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WELCOME

I am excited to announce that we have launched the 2024 edition of our Anti-Stigma Award, following the great success of the initiative over the past two years. We would like to recognise a European journalist for an article, news story or documentary

which has contributed to combating stigma and promoting a positive image of dementia and people living with dementia. The call is open until 15 June.

Still on the topic of awards, I have another exciting announcement: The 33rd Alzheimer Europe Conference, which took place in Helsinki last year, has won a prestigious Evento Award. The annual Evento Awards recognise Finland's best events, venues, speakers and companies, so we were truly delighted that our conference was a finalist in three categories (Paid Event, Charity/Social Event, and Event Impact) and that it won the Paid Event category. It was a great honour for our event to be recognised in this way. Our warmest congratulations go to all the award winners and our heartfelt thanks go to our conference co-hosts, the Alzheimer Society of Finland (Muistiliitto), and to the conference venue, the Messukeskus Helsinki Expo and Convention Centre.

Moving on to this year's conference, I would like to remind everyone that the call for abstracts for the 34th Alzheimer Europe Conference (#34AEC) will close on 15 May, meaning there are just a few days remaining, so please submit yours today, to avoid disappointment. Once the deadline arrives, our Scientific Committee will review all submissions and we will let applicants know the result during June. Registrations are also open and you can benefit from our reduced Early Bird fee until 15 July.

Speaking of conferences, it was a pleasure to attend the Alzheimer's Disease International (ADI) Conference in Kraków (Poland) this month, together with my colleagues Ana Diaz and Gwladys Guillory. Ana was a speaker at a symposium on "Advancing Global Dementia Risk Reduction through Multidomain Interventions", while I moderated a session on "Dementia as a public health priority". I also represented Alzheimer Europe at the ADI Council Meeting, prior to the conference.

Our ongoing European Election Campaign 2024 continues to garner support as we approach the EU elections in June. All three branches of the campaign (the Helsinki Manifesto, our public Call to Action, and the Dementia Pledge) aim to ensure that dementia is a policy priority at the European level and I invite you to please show your support, by signing our public Call to Action, asking MEP candidates to sign the Dementia Pledge and for European and national organisations to endorse our Manifesto.

Lastly, I want to highlight a new article called "Insights and recommendations for working collaboratively and improving care in Alzheimer's disease: Learnings from the Finding Alzheimer's Solutions Together (F.A.S.T.) Council", which has been published online in the journal Health Expectations and which I was pleased to co-author, alongside esteemed colleagues from Roche, Alzheimer Nederland, Alzheimer Hellas and ADI, among others.

I hope you enjoy our newsletter!

Jean Georges
Executive Director

Alzheimer Europe Board

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

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SPOTLIGHT ON EUROPEAN ELECTIONS

30 APRIL

Our European Election Campaign 2024 is gathering speed as the June elections grow nearer. Please show your support for our Call to Action, Dementia Pledge and Helsinki Manifesto!



In advance of the European Parliament elections between 6 and 9 June 2024, we are running our European Election Campaign 2024, aiming to make dementia a priority issue for decision-makers at a European level. The campaign 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, we point out that by 2025, 9.1 million people will be living with dementia in the European Union, rising to 14.3 million in 2050. We are therefore pushing for the condition to be shown greater attention by European decision-makers.

Our campaign has three distinct elements aimed at different audiences, demanding dementia be prioritised as a policy issue: The **Helsinki Manifesto** provides an outline of the current situation in relation to dementia across Europe, detailing specific demands for the European Commission Institutions and national governments. The Manifesto will be the basis of Alzheimer Europe's campaign work in the coming years. European and national organisations are invited to endorse the Manifesto. So far, the Manifesto has attracted the support of 67 organisations, projects and entities including the following six which endorsed it during the month of April:

- Radosny Dom Seniora
- Pattern-Cog
- Multi-Memo
- Accademia Scherma Milano
- Medico e Paziente

We urge national and European organisations, projects and other groups wishing to endorse our Helsinki Manifesto to get in touch: info@alzheimer-europe.org or to find out more, via our website: <https://bit.ly/AEHelsinkiManifesto>

