Alzheimer Europe

Newsletter
JULY-AUGUST 2024

HIGHLIGHTS

CONTENTS

WELCOME

The summer edition of our newsletter covers both July and August. Following the European elections which took place before the summer, and as the new legislative term begins, Alzheimer Europe began its summer by re-issuing an urgent call to European and national organisations and other entities to endorse the Helsinki Manifesto, which outlines the current situation in relation to dementia across Europe and makes specific demands for the EU, as well as for national governments. Help us make dementia a European priority! You can find out more in our special EU campaign section.

The European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) also held elections of their own, and the groups' new mandates have officially begun. Congratulations to Kevin Quaid and Lieselotte Klotz, the respective new Chair and Vice-Chair of the EWGPWD, and to Trevor Salomon and Sonata Mačiulskytė, the respective Chair and Vice-Chair of the EDCWG.

Some disappointing news reached us at the end of July, with the European Medicines Agency (EMA) issuing a negative decision on the marketing authorisation application for lecanemab for the treatment of early Alzheimer's disease (AD). The US Food and Drug Administration (FDA) granted traditional approval to lecanemab in July 2023, and it has also been approved by regulatory authorities in Japan, China, South Korea, Hong Kong, and Israel. Since the decision by the EMA, the UK's Medicines and Healthcare products Regulatory Agency has also granted marketing authorisation. Alzheimer Europe regrets the decision of the EMA, and hopes that re-examination will result in an outcome that enables more Europeans living with early AD to access lecanemab in the future. We also remain committed to a holistic approach to AD and other types of dementia where innovative new treatments are included alongside counselling, support and care of people with dementia and their carers throughout the disease process.

The Alzheimer's Association International Conference (AAIC) took place in Philadelphia (USA) this summer and I was delighted to be able to attend. We have included a special section with some highlights from AAIC, including the results of a new report from the Lancet Commission on Dementia Prevention, Intervention, and Care, highlighting the potential for dementia risk reduction and prevention by tackling modifiable risk factors.

Now to our own conference, which is taking place in just over a month. We are delighted to announce that ten early-stage researchers have won bursaries provided by the Alzheimer Europe Foundation to attend and present their innovative research and we look forward to welcoming them to Geneva. We also look forward to welcoming dementia researcher Golnaz Atefi, who is "Rolling for Dementia" during World Alzheimer's Month (September), to promote inclusivity and diversity in dementia care and research. She is making a World Record attempt of skating 1,000 km in one month and will share her results in Geneva!

Jean Georges, Executive Director

SPOTLIGHT ON EU ELECTIONS

15 JULY

Support the Helsinki Manifesto and help us make dementia a priority issue for European decision-makers!

Following the European Parliament elections which took place last month, and as the new European legislative term begins, Alzheimer Europe is re-issuing an urgent call to European and national organisations and other entities to endorse the "Helsinki Manifesto". This Manifesto outlines the current situation in relation to dementia across Europe and makes specific demands for the European Union (EU), as well as for national governments.

The Helsinki Manifesto 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, it points out that by 2025, 9.1 million people will be living with dementia in the European Union (EU), rising to 14.3 million in 2050.

The Manifesto, which will be the basis of Alzheimer Europe's campaign work in the coming years, is divided into the following policy areas:

- Health
- Research
- Disability and social rights
- Support for informal carers.

Under each policy area, a brief rationale for action is outlined, followed by a number of specific demands for European and national decisions-makers, including:

- Invest in improvements to support timely diagnosis, including access to imaging, biomarker testing and new treatment options
- Increase the funding allocated for dementia research, proportionate to its societal cost, bringing the total funding to at least the level of other non-communicable diseases (NCDs)
- Prioritise dementia in future health programmes, with dedicated funding for projects and actions, in line with other NCDs (e.g. cancer)
- Develop and implement a European Dementia Action Plan, to coordinate efforts and programmes across the domains of health, research and social affairs.

European and national organisations with a mutual interest in these policy areas are invited to endorse the Helsinki Manifesto. If your organisation would like to endorse the Helsinki Manifesto, please send an email to info@alzheimer-europe.org

Jean Georges, Executive Director of Alzheimer Europe, said:

"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 Helsinki Manifesto and associated campaign not only highlight the scale of the challenge presented by dementia but also offer concrete steps for how European decision-makers can take decisive action in the coming years. We encourage organisations to support the Manifesto, today and help us make dementia a European priority!"

You can find out more about the Helsinki Manifesto, including which organisations and entities have already endorsed it, here: https://www.alzheimer-europe.org/policy/campaign/alzheimer-europe-election-campaign-2024/helsinki-manifesto

Download the Helsinki Manifesto as a PDF booklet, here: https://www.alzheimer-europe.org/sites/default/files/2024-03/final_-_helsinki_manifesto_-_digital.pdf

Read a one-page summary of the Helsinki Manifesto, here: https://www.alzheimer-europe.org/sites/default/files/2024-01/final_-_helsinki_manifesto_2023_-_1_page_summary.pdf

Our Dementia Pledge campaign draws to a close after European Parliament elections

With the Helsinki Manifesto forming the basis of Alzheimer Europe's campaign work in 2024, the organisation is delighted to announce that, following the European Parliament elections between 6 and 9 June, its Dementia Pledge 2024 campaign has drawn to a close with an impressive 304 candidates signed up. This number breaks Alzheimer Europe's previous record of 230 pledgees signed up before the 2019 elections.

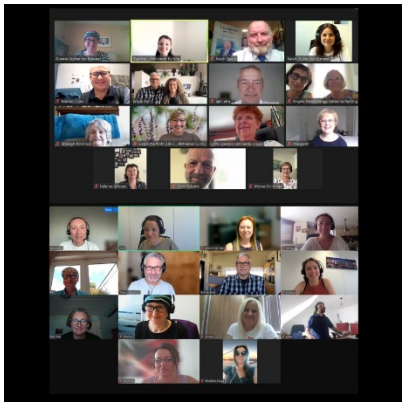
We would like to say a huge thank you to all of the associations who supported the campaign, contacted MEP candidates and played an integral part in making the campaign such a success! Additionally, we would like to thank the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) for their contributions to the campaign, helping us send strong messages to candidates that dementia needs to be a priority during the next parliamentary term. In the coming weeks, Alzheimer Europe will write to elected candidates, asking them to follow up on their commitment, as well as asking its national members associations to make contact, so as to establish a closer connection between MEPs and national Alzheimer's organisations.

We are also working to re-establish the European Alzheimer's Alliance (EAA) and will announce the new group after the summer. Following the Pledge campaign and the election results, we currently expect upwards of 70 members for this new incarnation of the EAA, which is a multinational and cross-party group that brings together MEPs to support European citizens living with Alzheimer's disease or another form of dementia, as well as their supporters/carers. For a detailed breakdown of the MEPs elected in each country, more information is available on the European Parliament website: https://election-results.eu/

ALZHEIMER EUROPE

26-27 JUNE

Members of the European Working Group of People with Dementia and of the European Dementia Carers Working Group meet online



To kick off the new term of office (2024-2027) of the European Working Group People with Dementia (EWGPWD) and of the European Dementia Carers Working Group (EDCWG) online social meetings were organised on 26 and 27 of June with each of the groups. During these online meetings, new and old members had the chance to meet each other. Members joining the groups were warmly welcomed by members of the previous term of office and had the chance to ask questions about the groups. In addition to the social gathering, there was a presentation about the upcoming elections for the Executive of both groups (Chairs and Vice Chairs). Alzheimer Europe would like to especially thank Chris Roberts and Sonata Mačiulskytė for their work as Chairs of the EWGPWD and EDCWG, respectively, during the last term of office, and Kevin Quaid, Margaret McCallion and Trevor Salomon as Vice Chairs.

15 JULY

European Working Group of People with Dementia begins new mandate and elects new Chairperson and Vice-Chairperson

We are pleased to announce that the membership of the European Working Group of People with Dementia (EWGPWD) has been renewed and that the new incarnation of the group officially began its mandate after the Annual General Meeting of Alzheimer Europe (18 June 2024). As of 15 July 2024, the group has voted in its Executive members, with Kevin Quaid (Ireland) becoming the group's new Chairperson and Lieselotte "Lilo" Klotz (Germany) its new Vice-Chairperson. Many congratulations to them both and a big thank you to the group's former Chairperson Chris Roberts (Chairperson from 2020-2024) and Vice-Chairpersons Margaret McCallion (Vice-Chairperson from 2022-2024) and Kevin Quaid (Vice-Chairperson from 2022-2024).

The EWGPWD is now composed of the following 14 members, four of whom are new to the group:

Chairperson

- Kevin Quaid, Ireland

Vice-Chairperson

- Lieselotte Klotz, Germany

Members

- Kjell Ehn, Sweden (new member)
- Nigel Hullah, United Kingdom
- Erla Jónsdóttir, Iceland
- Minna Kinnunen, Finland (new member)
- Real Larnou, Belgium
- Margaret McCallion, United Kingdom
- Angela Pototschnigg, Austria
- Chris Roberts, United Kingdom
- Shelagh Robinson, United Kingdom
- Jan Runar Eliassen, Norway (new member)
- Věra Ryšavá, Czechia
- Gerda Van Tongerloo, Netherlands (new member).

The EWGPWD was launched by Alzheimer Europe and its member associations in 2012. The group is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group

operates independently and members elect their own Chairperson and Vice-Chairperson. The Chairperson is also an *ex-officio* member on the Board of Alzheimer Europe, with full voting rights. For more information about the group, see: https://www.alzheimer-europe.org/about-us/european-working-group-people-dementia

Alzheimer Europe would like to express its gratitude to outgoing members Bernd Heise (Germany), Marguerite Keating (Ireland), Pia Knudsen (Denmark), Petri Lampinen (Finland), and Stephen John McCleery (Italy), for their important contributions and we wish them well. They will be sorely missed!

15 JULY

European Dementia Carers Working Group begins new mandate and elects new Chairperson and Vice-Chairperson

We are pleased to announce that the membership of the European Dementia Carers Working Group (EDCWG) has been renewed and that the new incarnation of the group officially began its mandate after the Annual General Meeting of Alzheimer Europe (18 June 2024). As of 15 July 2024, the group has voted in its Executive members, with Trevor Salomon (United Kingdom) becoming the group's new Chairperson and Sonata Mačiulskytė (Lithuania) its new Vice-Chairperson. Many congratulations to them both.

The EDCWG is now composed of the following 15 members, five of whom are new to the group:

Chairperson

- Trevor Salomon, United Kingdom

Vice-Chairperson

- Sonata Mačiulskytė, Lithuania

Members

- Peter Banda, Slovakia
- Paddy Crosbie, Ireland
- Sylva Dneboská, Czechia
- Chris Ellermaa, Estonia
- Emil Emilsson, Iceland (new member)
- Annick Germeys, Belgium (new member)
- Zornitsa Karagyozova, Bulgaria
- Barry Northedge, United Kingdom
- Hatice Sertaç Süslü, Turkey (new member)
- Liv Thorsen, Norway
- Olivera Vasilevska Danev, North Macedonia (new member)
- Roslynn Vella, Malta
- Christina Zioga, Greece (new member).

The EDCWG was launched by Alzheimer Europe and its member associations in 2022. The group is composed both of current carers, relatives and supporters of people with dementia, and of people with prior experience in a carer's role, within the five years prior to their first nomination to the group.

In tandem with the European Working Group of People with Dementia (EWGPWD) - a group composed entirely of people living with dementia themselves and set up by Alzheimer Europe and its members in 2012 – the carers group works to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of carers and supporters of people with dementia. The group operates independently and members elect their own Chairperson and Vice-Chairperson. The Chairperson is also an *ex-officio* member on the Board of Alzheimer Europe, with full voting rights. For more information about the group, see: https://www.alzheimer-europe.org/about-us/european-dementia-carers-working-group

Alzheimer Europe would like to express its gratitude to outgoing members Magnús Karl Magnússon (Iceland), Filomena Martins Cunha (Portugal), Paola Borghesi (Italy), for their important contributions and we wish them all the best for the future.

16 JULY

Alzheimer Europe hosts Alzheimer's Association Academy Meeting on palliative care

Alzheimer Europe regularly organises Alzheimer's Association Academy meetings, meant as informative workshops aiming to build the capacity of our member organisations. On 16 July, Alzheimer Europe organised a session dedicated to palliative care for people with dementia, which was hosted by Ana Diaz (Public Involvement lead at Alzheimer Europe). During this interactive meeting, four speakers shared their insights into the concepts and perception of palliative dementia care, Advance Care Planning, the role of novel technology in the provision of palliative care and the lived experience of caring for a loved one with dementia at the end of life.

The session was kicked off by Professor Jenny van der Steen, who is the chair of the Taskforce on Advance Care Planning of the European Association for Palliative Care. She presented about the importance of Advance Care Planning (ACP), defined as the "process of communication about future care and treatment preferences, values and goals with the person with dementia, family, and the healthcare team". She shared the results of a Delphi consensus study about specific

issues arising for ACP in dementia, which had been conducted between September 2021 and June 2022. Jenny underlined that the role of the person with dementia throughout the ACP process may change, owing to progressive difficulties in communicating, a decline in mental capacity and changing roles and involvement of the family. She further noted that discussions about ACP may also include treatment preferences for the end of life and that such discussions can already start outside of the healthcare setting.

Next, Professor Lukas Radbruch, who holds the Chair of Palliative Medicine at the University of Bonn, presented about the "Artificial Intelligence based Health, Optimism, Purpose and Endurance in Palliative Care for Dementia" project. AI4HOPE aims to assess whether and how novel technology can support and enhance palliative dementia care. In particular, the project will assess the feasibility of using physiological measures such as heart rate variability and facial emotion recognition to help monitor pain and distress in people with dementia. These could then be coupled to computerized psychosocial interventions, such as music therapy. Technologies developed within AI4HOPE are not meant as a replacement for human interaction and touch, but rather as enhancements aimed to complement the palliative care process. Lukas furthermore emphasized the need to tackle the stigma associated with the term "palliative care", which entails enhancing the quality of life of people living with an incurable illness such as dementia throughout the entire disease spectrum – not only at the end of life.

Dr Dianne Gove (Director for Public Involvement and Ethics at Alzheimer Europe) presented insights gathered from Alzheimer Europe's national member organisations, members of the European Working Group of People with Dementia and the European Dementia Carers Working Group, regarding their perception of the palliative care concept. She outlines that the term "palliative care" has traditionally mainly been linked to oncology. Even though the concept is in fact much broader than this, "palliative care" continues to be associated with the process of dying. This may be reinforced by the fact that in some countries, palliative care is only provided by hospices. A lack of familiarity with the term and a poor understanding of what palliative care entails may additionally contribute to fear and avoidance. Dianne concluded that governments and care providers should recognise that people with dementia are entitled to palliative care and improve equal access to it.

