Alzheimer Europe

Newsletter
JANUARY 2024

HIGHLIGHTS

CONTENTS

WELCOME

Alzheimer Europe has hit the ground running in 2024, with a very busy January, including launching four new publications: A position paper on anti-amyloid therapies for Alzheimer's disease; a guide on the United Nations Convention on the Rights of Persons with Disabilities and how national Alzheimer's associations can participate in the review process; our 2023 Dementia in Europe Yearbook, dedicated to legal capacity and supported decision-making; and, last but not least, a guide on inclusive travel and meetings for people with dementia, developed by the current members of the European Working Group of People with Dementia (EWGPWD) in collaboration with Alzheimer Europe and building on earlier work carried out by the EWGPWD in 2020. Special thanks go to the supporters and carers of members of the EWGPWD and to the European Dementia Carers Working Group (EDCWG) for their input on this last publication.
Our European Election Campaign 2024 got underway this month and will run until the European Parliament elections in June. The campaign aims to make dementia a priority issue for decision-makers at a European level and involves three distinct sections. The Helsinki Manifesto outlines the current situation in relation to dementia across Europe, detailing specific demands for the European Commission Institutions and national governments. If your organisation would like to endorse it, please get in touch. Our public Call to Action demanding that European decision-makers prioritise dementia, which you are invited to sign on our website. Finally, the Dementia Pledge 2024, a commitment which candidates standing for the European Parliament elections are invited to make, pledging their support in prioritising dementia and joining the European Alzheimer's Alliance (EAA) upon election. I am delighted to share that, after just two weeks, we already have 49 organisations supporting the Manifesto, 276 Call to Action signatories and a new EAA member. The campaign includes a series of short videos of members of the EWGPWD and EDCWG speaking out about why dementia must be a policy priority. We are sharing these on social media, together with the hashtag #DementiaNeedsEU. Please support us and share our campaign with your networks.
Another series of videos that we are proud to present is a set of interviews filmed during our recent series of consultations on Public Involvement in dementia and brain health research. The interviews are with members of the Advisory Boards of the six EU projects attending this international event, including members of the EWGPWD, as well as project researchers and the FNR - Luxembourg National Research Fund programme manager.
Our contributions to many different EU-funded projects is something that we are very proud of and our work in this area continues to grow, both in terms of volume and impact. We are delighted to be a partner in a brand new Innovative Health Initiative-funded interdisciplinary project aiming to transform Alzheimer's disease diagnosis, prevention and treatment. The project is called AD-RIDDLE and you can read more about it in our EU Projects news section.
Enjoy our new-look newsletter for 2024!

Jean Georges
Executive Director

SPOTLIGHT ON EUROPEAN ELECTIONS

15 JANUARY

Alzheimer Europe launches European Election Campaign 2024

In advance of the European Parliament elections between 6 and 9 June, Alzheimer Europe launched its European Election Campaign 2024, on 15 January, aiming to make dementia a priority issue for decision-makers at a European level.

In its campaign, Alzheimer Europe highlights World Health Organization (WHO) figures which show that dementia is the third leading cause of mortality in Europe and the seventh globally, with a societal cost in Europe estimated to be EUR 392 billion in 2019. Additionally, the organisation points out that by 2025, 9.1 million people will be living with dementia in the European Union, rising to 14.3 million in 2050.

Alzheimer Europe is therefore pushing for the condition to be shown greater attention by European decision-makers and has adopted a campaign with three distinct elements aimed at different audiences, demanding dementia be prioritised as a policy issue:

- The Helsinki Manifesto – An outline of the current situation in relation to dementia across Europe, detailing specific demands for the European Commission Institutions and national governments. The Manifesto will be the basis of Alzheimer Europe's campaign work in the coming years. European and national organisations are invited to endorse the Manifesto.
- A public Call to Action – A call demanding that European decision-makers prioritise dementia as a policy issue and implement the actions of the Helsinki Manifesto. All individuals are welcome to sign the Call to Action via Alzheimer Europe's website.
- The Dementia Pledge 2024 – A commitment which candidates standing for the European Parliament elections are invited to sign, pledging their support in prioritising dementia in the areas of health, research, disability policy and informal carers and pledging to join the European Alzheimer's Alliance, upon election. All candidates standing in the European Parliament elections are encouraged to sign the pledge.

As part of the campaign, Alzheimer Europe worked with members of the European Working Group of People with Dementia and the European Dementia Carers Working Group to create videos for use on social media, with members of the groups sharing their own experiences of dementia and calling for decision-makers to prioritise dementia as a policy issue.

Once the campaign has concluded, Alzheimer Europe will work with its national member associations to follow up with elected MEPs who supported the Dementia Pledge, to identify where dementia must be prioritised and to ensure that the aims of the Helsinki Manifesto are embedded in the Commission's priorities for the new legislative term.

Jean Georges, Executive Director of Alzheimer Europe, stated: "With the number of people living with dementia expected to substantially increase in the coming years, as well as the considerable societal costs associated, it is time for European decision-makers to prioritise dementia and dedicate the resources needed to address it across the domains of health, research, disability rights and support for informal carers. Our campaign aims not only to highlight the scale of the challenge presented by dementia but, through the Helsinki Manifesto, offers concrete steps for how European decision-makers can take decisive action in the coming years. We encourage members of the public to sign our Call to Action and invite all MEP candidates to sign the Dementia Pledge 2024!"

Sirpa Pietikäinen MEP (Finland) welcomed the launch of the campaign, explaining: "It is vital that MEPs take action to upgrade attention to neuro-degenerative diseases and to prioritise dementia at the EU level. We need to ensure that the European Parliament's positions are heard and that we are raising awareness and addressing the challenges that people with dementia face. We also need to hold the Commission accountable when it is necessary. This is an area where we can create meaningful and positive change and truly address the challenges that patients and their families face. It is our responsibility to create policies that create better EU and better everyday life in every Member State for people with dementia, so that everyone can live their lives the way they want to live it. I therefore strongly encourage all candidates standing in the European Parliament elections to sign the Dementia Pledge 2024 and work with Alzheimer Europe and national Alzheimer's associations to ensure that dementia is prioritised in the coming term."

An overview of the campaign, together with information about how European and national organisations can endorse the Helsinki Manifesto, how individuals can sign the Call to Action and how MEP candidates can sign the Dementia Pledge 2024, can be found on the Alzheimer Europe website at:
https://www.alzheimer-europe.org/policy/campaign/alzheimer-europe-election-campaign-2024

31 JANUARY

Our European Election Campaign 2024 is well underway with 276 signatories of our Call to Action and 49 organisations supporting the Helsinki Manifesto!

We are delighted to share the progress of our European Election Campaign 2024, in the runup to the European Parliament elections which will be taking place between 6 and 9 June. Our campaign aims to make dementia a priority issue for decision-makers at a European level. It has three strands to it:

The first is the **Helsinki Manifesto** which outlines the current situation in relation to dementia across Europe, detailing specific demands for the European Commission Institutions and national governments. We are grateful to the following organisations for endorsing our Manifesto and invite others to do the same. See here for more information: https://bit.ly/AEHelsinkiManifesto

There are 49 organisations currently supporting the Helsinki Manifesto:

- All 41 of our member organisations in 36 countries across Europe
- Alzheimer's Disease International (ADI)
- Council of Occupational Therapists for the European Countries (COTEC)
- Dementia Jersey
- Eurocarers
- European Federation of Neurological Associations (EFNA)
- European Institute of Women's Health (EIWH)
- International Psychogeriatric Association (IPA)
- Women's Brain Project

Many thanks to all of them!

The second strand to our campaign is a public **Call to Action** demanding that European decision-makers prioritise dementia as a policy issue and implement the actions of the Helsinki Manifesto. All individuals are welcome to sign the Call to Action via Alzheimer Europe's website: https://bit.ly/AECallToAction2024. We are delighted that we already have 276 signatories and we thank them all for their support. You can see the list of signatories, here: https://www.alzheimer-europe.org/policy/campaign/alzheimer-europe-election-campaign-2024/call-to-action-signatories

The third strand is the **Dementia Pledge 2024**, a commitment which candidates standing for the European Parliament elections are invited to make, pledging their support in prioritising dementia in the areas of health, research, disability policy and informal carers and pledging to join the European Alzheimer's Alliance, upon election. Our sincere thanks to our very first signatory for the **Dementia Pledge 2024**, MEP Pierre Larrouturou (S&D, France). All candidates standing in the European Parliament elections are encouraged to sign the pledge, either via: https://bit.ly/DementiaPledge2024 or by posting their support on social media (Twitter/X, Facebook, LinkedIn) using the hashtag **#DementiaPledge2024**

ALZHEIMER EUROPE

9 JANUARY

Alzheimer Europe adopts position on anti-amyloid therapies for Alzheimer's disease, issuing a call to action for timely, safe and equitable access

In a new position paper, and following engagement with its national members and the European Working Group of People with Dementia (EWGPWD), Alzheimer Europe calls for concrete actions to enable timely, safe and equitable access to anti-amyloid drugs, for patients who are most likely to benefit from these innovative new treatments for Alzheimer's disease (AD).

The growing prevalence and impact of AD has catalysed huge investments in research on its causes, diagnosis, treatment and care. After many high-profile failures, recent clinical trials of anti-amyloid drugs have marked a turning point for the field, leading to the approval of the first disease-modifying therapies for AD in the US. European regulators are currently evaluating whether there is sufficient evidence to approve these drugs for patients with mild cognitive impairment (MCI) or mild dementia due to AD.

Anti-amyloid drugs represent a new hope for people with AD. Classed as disease-modifying therapies, drugs such as lecanemab and donanemab can slow the progressive, clinical decline associated with AD, with the potential to give patients more time in the less symptomatic stages of the disease. However, the benefits and risks of initiating treatment with anti-amyloid drugs are multifaceted and complex, as are the patterns of evidence and effectiveness from clinical trials.

Access to anti-amyloid drugs hinges entirely on a timely and accurate diagnosis of AD, in the MCI or mild dementia stages, with biomarker confirmation of AD pathology. However, diagnosing AD remains challenging in clinical practice, excluding many from accessing patient-centred support, care and treatments. Currently, European healthcare systems are inadequately resourced to provide a timely diagnosis, let alone equitable access to anti-amyloid drugs, for all people with early AD who could benefit from treatment.

