back when they used to go to school. They then explained to the children the meaning of the worry worms, read their poem and they got to choose their own individual worry worm. Before leaving, their new, young friends showed the group their gratitude and affection by gifting each woman from the centre with a handmade heart, sealing their newfound friendship.



LIVING WITH DEMENTIA

7 October: Zornitsa Karagiozova writes about Alzheimer Bulgaria's participation in the annual "5 km RUN" in the city of Sofia for the fifth year in a row



Hello, my name is Zornitsa Karagyozova and I am a member of the European Dementia Carers Working Group (EDCWG) and of the association Alzheimer Bulgaria. I want to share some information regarding one of the initiatives that our association held in Sofia, Bulgaria in October 2023.

On 7 October, the "Alzheimer Bulgaria association" participated in the annual 5 kilometres run for the 5th year in a row. Traditionally, the aforementioned Dementia Run takes place on the first Saturday of October and is a natural extension of the celebration of 21 September, World Alzheimer's Day and of 1 October, International Day of Older Persons.

"Healthy prevention through sports!" and "Let's beat dementia together!" were the slogans that united not only the members of Alzheimer Bulgaria, volunteers at the association from various cities across Bulgaria, their relatives, friends and supporters, but also complete strangers who came to the idea that sports and particularly running can be a form of prevention against a wide variety of diseases, including Alzheimer's

and other types of dementia. Moreover, this initiative aimed to promote the creation of a friendly and understanding social environment for individuals affected by dementia and their relatives who take care of them on a daily basis. A total of 370 people

took part in the run. The youngest participants were in the age group between 8 and 14, and the oldest were between 80 and 84. In addition to that, 200 t-shirts branded with the logo and slogans of our association were distributed.

13 November: Member of the European Working Group of People with Dementia Lieselotte "Lilo" Klotz writes about the "PraWiDem" project

"Networking care practice and science in the care of people with dementia in long-term care through the 'Dementia Living Lab Approach' together with people with dementia"

Participation of people with dementia in research was the exception rather than the rule in Germany, until a few years ago. Arguments such as that we, the people with dementia, are not able to give appropriate consent to participate in research studies, that our ability to understand the implications of the study and make informed decisions is not sufficient, that we cannot provide accurate and reliable information or that the emotional burden is too high, are outdated. Countries like Scotland and the rest of the UK, that involve people with dementia in research, demonstrate this clearly.

I am very glad that, in recent years, there have been increased efforts to promote the participation of people with dementia in research also in Germany. Finally, guidelines and assistance modules have been developed to ensure ethical standards. The "PraWiDem" project is a wonderful example of this. And for me it is great, to be an active participant in this project. My name is Lieselotte Klotz. I was diagnosed with dementia at the end of 2017, which tore me out of my active and successful private and professional life and, since mid-2021, I have been a voluntary member of the "Living with Dementia" advisory board, the Dementia and Research Working Group of the German Alzheimer Association and of the European Working Group of People with Dementia (EWGPWD) at Alzheimer Europe. In Germany, we have had a national dementia strategy since 2020. One aspect of this strategy is that research into the care of people with dementia must be strengthened and improved. The specific project as part of this endeavour is "PraWiDem": <https://www.umh.de/einrichtungen/institute/gesundheits-und-pflegewissenschaften/prawidem>



PraWiDem is taking a new path. Science and practice support each other in order to find answers to current questions. This is to take place through a constant lively exchange (Living Lab). Based on the experiences of "The Living Lab in Ageing & Long-Term Care" in Maastricht, important topics such as improving the quality of life of people with dementia in need of care, improving the quality of care in Germany and supporting the working conditions of employees in long-term care are now also to be evaluated and improved in Germany: <https://pflgewissenschaft.uni-koeln.de/forschung/aktuelle-projekte/prawidem>

The approach is linked to Field of Action 4, of the National Dementia Strategy, which deals with the development, implementation and evaluation of new care concepts. Cooperating partners are: Heinrich Heine University Düsseldorf, Medical Faculty of Martin Luther University Halle-Wittenberg, University of Cologne, German Alzheimer Society e.V. (DAIzG).

The very special thing about "PraWiDem" is, that a dementia and research working group was founded right from the start, in 2022. Four people with dementia are now accompanying the project and will be a relevant pillar of the research team till 2024.

I am not the only one who is more than enthusiastic about the approach of developing, implementing and evaluating new care concepts that directly take into account the perspective of people with dementia and their relatives. All four of us think it's great and are highly motivated. We are consulted and can contribute our knowledge, our positive and negative experiences from our own lives and experiences as those affected and also as relatives. The atmosphere in our team is wonderfully benevolent, respectful and appreciative. We are very creative and everyone likes that.

Specific situations and questions from one of the practice locations are outlined and then we work on the questions arising in 60-90-minute Zoom meetings. Together with the researchers and practitioners, we talk openly and honestly about the respective perspectives, concerns, needs and wishes of people with dementia and their relatives and carers. We: Simone, Pieter, Roland and I, supported by Helga (DAIzG) started with a frequency of meeting every two months, and now we meet most months, for a Zoom meeting (at our own request). We can actively do something to improve care in Germany. That is highly motivating.

Our common motto is: To keep going and always try to do our best in every situation and get involved. "NOT WITHOUT US!" is our demand to research, politics and our environment.

30 November: "Wipe Away Those Stares" - Vice-Chairperson of the European Dementia Carers Working Group Trevor Salomon writes about his experience of taking part in a newly-launched film by Alzheimer's Society UK



A funny thing recently happened to me. I found myself the subject of many stares whilst travelling home on the train from film studios, where I'd spent time at the request of Alzheimer's Society, recording my reality of living with day-to-day dementia as a carer. The film (part 1 just released; part 2 to follow in the New Year) will be used across Alzheimer's Society's social media channels and website, and may also be featured on other websites.