Next, Paddy Crosbie (member of the Irish Dementia Carers Campaign Network and member of the European Dementia Carers Working Group) shared his experiences caring for his partner Derek, who sadly passed away in 2021. Paddy noted that even though the concept of palliative care can seem daunting at first encounter, for him personally, it also has a positive and comforting connotation, given his personal experience of it. He appreciates the fact that he himself was also included and looked after in the care process. Paddy furthermore noted that changing the term "palliative care" may not serve its purpose, as many people, especially in the later phases of the lives of their loved ones, derive comfort from it. Changing the terminology, he noted, may also dilute such positive expectations.

The session concluded with a discussion about the meaning of "palliative care", its appropriateness for people with dementia and necessary changes/improvements regarding terminology and the care process.

Find out more about the project: https://www.ai4hope.eu/

31 AUGUST

Congratulations to then ten early stage researchers who won Alzheimer Europe Foundation bursaries to attend and present at the 34th Alzheimer Europe Conference!

We are delighted to announce the early stage researchers who have been selected by our jury, to benefit from the bursaries provided by the Alzheimer Europe Foundation to attend and present at the 34th Alzheimer Europe Conference, in Geneva in October.

The selection of the ten bursaries was based on the best average scores each received from the jury members.

Here are the details for the special session we have organised to showcase their work, "Special symposium SS3. Dementia researchers of the future", taking place on 9 October from 12:00 - 13:00 and chaired by Iva Holmerová (Czechia) and Fania Dassen (Netherlands):

- SS3-01 Özlem Çiçek Doğan (Turkey): Understanding the experiences of individuals with dementia and their caregivers after the Turkey-Syria earthquakes: a qualitative study
- SS3-02 Natalia Soldevila-Domenech (Spain): Predictors of the cognitive response to multimodal lifestyle interventions for cognitive decline prevention: pooled analysis of four clinical trials
- SS3-03 Electra Chatzidimitriou (Greece): The predictive value of social cognition assessment over and above neuroimaging for 1-year functional outcomes in behavioral variant frontotemporal dementia
- SS3-04 Raphaella Paradisi (Greece): Modified Cued Recall test for the diagnosis of dementia of the Alzheimer's type in a Greek population of adults with Down syndrome: a validation study
- SS3-05 Matěj Kučera (Czech Republic): The role of risk factors in development of cognitive disorders and

cognitive decline in the Czech Republic and the Netherlands: comparative SHARE prospective study
- SS3-06 Eda Atay (Turkey): The effect of cognitive stimulation therapy on apathy, loneliness, anxiety and activities of daily living in elderly individuals diagnosed with Alzheimer's
- SS3-07 Nina Stopar (Slovenia): Risk factors for dementia among patients in memory clinic
- SS3-08 Marina Makri (Greece): An innovative online educational program on Neurodegenerative Genetic Counseling developed in Greece, Germany, Belgium, Spain and Turkey
- SS3-09 Gabriela Początek (Poland): The meanings of the life story of a person living with dementia and their tendency to "wander"-the narrative perspective of Polish caregivers
- SS3-10 Anja Mrhar (Slovenia): The effect of individual characteristics on the level of nutrition related knowledge: exploratory study for older adults across levels of cognitive impairment.

You can find more details about this and other sessions at our conference, in our detailed programme: https://www.alzheimer-europe.org/conferences/2024-geneva/detailed-programme

We currently have more than 850 delegates registered for our conference so make sure you get your place before late registrations close on 29 September! If you have not yet registered for our Annual Conference, you can do so via this link: https://www.alzheimer-europe.org/conferences/2024-geneva/online-conference-registration

AE NETWORKING

2 JULY	Ange and Lukas met with representatives of Roche to exchange about ongoing work regarding dementia research participation
2-3 JULY	Ange participated in meetings of the EMA Patients' and Consumers' Working Party
8 JULY	Owen attended the launch of the WHO IGAP implementation toolkit
9 JULY	Ange attended an online workshop for the Rethinking AD II initiative
10 JULY	Jean attended the monthly meeting of the LEADS coalition
11 JULY	Soraya had a meeting with the ADIS Young Adults Advisory Board
15 JULY	Daphne and Ange participated in the eBRAIN-Health General Assembly meeting
16 JULY	Alzheimer Europe organised an Alzheimer's Association Academy on "Palliative care in dementia"
17 JULY	Dianne and Sarah had attended the monthly Predictom WP1 meeting
22 JULY	Owen attended a WHO Europe briefing sessions on NSA engagement at 74 Regional Committee
FROM 28 JULY TO 1 AUGUST	Jean attended the Alzheimer's Association International Conference (AAIC) where he met with representatives of Alzheimer's Association, Alzheon, Biogen, Bristol Myers Squibb, CEO Initiative on Dementia, Eisai, European Alzheimer's Disease Consortium, Lilly, Prothena, US Against Alzheimer's and the World Dementia Council, (Philadelphia, USA)
28 JULY	Jean attended a meeting of the WW Fingers Network, (Philadelphia, USA)
31 JULY	Jean attended the Scientific Advisory Board of the Amsterdam Alzheimer Centre, (Philadelphia, USA)
5 AUGUST	Ange met with representatives of the InRAD initiative
14 AUGUST	Jean had a meeting with GlaxoSmithKline
21 AUGUST	Dianne and Sarah attended the monthly Predictom WP1 meeting
21 AUGUST	Ana and Sarah had a meeting with members in Sweden of the AD-RIDDLE Advisory Board

22 AUGUST	Dianne and Lukas had a meeting with members AI4Hope, the EAPC and In-Touch to discuss the development of a fact sheet on palliative care
23 AUGUST	Dianne and Ana had a meeting with the Executive of the EDCWG
26 AUGUST	Dianne and Sarah attended the Predictom project management board meeting
28 AUGUST	Owen, Ana and Daphne organised an update meeting with members of the EWGPWD, EDCWG and PI Pool on the EU elections
28 AUGUST	Owen attended a thematic meeting of the pan-European Mental Health Coalition on the mental health of the care workforce

SPONSOR OF THE MONTH

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

novo nordisk

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

EU PROJECTS

26 JUNE

The ADIS Advisory Board meets in Luxembourg to develop a brain health campaign for young adults

On 26 June, members of the ADIS Advisory Board gathered in Luxembourg. The meeting was attended and facilitated by Soraya Moradi-Bachiller (Public Involvement Officer at Alzheimer Europe, AE), Jesús Rodrigo (Confederación Española de Alzheimer, CEAFA) and Ana Diaz (Public Involvement Lead at AE).

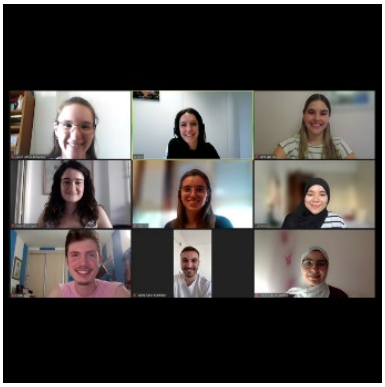
During the consultation, members of the ADIS Advisory Board and their supporters provided their views and opinions regarding the slogan, message, and poster developed with the ADIS Young Adults Advisory Board for the brain health campaign, which will be hopefully launched at the end of this year.

All the members and supporters participated actively and provided insightful feedback that will help AE to improve and further develop the brain health campaign for young adults.

Find out more about the ADIS project and its advisory board, here: https://www.adis-project.eu

11 JULY

Members of the ADIS Young Adults Advisory Board meet online to discuss the final details of the brain health campaign for people their age



On 11 July, the members of the ADIS Young Adults Advisory Board (ADIS YA-AB) gathered online. The session was also attended and facilitated by Soraya Moradi-Bachiller (Public Involvement Officer at Alzheimer Europe).

During the consultation, members of the ADIS YA-AB were asked what their views and opinions are about the materials developed for the brain health campaign (e.g. poster). There were also discussions about the specific messages that they would like to portray in the videos of the campaign, and how they could help with the dissemination of the campaign once ready. All the members participated actively and provided helpful feedback during this consultation that will help shape the brain health campaign for young adults.

23 JULY

EPND announces the launch of a Call for Expressions of Interest to leverage catalogued biosamples and datasets, advancing neurodegeneration research

The European Platform for Neurodegenerative Diseases (EPND) is working to accelerate global progress in neurodegenerative disease diagnostics, treatments, and biomarkers. Supported by the Innovative Medicines Initiative (IMI), EPND is establishing a data-and sample-sharing platform for collaborative, large-scale biomarker research. Alzheimer Europe is one of 29 public- and private sector partners in EPND, and is proud to co-lead its stakeholder engagement, public involvement and communications activities.

Earlier this year, EPND launched its extended Study Catalogue, which includes information on over 70 clinical research studies, across 12 disease areas with almost 240,000 participants. EPND now invites academic and industry researchers to submit an Expression of Interest to leverage neurodegeneration biosamples and data catalogued on the EPND platform. The Call is designed to test the full suite of functionalities of the EPND platform, helping to refine and adapt the platform to best meet the needs of neurodegeneration researchers.

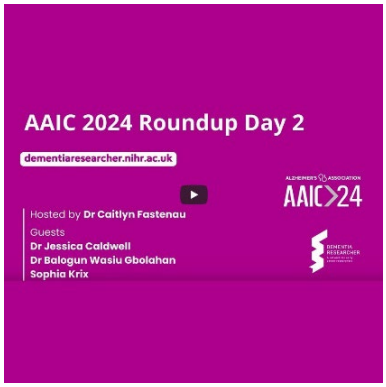
Successful proposals will benefit from an array of resources and services, including:

- Facilitated access to biosamples and datasets from neurodegeneration research studies
- Technical support for data harmonisation, saving time before initiating analysis
- Access to secure online workspaces, analytical tools and apps, via the AD Data Initiative's AD Workbench
- Ethical-legal guidance, helping researchers to understand and address compliance requirements.

EPND can also offer financial support in the range of EUR 10,000 – EUR 50,000 for successful academic proposals to cover biosample costs, although interested applicants are expected to apply with external funding sources to enable their research study. Selected applicants will join a robust community of researchers, working to accelerate the discovery of diagnostic and therapeutic solutions for neurodegenerative diseases. The deadline for submissions is 15 September 2024; selected applicants will be invited to submit a full proposal by 30 November. Learn more about the research Call and application process: bit.ly/EPNDResearch_Call

31 JULY

ADIS project featured in Dementia Researcher Podcast at AAIC



On 31 July, Dementia Researcher issued a podcast hosted by Caitlyn Fastenau sharing a few selected highlights from the third day of the Alzheimer's Association International Conference (AAIC) taking place in Philadelphia and Online, 28 July to 1 August.

Caitlyn Fastenau, PhD Candidate at University of Texas Health San Antonio, hosts the show with special guests:

- Balogun Wasiu, Postdoctoral Associate at University of Pittsburgh
- Jessica Caldwell, Director, Women's Alzheimer's Movement Prevention and Research Center, Cleveland Clinic
- And last but not least Sophia Krix, PhD Student at University of Bonn, working on the ADIS Project.

The AAIC brings together distinguished basic scientists, clinical researchers, early career investigators, clinicians and the care research community at the largest and most influential international conference on dementia science. They share theories and breakthroughs while exploring opportunities to accelerate work and elevate careers.

ADIS stands for "Early Diagnosis of Alzheimer's Disease by Immune Profiling of Cytotoxic Lymphocytes and Recording of Sleep Disturbances." The project is funded by the EU Joint Programme for Neurodegenerative Diseases Research (JPND). Alzheimer Europe is a partner of this consortium and leads its Public Involvement as well as communication activities. Watch the podcast here:

https://www.dementiaresearcher.nihr.ac.uk/podcast-aaic-2024-day-two/

27 AUGUST

Pattern-Cog project publishes its second newsletter

On 27 August, the Pattern-Cog project released its second external newsletter. Pattern-Cog is a multinational interdisciplinary consortium aiming to improve dementia prevention strategies by developing support tools for the detection of earliest signs of impeding cognitive decline which would allow early and personalised multidomain interventions. Funded by ERA PerMed, the three-year project includes six partners from five European countries The newsletter provides readers with the latest project updates including the important advances and major achievements made by each Work Package. The newsletter covers work of the Advisory Board, composed of the members of the European Dementia Carers Working Group (EDCWG). This issue also features interviews with two Pattern-Cog members Ruth Stephen from Karolinska Institutet and Gazi Saadmaan Hossain from the University of Eastern Finland.

You can read the newsletter here: https://pattern-cog.eu/welcome-to-the-second-issue-of-the-pattern-cog-newsletter/

28 AUGUST

Findings on usage tracking mechanism for dementia risk assessment presented at 34th Medical Informatics Europe Conference

On 28 August, Hannes Hilberger from the institute of eHealth, FH JOANNEUM participated in a session on mHealth, Wearable Devices at the 34th Medical Informatics Europe in Athens, Greece. In this article, he shares about his experience and research.

The primary objective of the usage tracking mechanism for dementia risk assessment was to monitor user interaction with the LETHE App. Specifically, this involved assessing whether participants are actively engaging with the application and identifying which features are utilised most frequently. To achieve this, we tracked a total of 20 different events, which included actions such as screen changes (e.g., opening the calendar) and accessing external resources. By monitoring these events, we could reconstruct the paths that participants take within the app and measure the time they spend using it. Our analysis of usage patterns focused on several tasks. Initially, we assessed overall app usage by converting event data into binary indicators (0 for no usage, 1 for usage) to determine daily engagement levels. Subsequently, we analysed session duration to measure the amount of time participants spent in-

teracting with the app during each session. Lastly, we examined engagement with educational content to identify which resources and which intervention domains captured users' attention the most.
After a six-month period, we found that approximately 39% of study participants used the LETHE App daily. Notably, usage rates were higher among participants in the intervention group compared to the control group. A similar trend was observed for session duration, with the intervention group averaging around 42 seconds per session. Interestingly, participants in the control group engaged with educational resources 41% more frequently than those in the intervention group. Furthermore, personalised features were among the most accessed components of the app, indicating a preference for tailored content over generic external resources.
The feedback received at the conference was very positive, particularly regarding the LETHE App, the overall project, and the findings presented in our submission. One common question from attendees concerned the language options available. We clarified that the app is available in multiple languages, more concretely in German, Finnish, Swedish, and Italian. Find out more about the project: https://www.lethe-project.eu/

EU project acknowledgements

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

EPND – grant agreement 101034344 (https://epnd.org/)

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

The **PatternCog** project was supported by the Luxembourg National Research Fund (INTER/PerMed21/15748787/Pattern-Cog), under the frame of ERA PerMed (https://pattern-cog.eu/)

EU DEVELOPMENTS

10 JULY

European Disability Forum publishes report on disabilities, technology and employment

The European Disability Forum (EDF) has published a report, "Digital Skills, Accommodation and Technological Assistance for Employment", which examines problems facing employees with disabilities across the EU and the UK.