Our public **Call to Action** demands that European decision-makers prioritise dementia as a policy issue and implement the actions of the Helsinki Manifesto. We are delighted to have already got **more than 4,400 signatories!** The three countries with the most signatories are: Italy (2,732), Sweden (429), and Spain (301). You can sign the Call to Action, today, via our website: <https://bit.ly/AECallToAction2024>

The **Dementia Pledge 2024** is a commitment which candidates standing for the European Parliament elections are invited to sign, pledging their support in prioritising dementia in the areas of health, research, disability policy and informal carers and pledging to join the European Alzheimer's Alliance, upon election. All candidates standing in the European Parliament elections are encouraged to sign the pledge. As at 30 April 2024, 65 candidates have signed up to the Pledge. The Pledge campaign will run until 9 June 2024, when the European elections will conclude. The list of signatories currently signed up to the Dementia Pledge 2024 can be viewed here: <https://bit.ly/DementiaPledge2024>

ALZHEIMER EUROPE

11 APRIL

Alzheimer Europe Conference wins international Evento Award in Helsinki



The Evento Awards, which took place on 11 April 2024 in Helsinki (Finland), recognised Finland's best events, venues, speakers and companies of 2023. We were delighted that the 33rd Alzheimer Europe Conference, which took place last October at the Messukeskus Helsinki Expo and Convention Centre, was a finalist in three categories (Paid Event, Charity/Social Event, and Event Impact). We were even more delighted to win the Paid Event category! Alzheimer Europe was represented at the awards ceremony by Conference Coordinator Gwladys Guillory (pictured), who attended alongside Paula Blomster, Congress Manager at Messukeskus.

Our warmest congratulations go to all the award winners and our heartfelt thanks go to our conference co-hosts, the Alzheimer Society of Finland (Muistiliitto), as well as to the conference venue, Messukeskus.

The annual Evento Awards have been held since 2014 (with a hiatus in 2021 due to the COVID pandemic).

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Evento Awards 2024 winners

- Events as part of strategy: iLOQ / NJ Production
- Promotion/lamonying: Muru Baby Baby Restaurant / Folk Finland
- Business transaction, paid: 33rd Alzheimer Europe Conference / Helsinki Exhibition Center
- Business event, free of charge: Atea Focus 2023 / Management Events Studio
- Consumer transaction, paid: Family match of Huuhukaji Finland – San Marino / Finnish Football Association
- Consumer event, free of charge: Music Centre holiday 2023 / Musiikkitalo oy
- Staffing transaction: Solita Wonderland / Downloadmo Group
- Hybrid event/virtual event: Sanoma Pro Balance / Pulp Agency
- Visual implementation: Nordic Business Forum / Visual45 & Creative Technology
- Charity / Social Event: Long game for Ukraine / Case
- Event venue: Pikku-Finlandia, Helsinki
- Host/moderator (public vote): Jenni Kivesilta
- Corners virtuoso (public vote): Olli - Pekka Kallio.

15 APRIL

Alzheimer Europe invites journalists to apply for its 2024 Anti-Stigma Award



On 15 April 2024, Alzheimer Europe and the Alzheimer Europe Foundation announced the launch of the 2024 edition of their Anti-Stigma Award, following the great success of the initiative over the past two years. This year, they would like to recognise a European journalist for an article, news story or documentary which has contributed to combating stigma and promoting a positive image of dementia and people living with dementia. The 2024 call will therefore focus on articles, videos or documentaries produced by journalists which address the stigma experienced by people with dementia and their carers. The award is open to journalists established in a [member country of Alzheimer Europe](#) for articles, news stories or documentaries which were produced and published in the past three years (2021-2024). Applications can be made by journalists themselves or by a nominating national Alzheimer's association. In those cases, the written consent of the nominated journalist needs to be sought. The award can be for stories covered by print media, radio or TV programmes or in social media channels.

The 2024 award will consist of a cash prize of EUR 5,000 for first place, a cash prize of EUR 2,500 for second place and a cash prize of EUR 1,250 for third place, each of which will be accompanied by a trophy. The winning journalists will be announced during a special award ceremony as part of the European Parliament Dementia Day, on 10 December 2024, in Brussels.