The Alzheimer Europe position paper addresses questions of anti-amyloid drug efficacy, safety and cost, highlighting three priority areas to ensure equitable access to these innovative treatments: effective communication of risks and benefits; an accurate, timely diagnosis; and healthcare systems preparedness. To address these challenges, Alzheimer Europe calls for concrete actions from industry, regulators, payers, healthcare systems and governments. These include:

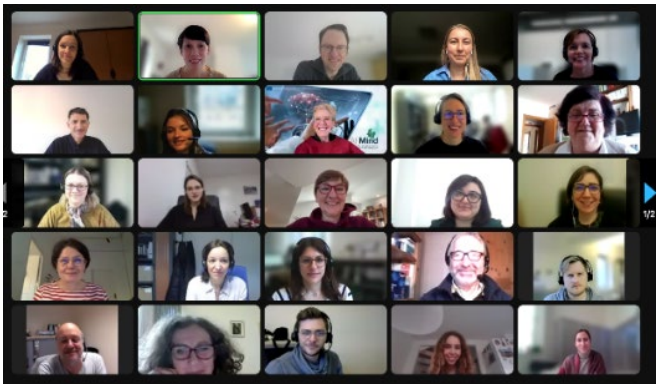
- Accessible, inclusive communication of the benefits and risks of anti-amyloid drugs, so patients can weigh the potential slowing of clinical decline against the side effects, financial costs and logistical burdens of treatment;
- The adoption of realistic, sustainable pricing policies for anti-amyloid drugs, coupled with clear reimbursement frameworks that reflect the true value of treatment for patients and society, without impacting the coverage of existing therapies that are hugely valued by people with dementia and their carers/supporters;
- Development of patient registries for long-term collection of real-world evidence on the efficacy and safety of anti-amyloid drugs, including data on outcomes that are meaningful for patients and their carers/supporters;
- Investment in infrastructures for diagnosis and treatment, with expansion of workforce capacity and capability supported by clear guidance on drug eligibility, and parameters for treatment initiation, safety monitoring and discontinuation;
- Implementation of biomarker-guided clinical pathways which support the diagnosis and treatment of AD in the early stages of disease, integrated alongside existing pathways focused on managing the symptoms of later-stage dementia;
- Continued investment in the development of diagnostics and treatments for other causes and stages of dementia, as well as support and care services that can help people live well with dementia at all stages.

Commenting on the position paper, Alzheimer Europe's Executive Director, Jean Georges, stated: "If anti-amyloid drugs are approved by European regulators, these innovative treatments should be accessible for patients most likely to benefit, with clear protocols to exclude those most likely to suffer serious side effects. Fair pricing policies are crucial, to support broad coverage and reimbursement. The development of disease-modifying therapies for early AD marks a turning point in the fight against the disease. However, the needs of people with more advanced AD, or less common forms of dementia, must not be overlooked. Research into other treatment options is essential, including symptomatic treatment for people with more advanced dementia, and preventative approaches throughout the lifecourse."

Our full position paper can be accessed on the Alzheimer Europe website:
https://www.alzheimer-europe.org/policy/positions/alzheimer-europe-position-anti-amyloid-therapies

23 JANUARY

First Alzheimer's Association Academy of 2024 addresses the topic of AI and dementia



On 23 January, we hosted our first Alzheimer's Association Academy meeting of the year. These capacity-building workshops bring together representatives of national Alzheimer's associations with members of the European Working Group of People with Dementia and European Dementia Carers Working Group, to learn about the latest advances in dementia research, policy, care and treatment from experts in those fields. The Academy meeting, which was moderated by Angela Bradshaw (Director of Research and Policy), was focused on the topic of Artificial Intelligence (AI) and dementia, and welcomed over 70 registrants from 18 countries. The first two speakers, Holger Frohlich (Fraunhofer SCAI, Germany) and Ira Haraldsen (Oslo University Hospital, Norway) showed how AI can power new research innovations aimed at improving dementia detection, diagnosis, prevention and treatment.

Holger highlighted some of the challenges facing healthcare systems, many of which lack the capacity to screen, diagnose and adequately treat people with Alzheimer's disease and dementia. Explaining that AI algorithms have the power to support more accurate, personalised diagnoses and detection, Holger outlined the goals of a newly-launched pan-European research project called PREDICTOM. This Innovative Health Initiative-funded project is creating an AI-enabled platform comprising screening and diagnostic tools that could be deployed in the community and in the primary care setting. Hol-

ger also spoke about the ADIS project, which is evaluating correlations between sleep disturbances and markers of neuroinflammation, using machine learning. Ira, speaking after Holger, focused her presentation on the AI-MIND project, a Horizon 2020-funded project which is developing tools for dementia risk screening in people with mild cognitive impairment (MCI). The AI-MIND tools, which are built around powerful machine learning algorithms, aim to shorten the diagnostic period from months or years to a matter of weeks. Ira explained how tools such as the AI-MIND Connector, which analyses data from functional brain networks measured using EEG and MRI, could provide access to a more personalised, rapid diagnosis delivered in the GP's office.

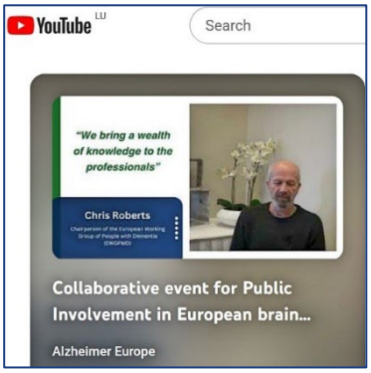
The next presentation was entitled "AI for rare disease diagnosis: a perspective for AD", delivered by Marcelo Martinez Conti of Foundation 29. Foundation 29 was launched by Julian Isla, whose son has a rare disease called Dravet Syndrome. Julian and Marcelo, who both have a background in computer science and IT, wanted to accelerate and improve the diagnostic process, and empower patients and their families to use, understand and share their clinical data. Foundation 29 therefore set out to develop AI-powered tools for doctors and patients, to support clinical decision-making and patient-driven diagnosis. Marcelo presented the dxGPT tool, which uses the ChatGPT system of large language models to suggest possible diagnoses when provided with information about symptoms. On the data side, the nav29 prototype tool is a personal health platform for patients to consolidate and share their medical records, ask questions about their health, and access summaries of patient-doctor interactions.

The next speakers, Soraya Moradi Bachiller and Daphné Lamirel (Public Involvement Officers at Alzheimer Europe), offered the perspectives of people living with dementia and their carers on AI. These perspectives were drawn from public involvement (PI) consultations in the context of research projects such as ADIS, eBRAIN-Health, AI-MIND and PatternCog. Soraya and Daphné identified some common themes in the responses, such as data privacy and confidentiality, bias and discrimination, and the impact of AI on the patient-doctor relationship. Explainability was also highlighted as an important consideration for people with dementia and their carers, including clear accountability for decisions made using AI-powered tools – coupled with access to tailored post-diagnostic support with actionable outcomes for patients.

The final speaker of the day, Saila Rinne, highlighted a few recent AI policy developments, including the new AI Act proposal, and the launch of AI and brain health research programmes by the European Commission. The AI Act proposal, for which provisional agreement was reached in December 2023, will categorise and regulate AI based on its risks to cause harm to individuals and society. Specific rules for high-risk AI aim to protect citizens from potential harm, whilst regulatory sandboxes are intended to promote innovation in a safe space. Turning to research and innovation, Saila described a new European partnership for brain health, bringing together the JPND, NEURON, and the Human Brain Project; and the Virtual Human Twins initiative, which aims to improve access to personalised prevention, early diagnosis, and tailored clinical pathways for all EU citizens. Concluding, Saila emphasised that patients and the public are the key stakeholders in these initiatives, explaining the EU approach to involving the public through advisory boards and representatives with lived experience of disease.

29 JANUARY

We present a series of interviews from our Public Involvement event in Luxembourg



In November 2023, at the first event of its kind, six European research projects joined together in a series of consultations focusing on Public Involvement in dementia and brain health research, organised by Alzheimer Europe.

At this event, 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.

During this collaborative event, Alzheimer Europe took the opportunity to produce a series of video interviews. These interviews are with members of the Advisory Board members of the six EU projects attending the meeting, researchers working on the project, the FNR programme manager and members of the European Working Group of People with Dementia (EWGPWD). The EWGPWD is also involved in a number of projects through its work with Alzheimer Europe and some of them are also members of the Advisory Boards of these projects. They all shared their experiences working on the various projects and the vital contributions of the Advisory Boards ensuring that research accurately reflects the preferences, needs and priorities of members of the public and their perspectives in different aspects of research processes and outputs/results.

https://www.youtube.com/playlist?list=PLO-PgQHI1WQU3TLkkEVg7uWRksmxidFGt

30 JANUARY

Alzheimer Europe releases “Guidelines on Inclusive Travel and Meetings for People with Dementia”

Alzheimer Europe is pleased to introduce its latest publication: the “Guidelines on Inclusive Travel and Meetings for People with Dementia”.

People with dementia are increasingly being invited to participate in meetings in various settings, such as in the context of Public Involvement for research projects, national policy working groups and other advocacy activities. It is imperative to include people with dementia in such activities to recognise the value of their perspectives and life experiences and guarantee that they can have a say in the development of research, policy and services. Alzheimer Europe’s new guidelines aim to ensure that meetings and travel arrangements are organised with accessibility and the specific needs of people with dementia in mind, promoting their well-being throughout.

The guide builds on previous work carried out with the European Working Group of People with Dementia (EWGPWD) in 2020 on inclusive meetings and travel. The topic was then revisited in 2023 in several consultations with the EWGPWD and with the European Dementia Carers Working Group (EDCWG).

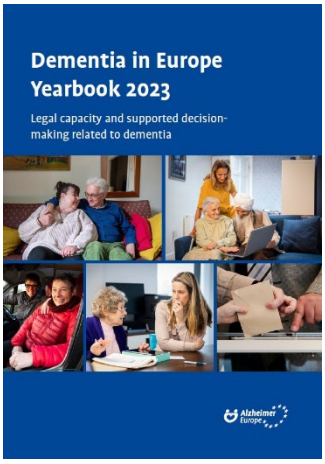
Drawing from both groups’ feedback and Alzheimer Europe's extensive experience in the field, the guidelines offer some practical guidance for anyone who is involved in planning meetings and discussions with people with dementia. Eight key areas are covered. These include: the practicalities of travel arrangements, the role of a supporter in meetings, financial aspects of travelling, accessible information, promoting the well-being of participants during a meeting and issues specific to online meetings. The final part of the guide includes tips for people with dementia and carers/supporters from some members of the EWGPWD and the EDCWG.

We encourage our network to use and share these guidelines with any other individual or organisation involved in organising meetings that include people with dementia. Organisations are invited to get in touch if they are interested in translating these guidelines into other European languages.

The publication can be downloaded, via our website: https://www.alzheimer-europe.org/resources/publications/guidelines-inclusive-travel-and-meetings-people-dementia

31 JANUARY

Alzheimer Europe report outlines challenges associated with legal capacity and dementia



On 31 January 2024, Alzheimer Europe launched its 2023 Dementia in Europe Yearbook dedicated to legal capacity and supported decision-making for people living with a diagnosis of dementia. The Yearbook examines the overarching European and International accords which set out how the rights and wishes of people with dementia are protected, especially where the capacity of a person may be affected by their illness, as well as how national laws and policies address this issue.

Specifically, the Yearbook provides an overview of the provisions of the Charter of Fundamental Rights (CFR), the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the HCCH 2000 Protection of Adults Convention (the Hague Convention) before exploring in detail how each European country addresses capacity in relation to issues such as the creation of wills, powers of representation and consent to treatment etc.

Across European countries, policies and legislation related to legal capacity vary considerably, with mechanisms for powers of representation (e.g. powers of attorney) and substitute decision making (e.g. guardianship), taking different approaches. Alzheimer Europe was keen to understand how legislation had developed to incorporate supported decision-making, reflecting the rights-based approach of European and International treaties. There was evidence of progress in some countries, including legislative reforms and development of resources which aim to maximise the autonomy of the individuals who may not have full legal or decision-making capacity. However, many countries have not reformed their systems in recent years and even where changes have been made, supported decision-making is still not widespread.

Alzheimer Europe noted that the European Commission’s proposals on cross-border arrangements do not reflect a more rights-based approach and do not acknowledge the need for such systems to be UNCRPD compliant (for example, by including reference to supported decision-making).