The report explores the causes of low employment of persons with disabilities, including inaccessible hiring processes and lack of accommodation, as well as a lack of access to assistive technologies and hostile workplace cultures. Other main findings include:

- Only 1 in 4 employers have developed accessible recruitment processes
- 81% of employers have no policy in place for the acquisition of assistive technology
- Only a quarter of employers are aware of and use public support to provide reasonable accommodation to workers with disabilities.

Some recommendations of the report include:

- Employers must invest in accessible technology, regardless of employees' disability status
- Public authorities should increase and publicise state aid available to employers to cover reasonable accommodation – and simplify the application process
- Technology companies should involve persons with disabilities when designing technological solutions.

The report is available at: https://www.edf-feph.org/digital-skills-accomodation-employment/

11 JULY

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

The EU4Health Civil Society Alliance (CSA) has published a letter to European Commission President nominee, Ursula von der Leyen, calling for the appointment of a Vice-President for Health, Wellbeing and Social Rights. The letter notes the importance of health in the European context and calls for a specific VP appointment to ensure:

- Health is maintained as a political priority on the EU agenda and the lessons from the COVID-19 pandemic are applied

- The European Health Union is further implemented, strengthened and deepened, with appropriate funding under the next Multiannual Financial Framework (2028-2034)
- Strong and coordinated EU health policies to counter pressing challenges and ensure the sustainability of health systems.

The full letter is available at: https://eu4health.eu/appeal-to-president-von-der-leyen-to-appoint-a-vice-president-for-health-wellbeing-and-social-rights/

22 JULY

European Commission publishes guideline on regulation on air passengers rights for persons with disabilities

The European Commission has published interpretative guidelines on Regulation 1107/2006 concerning Air Passenger Rights for persons with disabilities. These offer clear guidance to airlines, authorities and passengers regarding how to ensure their rights. The guidelines address various aspects, including the provision of assistance, accessibility of information, transport of mobility equipment and assistance dogs, and the application of safety requirements by carriers.

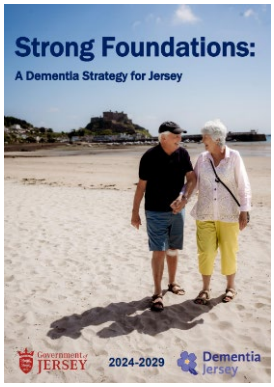
See the guideline, here:

https://transport.ec.europa.eu/document/download/0f48cd98-efa4-40a2-8e84-580b8950987b_en?filename=C_2024_5078_1_EN_annexe_acte_autonome_cp_part1_v3.pdf

POLICY WATCH

1 JULY

Jersey Government launches dementia strategy



The Jersey Government has launched "Strong Foundations: A Dementia Strategy for Jersey", a five year-dementia strategy developed in partnership with Dementia Jersey. The strategy sets out five priority areas to develop and improve the support available for people living with a dementia, their families and carers:

- Raising awareness of brain health and of dementia
- Diagnosing well
- Supporting people with a dementia and their families
- Developing, valuing and supporting the workforce
- Supporting Jersey to become a dementia-friendly and inclusive Island.

The strategy was developed with oversight from a steering group which included a person with dementia, family carers, members of the government from health and public health, representatives from Dementia Jersey and partners from the independent care sector. Engagement sessions and survey were to understand what is most helpful and what changes would make things better, collecting the views of people with dementia, their families and the professionals involved in their care and treatment, as well as members of the public. The full strategy is available at:

https://www.gov.je/government/pages/statesreports.aspx?reportid=5828

8 JULY

World Health Organization publishes toolkit for intersectional neurological conditions action plan

The World Health Organization (WHO) has published an implementation toolkit for the Intersectoral global action plan on epilepsy and other neurological disorders (IGAP), outlining specific actions and resources for countries to improve services for people with neurological disorders in line the targets set out in the IGAP.

The implementation toolkit is a resource for anyone involved in shaping neurology policies and services. It is primarily for policy-makers at national and subnational levels, but also for programme managers and service planners across various sectors. The toolkit is designed to correspond to the IGAP strategic objectives, focusing on five strategic areas:

- Prioritisation and governance
- Diagnosis, treatment and care

- Promotion of brain health and prevention of neurological disorders
- Research and information systems
- Approach to six specific high-burden neurological disorders, of which one is dementia.

The toolkit includes specific steps, as well as tools and resources, allowing plans for IGAP implementation to be adapted to the specific context of countries, recognising the advances in neurological care that may have already been made.

The implementation toolkit is available at:

https://www.who.int/publications/i/item/9789240096356

AAIC WATCH

28 JULY

Anavex Life Sciences presents findings from its Phase IIb/III study of blarcamesine in early AD

On 28 July, Anavex Life Sciences Corp., a clinical-stage biopharmaceutical company developing therapeutics for the treatment of neurodegenerative and neurodevelopmental disorders including Alzheimer's disease (AD), presented findings from its Phase IIb/III study at the Alzheimer's Association International Conference (AAIC).

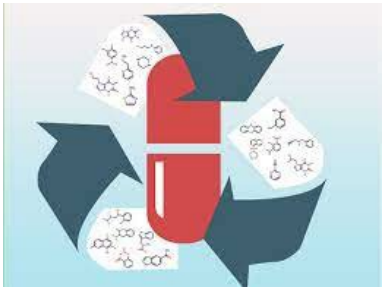
The trial included 508 participants with mild dementia or mild cognitive impairment due to AD, aged 60 to 85 years old. They were randomly assigned to receive the experimental drug blarcamesine (30 or 50 mg), or a placebo, once daily for 48 weeks. The study's main goals were to evaluate the benefits of blarcamesine on cognition, using the Alzheimer's Disease Assessment Scale-Cognition (ADAS-Cog13) and the Alzheimer's Disease Cooperative Study-Activities of Daily Living Scale (ADCS-ADL) as co-primary endpoints. Researchers found that blarcamesine significantly slowed cognitive decline by 34.6% at the 30 mg dose and by 38.5% at the 50 mg dose compared to placebo on ADAS-Cog13 at week 48. No significant differences were observed in ADCS-ADL scores. Findings also showed that blarcamesine significantly slowed cognitive worsening by 28.6% at the 30 mg dose and by 26.5% at the 50 mg dose compared to placebo at week 48 on the prespecified key secondary composite endpoint, Clinical Dementia Rating Scale Sum of Boxes (CDR-SB). Blarcamesine was relatively safe with no associated neuroimaging adverse events. Additionally, blarcamesine significantly slowed brain atrophy in key regions of interest, including the whole brain, total grey matter and lateral ventricles.

The company is planning to publish data in an upcoming peer-reviewed journal. Full regulatory submission of blarcamesine in Europe is expected in Q4 2024.

https://www.anavex.com/post/results-from-anavex-life-sciences-landmark-phase-iib-iii-trial-of-blarcamesine-presented-at-alzheime

28 JULY

New study published in JAMA finds that a blood-based biomarker test improves detection of Alzheimer's disease in primary and secondary care



A new research study, published this week in the Journal of the American Medical Association (JAMA) and presented at the Alzheimer's Association International Conference (AAIC) has demonstrated how a blood-based biomarker test can improve the accuracy of Alzheimer's disease diagnosis.

Gold standard diagnostic tests for Alzheimer's disease pathology include PET scans and analyses of cerebrospinal fluid taken from lumbar punctures. These tests directly detect the presence of amyloid plaques in the brain, but can be costly and invasive. As a result, the last decade has seen increasing interest and investment in research on blood-based biomarkers, measurable proteins in the blood which can indicate the presence of Alzheimer's disease pathology in the brain. In their new study, a team of researchers led by Oskar Hansson and Sebastian Palmqvist (Lund University, Sweden) evaluated the accuracy of a blood-based biomarker test for Alzheimer's disease pathology, showing how it could improve the accuracy of diagnosis in primary and secondary care.

The researchers analysed blood samples from 1,213 patients with cognitive complaints who were undergoing evaluation in Swedish primary care clinics (515 patients) or memory clinics (698 patients). The tests were carried out in two ways: a first set of samples was analysed in a single batch, and a second set of samples was analysed prospectively, with samples sent individually for analysis within 2 weeks of collection. This mimics the way samples are analysed in real-world clinics. The study used a test from C2N Diagnostics called PrecivityAD2, which performs mass spectrometry to calculate the ratios of two proteins: tau217 (phosphorylated and total tau217) and amyloid beta (amyloid beta-40 and amyloid beta-42). Based

on these test results, an Amyloid Probability Score is computed (termed the APS2 score) which indicates the likelihood of an individual having Alzheimer's disease pathology in the brain. APS2 results were compared to CSF or amyloid PET analysis, and clinicians in primary or secondary care were also asked if they thought patients had Alzheimer's disease, based on clinical examination, cognitive testing and a CT scan.
The results of the study showed that the PrecivityAD2 test had a diagnostic accuracy of 91% in the memory clinic cohort, and 89% in the primary care cohort. This did not differ substantially when samples were analysed in a single batch or prospectively. In comparison, primary care clinicians had an overall diagnostic accuracy of 58%, when looking for Alzheimer's pathology in the brain, with a diagnostic confidence of 5.8 (on a scale of 0-10, 10 being the highest level of confidence). Memory clinic specialists had an overall diagnostic accuracy of 71%, with an average diagnostic confidence of 6 on a scale of 0-10. According to Sebastian Palmqvist, the first author of the study, this underscores the lack of good, cost-effective diagnostic tools, particularly in primary care, and indicates the potential improvement in diagnosis with the adoption of this blood test in healthcare settings. Read the JAMA publication: https://jamanetwork.com/journals/jama/fullarticle/2821669

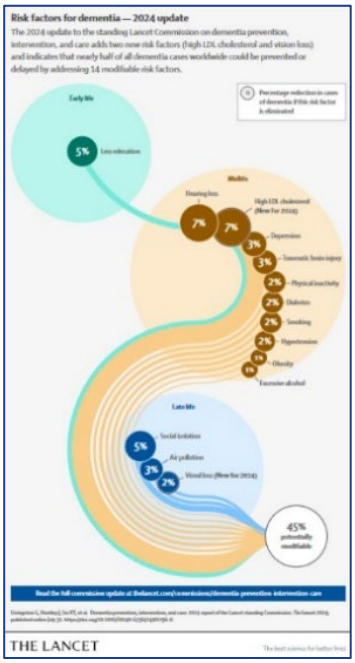
30 JULY

GLP-1 drug liraglutide may protect brain from AD

The glucagon-like peptide-1 receptor agonist (GLP-1) liraglutide may protect the brains of people with mild Alzheimer's disease (AD) and reduce cognitive decline, according to findings presented at the Alzheimer's Association International Conference (AAIC) 2024 in Philadelphia and online.
GLP-1 receptor agonists, which mimic the natural hormone glucagon-like peptide released by the stomach after eating, are known to aid in diabetes management, weight loss and reducing risks of heart diseases, strokes and kidney diseases. Researchers are exploring multiple ways to repurpose drugs either alone or in combination with another therapeutic, offering a promising avenue for AD research. This innovative and attractive strategy may help identify new targets for drugs that are already approved for other conditions, leveraging known safety profiles and mechanisms of action. Previous research in AD animal models suggested that liraglutide may have neuroprotective effects by reducing early forms of amyloid, normalising synaptic plasticity and cerebral glucose uptake, and improving memory and learning.
In the study presented at AAIC 2024, investigators from Imperial College London conducted a randomised, double-blind and placebo-controlled Phase IIb trial to evaluate the effects of liraglutide in people with mild AD. The ELAD study was funded by the Alzheimer's Association's Part the Cloud program. 204 participants with mild AD were enrolled in the UK and received either a daily subcutaneous injection of 1.8 mg liraglutide or placebo for a year. The trial excluded people with diabetes to try to control for any effects of that disease, which is itself a risk factor for AD. Before the study began, all participants had magnetic resonance imaging (MRI) to evaluate brain structure and volumes, glucose metabolism with PET scans and other tests looking at memory, comprehension, language and spatial orientation. These were repeated at the end of the study with regular safety visits.
The trial failed to meet its primary endpoint, which was the change in the metabolic rate of glucose in certain parts of the brain. However, secondary endpoints demonstrated statistically significant benefits. Participants who received liraglutide had nearly 50% less volume loss in several areas of the brain that are responsible for critical functions like memory, language and decision-making, compared to those who received placebo. This reduction in brain loss went along with 18% slower decline in cognitive function in a year. Similar to other GLP-1s, the most common side effects reported were gastrointestinal issues such as nausea.
Liraglutide is being developed by Novo Nordisk, a Danish multinational pharmaceutical company developing innovative biological medicines. The company is testing GLP-1 analogues in late-stage clinical trials, such as the EVOKE Plus trial evaluating semaglutide in people with early AD.
https://aaic.alz.org/releases-2024/glp-drug-liraglutide-may-protect-against-dementia.asp

31 JULY

2024 Lancet Commission underscores the potential for dementia risk reduction, identifying 14 modifiable risk factors across the life course



On 31 July 2024, the standing Lancet Commission on Dementia Prevention, Intervention, and Care published the results of their 2024 report, highlighting the potential for dementia risk reduction and prevention by tackling modifiable risk factors. During a dedicated session at the Alzheimer's Association International Conference in Philadelphia (USA) the Commission shared the main updates and changes from the 2020 report.
Since its establishment in 2017, the Commission

has evaluated evidence concerning potentially modifiable dementia risk factors, triangulating scientific evidence from various meta-analyses and intervention studies. The 2024 report reaffirms the potential for dementia risk reduction by addressing the existing twelve risk factors across the life course: low education, hearing loss, hypertension, smoking, obesity, depression, physical inactivity, diabetes, excessive alcohol consumption, traumatic brain injury, air pollution and social isolation. Moreover, new meta-analyses for depression and hearing loss were conducted and population attributable fractions recalculated.

In addition to the twelve existing factors, the Commission now includes higher LDL cholesterol as a midlife risk factor for dementia, based on new evidence from large cohort studies involving more than 1 million participants and a Mendelian meta-analysis of 27 studies. The Commission furthermore added untreated vision loss as a risk factor, citing evidence from two large meta-analyses. Population attributable fractions of all 14 risk factors have been calculated using data of the Norwegian Trøndelag Health Study (HUNT). According to the updated estimates, 45% of future dementia could potentially be prevented if all 14 risk factors were eliminated, with high midlife LDL cholesterol and untreated vision loss in late life contributing 7% and 2%, respectively.

Jean Georges, Executive Director of Alzheimer Europe, stated: "Alzheimer Europe welcomes this updated report and the hopeful message that nearly half of all future dementia cases could potentially be prevented. The organisation calls on national governments to include these findings in their local public health and risk reduction campaigns. As some of the risk factors originate at the societal level, large-scale policy changes are necessary to seize the full potential of risk mitigation and prevention."