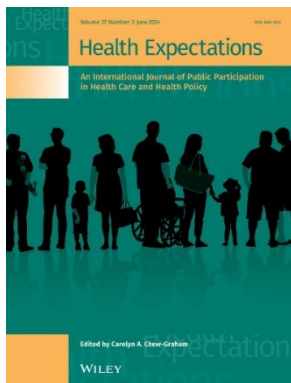
Interested journalists or national Alzheimer's associations wishing to nominate a particular journalist, should send in the completed application form by the deadline of 15 June 2024. Applicants may be short listed and asked to present their article, news story or documentary to the members of the Award Committee at an online meeting on 15 July. Travel and accommodation costs for the top three journalists will be covered by Alzheimer Europe, to attend the award ceremony in Brussels on 10 December.

More information can be found at: <https://www.alzheimer-europe.org/our-work/anti-stigma-award/anti-stigma-award-2024>
 The application form can be downloaded via: https://www.alzheimer-europe.org/sites/default/files/2024-04/anti-stigma_award_-_application_form.docx

Alzheimer Europe gratefully acknowledges the support of the sponsors of the Alzheimer Europe Anti-Stigma Award: Alzheimer Europe Foundation, C2N Diagnostics, Lilly and Roche.

17 APRIL

Article on insights and recommendations for working collaboratively and improving care in Alzheimer's disease published in journal Health Expectations and co-authored by Alzheimer Europe



A new article called "Insights and recommendations for working collaboratively and improving care in Alzheimer's disease: Learnings from the Finding Alzheimer's Solutions Together (F.A.S.T.) Council" has been published online in the journal Health Expectations. Jean Georges, Executive Director, Alzheimer Europe, is a co-author of this paper.

Article link: <http://doi.org/10.1111/hex.14040>

23-26 APRIL

Alzheimer Europe participates in Alzheimer's Disease International Council Meeting and Conference in Kraków



The 36th Global Conference of Alzheimer's Disease International (ADI) took place from 24 to 26 April 2024, in Kraków (Poland). Alzheimer Europe was represented at the

conference by Jean Georges, Executive Director; Ana Diaz, Public Involvement Lead; and Gwladys Guillory, Conference Coordinator.

On 23 April, Jean Georges represented Alzheimer Europe at the ADI Council Meeting, prior to the conference. He also moderated a conference session on 24 April, entitled "Dementia as a public health priority" with presentations on policy developments in Ireland, Hongkong, Scotland (United Kingdom) and the United States.

On 25 April, Ana Diaz spoke at the symposium on "Advancing Global Dementia Risk Reduction through Multidomain Interventions: Experiences from World-Wide FINGERS", where she presented on behalf of the EU-FINGERS project and the Multi-MeMo project regarding public involvement in dementia prevention research.

30 APRIL

Just two weeks left to submit your abstract for the 34th Alzheimer Europe Conference!

There are just two weeks left to submit your abstract for this year's Alzheimer Europe Conference (#34AEC). "New horizons - Innovating for dementia" will take place in Geneva, Switzerland, from 8-10 October 2024. Our call for abstracts, which covers



a broad range of topics, **will close on 15 May 2024**, so we encourage you to submit yours as soon as possible.

Alzheimer Europe, Alzheimer Schweiz Suisse Svizzera and Alzheimer Genève are calling for abstracts for oral and poster presentations on the following topics:

- Innovation in care and research
- Living with dementia
- Patient pathways
- Policy
- Inclusion and intersectionality

The call for abstracts will close on 15 May 2024. See here for more information: <https://www.alzheimer-europe.org/conferences/2024-geneva/call-abstracts>

Registrations are also open, with reduced Early Bird rates available until 15 July.

Click here to find out more about registration fees: <https://www.alzheimer-europe.org/conferences/2024-geneva/registration-fees>

Click here to register: <https://www.alzheimer-europe.org/conferences/2024-geneva/online-conference-registration>