One of the key points which emerged from the Yearbook was the difficulty in applying the UNCRPD General Comment No.1, particularly its view that substitute decision-making is discriminatory and should be abolished. Specifically, this approach overlooks the progressive nature of conditions such as dementia and gives no consideration to the practical difficulties that arise where no mechanism exists to take decisions,

should an individual not be able to do so themselves. Even in countries which have tiered levels of guardianship and/or supported decision-making articulated in its legislation, all recognise the importance of guardianship as a measure of last resort, where supported decision-making is no longer sufficient. The Yearbook also contains testimonies from a number of past and present members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG). Members of both groups shared their experiences of making and/or using powers of attorney or guardianship in relation to their own diagnosis or that of a family member. These experiences illustrate the importance of ensuring that members of the public understand how legal capacity works within their country and that they discuss their future wishes with those close to them. Additionally, these experiences show that systems should ensure that processes do not unduly burden families and maximise the autonomy of individuals for as long as possible.

Taking these issues into account, the Yearbook contains a number of recommendations aimed at both national and European decision-makers, encouraging them to improve their systems of legal capacity and supported-decision making by:

- Dedicating programmes of work within European Social Fund Plus (ESF+) / the Cohesion Fund of the European Commission to support the development of resources and projects which implement systems of supported decision-making for persons with disabilities.
- Adopting and implementing the proposed Commission Regulation on cross-border situations and the Council Decision on the Hague Convention.
- Reforming laws relating to substitute decision-making, moving towards a system which prioritises supported decision-making, aligning to the combined supported decision-making model contained in Alzheimer Europe's 2020 Ethics Report.
- Providing funding for the development of public-facing campaigns to raise awareness and understanding of powers of representation and encourage people to make these arrangements and/or advance directives, advising people where to go and whom to approach to get more information on the process.

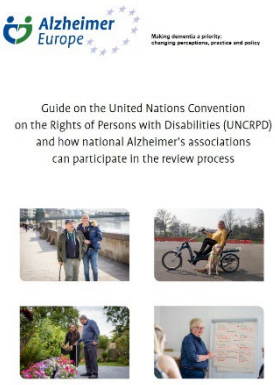
The full report can be accessed on the website of Alzheimer Europe at: https://bit.ly/AE2023Yearbook

31 JANUARY

Alzheimer Europe launches UNCRPD guide

Alzheimer Europe has published a new document, "Guide on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and how national Alzheimer's associations can participate in the review process".

The UNCRPD came into effect on 3 May 2008. Under the definition of disability set out in the Convention, dementia was recognised as a disability, placing obligations on governments to ensure that people living with dementia are supported, requiring that national policies and legislation aligned to the articles of the Convention and upheld the rights of individuals. However, many countries still do not recognise dementia as a disability and therefore, do not recognise their rights under the Convention.



Alzheimer Europe is therefore keen for its member organisations to engage in the UNCRPD review process, whereby the UNCRPD Committee reviews the adherence of a country to its obligations under the Convention. The Committee is reliant upon receiving information from a broad range of stakeholders, including non-governmental organisations, in order to formulate its List of issues/Concluding observations. Although the process cannot itself force governments to change policies or legislation, by drawing attention to gaps in implementation of the Convention, it represents the opportunity for concerns and evidence to be presented to an independent and external actor.

Alzheimer Europe has therefore created guide, outlining the purpose and background to the UNCRPD, as well as the review process, with a specific focus on how the Convention relates to persons with dementia. Additionally, it provides practical information about how Alzheimer's associations may involve themselves in the review process, with information about timescales, the format of contributions and the different types of opportunities for contributions (including Periodic Reviews, General Comments etc.). The guide also contains examples of where dementia has been specifically identified in the Concluding Recommendations of the UNCRPD Committee, demonstrating how issues relevant to people can be given a greater focus by engaging in the review process.

Alzheimer Europe is hopeful that by creating the UNCRPD Guide, its member associations will not only gain a greater understanding of why the UNCRPD process is highly relevant for their advocacy and campaigning activities but that it will also provide a useful and practical guide which enables them to be able to take part in the review process in future.

The guide can be downloaded at:

https://www.alzheimer-europe.org/resources/publications/guide-united-nations-convention-rights-persons-disabilities-uncrpd-and-how

31 JANUARY

EWGPWD meets online and provides feedback for the EPND project

On 31 January 2024, members of the EWGPWD joined an online meeting, together with Ana Diaz (AE Public Involvement Lead), Soraya Moradi-Bachiller and Daphné Lamirel (AE Public Involvement Officers). Members of the EWGPWD have been involved in Public Involvement activities as part of the EPND project, including providing their views on data sharing and consent forms as well as reflecting on how to communicate scientific terms to the general public, in particular with input on definitions included in a lay glossary. In this meeting, the discussion revolved around gathering further feedback on the glossary that AE is developing as part of the project. All the members gave very valuable feedback on how to display and organise the glossary on the EPND website and how to promote the glossary to an audience beyond the EPND project. The final part of the meeting was focused on discussing some organisational matters related to the EWGPWD including upcoming meetings, conferences and the election of a new Chair of the new term of the group.

31 JANUARY

Enjoyed 33AEC? Check out some of the blogs and other media from the event and mark the dates for our 2024 conference!

We are delighted to share some of the news and media from the 33rd Annual Alzheimer Europe Conference (33AEC) in Helsinki on 16-18 October, 2023, on our website:

https://www.alzheimer-europe.org/conferences/2023-helsinki/news-and-media-33aec

If you enjoyed 33AEC, we invite you to mark the dates of the 34th Alzheimer Europe Conference, which will take place in Geneva, Switzerland, from 8-10 October 2024!

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

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

www.mukes.fi/news

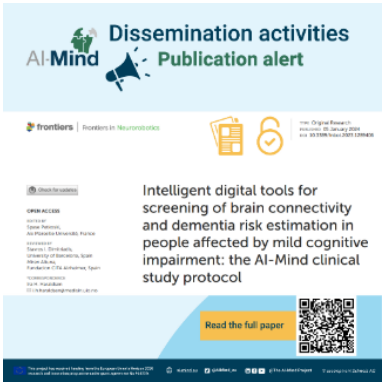
ALZHEIMER EUROPE NETWORKING

9 JANUARY	Jean and Ange had a meeting with Lilly
9 JANUARY	(Luxembourg, Luxembourg) the AE team had its New Year lunch
11 JANUARY	(London, United Kingdom) Jean attended the GSH Health Advisory Board
12 JANUARY	Gwladys and Kate had a meeting with the Alzheimer Society of Ireland about 36AEC
15 JANUARY	Daphné and Ange participated in a consultation with the PROMINENT Public Involvement Board
17 JANUARY	Jean had a meeting with Acumen Pharmaceuticals
17-18 JANUARY	(Barcelona, Spain) Chris and Soraya attended the ADIS General Assembly meeting
18 JANUARY	Gwladys attended a meeting on “All things EVENTS”
18 JANUARY	Owen attended a meeting on EDF’s strategy development
23 JANUARY	Alzheimer Europe organised an Alzheimer’s Association Academy on “Artificial Intelligence in Dementia”
24 JANUARY	Jean had a meeting with Roche
25 JANUARY	Owen attended EDF’s ENGO meeting
25 JANUARY	Jean had a meeting with Bristol Myers Squibb
25 JANUARY	Jean, Ange and Daphné attended the kick-off meeting of the AI4Hope project
25-26 JANUARY	(Amsterdam, Netherlands) Cindy attended the EMA Clinical Trials Data Analytics Workshop
31 JANUARY	Ana, Daphné and Soraya participated in a consultation with the EWGPWD

EU PROJECTS

5 JANUARY

The AI-Mind clinical study protocol is published



The AI-Mind project kicks off the new year with excellent news. A new AI-Mind consortium paper, "Intelligent Digital Tools for Screening Brain Connectivity and Estimating Dementia Risk in Mild Cognitive Impairment: The AI-Mind Clinical Study Protocol" has been published in Frontiers in Neurorobotics. Aligning with the European Commission's Open Science policy, this insightful paper is available in full open access.

In close collaboration across diverse institutions and disciplines, the AI-Mind project introduces an innovative method for early risk assessment using advanced artificial intelligence (AI) on multimodal data. Project partners develop two AI-based tools aiming not only to accelerate the diagnostic process but also to deliver highly accurate predictions regarding an individual's risk of developing dementia when prevention and intervention may still be possible. First, the AI-Mind Connector identifies dysfunctional brain networks through high-density magneto- and electroencephalography (M/EEG) recordings. Second, the AI-Mind Predictor utilises data from the Connector, enriched with cognitive tests, genetic and protein biomarkers, sociodemographic, and clinical variables to predict an individual's risk of developing dementia.

"The AI-Mind protocol paper is a great milestone in our research journey. The many following publications from AI-Mind partners will be detail-orientated and will refer to the interdisciplinarity of the AI-Mind project. We are excited to assure the reader of a thrilling 2024 and 2025 year with new insights into the presymptomatic dementia identification of risk with the use of new biomarkers.", shares Dr Ira Haraldsen, the AI-Mind coordinator.

The most recent publication delves into the clinical study protocol of AI-Mind, elucidating clinical, ethical, social, and technical challenges that the project addresses. Crucially, it lays the foundation for future scientific contributions by providing insights into the background of the AI-Mind study and the potential impact of the project on dementia risk assessment. The clinical study, as detailed in the publication, is expected to make significant contributions to ongoing discussions about the clinical assessment of AI-Mind across four European countries.

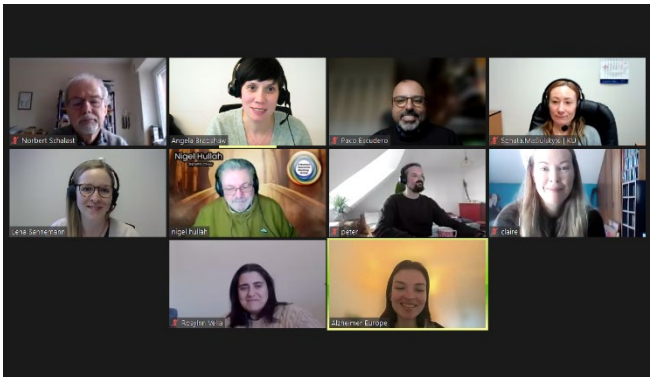
The AI-Mind project marks a significant milestone in leveraging AI to enhance early detection and intervention in dementia. It exemplifies collaborative efforts from experts across diverse fields, pushing the boundaries of neuroscience and artificial intelligence. The AI-Mind project also benefits from its integration into a network of major European initiatives, including The Virtual Brain, The Virtual Epileptic Patient, and EBRAINS AISBL service for sensitive data, HealthDataCloud.

Alzheimer Europe Executive Director Jean Georges, Director for Public Involvement and Ethics Dianne Gove, Public Involvement Lead Ana Diaz and Project Officer Cindy Birck are co-authors of this paper.

https://doi.org/10.3389/fnbot.2023.1289406

15 JANUARY

PROMINENT Public Involvement Board advises project researchers on the design of the clinical studies



On 15 January, the PROMINENT project convened a first meeting of its Public Involvement Board. This advisory board, which is organised and moderated by the Alzheimer Europe Public Involvement team, comprises people with mild cognitive impairment or dementia, carers, as well as older adults with an interest in brain health. The PROMINENT Public Involvement Board (PIB) was created to ensure that the needs, perspectives and preferences of people with dementia and carers are reflected in PROMINENT activities. It is a forum for collaboration and partnership between PROMINENT researchers and some of the most important end users of the PROMINENT platform: patients and carers.