The updated report includes a number of recommended measures to mitigate dementia risk at the population level. In addition to ensuring high-quality education for everyone and taking necessary actions to limit air-pollution exposure, the Commission recommends that hearing aids and eye tests should be made accessible for all. On an individual level, treating depression, hypertension, high midlife LDL cholesterol, obesity and diabetes is recommended, as is the cessation of smoking and the reduction of alcohol consumption, along with engagement in physical, social and cognitive activities.

Although Alzheimer Europe supports the conclusions of the Commission, the organisation also wishes to emphasise the importance of honest, empathetic and compassionate disclosure regarding the status of individual risk factors. Alzheimer Europe's 2023 position paper[1] on this topic underlines the need for risk disclosure to include clear expectations regarding the benefits of lifestyle modification and comprehensive information on how positive lifestyle changes can be put into practice. In addition, Alzheimer Europe emphasises the need to ensure representativeness of research studies to ensure applicability of their findings across diverse populations and groups, supporting the Commission's call for research on dementia risk reduction in under-represented cultures and ethnicities.

https://www.alzheimer-europe.org/sites/default/files/2023-11/2023-09_ae_position_on_disclosure_of_diagnosis.pdf

SCIENCE WATCH

1 JULY

TauRX announces the submission of a UK marketing authorisation application for HMTM

Medicines & Healthcare products Regulatory Agency

Earlier this month, the company TauRX Pharmaceuticals Ltd. announced the submission of a marketing authorisation application (MAA) for its drug hydromethylthionine mesylate (HMTM) to the UK Medicines and Healthcare products Regulatory Agency (MHRA).

HMTM is an oral treatment for mild cognitive impairment and mild to moderate dementia due to Alzheimer's disease. The MAA for HMTM is being reviewed under the Innovative Licencing and Access Pathway, an accelerated regulatory pathway for novel medicines aiming to treat life-threatening or seriously debilitating conditions for which there is a significant patient or public health need. In their press release, the company explained that the MAA is based on evidence from three Phase 3 clinical trials of HMTM, including recently-released data from the LUCIDITY trial. Read the full press release:

https://taurx.com/news-insights/taurx-submits-uk-marketing-authorisation-application-for-hmtm-as-a-treatment-for-alzheimers-disease

2 JULY

FDA grants traditional approval to donanemab for the treatment of early Alzheimer's disease

On 2 July, the US Food and Drug Administration (FDA) granted traditional approval to the anti-amyloid drug, donanemab, for the treatment of early Alzheimer's disease.

This approval means that there are now two disease-modifying treatments available to people with early Alzheimer's disease in the United States.

The approval of donanemab comes after the unanimous endorsement of its clinical efficacy by an FDA Advisory Committee last month. Donanemab, which is marketed by Eli Lilly under the Kisunla® brand name, targets amyloid-beta plaques that build up in the brain during the development of Alzheimer's disease. The FDA approved donanemab based on positive results from TRAILBLAZER-ALZ2, a Phase 3 trial which enrolled 1,736 participants with mild cognitive impairment or mild dementia due to Alzheimer's disease.

Prior to enrolment, TRAILBLAZER-ALZ2 participants received brain scans to confirm the presence of amyloid plaques in the brain, as well as the presence of tau, a predictive biomarker for Alzheimer's disease progression. Trial participants received an intravenous infusion of donanemab or a placebo every four weeks for up to 72 weeks. Participants were switched from donanemab to placebo once they achieved a pre-defined level of amyloid plaque clearance, as measured by PET imaging.

TRAILBLAZER-ALZ2 met its primary endpoint and all secondary endpoints measuring cognitive and functional decline. Among all 1736 participants, treatment with donanemab slowed decline by 22% on the iADRS scale, and 29% on the CDR-SB scale. Pre-specified subgroup analyses showed a greater benefit of donanemab for participants in the earlier stages of Alzheimer's disease, and for those with lower levels of tau in the brain.

Similar to other drugs in this class, the most common adverse events linked to donanemab included amyloid-related imaging abnormalities, also known as ARIA. ARIA most commonly present as temporary swelling in areas of the brain, and may be accompanied by small spots of brain bleeding. While ARIA usually does not cause symptoms, it can rarely cause seizures and other life-threatening symptoms. The incidence of serious ARIA in TRAILBLAZER-ALZ2 was 1.6%. Of note, participants carrying two copies of the ApoE e4 allele had a much higher incidence of ARIA.

Taking these safety concerns into account, the FDA included a black box warning of ARIA in the prescribing information for donanemab. This warning explains that donanemab can cause ARIA, and states that genetic testing for ApoE e4 should be performed prior to initiation of treatment. The prescribing information states that the presence of amyloid beta pathology should be confirmed prior to initiating treatment with donanemab, and that treatment may be stopped based on reduction of amyloid plaques to minimal levels on amyloid PET imaging. Safety monitoring must include regular MRI brain scans to detect ARIA, with an initial scan prior to starting treatment.

Alzheimer Europe welcomes the traditional approval of donanemab by the FDA and is encouraged by the availability of two disease-modifying treatments for early Alzheimer's disease in the United States. While these treatments are only suitable for people who are in the early stages of Alzheimer's disease, they represent an important advance for the Alzheimer's disease community, as therapies that can slow cognitive and functional decline.

European patients cannot yet access donanemab, as the drug is currently undergoing a full evaluation by the European Medicines Agency. Decisions by European regulators are expected later this year, and Alzheimer Europe hopes for a similarly positive outcome at European level.

Read the full FDA announcement, here:
https://www.fda.gov/drugs/news-events-human-drugs/fda-approves-treatment-adults-alzheimers-disease

Find the prescribing information, here:
https://www.accessdata.fda.gov/drugsatfda_docs/label/2024/761248s000lbl.pdf

3 JULY

2024 New study suggests that inflammation in early adulthood may be tied to midlife cognition

Higher levels of inflammation, our immune system's response to varied injuries and infections, in older adults have previously proved to be associated with an increased risk of dementia and cognitive decline. However, the specific link between inflammation in early adulthood and cognition in midlife is not yet clear.

In a new study published in Neurology Journal, a team of researchers led by Dr Amber L. Bahorik from the University of California, San Francisco (US) investigated the association between inflammation in early adulthood and lower cognitive abilities in midlife. This research followed 2,364 participants (mean age 50.2 years, 55% female and 57% white) of the CARDIA (Coronary Artery Risk Development in Young Adults) study, which investigated factors in young adulthood that may be tied to cardiovascular disease decades later in people initially healthy and aged between 18 and 30 years at enrolment. The participants of this study were tested four times (in years 7, 15, 20, and 25) over a period of 18 years for the C-reactive protein (CRP), an inflammatory marker. Five years after the last CRP measurement, cognition was assessed through a battery of tests evaluating verbal memory, processing speed, executive function, fluency, and global cognition. Researchers identified three CRP trajectories, corresponding to lower, moderate, or high CRP (i.e. inflammation) levels which remained mostly stable or increased over the 18 year-period this marker was measured. Compared to participants with lower stable levels of CRP, those with higher and moderate/increasing levels had higher probabilities of poor cognitive performance,

specifically observed for processing speed and executive function.
Although this study shows some limitations, such as the use of CRP as the only inflammatory marker, it seems that there may be an effect of inflammation on cognitive ageing starting in early adulthood. More research is needed to confirm this link and to develop possible strategies to delay cognitive impairment through the inflammatory processes early in life.

https://www.neurology.org/doi/10.1212/WNL.0000000000209526

4 JULY

Artificial Intelligence based diagnosis support tool improves diagnostic confidence in neurologist assessments

On 4 July, a team of USA and China based scientists published a paper about an Artificial Intelligence (AI) based diagnosis support framework for dementia in the journal Nature Medicine. The article is focused on the development and validation of the AI-based tool for diagnosing different causes of dementia using multimodal data. The researchers used nine datasets, comprising 51,269 participants altogether. The development of the multimodal Machine Learning (ML) framework was based on data modalities from these data sets including demographics, individual and family medical history, medication use, neuropsychological assessments, functional evaluations, and multimodal neuroimaging. The tool classified individuals with normal cognition, mild cognitive impairment, and dementia. Additionally, it could differentiate between Alzheimer's disease (AD), Lewy body dementia (LBD), vascular dementia (VD), prion disease (PRD), frontotemporal lobar degeneration (FTD), normal pressure hydrocephalus (NPH), systemic and environmental factors (SEF), psychiatric conditions (PSY), traumatic brain injury (TBI), and other dementia conditions (ODE).
Reporting on the model performance, the team reported that it achieved a microaveraged area under the receiver operating characteristic curve (AUROC) of 0.94, which indicates a high accuracy in classifying individuals with normal cognition, mild cognitive impairment, and dementia. Furthermore, they indicate that it was able to achieve a microaveraged AUROC of 0.96 in differentiating dementia etiologies. With regards to mixed dementia cases, it only mean AUROC of 0.78 for two co-occurring pathologies. The researchers were also interested in how well the model could improve neurologist assessments. They therefore investigated its predictions in a subset of 100 cases, and found that it exceeded neurologist-only evaluations by 26.25%. These predictions were aligned with biomarker evidence as well as *post mortem* findings.
The full open access article can be read here: https://www.nature.com/articles/s41591-024-03118-z

10 JULY

A Longitudinal Study on Neuroticism and Its Association with Dementia

Yaqing Gao, Najaf Amin, Cornelia van Duijn and Thomas Littlejohns dove into the relationship of neuroticism (i.e. a personality trait that describes a person with a general tendency towards negative emotions e.g. irritability, worry or self-consciousness) with incident dementia, neuroimaging outcomes and cognitive function. In their longitudinal study, the researchers used data from UK Biobank participants (n=174164) with a follow-up period of up to 15 years. The data used included neuroticism scores, genetic data, health and lifestyle information, neuroimaging outcomes, and cognitive function data.
The research team's findings suggest an association between neuroticism and dementia. Higher neuroticism was associated with an 11% increased risk of incident dementia, irrespective of the genetic predisposition to dementia. Furthermore, the researchers found that people who scored higher in neuroticism had a 15% higher risk of vascular dementia. Neuroticism was associated with higher cerebrovascular pathology and lower grey matter volume, suggesting a potential physical manifestation of the personality trait within the brain. The association of neuroticism with all-cause dementia and vascular dementia was found to be mediated by mental and vascular conditions. Their findings highlight the complex interplay between personality traits, mental health, vascular health, and dementia and the need for further research.
The study was published in the journal Alzheimer's & Dementia. To learn more about the paper, follow the link:

https://pubmed.ncbi.nlm.nih.gov/38984680/

11 JULY

New prediction models from the Amsterdam Alzheimer Centre provide personalised trajectories for cognitive decline

A new study, published today in the Neurology journal, describes prediction models which can provide personalised information on future cognitive decline for patients with early Alzheimer's disease. According to the study authors, these models could also inform discussions between doctors and patients on whether or not to start treatment with medicines including disease-modifying therapies such as lecanemab and donanemab.

Led by Pieter van der Veere and Wiesje van der Flier of Amsterdam University Medical Center, the study used data from the Amsterdam Dementia Cohort to construct prediction models of cognitive decline in amyloid-positive patients with mild cognitive impairment (MCI) or mild dementia due to Alzheimer's disease. In total, 961 participants were included, 310 of whom had MCI, and 651 of whom had mild dementia. The main cognitive outcome for the study was the MMSE score, a measurement of cognitive function that assesses attention, memory, language, ability to follow instructions, and orientation. The prediction models integrated many different data sources, including cognitive test scores, amyloid positivity (in cerebrospinal fluid or PET scans) and MRI measurements of brain volume and structure. Statistical models were used to calculate predicted decline patterns for individuals with MCI or mild dementia, with validation performed using data from the US-based Alzheimer's Disease Neuroimaging Initiative (ADNI) cohort. Finally, the models were embedded in a prototype *shiny* app and calculator, for ease of use by clinicians.

The resulting prediction models could be used to forecast the rate and speed of cognitive decline, predicting the time to reach a certain score on the MMSE or RAVLT cognitive tests. According to the authors, the overall performance of both models showed that variation between individual trajectories could be explained by factors such as age, sex, and baseline cognitive test score. They also highlighted the relatively small number of variables required, and the simplicity of the statistical modelling approach, which means that these models could be easier to apply in real-world clinical practice. Read the full article in Neurology:

https://www.neurology.org/doi/full/10.1212/WNL.0000000000209605

18 JULY

Physiological stress may weaken protective benefits of cognitive reserve

The ability to compensate for brain changes associated with dementia by the use of functional brain processes has been alluded to as cognitive reserve. First introduced by Neuropsychologist Yaakov Stern in the early 2000s, this heuristic construct is based on the observation that people with similar pathological burden showed differences in their cognitive functioning. As compared to brain reserve (the neuronal "capital" of a person), cognitive reserve is thought of as malleable by experience. In particular, factors such as education, occupation or leisure activity engagement have been proposed as "proxies" (i.e. correlates) of cognitive reserve.

Stress has emerged as a potential modifiable risk factor for cognitive decline and dementia. In particular, both psychological and physiological measures of stress have been associated with faster dementia progression and a higher risk for Alzheimer's disease. The link between stress and cognitive reserve in relation to cognition, however, is unclear. In a recent study published in the journal Alzheimer's and Dementia, a group of researchers based at the Karolinska Institutet in Stockholm (Sweden) has examined whether a composite measure of cognitive reserve is associated with cognitive functioning, and whether subjective and objective measures of stress explain these associations.

In particular, 113 participants of the Cortisol and Stress in Alzheimer's disease cohort study (Co-STAR) rated subjective stress levels and provided measures of saliva cortisol (thought of as reflective of physiological stress). Information about education, occupation, level of social contact and leisure activity engagement was used to derive a composite measure of cognitive reserve, the cognitive reserve index (CRI). Performance on neuropsychological tests of memory, processing speed, working memory and perceptual reasoning was assessed at baseline and throughout three years of follow-up. Furthermore, samples of cerebrospinal fluid were collected to assess levels of Alzheimer's disease biomarkers.

The authors found that higher CRI scores were associated with better cognition at baseline and follow-up. Controlling for salivary cortisol (but not the subjective stress measure) attenuated observed associations. CRI scores were not associated with AD biomarker levels. These findings suggest that stress may weaken the protective benefits of cognitive reserve and highlight the importance of stress reduction practices for promoting good cognitive functioning.

https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.13866

22 JULY

A new study provides insight into how the incidence, prevalence of dementia and associated risk factors have evolved over time

A recent article, published in the Lancet Public Health, analysed trends over time regarding the incidence and prevalence of dementia, as well as its risk factors.

Prevalence refers to the number of cases of dementia in a specific population at a particular time point or over a specified period of time while incidence refers to the rate of new cases of dementia occurring in a specific population over a particular period.