AE NETWORKING

2 APRIL	Jean attended the MIRIADE Supervisory Board
3 APRIL	Jean met with representatives of Project Alzheimer's Value in Europe (PAVE)
8 APRIL	Jean met with Roche
8 APRIL	Jean met with the EFPIA AD Platform
8-9 APRIL	(Riga, Latvia) Daphné and Sonata attended the REBALANCE project workshop on public and patient involvement (PPI) in preclinical research and the translation process from preclinical to early human studies
9-10 APRIL	(Helsinki, Finland) Ana and Chris attended the General Assembly meeting of the LETHE project
11 APRIL	(Helsinki, Finland) Gwladys attended the Evento Awards
11 APRIL	Ange spoke at the DSAD~ADAD conference (Genetically determined AD: cross-fertilisation between Down Syndrome and Autosomal Dominant AD)
12 APRIL	Lukas presented at the Annual Conference of the Netherlands Psychiatric Association
12 APRIL	Ana, Daphné, Owen and Sarah met with members of the European Working Group of People with Dementia and the European Dementia Carers Working Group to discuss Alzheimer Europe's EU election campaign
15 APRIL	Sarah and Soraya participated in the JAIN Challenge meeting with the European Working Group of People with Dementia
17 APRIL	Ana, Daphné, Sarah and Soraya participated in a consultation with the European Dementia Carers Working Group
18 APRIL	(Belval, Luxembourg) Chris attended the book release event for "50 essentials on science communication", organised by the University of Luxembourg and the Luxembourg National Research Fund (FNR)
18 APRIL	Jean attended the EU4Health Civil Society Alliance meeting
19 APRIL	The Conference Organising Committee for the 36 th Alzheimer Europe Conference met
22 APRIL	Ange joined an AD-RIDDLE project meeting with industry partners
22-23 APRIL	(Bonn, Germany) Soraya attended the PANEUCARE project kick-off meeting
23 APRIL	(Belval, Luxembourg) Ange attended a Luxinnovation Info and Networking day
23 APRIL	(Kraków, Poland) Jean attended the Council Meeting of Alzheimer's Disease International
23-26 APRIL	(Kraków, Poland) Jean met with representatives of Acumen Pharmaceuticals, Alzheimer Polska, Alzheimer's Society, Global Brain Health Institute, Lilly, Nasjonalföreningen, Novo Nordisk, TauRx and the World Dementia Council.
24-26 APRIL	(Kraków, Poland) Ana, Gwladys and Jean attended the Conference of Alzheimer's Disease International
25-26 APRIL	(Brussels, Belgium) Ange attended the European Alzheimer's Disease Consortium meeting
29 APRIL	The Conference Organising Committee for the 34 th Alzheimer Europe Conference met
29-30 APRIL	Soraya participated in consultations with the ADIS Young Adults Advisory Board (ADIS YA-AB)
30 APRIL	Ana and Ange presented at a Luxinnovation webinar on collaborations with patient groups



EU PROJECTS

5 APRIL

New paper on "Caregivers' attitudes toward blood-based biomarker testing for Alzheimer's disease" published by ABOARD and MIRIADE projects



In this study, published recently in the journal Alzheimer's & Dementia, the researchers from the ABOARD and MIRIADE projects found that the majority of participants were in favour of blood-based biomarker testing for Alzheimer's disease (AD). They were able to identify perceived benefits and hurdles, which they say will play an important role in increasing acceptance and smoothen implementation of blood tests in the future.

Read the full article here:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10870798/>

9-10 APRIL

LETHE consortium meets in Helsinki for Annual Assembly

On 9 to 10 April, the H2020-funded LETHE consortium gathered for their fifth annual General Assembly meeting in Helsinki, Finland hosted by the Finnish Institute for Health and Welfare.

The meeting focussed on sharing updates about the latest activities from the project, which aims to develop a personalised prediction and intervention model for early detection and reduction of risk factors causing dementia. The models are based on Artificial Intelligence (AI) and distributed Machine Learning.

Next, Vasileios Loukas from Foundation for Research and Technology - Hellas (FORTH) and Helena Untersteiner from Medical University of Vienna, presented on the logistics and timing for the project substudies (these include the use of smart glasses as well as Temi robots). The substudies are aimed to explore the added benefit of using novel technology to improve user adherence as well as engagement with the LETHE app.



This was followed by a recap and discussion on open tasks that are tied to the clinical sites where the LETHE study is being conducted, shared by Elisabeth Stögmann from Medical University of Vienna and team. The ensuing presentation focussed on how personalised messages can motivate participants in using the application, led by Jeroen Bruinsma from Maastricht University. The afternoon sessions started with an introduction to the applications of the smart glasses that

will be used in the project substudies, by Mattia Pirani from i2Grow. This was a great opportunity for the partners from the clinical sites to test and explore the technology in an interactive way.