PROMINENT aims to improve the management of Alzheimer's disease (AD), by developing, evaluating and validating a digital platform for personalised prediction, diagnosis and treatment of AD. The project, which is funded by the Innovative Health Initiative for a period of five years, will create a digital system to provide memory clinic doctors with evidence-based recommendations and individualised clinical decision

support. Patients will receive informational materials and reports designed to support their engagement in the clinical decision-making process.
Close involvement of people with dementia or MCI and carers in the development and evaluation of the PROMINENT system is key, to maximise the value, accessibility and utility for end users. The PIB consultation on 15 January was focused on the PROMINENT clinical evaluation study, which will obtain feedback from clinicians, patients and carers about the utilisation of the platform. In the consultation, which was moderated by Daphné Lamirel (Public Involvement Officer at Alzheimer Europe) and Lena Sannemann (clinical researcher at the University of Cologne), PIB members shared their views on the design of the evaluation study. An important topic was when and how to gather feedback from patients and carers in the evaluation study, with discussions identifying preferences for interviews, focus groups and surveys. PIB members also discussed the types of questions that could be asked during the evaluation study, highlighting areas that are particularly meaningful for patients and carers. A follow-up meeting is planned for February.

17-18 JANUARY

ADIS partners meet for General Assembly meeting in Barcelona

From 17 to 18 January (Barcelona, Spain and online), partners from the ADIS project met for their biannual General Assembly meeting.
The “Early Diagnosis of Alzheimer’s Disease by Immune Profiling of Cytotoxic Lymphocytes and Recording of Sleep Disturbances” – short ADIS project – is a JPND-funded 1.3 million EUR three-year project, coordinated by Fraunhofer SCAI.
The goal of ADIS is to thoroughly characterise the role of peripheral blood cytotoxic lymphocytes as potential markers for the early prediction of Alzheimer’s disease, and to investigate the influence of digitally assessed sleep disturbances on these markers.
The project meeting kicked off with opening remarks by project coordinator Prof. Holger Fröhlich (Fraunhofer SCAI), as well as meeting host and project collaborator Raquel Sanchez-Valle, Head of the Neurology Department (Fundació Clínic per a la Recerca Biomèdica - FCRB) welcoming all participants and providing an overview of the agenda for the two-day meeting.
Next, Vanessa Lage-Rupprecht (Fraunhofer SCAI), provided an overview of the latest work with regard to project management and the progress in terms of reporting, noting that all of the tasks are on track and the recruitment process of participants has been finalised. Looking at the project timeline she highlighted that the partners are now halfway through the project and next steps will focus on the start of the sample processing workflow as well as the application of the algorithms and agent-based modelling to the data. The project will conclude in June 2025.
This was complemented by Christophe Bintener (Alzheimer Europe) with an overview of the work done for the dissemination and communication tasks of ADIS. Updates revolved around the website, project channels, an introductory project clip as well as interviews with project partners.
The following presentation was given by project collaborators Andrea Del Val and Neus Falgàs from FCRB where they provided an overview of the recruitment procedure, clinical data and biosample acquisition, ethics and approvals as well as external dissemination activities. Recruitment involved 75 participants (25 with mild cognitive impairment due to Alzheimer’s disease, 25 people who have dementia due to Alzheimer’s disease as well as 25 healthy control participants. Andrea then delved deeper into the characteristics of the participating groups and highlighted that they will submit abstracts for two upcoming conferences.
The next presentations focused on immune profiling that will be conducted by ImmunoBrain Checkpoint LTD given by Kuti Baruch as well as single cell sequencing that will be conducted. Project partners from the Fraunhofer ITEM in Regensburg will thoroughly characterize peripheral blood mononuclear cells (PBMCs) derived from the samples and analyse their functional status. They will use comparative single-cell immune repertoire and transcriptome sequencing for this as explained by Stefan Kirsch.
The morning ended with a demonstration of ALTOIDA: a novel tablet-based digital biomarker to assess neurodegenerative diseases by PhD Adrià Tort from FCRB. ALTOIDA is part of the assessment battery that is used in the ADIS study.
This was followed by a lunch break, after which guest speaker Prof. David Bartrès-Faz (University of Barcelona) spoke about Brain Health determinants in advanced age and across the lifespan, which led to lively discussions with partners.
The afternoon then revolved all around agent-based modelling with a presentation by Liad Doniza from the Tel Aviv University, where he explained the system which is based on a definition of initial conditions as well as the application of the agent-based model itself (a process in which interactions of included values are calculated to learn about the amount of different cytokines and state/polarization of cells).
The partners then took a walk through Barcelona and met for a well-deserved dinner in the Gothic Quarter of Barcelona.
The second day kicked off with the second part of discussions focused on Artificial Intelligence and statistical modelling, with a focus on Fraunhofer SCAI’s work by Sophia Krix. Here, she gave an outline of the current status of work with regards to the modelling of Alzheimer’s disease datasets with Variational

Autoencoder Modular Bayesian Networks (VAMBN), the modelling of sleep cycles and actigraphy data as well as the modelling of scRNA seq data and integration with the agent-based modelling.

Last but not least, Soraya Moradi-Bachiller (Alzheimer Europe) spoke about the consultations with the ADIS Advisory Board. The Board is comprised of five people (living with Mild Cognitive Impairment due to Alzheimer's disease) from Spain who participate in Spanish consultations as well as members of the European Working Group of People with Dementia who participate in English consultations. Recent consultations focused on informed consent for primary research as well as for data and sample sharing, but also the values and challenges associated to an early Alzheimer's disease diagnosis.

The meeting was then formally closed by Holger Fröhlich who thanked all attendees for their contributions and the constructive exchange.

https://adis-project.eu/

30 JANUARY

IHI launches new interdisciplinary initiative to transform Alzheimer's disease diagnosis, prevention and treatment

Members of the AD-RIDDLE consortium announced today that they will begin a new initiative that aims to bridge the gap between Alzheimer's research, implementation science, and precision medicine. The AD-RIDDLE programme will develop a toolbox platform for timely detection and diagnosis of Alzheimer's disease and dementias, to match individuals with the right interventions at the right time, and enabling people to better understand what they can do to reduce risk and prevent cognitive decline.

With new disease modifying therapies on the horizon, there is an enormous potential for prevention, opportunities for more timely diagnosis and personalised treatment options, and overall health-economic benefits in the long term. AD-RIDDLE, which stands for "Real-world implementation, deployment and validation of early detection tools and lifestyle enhancement", aims to address the pressing need for effective preventive, diagnostic and therapeutic solutions, implemented at scale, and for increased engagement of individuals and caregivers with disease prevention, management and care.

AD-RIDDLE aims to unlock efficiencies for AD diagnosis and treatment, removing barriers to entry that traditionally slow down patient access to healthcare providers and precision medicine. The project will create a modular toolbox platform designed to provide support at all stages of the clinical pathway. The AD-RIDDLE platform will include a digital community engagement portal, comprising self-guided assessment tools for older adults, pathways for timely referral to healthcare professionals, and resources that are tailored and actionable. Healthcare professionals will also have access to an array of screening tools for increased accuracy in risk detection and early diagnosis, including digital cognitive assessments and blood-based biomarkers, as well as a decision support toolkit, powered by validated algorithms for differential diagnoses, prevention, and care. Patients will gain access to personalised therapies which can be physician-supported or self-guided, including lifestyle interventions and pharmacological treatments, matching patients to the right interventions at the right time. Finally, a real-world testing study will be conducted in different healthcare settings (e.g. memory clinics, primary care) across six European countries and will provide extensive evidence to support implementation of diagnostic tools, treatments and lifestyle interventions.

Thanks to funding from the Innovative Health Initiative (IHI) and UK Research and Innovation (UKRI), the AD-RIDDLE consortium will begin a five-year effort to transform how Alzheimer's disease (AD) is detected, diagnosed, and treated across healthcare settings. Co-led by Miia Kivipelto (Karolinska Institutet, Sweden) and Niranjan Bose (Gates Ventures), the consortium brings together academic and industry partners, healthcare providers, regulatory bodies, and patient organisations. AD-RIDDLE builds on existing technology, biomarkers, tools, and interventions, many developed by the consortium partners through prior EU-funded initiatives, including studies building on the FINGER multidomain dementia prevention trials. Alzheimer Europe is a partner in AD-RIDDLE, and will lead public involvement and communication activities, also supporting the development of socioethical and policy guidance for societal implementation of the platform. Through these activities, AD-RIDDLE will be shaped to meet the needs, values and perspectives of people affected by cognitive impairment or dementia and their caregivers, with effective engagement of key stakeholders in the wider dementia community.

"With new research on the efficacy of multi-domain lifestyle interventions and the promise of disease-modifying therapeutics, there is renewed hope for patients, caregivers, and healthcare providers, and a window of opportunity for substantial progress," said Miia Kivipelto, Professor, Research Director and Senior Geriatrician at the Karolinska Institutet and Karolinska University Hospital, and Principal Investigator (PI) for the AD-RIDDLE project. "AD-RIDDLE represents the greatest opportunity yet for cross-sector progress in Alzheimer's research and care."

Read the full press release:
https://www.eurekalert.org/news-releases/1032693

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

EU project acknowledgements

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

AD-RIDDLE – grant agreement 101132933
AI-MIND – grant agreement 964220
Prominent – grant agreement 101112145

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

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SPONSORS OF THE MONTH

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

Read more about sponsorship opportunities here:

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

MEMBERS OF THE EUROPEAN ALZHEIMER'S ALLIANCE

European Alzheimer's Alliance

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

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

EUROPEAN ALZHEIMER'S ALLIANCE

26 JANUARY

Pierre Larrouturou MEP signs pledge and joins European Alzheimer's Alliance

Pierre Larrouturou MEP (S&D, France) has signed Alzheimer Europe's Dementia Pledge 2024 and in the process, joined the European Alzheimer's Alliance, following an approach by France Alzheimer.

Mr Larrouturou has been a member of the European Parliament since July 2019. His European Parliament profile can be viewed at:
https://www.europarl.europa.eu/meps/en/197698/PIERRE_LARROUTUROU/home

EU DEVELOPMENTS

11 JANUARY

Eurostat launches disability thematic section

The European Union statistics body, Eurostat, has launched thematic section on disability, which gathers together all data, methodology, publications and information on related statistical legislation.