The study by Karen de Sola-Smith and others is a systemic review, which included cohort studies that adjusted their data for age to take into account population ageing. Most existing cohort studies included in the review were from high-income areas such as Europe, Japan and the United States.

The review found that the incidence of dementia is decreasing in most high-income countries, and the overall prevalence is either stable or declining. However, there were some differences among regions, for example, no decline in prevalence was found among farmers in France.

The authors explain that this general decrease in dementia incidence has been accompanied by an increase in rates of education and a decline in smoking rates, across high-income countries. Their calculations show an association between reduced smoking, better education and the decrease in dementia incidence. They also found that over time, diabetes, hypertension and obesity have contributed more (in relative terms) to dementia risk, with hypertension having the largest effect in most study populations.

The authors postulate that compulsory education policies and measures to discourage smoking have beneficially impacted the incidence and prevalence of dementia. However, they also highlight a growing concern about cardiovascular health issues and their link to dementia risk.

Some limitations of this study include the lack of ethnically diverse study populations and the fact that the review focuses mostly on high-income countries. Low-income countries may exhibit different trends regarding dementia. Additionally, the studies included in the review are at least ten years old, making it hard to know how trends may have changed recently.

https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(24)00120-8/fulltext

26 JULY

Alzheimer Europe regrets that negative European Medicines Agency opinion on lecanemab may deprive Europeans with Alzheimer's disease from medicines available in the US and elsewhere

On 26 July 2024, the Committee for Medicinal Products for Human use (CHMP) of the European Medicines Agency (EMA) issued a negative opinion on the marketing authorisation application of Eisai for lecanemab for the treatment of early Alzheimer's disease (mild cognitive impairment or mild dementia due to Alzheimer's disease). In its opinion, the CHMP found that the benefits of treatment are not large enough to outweigh the risks associated with lecanemab.

Alzheimer Europe regrets this negative decision by the CHMP. People living with Alzheimer's disease and their families had high hopes and expectations about the introduction of new treatment options in Europe. The US Food and Drug Administration (FDA) granted traditional approval to lecanemab in July 2023, after unanimous endorsement of its clinical efficacy by an advisory committee. Key US payers including Medicare agreed to provide broad coverage for lecanemab, for eligible patients with early Alzheimer's disease. Lecanemab has also been approved for treatment of early Alzheimer's disease by regulatory authorities in Japan (25 September 2023), China (3 January), South Korea (27 May), Hong Kong (11 July) and Israel (12 July).

The refusal by the EMA means that Europeans with early Alzheimer's disease will not have access to treatment options that are available to patients in the US and other countries. The EMA decision will affect people with Alzheimer's disease in the European Union, Iceland, Liechtenstein and Norway. Separate applications are pending with Swissmedic and the Medicines and Healthcare products Regulatory Agency for patients in Switzerland and the United Kingdom and Alzheimer Europe hopes that these regulatory agencies will come to a positive decision.

After several high-profile failures, recent clinical trials of lecanemab and other anti-amyloid drugs had marked a turning point for the field. The global Phase 3 Clarity AD study met all

its primary and secondary endpoints, demonstrating a 27% reduction in clinical decline after 18 months of lecanemab treatment on the global cognitive and functional scale, CDR-SB. Side effects including brain swelling and microbleeds (termed "amyloid-related imaging abnormalities" or ARIA) were relatively common, with severe symptoms reported in 0.7% of trial participants. To address these safety concerns, the FDA included a black box warning of ARIA in the prescribing information for lecanemab, stating that genetic testing for ApoEε4, a risk factor for ARIA, should be performed prior to initiating treatment. Regular monitoring with MRI scans was also recommended by the US regulator.

Alzheimer Europe welcomed the traditional approval of lecanemab by the FDA, as well as the considered approach to identify patients most likely to benefit from treatment and exclude those at greatest risk of harmful side-effects. The Alzheimer Europe position paper on anti-amyloid therapies for Alzheimer's disease underlined the importance of equitable access to these innovative treatments, with inclusive communications allowing patients to weigh the potential slowing of clinical decline against the side effects, costs and burdens of treatment.

The organisation is deeply disappointed that people with Alzheimer's disease in Europe will now be excluded from access to lecanemab, without the possibility to make individual choices based on a personal analysis of treatment risks and benefits. Alzheimer Europe hopes that real-world findings from the FDA-mandated patient registry, or from ongoing trials of lecanemab, will provide the necessary scientific evidence for EU regulators to reconsider their position.

Jean Georges, the Executive Director of Alzheimer Europe stated: "We understand that lecanemab is not a wonder drug for all people with Alzheimer's disease. However, the existence of a first disease-modifying drug, with a novel mode of action, constitutes an undeniable, major advance for a field which has been waiting for new medicines for over two decades. Lecanemab has demonstrated effects on disease progression, as well as on secondary endpoints such as quality of life and caregiver burden. Instead of excluding all patients from this new treatment due to safety concerns, we would have hoped that the European Medicines Agency would authorise the medicine with a clear risk management plan to address potential side effects."

The negative opinion on the lecanemab marketing authorisation approval by the EMA represents a major setback for the Alzheimer's disease community in Europe. However, Alzheimer Europe remains encouraged by the number of companies and organisations continuing to invest in research and the new treatment options currently being developed. The organisation therefore reiterates its call for continued research into other treatment options, including symptomatic therapies and treatments for people in more advanced stages of dementia.

In addition, Alzheimer Europe remains committed to a holistic approach to Alzheimer's disease and other types of dementia where innovative new treatments are included alongside counselling, support and adequate care of people with dementia and their carers throughout the disease process. You can find details of the CHMP recommendation here:
https://www.ema.europa.eu/en/medicines/human/EPAR/leqembi
and the Eisai press release here:
https://www.eisai.com/news/2024/news202455.html

1 AUGUST

Our member organisations react to the EMA opinion on lecanemab

On 26 July 2024, the Committee for Medicinal Products for Human use (CHMP) of the European Medicines Agency (EMA) issued a negative opinion on the marketing authorisation application of Eisai for lecanemab for the treatment of early Alzheimer's disease (mild cognitive impairment or mild dementia due to Alzheimer's disease). In its opinion, the CHMP found that the benefits of treatment are not large enough to outweigh the risks associated with lecanemab, an anti-amyloid drug that has been approved by regulators in the US, Japan, China, South Korea, Hong Kong, and Israel.

The EMA decision will affect people with Alzheimer's disease in the European Union, Iceland, Liechtenstein and Norway. Separate applications are pending with Swissmedic and the Medicines and Healthcare products Regulatory Agency, for patients in Switzerland and the United Kingdom. Read some of the reactions to the EMA decision from our member associations, by clicking the links below.

- Czechia (Česká alzheimerovská společnost): https://www.alzheimer.cz/clanky/novinky-cals/alzheimer-europe-lituje-rozhodnuti-ema/
- Denmark (Alzheimerforeningen): https://www.alzheimer.dk/nyheder/2024/medicinen-lecanemab-risikerer-ikke-at-blive-godkendt-i-eu/
- France (France Alzheimer) https://www.francealzheimer.org/leqembi-commercialisation-refusee-en-europe/
- Germany (Deutsche Alzheimer Gesellschaft): https://www.deutsche-alzheimer.de/artikel/alzheimer-medikament-leqembi-nicht-zugelassen-deutsche-alzheimer-gesellschaft-zur-entscheidung-der-europaeischen-arzneimittel-agentur-ema
- Ireland (Alzheimer's Society of Ireland) https://alzheimer.ie/creating-change/awareness-raising/statements/
- Netherlands (Alzheimer Nederland) https://www.alzheimer-nederland.nl/nieuws/alzheimermedicijn-lecanemab-niet-beschikbaar-in-europa
- Poland (Polskie Stowarzyszenie Pomocy Osobom z Chorobą Alzheimera): https://alzheimer-waw.pl/komunikat-dla-mediow-aux-medias-medien-mitteilung/

- Spain (Confederación Española de Alzheimer) https://www.ceafa.es/es/que-comunicamos/notas-de-prensa-y-comunicados/ceafa-se-suma-a-la-postura-de-alzheimer-europe-y-lamenta-que-la-opinion-negativa-de-la-ema-sobre-el-lecanemab-prive-a-los-europeos-con-enfermedad-de-alzheimer-de-los-medicamentos-disponibles-en-estados-unidos-y-en-otros-paises
- Switzerland (Alzheimer Schweiz Suisse Svizzera): https://www.alzheimer-schweiz.ch/fr/medias/article/lema-soppose-a-la-mise-sur-le-marche-du-lecanemab
- Sweden (Demensforbundet): https://www.demensforbundet.se/ema-europeiska-lakemedelsmyndigheten-avslar-den-nya-bromsmedicinen-mot-alzheimer-lecanemab-leqembi-i-europa/
- United Kingdom (England, Wales and Northern Ireland; the Alzheimer's Society): https://www.alzheimers.org.uk/news/2024-07-26/alzheimers-society-responds-eus-rejection-lecanemab

11 AUGUST

European Alzheimer's Disease Consortium (EADC) publishes a new position statement

On 11 August, academic clinicians from the European Alzheimer's Disease Consortium (EADC) discussed the critical relevance of introducing β-amyloid-targeting antibody treatments for Alzheimer's disease (AD) into clinical care.

The paper begins by noting the increasing societal burden of dementia before addressing the new treatments currently in development, including anti-amyloid therapies. The target population of these recent clinical trials includes people in the early stages of AD (mild cognitive impairment and mild dementia due to AD). Each drug works slightly differently, by targeting β-amyloid at a different stage of plaque formation.

Aducanumab was the first antibody to show the association of amyloid lowering with slowing of symptomatic decline in a phase 2 clinical trial. Lecanemab was the first antibody with demonstration of clinical efficacy in a phase 3 study. The EADC stressed that while lecanemab has been approved by regulatory authorities in China, Hong Kong, Israel, Japan, South Korea, the United Arab Emirates and the US, the European Medicines Agency (EMA) issued a negative opinion on 26 July 2024. In its opinion, the Committee for Medicinal Products for Human Use (CHMP) of the EMA found that the benefits of treatment are not large enough to outweigh the risks associated with lecanemab. Donanemab, the second amyloid-targeting antibody with proof of efficacy has been fully approved by the FDA in July 2024.

The paper highlights the outcomes of clinical trials investigating lecanemab and donanemab, as well as the clinical meaningfulness of the observed effects. It also addresses the side effects of β-amyloid-targeting antibodies, barriers to access and the costs associated with treatment.

The position statement calls for significant improvements in the treatment of AD. Regarding β-amyloid-targeting antibodies, their effects are considered as meaningful, with potential side effects deemed manageable. However, it is assumed that only a fraction of all early AD patients will eventually receive treatment due to narrow eligibility criteria and barriers of access.

In conclusion, the EADC investigators strongly endorse the use of these new compound in clinical practice for selected patients with treatment documentation in registries. They pointed out that this represents a critical step in advancing AD treatment and in shaping the health care systems for the new area of molecular-targeted treatment for neurodegenerative diseases. Read the EADC's full position statement, here: https://doi.org/10.14283/jpad.2024.153

22 AUGUST

Alzheimer Europe welcomes the approval of lecanemab by the UK's Medicines and Healthcare products Regulatory Agency

On 22 August 2024, the UK Medicines and Healthcare products Regulatory Agency (MHRA) announced the approval of lecanemab for the treatment of early Alzheimer's disease (mild cognitive impairment and mild dementia due to Alzheimer's disease). The approval is based on data from the Phase 3 Clarity-AD study, which demonstrated a 27% reduction in clinical decline after 18 months of lecanemab treatment on the global cognitive and functional scale, CDR-SB. In its press release, the MHRA found that lecanemab met regulatory standards for safety, quality and effectiveness. The National Institute for Health and Care Excellence (NICE) has also issued draft guidance on the use of lecanemab, stating that its clinical benefits are too small to justify the costs of the drug to the National Health Service (NHS). A public consultation is ongoing, with a final recommendation on coverage expected towards the end of 2024.

Alzheimer Europe welcomes the positive decision by the MHRA, which represents an important advance for the Alzheimer's disease community in the UK and hopes that NICE will recommend NHS coverage for lecanemab in its final decision.

The US Food and Drug Administration (FDA) granted traditional approval to lecanemab in July 2023, after unanimous endorsement of its clinical efficacy by an advisory committee. Lecanemab has also been approved for treatment of early Alzheimer's disease by regulatory authorities in Japan, China, South Korea, Hong Kong, Israel and the United Arab Emirates. The positive recommendation from the MHRA means that people with Alzheimer's disease in the UK will also have access to treatment options that are available to patients in the US and other countries. Alzheimer Europe reiterates its disappointment about the negative opinion of the European Medicines Agency on 26 July, which may exclude Europeans from accessing lecanemab, worsening inequities in access to novel treatments for Alzheimer's disease.

Alzheimer Europe appreciates and supports the considered approach that the MHRA has taken to manage the risks associated with lecanemab treatment and exclude those most likely to develop amyloid-related imaging abnormalities (ARIA), potentially harmful side-effects which are linked to brain swelling and micro-bleeds. The MHRA has limited the indication for lecanemab to exclude people with two copies of the ApoE4 gene, those on antithrombotic medicines and people who have been diagnosed with cerebral amyloid angiopathy, all of whom are at greater risk of developing ARIA. A controlled post-authorisation safety study will be conducted to investigate the safety and benefit-risk profile of lecanemab in routine clinical practice.

The FDA adopted a similar approach to manage risk, including a black box warning of ARIA in the prescribing information for lecanemab, stating that genetic testing for ApoE4, should be performed prior to initiating treatment. In adopting this approach, regulators enable patients to make individual choices based on a personal analysis of treatment benefits and risks. To support decision-making, Alzheimer Europe emphasises the importance of accessible, inclusive communication of the benefits, risks, costs and logistical burdens of treatment, as outlined in the organisation's position paper[1] on anti-amyloid therapies for Alzheimer's disease.

Jean Georges, the Executive Director of Alzheimer Europe stated: "We welcome the approval of lecanemab by the MHRA, enabling people with early Alzheimer's disease in the UK to access a disease-modifying drug that is available in many other countries. We now look to health authorities to ensure access to lecanemab in the UK, and to prepare the healthcare system for delivering timely diagnoses for people with early Alzheimer's disease, together with efficient safety monitoring for potential side effects."

Approval of the lecanemab marketing authorisation application by the MHRA is a major step forward for people affected by Alzheimer's disease in the UK. While we regret the negative opinion of the EMA, Alzheimer Europe hopes that re-examination of the opinion will result in an outcome that enables more Europeans living with early Alzheimer's disease to access lecanemab in the future. In addition, the organisation remains committed to a holistic approach to Alzheimer's disease and other types of dementia where innovative new treatments are included alongside counselling, support and adequate care of people with dementia and their carers throughout the disease process.