After that, the technical setup was discussed, including a recap as well as open tasks. Hannes Hilberger (FH Joanneum) explained the data flow and processing from collection to the study coordinators works, and Ignacio Lamata Martinez (EGI Foundation) provided an overview of current resources planned for the data processing.

This was followed by sharing communication and dissemination efforts. Jon Switters from the Lisbon Council gave an overview on the current Key Performance Indicators & Chris Bintener from Alzheimer Europe updated the consortium on the communication towards the Alzheimer's community, including participation at the Alzheimer Europe conference.

The second day of meeting opened with the Artificial Intelligence and data analytics plans discussed by Markus Bödenler from FH Joanneum & Thomas Kassiotis from Foundation for Research and Technology - Hellas.

After that, Matteo Colombo from i2Grow & Sten Hanke from FH Joanneum led the discussion on exploitation and data ownership.

Next up was Lelia Ataliani from Infotrend Innovations, who spoke about an update on the Data Management Plan, which ensures that our data is findable, accessible, interoperable and re-usable.

Nico Kaartinen from Kaasa solution GmbH then showcased the robot setup for LETHE substudies. Last but not least, Ana Diaz from Alzheimer Europe discussed next plans for the public involvement activities to ensure the project will have a meaningful impact for end users. The meeting concluded after a recap of the publication plans with many scientific papers being planned.

12 APRIL

ABOARD - Dutch project celebrates three years



The five-year ABOARD project celebrated its third anniversary this month. Led by Wiesje van der Flier Scientific director at Alzheimer Center Amsterdam, ABOARD is a public-private project which aims to prepare for a future in which Alzheimer's disease (AD) is stopped before dementia has started. This is being done by: improving diagnosis, developing personal risk profiles, initiating nationwide data collection with a focus on patient-reported outcomes, and a focus on prevention strategies. Colleagues from PGGM hosted the third anniversary event and the theme was "impact". Keynote speaker Craig Ritchie, shared his personal journey to make an impact on healthcare for patients with AD.

The project's researchers gave presentations, showcasing examples with societal impact, such as the discovery of the SORL1 gene as a novel genetic mutation causing AD (Henne Holstege), and apps supporting prognosis in the consultation room (Mathijs Rosbergen, Pieter van der Veere).

The first ABOARD scientific impact awards were given to Madison Honey, Pieter van der Veere, Lotte Truin and Hana Marie Broulíková. There was also a mentoring programme panel session, chaired by Irene Heger and Marco Blom (Alzheimer Nederland).

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

17 APRIL

Members of the Pattern-Cog Advisory Board meet online to discuss risk predictions for Alzheimer's disease in cognitively healthy people

On 17 April, members of the European Dementia Carers Working Group (EDCWG) who also serve as



the Pattern-Cog Advisory Board (Pattern-Cog AB) gathered online. The consultation was also attended by Ana Diaz (Public Involvement Lead, Alzheimer Europe), Daphné Lamirel and

Sarah Campill (Public Involvement Officers), and facilitated by Soraya Moradi-Bachiller (Public Involvement Officer, Alzheimer Europe).

During the consultation, members of the Pattern-Cog AB were presented a scenario where they would be given a risk prediction for cognitive impairment by their doctor. They were then asked what their views and opinions were about this risk prediction and what type of support they would expect and want from their national Alzheimer's associations.

Members who attended this meeting participated actively and provided insightful feedback during this consultation, which is part of a series of meetings that will help understand the needs cognitively healthy people might have in case of receiving a risk prediction for cognitive impairment, as well as how Alzheimer's associations can support this possible future scenario.

22–23 APRIL

Members of the PanEUCare expert group gather for the first time in Bonn



On 22-23 April, members of the PanEUCare expert group gathered for the kick-off meeting in Bonn (Germany) hosted by the German Center for Neurodegenerative Diseases (DZNE).

René Thyrian, researcher lead at DZNE and Board member at Alzheimer Europe, welcomed all the participants and paved the way for two days of informative and fruitful discussions. During the meeting, with representatives from 17 different countries, participants focused on sharing their national and regional gaps in health and social care for dementia, as well as on exchanging models of good practice between countries. PanEUCare expert group members also highlighted challenges in dementia diagnosis and post-diagnostic support services and care in their respective countries, and what the solutions could be to overcome these challenges.