The data available include disability prevalence, income and living conditions, social protection, access to the labour market, as well as on health and care services. It allows for the situation of persons with disabilities across EU countries to be compared and to assess whether they enjoy equal opportunities and full participation in all aspects of life. During 2024, Eurostat will continue to work on this section by releasing new

data on aspects relating to life satisfaction, access to education and training, as well as on leisure and social participation. Further information on the thematic section on disability is available at:
https://ec.europa.eu/eurostat/web/disability/overview

17 JANUARY

European Parliament adopts position on EU Disability Card

The European Parliament has adopted its mandate for negotiations with the Council on the subject of the EU Disability Card and the Parking Card for persons with disabilities.
Parliament's mandate, prepared by the Employment and Social Affairs Committee (EMPL), introduces deadlines for issuing and renewing the cards – within 60 days for the EU disability card and within 30 days for the parking card. It also includes an option to request a digital version of the parking card, to be ready within 15 days. MEPs have also proposed that both cards should be available in physical and digital format and free of charge.
To ensure access to benefits and social assistance for those working or studying in another member state, MEPs amended the proposal to temporarily protect European Disability Card holders that move to another member state for work or study, until their status is formally recognised.
The Parliament's position also calls for Member States and the European Commission to raise citizens' awareness about both Cards, including by setting up a website with information on how to obtain, use and renew the cards. Negotiations with Council will begin at the end of January, with Member States having previously agreed their position in December 2023.
Further information on the Cards and Parliament's negotiating position is available at:
https://www.europarl.europa.eu/news/en/press-room/20240112IPR16765/parliament-ready-for-talks-on-an-eu-wide-disability-card

24 JANUARY

EU4Health Civil Society Alliance launches campaign manifesto

The EU4Health Civil Society Alliance, consisting of more than 30 health civil society organisations, has launched its campaign manifesto in the run up to the European Parliament Elections in 2024. The campaign aims to ensure that health remains high on the EU's political agenda.
The manifesto contains 10 key priorities, focusing on strengthening EU policymaking in public health, delivering stronger policies to improve public health and encourage health to be included across policy areas.
The full Manifesto is available at:
https://eu4health.eu/eu-2024-elections-10-priorities-to-secure-health-on-the-political-agenda/
Organisations can endorse the Manifesto at:
https://docs.google.com/forms/d/e/1FAIpQLSdvIIIuST3qFiU-blsDH-fJNZ7Gs6OiEsZ-Qrn26NgVXpSyYiw/viewform

24 JANUARY

Civil society organisations publish open letter to European Institutions

On 24 January, European civil society published an open letter to the Presidents of the European Commission and the European Parliament, and the Belgian presidency of the Council of the European Union.
The signatories of the letter urge the three main institutions of the EU involved in decision-making to take concrete measures to implement an open, transparent and regular dialogue with civil society organisations in all policy areas, as set out in Article 11 of the Treaty on European Union. Specifically, the letter calls for the Institutions to:

- Initiate an inter-institutional agreement on civil dialogue
- Establish within each institution leadership positions in charge of relations with civil society
- Encourage and promote greater cooperation between civil and social actors.

The open letter was initiated by the Civil Society Organisations' Group of the European Economic and Social Committee (EESC) and Civil Society Europe and includes specific proposals for implementation. The letter gained the support of a total of 156 signatories from 26 Member States. The signatories include 39 European networks, 85 national organisations and 60 Members of the EESC's Civil Society Organisations' Group1. Alzheimer Europe was one of the signatories of the open letter. The full open letter is available at:
https://civilsocietyeurope.eu/wp-content/uploads/2024/01/Press-Release-EN-EUcivilDialogueNow.pdf

26 JANUARY

EMA oganises an ACT EU Clinical Trials Analytics Workshop

The Accelerating Clinical Trials in the European Union (ACT EU) initiative has been launched by the European Commission, European Medicines Agency (EMA) and Heads of Med-

icines Agencies (HMA) in January 2022. The vision is to transform the EU into a region that supports clinical trial development and enable collaboration and innovation at all stages of the clinical research lifecycle. ACT EU aims to transform how clinical trials are initiated, designed and run to further promote the development of high quality, safe and effective medicines, and to better integrate clinical research in the European health system.

Over the years the EMRN (European Medicines Regulatory Network) has collected a wealth of data about clinical trials through their clinical trials registers. These data are used to support regulatory decision-making, but their potential uses extend far beyond that scope.

On 25 and 26 January, EMA organised a Clinical Trials Analytics Workshop, under the ACT-EU initiative, in Amsterdam (the Netherlands). The focus of the two day workshop was on Data Analytics in Clinical Trials, looking at how data can be better used to improve public health. During this event, stakeholders had the opportunity to present and discuss how they are using or planning to use these data. Participants shared their use cases with clinical trials data. An use case for the data might be, for example, a description of how an individual or organisation intends to use the data to accomplish a specific objective, the expected outcomes and benefits of using the data in that way. The use cases will be gathered into an EU research agenda on clinical trials analytics under which specific research projects may be funded. Participants also identified evidence gaps in the EU environment that might be addressed by access to data, data analysis and funding. These discussions will help guide EU decision-makers on improving access and usability of clinical trials data. AE Project Officer Cindy Birck attended the workshop.

https://www.ema.europa.eu/en/events/act-eu-clinical-trials-analytics-workshop-january-2024

29 JANUARY

EU4Health Civil Society Alliance writes to Belgian Presidency of EU

The EU4Health Civil Society Alliance has published an open letter to Belgian Prime Minister, Alexander De Croo, and Deputy Prime Minister and Minister of Health, Frank Vandenbroucke, ahead of the EUCO meeting on 1 February 2024, calling for them to reverse a draft decision redeploying EUR 1 billion from the EU4Health programme (20% of the overall programme) to other EU policies in the current Multiannual Financial Framework (MFF).

The letter highlights that recent crises, including the COVID-19 pandemic and the ongoing war in Ukraine, have demonstrated that the redeployment of large amounts of funds within the MFF must not undermine the efforts long-term efforts to to build and maintain EU public health capacity.

The letter further notes that health is a clear priority of the Belgian Presidency and that a disproportionate cut would have a significant negative impact for the future of EU health policy and the health of EU citizens. Alzheimer Europe has signed up to the letter. The letter is available at:

https://eu4health.eu/concerns-over-eu4health-cuts-letter-to-prime-minister-de-croo-and-health-minister-vandenbroucke/

POLICY WATCH

22 JANUARY

The National Health Plan for Dementia in Portugal has a new Coordinator

After a year without a Coordinator, at the beginning of 2024, Manuel Caldas de Almeida, a doctor with a lot of experience in the areas of ageing and dementia, was designated by the Secretary of State for Health Promotion, to be the new Coordinator of the Executive Committee of the National Health Plan for Dementia.

Alzheimer Portugal continues to be part of the Executive Committee, a responsibility that the organisation will continue to embrace with strong commitment.

The Dementia Health Strategy remains the same. It “defines the principles that care for People with Dementia must comply with, the criteria to be used in preventive intervention, the measures to be adopted regarding early detection, measures to access medical diagnosis as well as comprehensive diagnosis, and the scaling of therapeutic responses at the three levels of healthcare, clarifying a care pathway for People with Dementia, based on the principles of ethics, proximity, accessibility, equity and continuity.”

Despite the National Health System Reform, which implies the replacement of former structures, the main topics are preserved, such as:

- the informatic registration of the diagnosis at primary and hospital care. This will allow the identification of cognitive disorders and the improvement of the interoperability of information systems among the different levels of care. The final aim is to make possible the definition of an Individual Care Plan tailored to each person with dementia.
- the creation of specific units, named “Unidades Coordenadoras Funcionais para as Demências” aiming to assure a better collaboration between the different levels of care and between these and people with dementia, family members and carers, to define the diagnosis and treatment pathways.

Alzheimer Portugal hopes that the promised national awareness campaign on dementia will also take place soon, helping to combat stigma and misconceptions around dementia and people living with Alzheimer's disease or other forms of dementia, as well as their carers / supporters. The organisation also looks forward to the speeding up of the availability of funds for the training/qualification of professionals working in this field.

Alzheimer Portugal believes that the Helsinki Manifesto will be of great help for the work of this Executive Committee, not only for its content but also because of the campaign that the organisation will develop within the framework of the Alzheimer Europe Elections Campaign 2024, highlighting that Portuguese policy makers must act in order to recognise dementia as a national priority

.

SCIENCE WATCH

4 JANUARY

European Bank for induced Pluripotent Stem Cells successfully completes pivotal Public Patient Involvement session in partnership with Alzheimer Europe

The European Bank for induced Pluripotent Stem Cells (EBiSC, www.EBiSC.org) is a not-for-profit biobank which stores and shares stem cells that can be used for research.

The EBiSC is pleased to announce the successful completion of a pivotal Public Patient Involvement session in partnership with Alzheimer Europe. This session stands as a testament to EBiSC’s commitment to incorporating and respecting patient perspectives into EBiSC frameworks designed to securely share iPS cells and data with researchers worldwide.

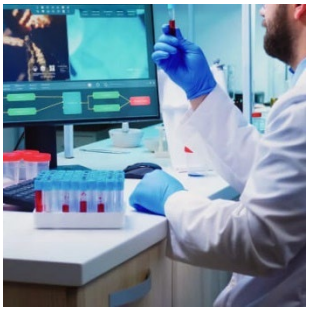
The collaboration between EBiSC and Alzheimer Europe has enabled EBiSC to receive patient insights which will inform not only how EBiSC operates day to day, but also more broadly, EBiSC’s ethical and legal frameworks and communication with the general public.

EBiSC would like to extend a huge thank you to the European Working Group of People with Dementia for their feedback, discussion and insights, and is excited to harness and share more about these learnings moving forward, leveraging this collaboration's outcomes to further develop and grow EBiSC.

Find out more about EBiSC, here:
https://ebisc.org/

8 JANUARY

Athira Pharma provides 2024 clinical pipeline outlook



On 8 January, Athira Pharma, a late clinical-stage biopharmaceutical company focused on developing small molecules to restore neuronal health and slow neurodegeneration, provided a clinical pipeline outlook and business update for 2024.

The company announced completion of enrollment in its Phase II/III LIFT-AD clinical trial of fosgonimeton as a potential treatment for mild-to-moderate Alzheimer’s disease (AD). This trial enrolled 315 participants who received 40 mg fosgonimeton or a placebo for 26 weeks once daily by subcutaneous injections. The primary endpoint is the Global Statistical Test (GST), a composite of the co-key secondary endpoints ADAS-Cog11 and ADCS-ADL23. Key secondary and exploratory endpoints include changes in plasma biomarkers of neurodegeneration, protein pathology, and neuroinflammation. Topline data from LIFT-AD are expected in the second half of 2024.

Eligible participants who complete the LIFT-AD or ACT-AD (exploratory Phase II clinical trial) trials can participate in the open label extension trial (OLEX) and are able to receive up to 30 months of open-label treatment. So far, more than 85% of those who completed either study have been enrolled in OLEX, with 60 participants continuing treatment beyond 18 months.