Read the MHRA press release: https://www.gov.uk/government/news/lecanemab-licensed-for-adult-patients-in-the-early-stages-of-alzheimers-disease

Read the NICE press release: https://www.nice.org.uk/news/articles/benefits-of-new-alzheimer-s-treatment-lecanemab-are-too-small-to-justify-the-cost-to-the-nhs

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[1] https://www.alzheimer-europe.org/policy/positions/alzheimer-europe-position-anti-amyloid-therapies

Declaration of interests: Alzheimer Europe had an audited income of EUR 2,404,596 in 2023. Sponsorship by the developing companies of lecanemab (Eisai and Biogen) amounted to EUR 37,500 or 1.56% of total income. Sponsorship by pharmaceutical companies is only accepted in accordance with the organisation's Sponsorship guidelines and, in line with the European Medicines Agency criteria for patient organisations, declared in full transparency on the Alzheimer Europe website: https://www.alzheimer-europe.org/about-us/governance/finances/alzheimer-europe-sponsors

30 AUGUST

LuMind IDSC and NTG on Intellectual Disabilities and Dementia Practices invite clinicians and researchers to participate in a survey on Down syndrome-associated AD

The LuMind IDSC Foundation and the National Task Group (NTG) on Intellectual Disabilities and Dementia Practices are US-based, non-profit organisations advocating for services and supports for people with intellectual disability and their families who are affected by Alzheimer's disease (AD) and dementias.

They are currently working to build consensus around the clinical stages of Down syndrome-associated Alzheimer's Disease (DS-AD), involving a survey to consolidate clinical perspectives on the staging of DS-AD, specifically focusing on

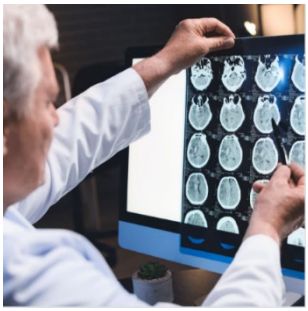
Mild Cognitive Impairment in Down Syndrome (MCI-DS) and DS-AD Dementia.
This survey is part of an ongoing project that seeks to gather broad insights from clinicians and researchers across various specialties and industry. Responses will help achieve consensus on how these conditions present in clinical practice and will inform future research, clinical practice, and policy decisions.
The survey should take around 30-45 minutes to complete, with a deadline of 10 September. The survey can be accessed here:

https://www.surveymonkey.com/r/DSADSurvey

30 AUGUST

Recent data shows that the number of people diagnosed with dementia has reached a record high

In the past year, a record number of people in England have been diagnosed with dementia, according to NHS data. As of June, 487,432 people had a diagnosis of dementia, the highest number ever recorded. Despite this, the diagnosis rate is still below the pre-pandemic level, with 65% of estimated cases being diagnosed, short of the NHS's 66.7% target last achieved in 2019. England has one of the highest dementia diagnosis rates globally, with high-income countries typically diagnosing only 20-50% of cases. This success is attributed to proactive efforts by specialist nursing staff in care homes.



Dr Jeremy Isaacs, NHS England's national clinical director for dementia, praised the progress but acknowledged more work is needed. The number of people having their dementia medication reviewed has also risen, showing improved follow-up care.
https://www.england.nhs.uk/2024/07/dementia-diagnoses-in-england-at-record-high/#:~:text=Latest%20data%20shows%20a%20record,a%20form%20of%20the%20disease

MEMBERS' NEWS

11 AUGUST

The Alzheimer Society of Ireland pays tribute to Ronan Smith, a leading dementia advocate and former Chair of the Irish Dementia Working Group, who has passed away

It was with deep sadness that The Alzheimer Society of Ireland (The ASI) heard, on 11 August, of the passing of Ronan Smith, a leading dementia advocate and former Chair of the Irish Dementia Working Group (IDWG) Steering Committee and The ASI Board of Directors. Ronan was highly respected by all the staff and volunteer advocates. He was a real gentleman and had a rare gift of being a terrific listener and conversationalist. Over many years, The ASI had the privilege to engage with Ronan as a leading advocate for the voice of people living with dementia.
The ASI is grateful to Ronan for his work speaking publicly about living with dementia, he was a pioneer and an innovator and always encouraged new and diverse voices. Ronan's choice to be open about dementia broke down so many barriers and opened so much understanding of dementia in Irish society. Ronan's passing has been deeply felt by everyone at The ASI, the board members, staff, volunteers and fellow advocates. Our thoughts and prayers are with Ronan's family, especially Miriam, Hannah and Loughlin. May Ronan rest in peace.

20 AUGUST

The Alzheimer Society of Ireland launches pre-budget submission 2025 #EqualDementiaSupports

On 20 August, The Alzheimer Society of Ireland (The ASI) made a Pre-Budget Submission (PBS) 'Equal Dementia Supports – Building on Momentum in 2025' to the Irish Government for funding for the year ahead. With a strong PBS grounded in the lived experience of dementia, the event saw incredible cross-party support, with 55 elected representatives in attendance and a visit from the Minister of State for Mental Health and Older People, Mary Butler. The event garnered national media coverage.
The ASI is calling on the Government to improve equity of access to dementia supports and services across Ireland. Increased investment is needed in community services, acute

services, mental health supports, social protection, dementia research and the dementia workforce.

The PBS took place following months of robust consultation with stakeholders, including people with dementia and those who support them, The ASI team including operations, dementia advisers, the Senior Management Team, the Irish Dementia Working Group and the Dementia Carers Campaign Network. Find out more about The Alzheimer Society of Ireland Pre-Budget Submission, here.

Pictured: Mary McIntyre, Irish Dementia Working Group member, and her husband Tony, Dementia Carers Campaign Network member, attend the launch of The Alzheimer Society of Ireland Pre-Budget Submission 2025

27 AUGUST

Alzheimer Bulgaria created The Social Store to empower older people through “Woollen Therapy”

Alzheimer Bulgaria is dedicated to bringing better quality of life to people with dementia and their relatives and caregivers. Thus they created The Social Store, a social enterprise aimed at supporting elderly individuals in Bulgaria by providing them with an opportunity to create and sell handcrafted items or “hobby-products.”

Alzheimer Bulgaria focuses on activities like knitting because this activity is more than just a pastime. Knitting is a social phenomenon that many refer to as “woollen therapy.” Knitting improves coordination and motor skills, reduces stress, enhances mood, and boosts self-esteem. It exercises concentration, spatial navigation, visual processing and memory retention. Daily knitting can help preserve brain function.

The Social Store provides a platform for elderly individuals to create and sell their handmade products. These items are a reflection of their hobbies and sometimes passions that many of the elderly participants have longed to explore throughout their lives but never had the chance to pursue until now. By engaging elderly people in activities like knitting or any handmade product activity, Alzheimer Bulgaria helps alleviate symptoms of depression, anxiety, and cognitive deterioration, while also improving participants’ sense of self-worth and social interaction.

The Social Store strives to create a supportive community where elderly people can remain active and continue to contribute to society. The goal is to promote therapeutic activities, non-medical interventions like the hobby-products and bring some new services like art therapy, dog therapy and music therapy. For more information: https://socialstore.bg/en/shop/

27 AUGUST

The Panhellenic Federation of Alzheimer’s Disease & Related Disorders completes the piloting phase of its CURATE-D project

The European Erasmus+ project ‘A Game-based methodology for empowering dementia-friendly communities and equal access to Culture for people with Dementia (CURATE-D)’, aiming to promote equal opportunities, accessibility and social inclusion for people with dementia in cultural experiences, has successfully concluded the piloting phase with training workshops taking place in Greece, Spain and Ireland. The organisations in the consortium, working with professional carers of people with dementia and professionals working in the cultural field, implemented piloting workshops based on the methodology and tools generated in WP3 and practiced them in real conditions. The consortium has collected its feedback and will develop a report on final considerations on the methodology of the CURATE-D project. This will be helpful material for other organisations that want to apply the methodology and tools in their context.

In Thessaloniki, Greece, The Panhellenic Federation of Alzheimer’s Disease & Related Disorders, in collaboration with the coordinator of the project, Challedu, has delivered two different pilot training workshops. On 15-16 June, the first took place with the participation of professionals working in the dementia field. On 20-21 June, the second took place in the Archaeological Museum of Thessaloniki with the participation of professionals working in the cultural field. During the pilots, they tested the learning training guide for professional carers of people with dementia, the learning training guide for staff working in the cultural field and the serious game of CURATE-

D, using an interactive and experiential game-based learning method.
After being finalised based on the feedback from professionals during the piloting, all the aforementioned materials will be freely available on the project's website: https://curate-d.eu/
The results of CURATE-D are being developed collaboratively since the beginning of the project by the project partners: Challedu, the coordinator; Panhellenic Federation of Alzheimer's Disease and Related Disorders, Thessaloniki and Herakleidon Museum of Athens (all three located in Greece); The Gaiety School of Acting (GSA) of The National Theatre School of Dublin, Ireland; and the Association of Relatives of Alzheimer (AFAV) of Valencia, Spain.

27 AUGUST

The Alzheimer Society of Ireland introduces its new research webinar series and welcomes its Dementia Research Advisory Team to Twitter/X

As World Alzheimer's Month approaches, The Alzheimer Society of Ireland (The ASI) introduces its new dementia dialogues: Breaking down research webinar series 2024. The series will host a one-hour webinar each month from September to December, covering different research topics of interest to people with dementia, family carers, supporters, and the wider public. Topics will include walking reminiscence interventions, disease-modifying therapies, harnessing community information and support for people living with young-onset dementia and genetics and dementia.
The first webinar will take place on 4 September and The ASI will be joined by Prof. Richard Roche from Maynooth University, Co. Kildare. If you are interested in registering, you can click here
On 12 September, The ASI will co-host a one-day conference with Dementia Research Network Ireland which will share insights into the science behind dementia. This event will also be streamed live online. You can register here for tickets.
In other news, The ASI is proud to welcome the Dementia Research Advisory Team (DRAT) - its dedicated Person Public Involvement (PPI) panel to X (formerly known as Twitter). The DRAT members are people living with dementia and family caregivers committed to affecting positive and meaningful change in the research space. The members collaborate with researchers in a PPI capacity to improve the relevancy and efficacy of dementia research. By drawing on their personal expertise, the DRAT members ensure the lived experience of the condition is kept central to the research process. Consistently demonstrating PPI leadership and innovation, the members are excited to showcase their many collaborations and engage with the research and PPI community via their new social media presence. To keep up to date with the work of the

Dementia Research Advisory Team and to learn more about PPI, please follow **@DRAT_ASI**

Pictured: from left to right, Dr Laura O'Philbin, Ciara O'Reilly, Dr Diane O'Doherty of The ASI's Research & Policy Team and Cormac Cahill, Head of Advocacy, Research & Public Affairs at The ASI.

27 AUGUST

A Danish project collaboration, "United around Dementia", aims to increase awareness on dementia

On 27 August, the first part of a new documentary from the Danish Broadcasting Corporation, DR, appeared on television. The series, "The Dementia Choir", follows 17 people with dementia on their shared journey through ups and downs, getting ready for a big concert.
The TV concept is well known from Norway, where it brought much attention to dementia. To harness the expected momentum, the Danish Alzheimer Association, together with DR, House of Song (Danish cultural institution with focus on broadening singing activities across Denmark), and the University of Aalborg joined forces in collaboration on the project "United around Dementia" (The Centre for Documentation and Research in music therapy at the University of Aalborg has developed training material for the courses in dementia-friendly singing).
The project, which is funded by the Lundbeck Foundation, not only focuses on broadening awareness of dementia and risk reduction, it also aims at inspiring people with dementia to join activities, such as singing in a choir, which both stimulate the brain and support social interaction. This is where the collaboration between the different parties shows its strength.

While DR sets extensive editorial focus on dementia across its platforms, covering everything from podcasts, radio and news articles, to sing along-videos for use at home, the other parties focus on converting knowledge into action.
Together with experts in music therapy from University of Aalborg, House of Song provides dementia choir and singing courses in their facilities across all of Denmark, as well as online. The first courses target choir conductors, the latter target professionals working in nursing homes and activity centres. The goal is to help professionals start dementia choirs across the country and increase singing activities in nursing homes.
The Danish Alzheimer Association, which also heads the project, puts full attention on risk reduction and knowledge sharing online – among other things with a series of expert webinars, the option to test your brain health, and a digital calendar, funded by BioArctic, gathering local dementia activities across all of Denmark in one single overview. The project lays a solid foundation for new risk reduction initiatives to come, and the Danish Alzheimer Association welcomes future collaborations.

27 AUGUST

Alzheimer Iceland participates in the Reykjavík Marathon

Alzheimer Iceland is a yearly participant in the Reykjavík Marathon. Runners in the marathon can choose a charity to run for. Alzheimer Iceland has been fortunate to receive big donations through the years. The runners are provided with a t-shirt and a headband and are supported throughout the course.
The team of dedicated runners, including people living with dementia, carers, volunteers, staff, and supporters, are taking on the challenge to raise crucial funds and awareness for Alzheimer Iceland. This year, a service centre for people in the early stages of dementia called Seiglan (which means “resilience”) also participated. This group of people living with dementia who have been training for the last months are motivated by the cause they are running for and they make sure they are physically active.
The marathon not only offers a platform to raise money and awareness but also provides an opportunity to connect with supporters, share stories, and build a sense of community. Alzheimer Iceland is extremely grateful for the outpouring of support which enables them to continue their work towards a better future for people living with dementia and their families. Go team Seiglan!

27 AUGUST

Greek Alzheimer Association recently hosted third transnational project meeting of De-Sign Erasmus+ project in Thessaloniki

On 27-28 June, the Greek Alzheimer Association hosted the third transnational project meeting of the De-Sign Erasmus+ project in Thessaloniki. The objectives of the De-Sign project focus on promoting the full participation and social inclusion of deaf people by creating opportunities for equal access to dementia health services in Austria, Germany, Greece, and Italy by informing different groups of people involving deaf people as well as their family members, health professionals and the public.
Moreover, a second objective is to adapt the first Cognitive Screening Test (CST), initially created by Atkinson *et al.* (2015), into the sign languages of Austria and Greece. During the meeting, participants presented their work about the raising awareness training material delivered in deaf communities in their countries, whereas the CST in Austrian and Greek sign languages was also presented through a digital platform. The forthcoming year training about the use of the platform will be also delivered among health professionals, while normative data about the first CST in Austrian and Greek sign languages will be published to facilitate dementia detection in deaf older adults.

27 AUGUST

Alzheimer Association of Larissa (Greece) helps people with dementia overcome heat stress with floral scents

The constant heatwaves have increased the anxiety of people with dementia, leading them to seek pleasant and relaxing activities. However, in order to manage heat stress and to strengthen the mental and physical strength of the beneficiaries, the Alzheimer Association of Larissa carried out an activity with aromatic summer flowers.