I had been given an insight into the topics I might be asked but frankly that turned out to be but a mere framework because, once conversation began, the interviewer was bound to follow

up with impromptu questions which took discussion off into unexpected tangents! Actually, I prefer it this way; it seems a lot more natural and flows better than anything pre-planned. Sometimes, I was asked to repeat my answers, but frame them in a slightly different way in order to place greater emphasis in some areas of my responses. The challenge was trying to remember what I'd said in the first place!

There are many people involved in creating professional quality output at film studios – the lighting and sound specialists, the camera operators, the interviewer, the director, the support personnel. A lot of effort, a great deal of time, infinite patience and all in the knowledge that hours of input will probably result in less than a couple of minutes of edited output.

I left the studios having greatly enjoyed the experience and fascinated by the work that went into the creation of the film which, as you can see, also features other carers as well as people living with dementia:

<https://www.youtube.com/watch?v=4pYy01ZqygA>

When I eventually arrived home, I looked in the mirror and realised I hadn't washed off the makeup which was applied to my face to compensate for the glare of the studio lights...hence all the stares on my journey home. You can tell I'm an amateur when it comes to being in a studio!



DEMENTIA IN SOCIETY

14 November: Mahon Point Shopping Centre in Cork is Ireland's first dementia-inclusive shopping centre



On 14 November 2023, The Alzheimer Society of Ireland (The ASI) launched Mahon Point Shopping Centre in Co. Cork as the first dementia-inclusive shopping centre in Ireland. In a major

step towards creating a positive and welcoming environment for people living with dementia and their families, ensuring inclusivity for all, The ASI teamed up with Mahon Point Shopping Centre to roll out the first dementia-inclusive shopping centre in the country. The event garnered significant national and local media attention.

Speaking ahead of the launch, Head of Operations at The ASI, Siobhan O'Connor, said:

"This is a huge step forward in our quest to create a dementia-inclusive shopping centre; we're so grateful to the Mahon Point Management Team and its tenants for taking the brave steps to become the first of its kind in Ireland. We hope that more centres will follow their shining example and join Mahon Point to create an Ireland where people with dementia and their families can carry out their daily lives securely."

The ASI welcomed the Lord Mayor of Cork Cllr Kieran McCarthy at the launch, along with service users and their supporters and volunteers.

As part of the 'Creating a Dementia Inclusive Shopping Centre Programme', Management and staff at Mahon Point Shopping Centre, together with staff members from each of the stores, received Dementia Awareness training so that they will have the knowledge and skills to create a welcoming, enjoyable, and safe shopping experience for people living with dementia their family members and carers. The training was on areas including: What is Dementia? Signs and Symptoms,

Communication, and Creating a Dementia Inclusive Community.

Mahon Point will be the first shopping centre in Ireland to be awarded the Dementia Inclusive Community Friends of ASI accreditation and to display the emblem.

63% of people with dementia in Ireland live at home, in the community.

For more information about the #FriendsOfASI initiative, please contact friendsofasi@alzheimer.ie.

JOB OPPORTUNITIES

30 November: Dementia UK seeks to employ two research fellows to support delivery of its new Research Strategy

Research is a key element in Dementia UK's strategic aims and runs throughout all its approaches to supporting people with dementia and their families. Their research is focused on care not cure, helping to improve lives and support their Admiral Nurses. As part of the Research and Publications Team,

Dementia UK is seeking to employ two research fellows to support the delivery of its Research Strategy, which was launched in September 2023.

This role will support in designing and undertaking literature reviews, developing review questions in collaboration with Dementia UK's patient and public involvement group. The successful applicants will lead on data collection conducting interviews with people with dementia, carers, Admiral Nurses or other key stakeholders, analysing that data and disseminating the research findings. They will also collaborate with other researchers, representing Dementia UK in supporting and advising researchers in the field of dementia care.

The deadline for applications is 11 December. To find out more about the role and how to apply, please visit:

<https://www.dementiauk.org/about-us/work-for-dementia-uk/job-vacancies/research-fellow/>



Contact Alzheimer Europe:

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

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).

Alzheimer Europe Staff:

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

AE CALENDAR 2023

Date	Meeting	AE representative
4 December	EMA Big Data Stakeholder Forum	Angela
4 December	Alzheimer Europe Board (Brussels, Belgium)	AE Board and staff
5 December	Alzheimer Europe Company Round Table (Brussels, Belgium)	AE Sponsors, Board and staff
5 December	European Parliament Lunch Debate "Inequalities in dementia care and treatment in Europe" (Brussels, Belgium)	AE supporters, members and staff
5-6 December	Alzheimer Europe Public Affairs Meeting (Brussels, Belgium)	AE members and staff
7 December	EMA Network Advisory Group on Raw Data	Angela
8 December	Meeting with INTERDEM	Jean
12 December	Rencontres France Alzheimer (Paris, France)	Angela
12 December	Italian Knowledge Leaders (Florence, Italy)	Gwladys
12 December	Social gathering with the ADIS Advisory Board members	Soraya and Ana
13 December	Online Consultation of the EWGPWD	Ana, Soraya and Daphné
14 December	CEOi Digital Cognitive Assessments Workgroup meeting	Angela
15 December	Meeting with EFPIA AD Platform	Jean
15 December	Online Consultation of the EWGPWD	Ana, Soraya and Daphné
18 December	Online end of year social with the EWGPWD	Ana, Soraya and Daphné
19 December	Christmas social gathering with the EU-FINGERS and LETHE Advisory Board members	Ana, Cindy

CONFERENCES 2024

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



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New horizons –
Innovating for dementia
Geneva, Switzerland
8 - 10 October 2024 #34AEC
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