In addition, the company recently reported findings from the exploratory SHAPE Phase II clinical trial, which investigated the use of fosgonimeton in people with Parkinson’s disease

dementia and dementia with Lewy Bodies. Fosgonimeton was generally well tolerated, with a favorable safety profile. The results showed positive effects on several cognitive measures in people who received fosgonimeton 40 mg compared to those receiving placebo over the 6-month double-blind treatment period. However, the primary endpoint, a composite score of the change in Event-Related-Potential (ERP) P300 latency and cognitive assessment (ADAS-Cog13), was not met compared with placebo.
https://investors.athira.com/news-releases/news-release-details/athira-pharma-provides-2024-clinical-pipeline-outlook-and

9 JANUARY

Mitochon Pharmaceuticals receives approval from EMA to initiate a biomarker study in neurodegenerative diseases

On 9 January, Mitochon Pharmaceuticals, a biotechnology company focused on developing drugs that target the mitochondria for a host of serious diseases with significant unmet medical needs, announced that it was awarded approval from the European Medicines Agency (EMA) to initiate a new biomarker study in neurodegenerative diseases.
The aim of this Phase I/IIa study is to show safety of MP101 in people with Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS), Huntington's Disease (HD) and Alzheimer's disease (AD) and demonstrate meaningful changes in disease specific biomarkers. MP101 is an oral brain penetrant mitochondrial stimulator, that improves central nervous system survival and function. Participants will receive MP101 once daily in this 14-day pilot study. Successful completion of this study will provide the basis for long term Phase IIb clinical studies in ALS, MS, HD, and AD, leading to the first mitochondrial specific therapy for these truly insidious diseases.
https://www.mitochonpharma.com/news/european-medicines-agency-ema-greenlights-mitochon-pharmaceuticals/

9 JANUARY

CSF analysis reveals five molecular subtypes of AD, according to new research from Amsterdam UMC

On 9 January, a team of researchers at Amsterdam University Medical Center published new findings in the Nature Aging journal, identifying five molecular subtypes of Alzheimer's disease. These findings, which are based on analyses of cerebrospinal fluid samples, shine a light on the biological heterogeneity of Alzheimer's disease, and the potential need for tailored treatment to optimise patient outcomes.
Amyloid and tau are often cited as culprit proteins in Alzheimer's disease (AD), forming plaques and tangles that damage brain cells and prevent normal functioning. However, there are many biological processes and drivers of AD, such as inflammation or problems affecting blood vessels. In their Nature Aging paper, Pieter Jelle Visser and Betty Tijms use advanced analytical techniques to probe the composition of cerebrospinal fluid (CSF) samples from 419 people with AD, compared to people who don't have AD. By examining 1058 proteins found in CSF samples from people with AD, they show that there are five biological variants within this group, each with defined molecular characteristics. For example, the first variant is characterised by increased amyloid production, while a second subtype shows disruption of the blood-brain barrier, and reduced amyloid production.
The research team also expanded their analysis to genetic and clinical characteristics, showing that changes in CSF samples in different subgroups may also be associated with distinct genetic risk profiles, and clinical characteristics. For instance, the 137 individuals in subtype 1 had the longest average survival time (approximately 8.9 years), with over-representation of a TREM2 risk variant. While the 56 individuals in subtype 5 showed evidence of blood-brain barrier dysfunction, and a higher risk of progression from MCI to dementia. These findings have potential implications for therapy, as people from different subtypes may respond more or less well to different types of treatment.

9 JANUARY

Lecanemab approved for the treatment of early Alzheimer's disease in China

On 9 January, Eisai and Biogen announced that their anti-amyloid drug, lecanemab, has been approved in China. Lecanemab is an antibody that targets plaques of amyloid-beta proteins, which accumulate in the brain during the development of AD. The drug, which is marketed under the brand name Leqembi™ in the US, received regulatory approval from the Japanese authorities last September, following traditional approval by the US Food and Drug Administration in July.
Approval by the Chinese medicines authority was based on the CLARITY-AD study, a Phase 3 clinical trial that showed a substantial reduction in brain amyloid, as well as a 27% slowing in clinical decline after 18 months of lecanemab treatment. Similar to Japan and the US, lecanemab is approved for the treatment of mild cognitive impairment or mild dementia due to Alzheimer's disease. In their press release, the companies explained that they are preparing to launch lecanemab in China within the second quarter of Eisai's upcoming financial year (July-September 2024).

10 JANUARY

AmyriAD Therapeutics is looking to evaluate its lead AD candidate AD101 in three upcoming Phase III studies

AmyriAD Therapeutics a late clinical-stage pharmaceutical development company focused on advancing therapies for Alzheimer's disease (AD), is developing AD101, a small synthetic molecule that modulates calcium channels to promote the release of acetylcholine, a neurotransmitter, in the brain.

Data from several clinical trials showed that AD101 is well tolerated and suitable for once-daily oral administration. In randomised, double-blind and placebo-controlled clinical trials, AD101 was administered as an add-on to stable donepezil therapy. Adverse events or safety of tolerability did not change when AD101 was added onto treatment with donepezil, as compared to donepezil alone. Furthemore, a randomised, double-blind and placebo-controlled Phase II study of AD101 added on to a stable dose of 10mg/day donepezil demonstrated statistically significant additive improvement over that of donepezil alone in tests of global function and cognition.

The company is planning to launch a Phase III clinical trial program with AD101 in people with mild to severe AD. The first trial is planned to start in Q3 2024 in US and the second trial in Q1 2025 in Europe and Southeast Asia. These two 24-week, randomised, double-blind and placebo-controlled trials will be designed as adequate and well-controlled studies for safety and efficacy that will enrol 500 participants each. A group of participants will receive a single dose of the AD101/donepezil combination treatment while the other group will be given a placebo/ donepezil combination. According to the company, the Phase III endpoints must demonstrate that the drug improves cognition and global function, using the ADAS-Cog and AGS-CGIC tests. Once participation is completed in both trials, an open label Phase III extension study will be pursued to characterise long term safety and efficacy of the treatment.

https://www.clinicaltrialsarena.com/news/amyriad-leaves-no-leaf-unturned-with-upcoming-phase-iii-alzheimers-trials/?cf-view&cf-closed

18 JANUARY

Hearing loss is associated with cognitive decline, new study shows

In a new study published in the journal Alzheimer's & Dementia, researchers from the Maastricht University (The Netherlands) examined the association between prevalent and incident hearing loss and cognitive change. Data were used from the Maastricht Aging Study, a large prospectivge cohort study on determinants of cognitive aging in community-dwelling adults. A total of 1,823 participants (24-82 years) underwent a comprehensive assessment of medical status, lifestyle, and anthropomorphic and neurocognitive measures at baseline, 6 and 12 years.

Results suggested that prevalent and incident hearing loss were associated with faster cognitive decline in verbal memory, executive function, and information processing speed, independent from demographics and other modifiable risk factors. Decline was steady from baseline to 6 and 12 years for prevalent hearing loss. For incident hearing loss, decline was confined to 6- to 12-year follow-up, suggesting that onset of hearing loss preceded or coincided with onset of decline. No differences in cognitive decline over time were found between participants who had hearing aids compared to those without, therefore hearing aids showed no clear benefit. Authors concluded by saying that their findings support the notion that hearing loss is a risk factor for cognitive decline and dementia.

https://doi.org/10.1002/alz.13606

22 JANUARY

Blood biomarker test shows strong diagnostic accuracy for Alzheimer's disease pathology, according to new research published in JAMA Neurology

A team of researchers have shown that a commercially-available blood biomarker test has comparable accuracy to cerebrospinal fluid (CSF) biomarkers in detecting Alzheimer's disease pathology. The new research was published in JAMA Neurology on 22 January, and suggests that blood tests may be viable alternatives to more invasive lumbar punctures and CSF analyses, which are traditionally used to detect Alzheimer's disease pathology.

A well-established hallmark of Alzheimer's disease is the presence of amyloid plaques in the brain. Current gold standard tests to detect amyloid involve PET scans or lumbar punctures, with analyses of the extracted CSF. However, these

tests are both costly and invasive, and challenging to administer at scale in the community or primary care setting. In recent years, substantial efforts have been invested into the development and validation of blood-based biomarkers. pTau217 is one of the leading candidate biomarkers, with several studies showing that the levels of pTau217 in the blood is significantly increased in people with AD. In the new JAMA Neurology paper, researchers aimed to determine the utility of a commercially available blood test for pTau217 for detecting AD pathology across different populations.

The cohort study examined data from three clinical research studies: the TRIAD and WRAP US-based cohorts, and the SPIN cohort which is based in Spain. Each cohort involves participants with and without cognitive impairment, with data on their amyloid and tau status measured by the gold-standard PET and CSF tests. In total, the research team (led by Henrik Zetterberg and Nicholas Ashton from the University of Gothenburg in Sweden) evaluated data from 786 participants, comparing the accuracy of pTau217 blood test results to the results of CSF tests, using PET scan results to categorise the amyloid positivity of participants.

The pTau217 tests proved highly accurate in identifying people with elevated amyloid beta and tau levels in the brain, measured using PET scans. The accuracy of the pTau217 test was comparable to that of the CSF biomarker tests, validated across the three cohorts. Looking longitudinally, pTau217 values showed an annual increase only in individuals with amyloid beta positivity on their PET scans, further validating its utility even in the earlier, mild cognitive impairment stages of AD.

https://jamanetwork.com/journals/jamaneurology/fullarticle/2813751

24 JANUARY

33-country Delphi study into advance care planning in dementia recently published in journal Alzheimer's & Dementia

An article with the findings of a 33-country Delphi study into advance care planning (ACP) in dementia, was recently published in the journal Alzheimer's & Dementia. Existing ACP definitional frameworks apply to individuals with decision-making capacity. This new study aimed to conceptualise ACP for dementia in terms of its definition and issues that the researchers felt deserved particular attention (capacity, family, engagement, and communication). The article in Alzheimer's & Dementia offers a consensus definitional framework of ACP in dementia, covering all stages of capacity and including family carers. Fluctuating capacity was visualised in relation to roles and engaging stakeholders.

The Delphi panel, composed of around 50 people, included Dianne Gove, Director for Public Involvement and Ethics, Alzheimer Europe. You can read the full article (open access), here:

https://doi.org/10.1002/alz.13526

29 JANUARY

Research suggests outdated medical procedure could have caused Alzheimer's disease in treated patients

A study published in the journal nature medicine explored the possibility of human transmission of Alzheimer's disease (AD) pathology through a medical procedure that has been discontinued decades ago. The group of English researchers investigated eight individuals who received childhood treatment with cadaver-derived pituitary growth hormone (c-hGH).

Background of this recent investigation is previous research by the team where they reported on the human transmission of Aβ pathology and cerebral amyloid angiopathy in relatively young adults who had died of iatrogenic Creutzfeldt–Jakob disease after childhood treatment with c-hGH.

In their most recent study, they reviewed eight individual cases who were treated with c-hGH some decades ago but did not develop Creutzfeldt–Jakob disease. Five out of these eight individuals developed early-onset dementia between the ages of 38 and 55. In three of these cases, AD was already confirmed prior to the referral to the National Prion Clinic (The National Prion Clinic (NPC) forms part of the United Kingdom national referral system for suspected prion diseases). Each showed different symptoms, fitting the criteria for probable AD. Among the last three people studied; one showed symptoms of mild cognitive impairment; one had subjective cognitive symptoms and the other was asymptomatic. The time from c-hGH exposure until symptoms appeared was between 30 and 40 years.

The researchers emphasize that AD caused by medical procedures is rare and there's no evidence of transmission through everyday activities. However, they suggest revisiting safety measures of medical procedures to prevent any accidental transmission.

https://doi.org/10.1038/s41591-023-02729-2

MEMBERS' NEWS

18 JANUARY

Dementia Lithuania premieres series of short films called "Stories of Life with Dementia"

The association Dementia Lithuania is premiering a series of short films under the title “Stories of Life with Dementia”. They tell stories of families living in various cities across Lithuania and who are caring for a person with dementia. The heroines of the stories are women who take care of their husbands, mothers, fathers, and grandfathers. The stories of these strong women tell how dementia adjusts plans, allows you to rediscover who your loved ones and friends are, and choose: "Will I be a victim of my situation or will I accept it with my head held high?"

The first film, “I live his life”, premiered in January 2024 and tells the story of Vida, who is a carer to her husband Vladas, and their daughter Viktorija. Vladas has been living with dementia for 15 long years, He went to the doctor because of memory problems, but, at the time, the doctor found no reason to refer him for further examination. The examination was performed five years later, when the disease has substantially progressed, and still, a false diagnosis was made. Finally, in 2021 the family received the answer that Vladas had Alzheimer's disease.