Alzheimer Europe Public Involvement Officer Soraya Moradi-Bachiller attended the meeting, where she presented the findings of the European Dementia Monitor 2023 and explained how Public Involvement could help find solutions for the gaps and challenges in social and health care in the context of dementia. PanEUCare is an international EU Joint Programme - Neurodegenerative Disease Research (JPND) expert group of

scientists in the field of dementia care research with a focus on multidirectional knowledge transfer.

30 APRIL

PROMINENT updates on recent progress

PROMINENT is a collaborative pan-European public-private partnership funded through the Innovative Health Initiative (IHI) for five years. PROMINENT will create a digital platform for implementing precision medicine in neurodegenerative disease.



The first application of this platform is to assist clinicians with individualised decision support in the evaluation of patients with suspected cognitive impairment due to dementia. The goal is to help clinicians make optimal use of emerging technologies to diagnose and treat dementia disorders, such as new blood biomarkers and disease-modifying therapies for Alzheimer's disease.

As the consortium looks back at a fruitful collaboration in 2023, the project teams have been busy over recent months. This article provides an overview of the latest activities.

The prediction models and diagnostic algorithms team (Work Package 1 – WP1), led by Karolinska Institutet, established research questions, defined inclusion and exclusion criteria, designed a search strategy, based on which it performed a systematic scoping review on diagnostic and prognostic multimodal prediction models in Alzheimer's disease. The protocol for the systematic review has been published online: doi.org/10.17605/OSF.IO/ZKW6G

The deliverable report to the IHI about this work is about to be submitted and work on a peer reviewed publication about this in collaboration with members from Alzheimer Europe has started. You can read an interview with Xin Xia, who is leading on this work here: <https://www.ih-prominent.eu/spotlight-on-early-career-researchers-an-interview-with-xin-xia/>

In the pursuit to develop its own model to prediction disease courses in neurodegeneration, partners from the Barcelonaβeta Brain Research Center (BBRC) created a data template with the common fields between the model training cohort's data, using their data dictionaries as a reference. This document will be used as a basis for the inclusion of variables for the predictive models. Alzheimer Europe visited BBRC to learn more about their work and filmed them explaining the predictive modelling approaches as well as their usefulness. You can watch the videos here: <https://www.ih-prominent.eu/research-behind-the-scenes-with-oriol-grau-and-fer-ran-lugo-barcelona%ce%b2eta-brain-research-centers-involvement-in-the-prominent-project/>

The team responsible for the digital platform development (WP2) highlighted that the tool for DaTSCAN quantification,

cDAT, has received CE-marking and it is reviewed by Food and Drug Administration (FDA) for the US market.

An important part of the platform is cNeuro. This is a continuation of the previously developed PredictND tool. cNeuro is a so-called 'clinical decision support system (CDSS)', that combines all available clinical data, including demographics, neuropsychological test results, CSF biomarkers, APOE genotyping, and automatically defined MRI features (cMRI⁶⁰) to distinguish between the four most prevalent disease groups (Alzheimer's disease, Lewy Body Dementia, Frontotemporal dementia, and vascular dementia) and cognitively healthy controls. You can read an interview with Aniek van Gils, PhD student at Amsterdam UMC who recently published a paper on a usability study of cNeuro in memory clinics here: <https://www.ih-prominent.eu/spotlight-on-early-career-researchers-an-interview-with-aniek-van-gils/>

The development of patient and caregiver reports is currently ongoing with the incorporation of feedback from the PROMINENT Public Involvement Advisory Board which is led by Alzheimer Europe, you can read about the consultation here: <https://www.ih-prominent.eu/prominent-public-involvement-board-advises-project-researchers-on-the-design-of-the-clinical-studies/>

The third meeting of the Public Involvement Board will take place via Zoom on 29 May. During this meeting, the group will provide feedback on the clinical study protocol and participant-facing material.

The real-world evidence generation team (WP3) is near finalisation of the list of contact persons at relevant Health Technology Assessment (HTA) agencies in a selection of countries to approach for a survey and interviews. This survey is currently being developed and reviewed on an ongoing basis. Its goal will be to collect information from the HTA-agencies to identify key endpoints for follow-up and evaluation of novel disease modifying therapies.