The flowers used were basil, petunias, carnation, blue jasmine, marigold and evening primrose. The contact with the colourful pots, the smell of the fragrance given off by the flowers, the different colours seen in the daily watering and care, took the beneficiaries on a journey through the senses, evoking vivid memories, emotions and autobiographical experiences.

The scent of gardenias led Maria to describe a trip to Pelion, when she was a first-grade student and the purchase of a gardenia pot as a gift for her grandmother. Touching on the marigolds, Glykeria talked about her grandmother's vegetable garden, where she had okra among the eggplants (aubergines), peppers and zucchini (courgettes). The other participants talked about the colourful petunias they had on their balconies and the night flowers that scented the courtyards every summer. Each flower is a story and a healing dialogue. Worry about the heat and stress turned into calm.

29 AUGUST

The ALZ-AWARENESS project is dedicated to enhancing dementia awareness and support in remote communities in Turkey

The Turkish Alzheimer Association has 20 active branches throughout the country, yet some regions are quite remote in terms of accessibility to information and training. In order to solve the problem, in 2023, the Association focused its efforts on implementing a project called ALZ-AWARENESS, supported within the scope of the Sabancı Foundation 2023-2024 Grant Programme. The ALZ-AWARENESS project is dedicated to enhancing dementia awareness and support in remote communities across the country. This initiative involves organising two-day face-to-face training sessions in five cities that are selected based on criteria such as their physical distance from Association Headquarters and accessibility to information and where there is no active branch in the immediate neighbourhood, namely Erzincan, Diyarbakır, Şanlıurfa, Artvin and Tunceli.

The training programme comprises four comprehensive modules:

- Module 1: Understanding dementia, provides a fundamental understanding of dementia, emphasising caregiving skills and effective communication strategies. Participants gain insights into the challenges faced by people with dementia and their caregivers, equipping them with essential knowledge to provide better care.
- Module 2: Group psychotherapy and psychodrama, introduces group psychotherapy and psychodrama techniques fostering a supportive environment. Attendees learn to address the emotional and psychological needs of people with dementia and their families, promoting holistic well-being.
- Module 3: Social and legal rights, educates participants on the social and legal rights of people with dementia and their caregivers recognising the importance of advocacy and support. Empowering them with knowledge of available resources and legal protections to improve the quality of life of those affected.
- Module 4: Dementia champion training, aims to train volunteers to become dementia champions for their communities. They receive specialised training and guidance to raise awareness within their regions, creating a supportive network.

The project seeks to bridge the knowledge gap and promote dementia care in remote communities, by dispatching experts from the headquarters such as neurologists, nurses, psychologists, lawyers, social workers, etc. to carry out interactive and semi-fictional trainings specifically tailored to the needs of these areas. The initiative aims to create a stronger support system for families by building a network of informed and caring individuals who can make a positive impact on the lives of people with dementia and their families. Anticipating the positive impact of these training sessions, the ALZ-AWARENESS project envisions the formation of local branches in remote communities which would serve as hubs of knowledge and support, further strengthening the network of care and advocacy for people with dementia and their families.

During the trainings, the knowledge and skills of the participants are measured and reported through surveys and interviews. Participants are given a booklet prepared by the Alzheimer Association of Turkey within the scope of the project to spread information around them. Monthly communication is maintained with the Awareness Ambassadors, who are trained to carry out voluntary activities to raise awareness in their regions; their feedback is collected from the Awareness meetings they organise and they are updated on issues such as new treatments, regulations, laws and legislation.

LIVING WITH DEMENTIA

27 JULY

"Sometimes it's hard to say no" writes Trevor Salomon, Chairperson of the European Dementia Carers Working Group, who recently took on the role of Relatives Ambassador at his wife's care home

Earlier this year I received a call from the manager of the care home, where my wife is a resident, asking me to drop by her office on my next visit. Such calls will always lead to much speculation so I wondered what was wrong!

I needn't have been concerned. Over a cup of coffee in her office, the manager asked me if I would consider taking on the voluntary role of Relatives Ambassador for the home. My immediate thought reaction was to decline because I already had a pretty full calendar but thinking rapidly on my feet, I realised this might be an opportunity to play my part in bridging any gaps between care home residents, their families, and the care home staff. So, I said I'd accept the role on condition it had a framework to it and wasn't simply a job title without portfolio.

We agreed that my priority deliverable would be to help the home with its outbound email communications to family members. The home excels in caring – it's not my core skill by a long way, nor should it be. On the other hand, I'm a fairly competent copy writer - it's something for which they constantly receive criticism.

Next on my list was to act as a conduit for relatives with concerns but who felt unable to complain for fear that any criticisms might be held against them or their resident family member. I've learnt in life that it's all about how you complain, what words you use and the tone of your voice and not so much the substance of the issue itself. I didn't want to get involved in specific family problems but instead guide them on how to approach airing a problem and ensuring a resolution is achieved in a timely manner.

Advocacy came up next which is quite easy for me because I've always been laser focussed on the rights of care home residents and am therefore comfortable discussing dignity and best possible care matters with the manager.

Then we talked about encouraging family involvement in activities and events in order to build a community spirit and in this context the manager agreed that I should host regular on-site morning cafés which would not be attended by any staff members such that open, unhindered discussion would flow on matters common to everyone. Usually these are things such as the quality of food, reception not answering inbound calls in a timely manner, on-site car parking, room cleanliness, the quality of full-time staff versus agency staff. I don't think any of these is unique to my wife's home but people feel it's cathartic to be able to collectively express their views.

Five months into the role, I'm finding that it's not taking up as much of my time as I'd anticipated and working with the manager, we're now looking at continuous feedback loops based on her regular outreach to family members, underpinned with surveys. I've enjoyed getting to know her on a much more 1:1 basis and with the home at 100% occupancy I'm convinced that the role of Relatives Ambassador does indeed add value to fostering a supportive community, ensuring transparent communication, and enhancing the overall care experience for residents and their families.

6 AUGUST

Trevor Salomon, Chairperson of the European Dementia Carers Working Group, writes a letter to the UK Chancellor of the Exchequer highlighting the need for more support for dementia

With a new Government in place in the United Kingdom, Trevor Salomon, Chairperson of the European Dementia Carers Working Group (EDCWG) was approached by the Alzheimer's Society to write a letter to the Chancellor of the Exchequer, Rachel Reeves, from his perspective as a carer/campaigner, stressing the need for more support for dementia, in particular financial support.

The letter formed part of a welcome pack, delivered in a ministerial-style briefcase, outlining the Alzheimer's Society's calls and asks, but also positioning the organisation as an ally and including information about their support resources.

Here is the text of the letter, dated 6 August 2024:

Dear Chancellor,

I am a carer for my wife, Yvonne, who has been living with young onset dementia since 2009 when she was just 53 years old.

For the first 10 years I coped alone looking after her at home until her double incontinence became a tipping point for me when I realized that she needed 24x7 professional care, something which I could not give her.

With dementia now recognized as the biggest cause of death in the UK, I ask myself why there is so little humanity and compassion shown by successive Governments towards those living with this baffling disease as well as to their carers? We and our families bear the financial brunt of care costs because dementia is so underfunded. How, in 2024, and by what yardstick can this possibly be deemed fair given that dementia is now considered one of the six major health conditions of our time?

Next year, my wife's savings will dry up, after being a self-funder in her care home for over six years. I am sure you can imagine how much we have spent on her care, but I will tell you anyway; it is many hundreds of thousands of pounds. And yet I begrudge none of it because her care has been exemplary, including throughout the dark days of the pandemic when I could not visit her for almost 14 months.

However, when her money runs out, she will be at the dual mercies of the local authority for funding and the empathy of the care home management in accepting a lower contribution for her fees than they have hitherto been receiving since 2019 when she became a resident.

I am already stressing about the outcome and at the same time am hugely disappointed by the Government's decision not to proceed with the cap on social care costs in England. Whilst understanding the pressures you face with budgeting, it's surely time to bring hope and financial support to the almost 1,000,000 people impacted by dementia and their families who, like me, bear the emotional, physical and cost burden of caring for loved ones.

If reform is not introduced now, then when?

Thank you for taking the time to read my letter. I look forward to your response.

Yours faithfully,

Trevor Salomon

19 AUGUST

Annick Germeys, new member of the European Dementia Carers Working Group, writes "Broken brain cells, but a head full of memories" about her husband Geert and his sculpture

My name is Annick Germeys, and since June, I have been a member of the European Dementia Carers Working Group (EDCWG). In October 2022, my husband Geert Mathys was diagnosed with early-onset Alzheimer's at the age of 53. This news hit us like a bombshell. You process the diagnosis, mourn what is lost, you live difficult times.

But a person with (early-onset) dementia still has a life to live. As a caregiver, you must take on tasks that your partner can no longer manage. I took over the control of my partner's life. However, beyond taking on many responsibilities, I also wanted to ensure that Geert's cognitive reserves would not deplete too quickly. I spent extra time maintaining social connections, engaging in active and creative pursuits, and planning enjoyable activities to fill our days. In short, I did everything I could to keep Geert's brain stimulated while also ensuring that we could still enjoy the time we have together. I would like to share with you one of my husband Geert's passions and his fight to challenge his creative mind, in hopes of slowing down the progression of early-onset dementia and spent good times pleasantly.

About eight years ago, I began studying ceramics at the part-time art education programme at knst.beeld in Hasselt, our home town. Working with clay has since become my form of mindfulness. I learned to create, developed entirely new skills, and most importantly, found peace in my head. Geert saw how passionate I was about it and decided to take up sculpture and spatial art during an open day at the Academy. He started it shortly before he was diagnosed. Now, for him, being creative is equally important. Unconsciously, but crucially, he stimulates his brain by creating, learning new skills, and also enjoying meaningful social contact. He eagerly looks forward to the lessons he attends twice a week. This artistic outlet, as mentioned earlier, unknowingly serves as a form of cognitive training. I am glad that Geert receives full support from the Academy, and that his teacher Diane Gielen is making this inclusion journey possible.

Geert's creative side was also highlighted in the VRT1 programme "Restaurant Misverstand" (The Restaurant That Makes Mistakes), in which he participated this year. The programme featured Geert working on his sculpture at the Hasselt Academy of Arts. After the TV show, Alzheimer Liga Vlaanderen wanted to surprise all the participants with a special gift. They asked the caregivers how they could bring joy to the participants while also raising awareness about early-onset dementia. Since Geert was so passionate about his sculpture, I chose to highlight this aspect. He had worked so hard on it, and his teacher, Diane, provided exceptional support.

When I learned that his sculpture would be displayed at the Royal Museum of Fine Arts Antwerp (KMSKA), I was pleasantly surprised. Exhibiting your work at the KMSKA is every artist's dream. This was all organised as a special surprise for Geert, with an official opening arranged by Alzheimer Liga Vlaanderen and the KMSKA. The cast of Restaurant Misverstand was present at the opening, along with friends and acquaintances. Geert had no idea, and it was a complete surprise, making it an extraordinary experience.

Geert named his sculpture "My Broken Head" (Mijn Kapotte Kop). At the front, you see numerous small spheres, representing Geert's perception of his brain cells dying off. The head is large, symbolising the many memories Geert holds, which are slowly fading. Geert chose the colour red, the colour of love.

Initially, the sculpture was supposed to remain at the KMSKA for two weeks, but after talking with the museum, I was able to arrange for it to be displayed until the end of August. The exhibit has moved many people.

The sculpture is beautifully showcased, and my wish for it to continue drawing attention and finding a new home has come true. Starting in September, it will be exhibited for two months at the Provincial and City Library of Hasselt, our hometown. In the library, there will be extra attention and a themed display about (early-onset) dementia. Hasselt aims to be a dementia-friendly city and will use September, including World Alzheimer's Day on 21 September, to raise extra awareness about this issue. The film that was made about Geert's artwork, the surprise, and the opening at the KMSKA will also be shown there. The film can be viewed by everyone (in Dutch, with Dutch subtitles) via: https://www.youtube.com/watch?v=M5Yfi408oLs. We want to raise awareness about early-onset dementia and, above all, emphasise that there is still life after the diagnosis. I hope that the sculpture will continue its journey to other locations.

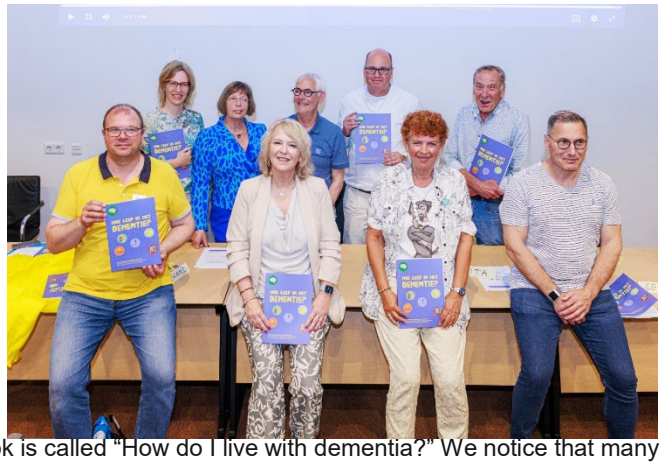
About the Sculpture

This work by Geert portrays the reality of Alzheimer's, where every detail of what was once a vibrant mind now crumbles due to the disease. It symbolizes the slow decline of cognitive functions and identity. Geert views it as an acceptance and embrace of

the disease as an inevitable companion. The sculpture reminds us that while new memories may fade, old ones still exist and can be cherished. Through this creation, Geert seeks to draw attention to the value of memories and empathy for those living with Alzheimer's. The sculpture encourages us to cherish what remains of a person's essence, despite the gradual fading.

27 AUGUST

Gerda Van Tongerloo, new member of the European Working Group of People with Dementia, introduces Dutch co-researchers' group on dementia called "Brain Power"



My name is Gerda Van Tongerloo. I am a member of the European Working Group of People with Dementia and very active in the Netherlands as well. I want to tell you a bit more about the Dutch research group "Brain Power", of the HU University of Applied Sciences Utrecht. Brain Power is a group of experts with dementia who are involved as co-researchers in the research "Everyday life with dementia" by PhD candidate Jacoba Huizenga. This is unique because the people with dementia are not solely participants. No, we are the co-researchers of this research.

The group Brain Power has made , based on the research, a special book about our experiences of living with dementia. This is one of the first books about this topic written by people with dementia themselves. We are very proud that we finished it. The book is called "How do I live with dementia?" We notice that many people are interested in this book, also outside of the Netherlands! The readers are very delighted to read about personal insights and useful tips. The reader can relate to his or her own situation. The book covers topics such as changes in behaviour, meaningful activities, and relationships with family and friends. It also includes inspiring stories from experts and individuals living with dementia.