The director is Ieva Petkutė (Dementia Lithuania) and the operator is Eglė Gudonytė. The production of the films was implemented by the NGO Socialiniai meno projektai in cooperation with Dementia Lithuania, as part of the project "Towards a Dementia Strategy: Situation Analysis and Awareness Raising", which is part of the Active Citizens Fund, financed by the European Economic Area (EEA) financial mechanism. The project was supported by Vilnius city municipality.

Watch “I live his life”:
https://youtu.be/WhDUaZTl1fg?si=SGPsY2kTomyI1Clo

18 JANUARY

Dementia Lithuania presents podcast series "About dementia from different perspectives" to challenge the unknown

The association Dementia Lithuania has created a series of six podcast shows in a series called "About dementia from different perspectives". As the title of the programme suggests, the intention was to reveal the diversity of aspects related to experiences, challenges and possibilities, when trying to “befriend the beast" of the unknown that, to date, still surrounds dementia.

The programme was developed by Ieva Petkutė, president of Dementia Lithuania. It includes conversations with six women. Each of them has shaped a unique insight into dementia from where they stand, with a mixture of everything – hope, curiosity, empathy and respect: Jolita Švatienei, who is taking care of her mother who has frontotemporal dementia, in the small town of Akmenė, and Dr Aistė Bartkevičienė who is the carer for her grandmother, share two unique yet somewhat aligned experiences of finding ways to navigate lives radically transformed by the condition of their loved ones; Neurologist Dr Greta Pšemeneckienė offers an unedited insight into the experience of a professional concerning matters and experiences that are largely unknown to the public, about working in the field of dementia. Social worker Simona Šimukonienė shares professional and personal experiences of addressing the challenges caused by dementia; A well-known dietitian Vaida Kurpienė introduces how to support ourselves and our loved ones with dementia, by making the right food choices, and how these choices are related to other aspects of health; Lawyer Simona Vilkelytė, who has personal experience of taking care of her mother with dementia, explores legal aspects that can help us to make sure that the rights of people living with dementia and their carers are taken into account.

The series "About dementia from different perspectives" was created as part of the project "Towards a Dementia Strategy: Situation Analysis and Awareness Raising", which is part of the Active Citizens Fund, financed by the EEA (European Economic Area) financial mechanism. The project is implemented by the NGO “Socialiniai meno projektai” and the association Dementia Lithuania. The conversations were led by Laura Budreckytė.

22 JANUARY

Alzheimer Scotland's winter campaign "We're all in" focuses on dementia research

Alzheimer Scotland's winter campaign for this year focuses on dementia research and celebrates the idea that each of us, in our own unique way, can contribute to the multifaceted landscape of dementia research. The "We're all in" campaign features personal video messages from members of the Scottish Dementia Working Group, Kenny (pictured, left) and Rynagh (pictured, right), who share their insights into the importance of research and what participating in research means to them.

23 JANUARY

Celebrating ten years of national dementia advocacy in Finland

The national working group of people with dementia and their caregivers in Finland celebrated their 10th anniversary in November. During the past decade, the members of the group have worked to ensure that the work of the Alzheimer Society of Finland reflects the priorities and views of those living with dementia and their loved ones.

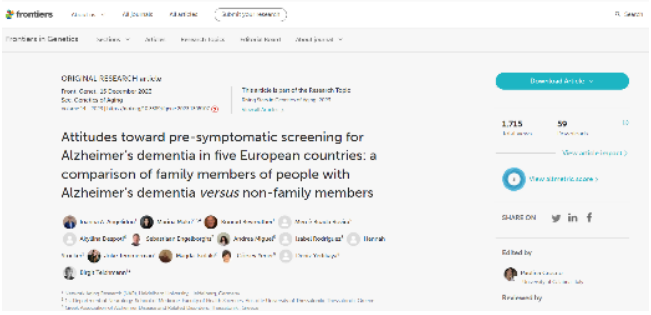
Representing Finland geographically, they continue to contribute by bringing up topical issues, giving presentations and doing various other forms of advocacy work. One of the members represents people with dementia on the Board of the Society. The group has also inspired the setting up of 14 regional working groups across the country.

With anniversary celebrations over now, the working group is planning their future work. Keeping an eye on the implementation of the recent service structure reform of social welfare and health care, a few other legislative reforms as well as the 2025 local and regional elections, the group is bound to keep busy!

24 JANUARY

Alzheimer Hellas shares some achievements of GECONEU Erasmus+ project including new paper exploring attitudes toward pre-symptomatic screening for Alzheimer's dementia in five European countries

In the latest edition of the journal Frontiers in Genetics, the GECONEU Erasmus+ project (Genetic counselling in European universities: The case of neurodegenerative diseases) sheds light on attitudes toward pre-symptomatic screening for Alzheimer's dementia across five European countries. The study, titled "Attitudes toward pre-symptomatic screening for Alzheimer's dementia in five European countries: a comparison of family members of people with Alzheimer's dementia versus non-family members," investigates the acceptance of screening among family and non-family members in Belgium, Germany, Greece, Spain, and Turkey. The research, using the "Perceptions regarding pRE-symptomatic Alzheimer's Disease Screening" questionnaire (PRE-ADS), found that variations in screening acceptability are influenced by both family history and cultural factors. With 56.9% expressing a positive intention toward pre-symptomatic Alzheimer's disease screening, the study underscores the need to tailor healthcare services based on cultural nuances.



Read the full article:
https://www.frontiersin.org/articles/10.3389/fgene.2023.1305107/full

The main goal of this project was to develop a free e-learning course, an introductory programme in genetic counselling for neurodegenerative disorders. This course was designed for students of Health and Life Sciences, Biomedical Sciences, and professionals in the field of Health Sciences
http://www.genecounsel.eu/index.php/test1

It has been developed in six languages, English, German, Greek, Dutch, Spanish and Turkish by the consortium of the GECONEU project. In this phase, the course will be tested by 25 students from the participating countries.

For more information, you can visit the website:
http://www.genecounsel.eu/

25 JANUARY

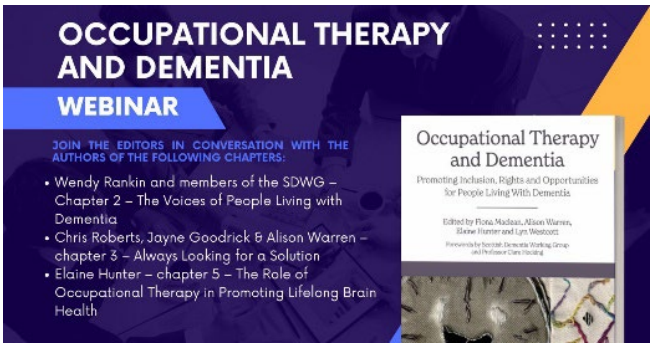
Barry and Margaret Northedge speak at "NHS Dementia Workforce Excellence in Acute Care" event in Scotland

The importance of working in partnership with family carers was the key message from National Dementia Carers Action Network (NDCAN) members Maureen Huggins and Barry Gale at a recent NHS staff dementia training event in Scotland. Both members presented and shared their stories of the hospital care experienced by their loved ones with dementia. More importantly, they also gave their perspectives on how they would like staff in hospitals to support people living with dementia and their carers.

Scottish Dementia Working Group member Margaret Northedge (pictured, left) and her husband NDCAN member and member of the European Dementia Carers Working Group, Barry Northedge (pictured, right) also gave an insightful presentation at this event, on "living well with dementia" and spoke about various activities that Margaret participates in, to demonstrate how it is possible to live well following diagnosis.

25 JANUARY

Scottish Dementia Working Group members attend webinar introducing new "Occupational Therapy and Dementia" book with foreword by group member Margaret McCallion



A recent webinar, held in the latter part of 2023 and highlighting an informative new book that has been produced by Scottish Allied Health Professional (AHP) colleagues, was attended by members of the Scottish Dementia Working Group (SDWG). The publication examines how core elements of occupational therapy may support a person living with dementia through valued activity in continuing engagement, sustaining their identity and sense of purpose. It includes a foreword by SDWG member Margaret McCallion, who is also Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD) and during the webinar, Margaret read her contribution to the book, which closed with her plea to “always see the person as a person”.

Contributing authors include EWGPWD Chairperson Chris Roberts and his wife and supporter Jayne Goodrick.

26 JANUARY

Spominčica – Alzheimer Slovenia validates Erasmus+ project “mHEALTH-AD” training programme for enhancing the adoption of mobile health technologies by persons with mild-dementia

Spominčica Alzheimer Slovenia is a partner in the Erasmus+ project mHEALTH-AD that aims to develop a training programme for enhancing the adoption of mobile health technologies by persons with mild-dementia and increasing their mhealth competencies.

In addition to general mHealth technologies, there are specific applications for people with dementia that can support, for example, cognitive training, health and safety monitoring or social and leisure activities.

A comprehensive set of training materials was created to be used to facilitate the development of competencies to enhance their health self-management with mHealth solutions. Additionally, a digital serious game was developed, aimed at improving their understanding of mHealth concepts, highlighting the associated benefits, boosting motivation, and assessing their comprehension of healthy practices. Also, an e-Training Platform was developed to support the overall training experience.

Each partner of the project held a piloting session to validate the materials produced. Spominčica Alzheimer Slovenia introduced the "mHealth for Training Health Conditions" module, which emphasises the importance of tracking and monitoring health parameters and modifying behaviour for optimal health, including quality of sleep monitoring. Additionally, Spominčica presented the "mHealth for Communication and Planning" module, focusing on communication and planning services and apps. This module covers effective communication through applications and appropriate methods for interacting with older adults experiencing memory difficulties. Examples include the use of personal planners, medication planning and reminders, hydration app alerts, and activity calendars. Spominčica has also presented and tested the mHealth-AD digital

serious game for training the use of mHealth technologies through simulated scenarios.
Participants in sessions actively took part in group discussions on mHealth technologies sharing their own experiences with home technology use, including the use of smartwatches, monitoring sleeping, and daily medication reminders. Some enjoyed the engaging serious game, playing and assisting the avatar in achieving health goals through mHealth technologies. Others, less comfortable with digital tools, required assistance. The validation sessions were successful; participants felt confident about using technologies after covering essential information. Read more about the project and access the e-training platform: https://mhealth-ad.eu/

26 JANUARY

Spominčica opens a new activity Centre for people with dementia: a place to meet, socialise and stay active

This year Spominčica opened in its facilities the first Centre for Activities for Persons with dementia in Slovenia.
The opening of the centre represents an important achievement for people with dementia and those with cognitive decline.

It is important for people with dementia to maintain their remaining functions in the early stages of the disease by motivating and involving them in various activities. With this form of socialising, Spominčica (Alzheimer Slovenia) also contributes to the fact that relatives or caregivers of people with dementia will be able to spend more time for themselves and their needs, while their family member will be safe and in good company.
Initially, the centre will carry out activities once a week. Participants will take part in cognitive exercises, physical activities and other activities.

LIVING WITH DEMENTIA

18 JANUARY

Vice-Chairperson of the European Working Group of People with Dementia Kevin Quaid writes about his new hearing aids and how they instantly improved his life

“I have recently gained a lot of first-hand knowledge of dementia and hearing problems. About twenty years ago, when I was doing a medical exam for a job I had just got, they told me that I would want to keep a check on my hearing as I was getting older, in case it was getting worse. I forgot about this and, over the course of time, probably naturally enough, my hearing did get worse. I never thought about the impact it would have on someone who has dementia and especially someone who has Lewy Body Dementia, as I do.