The implementation, evaluation and validation study team (WP4) has prepared synopses for the evaluation and validation study, which is currently being circulated for feedback from all team members. Furthermore, they have started the process of identifying and contacting potential new partners for WP4 and held a consultation meeting with the Public Involvement Advisory Board to gather feedback on the design of the evaluation and validation study. You can read about the consultation here: <https://www.ih-prominent.eu/our-public-involvement-board-gathered-online-for-its-second-consultation/>

The dissemination, communication and dissemination team (WP5) has been busy with website updates, writing news posts referred to above, setting up the newsletter (which you can read [here](#)) and sharing interesting updates related to PROMINENT on social media channels. Make sure to subscribe to the channels to not miss out on news related to precision medicine in neurodegeneration: https://linktr.ee/IHI_PROMINENT

The project management team (WP6) is happy to report that the amendment 1 for the inclusion of FBHI, FINGERS Brain Health Institute as project participant has been accepted after an EU review. The interim financial report has been finalised and a financial webinar was held online in February. The online workshop included important EU/IHI rules, an introduction to the Participant Portal, tips on what is important to think of, and what underlying documents need to be saved to be compliant with EU rules.

The PROMINENT project has also initiated discussions with new clinical sites and one private member to onboard the project consortium.



Alzheimer's Society
Annual Conference
 Making dementia a priority for all
 14 May 2024
 etc.venues, 155 Bishopsgate,
 London and online

[Book your place](#)



Dementia Involvement Awards
 10 September 2024
 London

Alzheimer's Society
 Together we are help & hope
 for everyone living with dementia

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:

- LETHE - grant agreement 101017405 (<https://www.lethe-project.eu/>)
- Prominent - grant agreement 101112145 (<https://www.ihl-prominent.eu/>)



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



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SPONSOR OF THE MONTH

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

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



MEMBERS OF THE EUROPEAN ALZHEIMER'S ALLIANCE

Currently, the total number of MEPs in the Alliance stands at **96**, representing **26** Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance (EAA):



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

EU DEVELOPMENT

8 APRIL

Civil Society Organisations call for stronger action on long-term care



On 8 April, a group of 16 civil society organisations issued a joint call, urging the EU to take further action to implement the 2022 Council Recommendation on access to affordable high-quality long-term care. The call was issued to coincide with the Belgian Presidency's organisation of a high-level conference on the European Pillar of Social Rights on 15-16 April. As part of this, the organisations call on the European Union to set up a European Long-Term Care Platform under the next

legislature as part of the European Pillar of Social Rights Action Plan. This Platform would gather national coordinators on long-term care, national and EU-level civil society organisations representing and supporting persons in need of care and their families, and service providers, as well as social partners. The call envisages that an enhanced formal dialogue with civil society and social partners should also monitor investments in long-term care, as well as acting as a key channel for sharing of information about the European monitoring and evaluating procedures regarding national measures on long-term care. The full call is available at: <https://coface-eu.org/joint-statement-long-term-care-platform-2024/>

10 APRIL

European Parliament adopts position on revision of pharmaceutical legislation



On 10 April, the European Parliament adopted its position on the proposed reforms of EU pharmaceutical legislation.

The legislative package, covering medicinal products for human use, consists of a new directive (adopted with 495 votes in favour, 57 against and 45 abstentions) and regulation (adopted with 488 votes in favour, 67 against and 34 abstentions).

The Parliament has proposed a minimum regulatory data protection period (during which other companies cannot access product data) of seven and a half years, in addition to two years of market protection (during which generic, hybrid or bi-similar products cannot be sold), following marketing authorisation.

Furthermore, pharmaceutical companies would be eligible for additional periods of data protection if their particular product addresses an unmet medical need (+12 months), if comparative clinical trials are being conducted on the product (+6 months), and if a significant share of the product's research and development takes place in the EU and at least partly in collaboration with EU research entities (+6 months). However, MEPs also want a cap on the combined data protection period of eight and half years.

A one-time extension (+12 months) of the two-year market protection period could be granted if the company obtains marketing authorisation for an additional therapeutic indication which provides significant clinical benefits in comparison with existing therapies. Orphan drugs (medicines developed to treat rare diseases) would benefit from up to 11 years of market exclusivity if they address a "high unmet medical need".