This year, the INTERDEM Academy Publication Award was awarded for the scientific article "What matters most: Exploring the everyday lives of people with dementia," written by Jacoba Huizenga and team. In this article, the concept of "everyday life" is explored from an interdisciplinary and social perspective. Through this lens, the research shows that it is possible to understand experiences outside traditional healthcare paradigms. In the research, creative participatory research methods are used. The research group Brain Power is the perfect example for participatory research. The INTERDEM award will be presented to Jacoba Huizenga in Geneva during the Alzheimer Europe Conference. Jacoba and I will present the research at the conference (QOP5-01 What matters most in everyday life: empowering the voice of people living with dementia through collaborative research).

Pictured: Brain Power group at the launch of their book "How do I live with dementia?", June 2024

27 AUGUST

Lieselotte Klotz, newly-elected Vice-Chairperson of the European Working Group of People with Dementia, writes about the urgent need to prioritise dementia

As someone who is closely involved in the care of people with dementia, I have first-hand experience of the challenges and the urgent need to prioritise dementia as a central issue for policymakers. Dementia is more than just a medical challenge; it represents a social and economic crisis affecting millions of people worldwide, including families, communities, and healthcare systems.

One of the most compelling reasons to prioritise dementia is the sheer scale of the problem. With an ageing population, the prevalence of dementia is rapidly increasing. In many countries, including Germany, health and social systems are struggling to meet the growing demand for care for people with dementia. The lack of precise epidemiological data further complicates the issue, making it difficult to plan and allocate resources effectively. Accurate data is necessary to understand the number of people affected, their geographic distribution, and the specific needs of people with dementia.

Economically, the impact of dementia is significant. Care costs are high, and families often bear most of these expenses. Early diagnosis and intervention can significantly reduce these costs by slowing the progression of the disease and improving the quality of life for those affected. Moreover,

many caregivers are forced to leave the workforce or reduce their working hours, leading to productivity losses and financial burdens for households. This is not just a personal issue but also affects the broader economy.
Socially, dementia places a tremendous burden on families. The physical and emotional strains associated with caring for a loved one with dementia are considerable and often lead to burnout and psychological stress. Many caregivers feel isolated and overwhelmed due to a lack of necessary support and resources. Additionally, stigma and social isolation are common issues faced by people with dementia and their families. Raising awareness and promoting acceptance are crucial steps in addressing these social challenges.
The current state of care for people with dementia in many countries, including Germany, is often described as a "patchwork" or "jungle", with services varying greatly depending on location. This inconsistency is due to the complex nature of the healthcare system, which involves multiple levels of government and numerous regulations. The lack of coordination and integration between medical, social, and nursing services leads to gaps in care and confusion for those seeking help.
Addressing these challenges requires a comprehensive approach. Policymakers must prioritise the development of integrated care models that bring together medical, social, and support services. Investments in specialised training for medical professionals and the establishment of more dementia-friendly care facilities are essential. In addition, public health campaigns focusing on risk reduction and awareness can help educate the public and reduce stigma.
In conclusion, prioritising dementia by policymakers is not only necessary but urgent. Through a coordinated and determined approach, we can ensure that people with dementia, as well as their families and caregivers, receive the necessary support and care. This includes financial investments, support systems, research funding, and public awareness initiatives. Only through such efforts can we hope to meet the growing challenges of dementia and improve the quality of life for all those affected.
As Vice-Chair of the European Working Group of People with Dementia (EWGPWD), I am incredibly proud of the work that we and Alzheimer Europe are doing, together, to advance the dementia movement in Europe. The initiatives we have launched in recent years clearly show how important it is to put the voices of people with dementia and their families at the centre of our work. Through groups like the EWGPWD and the European Dementia Carers Working Group (EDCWG), we give a voice to those who are often overlooked. I am also impressed by our engagement in European politics. The campaign to prioritise dementia shows that we are not just focused on raising awareness but are actively working to bring about concrete political change. These efforts are essential to ensure that people with dementia receive the support and recognition they deserve. It is an honour to be part of this movement, and I look forward to continuing to work with our dedicated team and partners towards a better future for people with dementia.

DEMENTIA IN SOCIETY

31 AUGUST

Dementia researcher Golnaz Atefi is "Rolling for Dementia" to promote inclusivity and diversity in dementia care and research

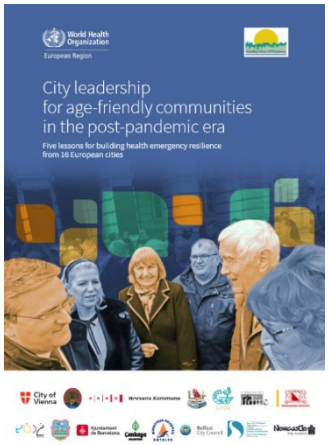
During World Alzheimer's Month this September, Golnaz Atefi, a dementia researcher based at Alzheimer's Centre Limburg, is embarking on a unique and challenging journey: skating over 1,000 km in 30 days across Europe to raise awareness about the importance of diversity and representation in dementia research.
"If I successfully skate 1,000 km in one month, it will set a world record for the farthest distance ever skated by a female skater. I am determined to achieve this to raise awareness for dementia", she said.
The central message of her campaign is clear: "Without proper representation, we risk stifling innovation." Through her PhD research as part of the DISTINCT network, Golnaz aimed to improve the lives of people with dementia and family caregivers through technology. She recognised the immense potential of technology to transform health and dementia care by narrowing gaps and providing accessible support. "When implemented sustainably and at scale, these tools could offer equitable access to high-quality care for individuals worldwide, addressing global health and wellbeing disparities. However, these innovative technologies could also exacerbate existing healthcare disparities and contribute to digital exclusion, particularly for older adults who may be unable or unwilling to access or use these services due to socio-economic and cultural barriers, lack of digital literacy, and affordability issues", she

commented. This awareness-raising effort is part of her current fellowship with University College London, building on insights gained from her PhD research.
Throughout her journey, Golnaz will interview researchers, healthcare professionals, and community members to discuss the challenges and opportunities in making dementia research more inclusive. She noted that "the skating itself may not be the most challenging part, but using it as a medium to raise awareness is. This effort requires collaboration from professionals and organizations to share their insights, experiences, solutions, and recommendations so that together, we can raise awareness in an engaging and impactful way". The interviews, along with the highs and lows of her journey, will be shared through daily vlog posts and behind-the-scenes moments on the Dementia Researcher YouTube channel.
Stay tuned for updates, and if you are attending the 34th Alzheimer Europe Conference (#34AEC) please feel free to connect with Golnaz to share your insights or even skate part of the way with her during this campaign to raise awareness and promote inclusivity in dementia research. Interviews with INTERDEM members will also be disseminated via the INTERDEM website.

PUBLICATIONS AND RESOURCES

9 JULY

New WHO report highlights strategies for age-friendly cities in post-pandemic era



How to create resilient, adaptive, and inclusive urban environments for older citizens is the subject of a newly launched policy brief by WHO/Europe and the Healthy Ageing Task Force (HATF) from the WHO Healthy Cities Network. "City leadership for age-friendly environments in the post-pandemic era" is targeted at planners, policy-makers, and politicians, and draws on lessons learned during the COVID-19 pandemic and other emergencies.
The COVID-19 pandemic and other health emergencies disproportionately impacted older populations, prompting cities to develop innovative solutions to address survival, equity, adaptation, and inclusion. The report identifies five crucial lessons to inform future health emergency responses.
1. Build resilience together. City leadership during the pandemic demonstrated the effectiveness of integrated systems combining various sectors and government levels. This collaborative approach is essential for future preparedness and response.
2. Adopt a resilience cycle. Experiences from the pandemic should shape a continuous cycle of preparedness, response, and recovery to enhance resilience against future health crises.
3. Adopt an all-hazards approach. Given limited resources, cities must employ mechanisms developed during the pandemic to prepare for and respond to a range of health emergencies.
4. Invest in community infrastructure. Long-term investment in social, physical, and economic infrastructures is vital for building age-friendly cities, as evidenced by HATF cities.
5. Ensure older people have a voice. Effective policies must earn the trust and support of older citizens. Their voices should be heard and acted upon, ensuring their needs are met and their contributions valued.
The report underscores the importance of not leaving the older population behind in city planning and emergency responses. "Older adults should not always be perceived as vulnerable; they bring a lifetime of experience that is invaluable during crises. By including them in emergency planning and creating age-friendly environments, we ensure no one is left behind and build stronger community resilience even in emergency contexts," said Dr Yongjie Yon, Technical Officer on Ageing and Health in WHO/Europe's Division of Country Health Policies and Systems.
Download the report, here: https://www.who.int/europe/publications/i/item/WHO-EURO-2024-8409-48181-74811

30 JULY

TouchNEUROLOGY publishes new online content from 10th Congress of the European Academy of Neurology on "Late-breakers in movement disorders, aging and dementia"

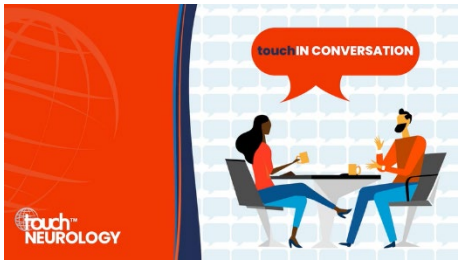
The 10th Congress of the European Academy of Neurology (EAN 2024) was held from 29 June to 2 July in Helsinki, Finland. As every year, the EAN Congress covered a wide array of topics in neurology. Key data presented at the congress not only highlighted significant advancements in these areas but also provided insights that could shape future clinical practices.
Dr Miguel Miranda (Unidade Funcional de Neurologia, Hospital de Cascais Dr. José de Almeida, Cascais, Portugal) joins touchNEUROLOGY in this video, to discuss key topics and highlights from the Late-Breaking News session he chaired at EAN, as well as unmet medical needs in dementia, aging and movement disorders.

Watch the video:

https://touchneurology.com/alzheimers-disease-dementia/conference-hub/highlights-of-ean-2024-movement-disorders-aging-and-dementia/

22 AUGUST

TouchNEUROLOGY publishes new online activity called “Let’s talk about agitation in Alzheimer’s dementia: Prevalence, behavioural symptoms and reaching a diagnosis”



In this activity, which is jointly provided by USF Health and touchIME in collaboration with the Gerontological Society of America (GSA), a gerontological nurse practitioner and a family care partner discuss the prevalence and typical presentation of agitation at different stages of Alzheimer’s dementia. Early recognition and diagnosis is important; it enables the implementation of best practice management strategies to reduce the overall burden of agitation for people living with Alzheimer’s dementia and their care partners.

Watch the video:

https://touchneurologyime.org/lets-talk-about-agitation-in-alzheimers-dementia-prevalence-behavioural-symptoms-and-reaching-a-diagnosis/

31 AUGUST

Fondation Médéric Alzheimer invites professionals using digital devices and psychosocial interventions to complete a flash survey in advance of its related symposium in Geneva

The Fondation Médéric Alzheimer is organising a symposium during the upcoming 34th Alzheimer Europe Conference in Geneva, on the theme of "Digital devices and psychosocial interventions: challenges and issues". The symposium aims to provide an overview of the digital devices used in the implementation of psychosocial interventions, and to discuss the challenges and barriers to their use. It will take place on Wednesday 9 October, from 17.30-18.30.

A flash survey has been launched by Fondation Médéric Alzheimer, to find out what type of digital devices professionals use for which psychosocial interventions, as well as to establish the added value of these devices and the difficulties encountered by professionals when using them. The survey also looks at training, and at feedback from people with dementia and their carers.

The results of the flash survey will be presented and discussed by the speakers at the symposium in Geneva, with concrete examples provided. The speakers will be Christine Tabuenca (Fondation Médéric Alzheimer), Nigel Hullah (European Working Group of People with Dementia), and Maribel Pino (Broca Living Lab).

If you are a professional working with digital devices and psychosocial interventions for people with dementia, you are invited to complete the survey, via this link: https://app.keysurvey.fr/f/41740941/4e94/

AE CALENDAR 2024

DATE	MEETING	AE REPRESENTATIVE
3 September	Meeting with EFPIA AD Platform	Jean
3 September	Meeting with Novo Nordisk	Jean
3 September	Meeting with Alzheimer's Disease International and US Against Alzheimer's	Jean
3 September	AD RIDDLE WP7	Ana, Sarah, Lukas, Dianne and Ange
3 September	Urge to Act kick-off call	Dianne
4 September	Meeting with US Alzheimer's Association	Jean
6 September	WHO European Region meeting on engagement with civil society	Lukas
6-7 September	20th Anniversary Conference of Malta Dementia Society (Malta)	Jean
12 September	EFPIA Patient Think Tank	Owen
13 September	Alzheimer Europe Anti-Stigma Award Committee	Jean
17 September	Alzheimer's Association Academy "Anti-amyloid treatments for Alzheimer's disease"	AE members and staff
17 September	AD-RIDDLE HTA Forum	Ange and Ana
18 September	HOMEDEM project	Dianne, Ana
18 September	Predictom WP1	Dianne, Sarah
18 September	Company Round Table	AE Board and sponsors
19 September	EU4Health Civil Society Alliance	Jean and Owen
19 September	Lethe Advisory Board	Ana
23 September	European Commission monitoring meeting for RECOGNISED project	Ange
24-25 September	TClock4AD summer school (Milan, Italy)	Cindy
24-25 September	Interim review meeting for the EPND project	Ange
26 September	SciCom (Luxembourg)	Chris and Lukas
30 September	Alzheimer Europe Board	AE Board and staff
30 September-1 October	Predictom Consortium (Germany)	Dianne, Sarah

CONFERENCES 2024

DATE	MEETING	PLACE
18 September	"Glimpses into Alzheimer's : What the option of MAiD Meant to Us", https://www.eventbrite.ie/e/glimpses-into-alzheimers-what-the-option-of-maid-meant-to-us-tickets-974287479077	Dublin, Ireland
18-20 September	20th EuGMS Congress - "From Healthy Ageing to Complex Needs in Older Adults", https://eugms2024.com/	Valencia, Spain
25-27 September	IPA 2024 International Congress - Crossing Oceans and Connecting People to Improve Mental Health for Older Adults, https://www.ipa-online.org/events/2024-international-congress	Buenos Aires, Argentina
8-10 October	34th Alzheimer Europe Conference – New horizons – Innovating for dementia, https://www.alzheimer-europe.org/	Geneva, Switzerland
29 October – 1 November	17th Clinical Trials on Alzheimer's Disease (CTAD), https://www.ctad-alzheimer.com/	Madrid, Spain
13-16 February 2025	14th Panhellenic Conference on Alzheimer's Disease and 6th Mediterranean Conference on Neurodegenerative Diseases, https://www.alzheimer-conference.gr/index.php/en/	Thessaloniki, Greece
20-22 March 2025	19th World Congress on Controversies in Neurology (CONy), https://cony2025.comtecmed.com/	Prague (Czech Republic)

Co-funded by the European Union

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34th Alzheimer Europe Conference

New horizons – Innovating for dementia

Geneva, Switzerland

8 - 10 October 2024 #34AEC

www.alzheimer-europe.org/conferences