Around September 2023, I got my hearing checked and was surprised, as I had no idea how bad it had got until I got my hearing aids. When you get a diagnosis, like mine, of Lewy Body Dementia, a diagnosis that is both progressive and incurable, you come to terms with the fact that you are going to start to lose your faculties, bit by bit, and that’s pretty much that, but not when it comes to your hearing and sight.

The day my hearing aids were put in, I got back my full hearing and I was literally overjoyed! It was like I was after winning a major battle in my struggles with Lewy Body Dementia; little did I know the benefits that would follow! The hallucinations that I have, because of my Lewy Bodies, are less frequent. The buzzing that was in my head when I would be in a quiet room or space is completely gone, as long as my hearing aids are in. The fact that I take them out at night doesn’t mean that the effects they have on me by day stop working, quite the opposite, as although I still have bad nightmares and dreams sometimes, they are not as bad as before and, when I wake up now, I always know where I am and who I am, so the level of fear has dropped by at least 75%.

During Christmas, I was able to attend family gatherings with a large group of people and I was able to have and to hear conversations. I no longer feel as if I have to walk away from someone because I cannot hear them, I no longer have to let on that I don't know what people are saying. I don’t have to ask "can you say that again?”. The benefits are not just felt by me, but by my wife as well, who has said that her role as a spousal carer has been made so much easier.

I cannot recommend enough the value of getting your hearing checked as early as possible but especially after getting a diagnosis of dementia, particularly Lewy Body Dementia. It's something I put off for years. Take my advice and do it today as I have found that it’s a game changer and the difference is as clear as the difference between night and day.”

DEMENTIA IN SOCIETY

18 JANUARY

Submission open for participation in the World JAIN Challenge 2024

The Joint Artificial Intelligence Network (JAIN) organises its World JAIN Challenges to seek out and recognise the best prototypes and products based on artificial intelligence, that help people to live well with dementia at home, as there is a real need for innovative technologies in this field. If you are involved in or are aware of a promising technology or good products in this area, within your network, then you are invited to submit a prototype or product. The deadline for submissions is **29 February 2024 at 12:00 (noon) CET**.

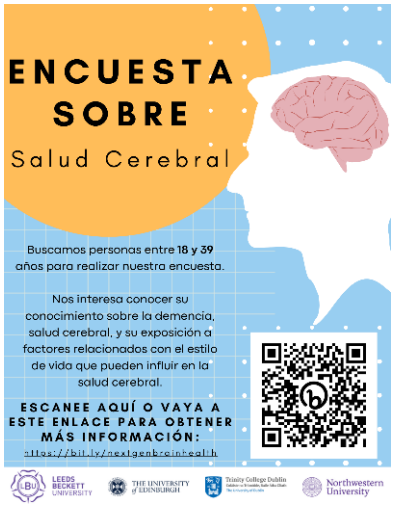
For more information and to find the criteria for participation and registration, please visit:
https://www.jainprojects.com/registration-jain-challenge-2024/

18 JANUARY

Next Generation Brain Health Survey open for feedback from young adults aged 18-39 years

Edinburgh University and the Academic and Clinical Central Office for Research and Development (accord) are asking young adults between the ages of 18 and 39 to fill in their online brain health survey. The survey is available in English, Spanish, Hindi and Mandarin (as the four most widely spoken

languages, globally). Spanish speakers are particularly requested to participate.
Read the information sheet about the survey, here: https://drive.google.com/file/d/14hloszDZqVcdX4tOp-JhH5OYIKWk1im97/view?pli=1
Please contact the Next Generation Brain health research team at: generationbrainhealth@gmail.com if you have any questions.
You can access the survey here: https://prevent-fearstudy.qualtrics.com/jfe/form/SV_9MpII7AOz9VyuzQ



23 JANUARY

Women's Brain Project Foundation launches fundraising campaign to support its aim to create the world's first sex and gender research institute

For seven years, the Women's Brain Project (WBP), an international non-profit organisation, has been raising awareness and carrying out research about sex-based brain differences. Over 120 scientific and policy papers have addressed these issues, but understanding why Alzheimer's predominantly affects women or why depression diagnoses skew towards women requires extensive research. The WBP aims to establish the world's first Sex and Gender Research Institute, and has launched a fundraising campaign to help it achieve this goal.
Find out more about the WBP: https://www.womensbrainproject.com/
Watch the campaign video: https://www.youtube.com/watch?v=iFUOlbRECcU
Read about the funding campaign and contribute, via: https://www.gofundme.com/f/girls-just-wanna-have-brain-research-funds

NEW PUBLICATIONS AND RESOURCES

7 DECEMBER

National Dementia Carers Action Network member Marion assists in development of new guidelines by the Scottish Intercollegiate Guidelines Network

National Dementia Carers Action Network (NDCAN) member Marion spent well over two years assisting in the development of new Scottish Intercollegiate Guidelines Network (SIGN) guidelines on the assessment, diagnosis, care and support for people with dementia and their carers.
As a part of the launch, Marion was delighted to co-host a webinar to promote and explain the content of the evidence-based guidelines, which cover the diagnosis of dementia, post-diagnostic support, non-pharmacological distressed behaviours, grief and dementia, changing needs, and palliative approaches.

31 DECEMBER

TouchNEUROLOGY publishes new edition of its journal touchREVIEWS in Neurology

The latest edition of touchREVIEWS in Neurology features a diverse range of free-to-view, topical articles covering therapeutic areas relevant to neurologists and other practitioners involved in the care of patients with neurological illness.
Editor-in-Chief, Dr Cristian Constantinescu (Cooper University Hospital, Cherry Hill, New Jersey, USA), commented:“In the latest edition of touchREVIEWS in Neurology, we are pleased to present a collection of insightful articles that highlight the current landscape and future directions in neurological research and treatment. Topics include the latest data from the PROOF-HD trial, the future of Dravet syndrome research, updates in the use of vamorolone and steroids for DMD, and many more." Explore touchREVIEWS in Neurology Volume 19, Issue 2, 2023, here: https://touchneurology.com/journals/touchreviews-neurology/touchreviews-in-neurology-volume-19-issue-2-2023/?utm_medium=campaign&utm_source=email&utm_campaign=DecNews

AE CALENDAR 2024

DATE	MEETING	AE REPRESENTATIVE
5 February	Virtual engagement session on NSA Engagement Plan for WGO	Jean
15 February	Consultation with the PROMINENT Public Involvement Board	Ange and Daphné
20 February	Alzheimer's Association Academy	AE members and staff
22 February	The Good Lobby - How can civil society can influence the EU	Owen
26 February	Alzheimer Europe Board	AE Board and staff
27 February	Consultation with the ADIS-Advisory Board	Soraya and Ana

CONFERENCES 2024

DATE	MEETING	PLACE
5-9 March	AD/PD 2024 – Advances in science & Therapy, https://adpd.kenes.com/	Lisbon, Portugal
12 March	"50 Shades of Memory Work – Intergenerational activities with foreign-born older people", www.mukes.fi/news	Online
14 May	Alzheimer's Society Annual Conference, Making dementia a priority for all https://www.alzheimers.org.uk/dementia-professionals/conferences-and-events/annual-conference	London, United Kingdom
8-10 October	34th Alzheimer Europe Coference – New horizons – Innovating for dementia	Geneva, Switzerland

Co-funded by the European Union

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

34th Alzheimer Europe Conference

New horizons – Innovating for dementia

Geneva, Switzerland

8 - 10 October 2024 #34AEC

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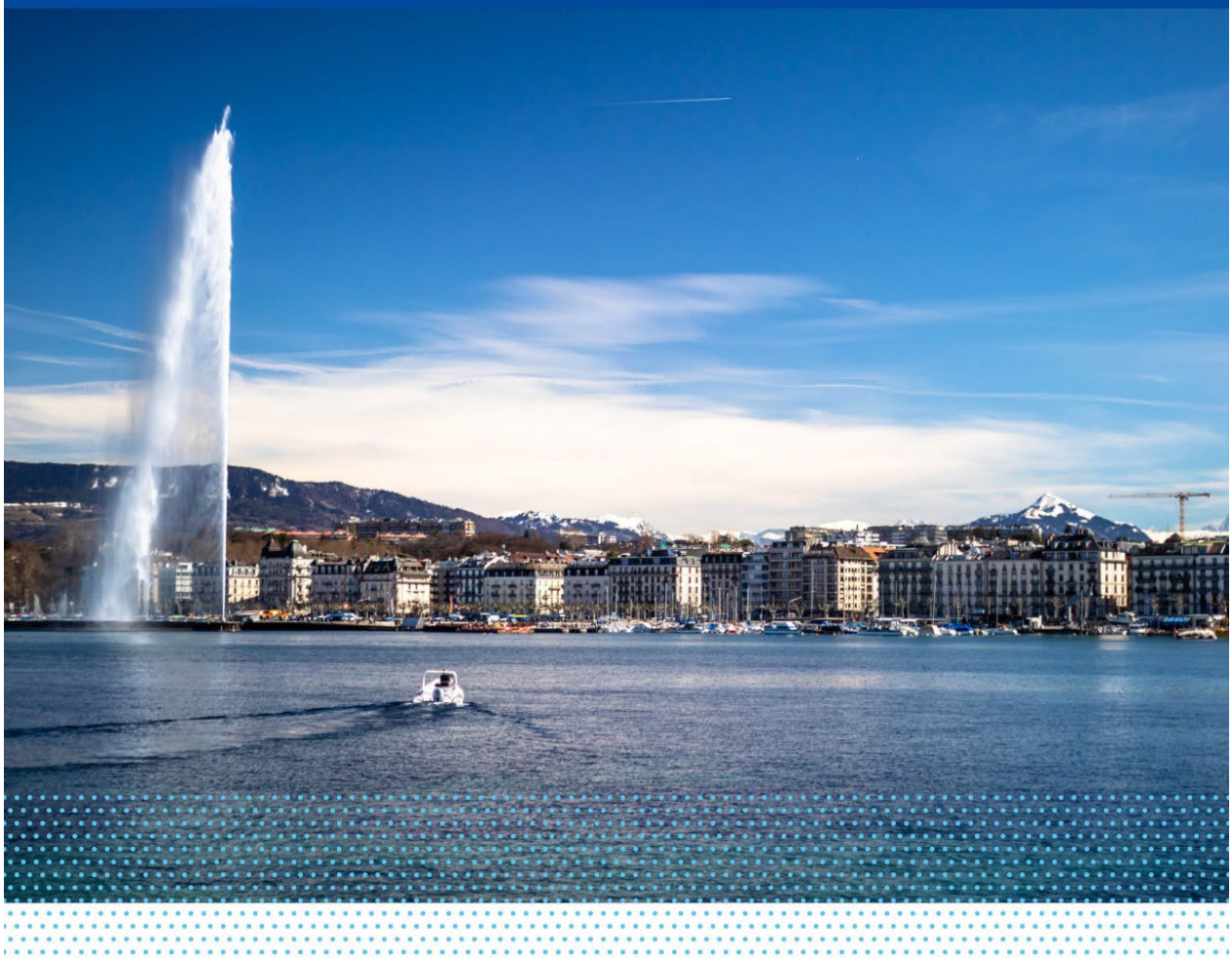

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