The file will be followed up by the new Parliament after the 6-9 June European elections. Further information on the Parliament's position is available at:

<https://www.europarl.europa.eu/news/en/press-room/20240408IPR20308/parliament-adopts-its-position-on-eu-pharmaceutical-reform>

16 APRIL

Belgian Presidency holds summit on European Pillar of Social Rights

On 16 April, at the conclusion of a High-Level Conference on the European Pillar of Social Rights EPSR hosted by the Belgian Presidency in La Hulpe in Belgium, the EU, social partners and civil society have renewed their commitment to a stronger social Europe.

At the event, the European Parliament, the European Commission, Belgium on behalf of the other 26 EU Member States

and the European Economic and Social Committee, amongst others, signed a Declaration on the Future of the EPSR. In the declaration, they pledge to continue implementing the EPSR. The text proposes initiatives for the EU's future social agenda in the next legislative term and reaffirms the Pillar as the guiding framework for EU social policies. The renewed commitment agrees to:



- Review and update the EPSR Action Plan in 2025 and propose new actions at EU level to achieve the 2030 EU headline targets for employment, skills and poverty reduction.
- Intensify the EU's equality, anti-discrimination and anti-racism strategies to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation through an intersectional approach.
- Develop an ambitious second phase of the 2021-2027 Strategy for the Rights of Persons with Disabilities and mainstream the disability perspective in EU-policies.
- Further mainstream the EPSR in all relevant policy domains, strengthen the use of distributional impact assessments and promote sustainable public procurement.

The full La Hulpe Declaration is available at: <https://belgian-presidency.consilium.europa.eu/en/news/eu-social-partners-and-civil-society-renew-their-commitment-to-a-social-europe/>

24 APRIL

European Commission launches Critical Medicines Alliance

On 24 April, the European Commission's Health Emergency Preparedness and Response Authority (HERA) launched the Critical Medicines Alliance bringing together national authorities, industry, healthcare organisations, civil society representatives, the Commission and EU agencies to identify the best measures to address and avoid shortages of critical medicines.



The Alliance will focus on industrial policy and complements the reform of the EU's pharmaceutical legislation. It has 250 registered members, including ministries of governmental agencies representing Member States, industry representatives and non-governmental organisations. The Alliance has three overarching strategic goals:

- Work to enhance security of supply
- Strengthen availability of medicines
- Reduce EU supply chain dependencies.

To strengthen security of supply, the Alliance will develop strategic recommendations to address and avoid shortages. Key

factors being analysed include an over-dependency on a limited number of external suppliers, limited diversification possibilities, and limited production capacities. The recommendations will form together of a multi-year 'Strategic Plan', containing milestones and corresponding deadlines for their implementation.

The Alliance will also look at how market incentives, such as the possibility to expand the use of capacity reservation contracts and joint procurement can be used to enhance security of supply of critical medicines.

POLICY WATCH

9 APRIL

WHO issues call for public consultation on preferred product characteristics of blood-based biomarker diagnostics for Alzheimer's disease



On 9 April, the World Health Organization (WHO) issued a call for public consultation on its preferred product characteristics (PPC) of blood-based biomarker diagnostics for Alzheimer's disease (AD).

The deadline to respond is **10 May 2024**.

Receiving a timely and accurate AD diagnosis is a prerequisite for accessing services and support for the person, families, and care partners. Currently, a diagnosis of AD is based on clinical judgement, which can be supported by imaging techniques and laboratory analysis of cerebrospinal fluid (CSF). However, there is a global shortage of qualified health professionals and access to imaging and CSF analysis is similarly limited, particularly in low- and middle-income countries (LMICs), where the number of specialised healthcare workforce is significantly lower and health systems' infrastructure and funding is unable to sustainably provide such services to populations.

Scientific evidence on the use of blood-based biomarkers to support the diagnosis of AD has shown promising advances in recent years. However, current AD blood tests are being investigated in highly resourced, carefully controlled clinical settings and in populations with limited diversity. The real-world implementation of AD blood tests requires further validation on a larger scale, considering the clinical contexts in which they will be utilized particularly in LMICs.

Biomarker tests are needed to support the diagnosis of AD to benefit people and carers around the world. Such tests are

The Alliance is launched for a period of five years. Its first recommendations on actions are foreseen by the end of the year. More details on the Alliance are available at: https://ec.europa.eu/commission/presscorner/detail/en/ip_24_2229

essential to rule-in or rule-out AD and support clinical decision-making.

WHO Preferred Product Characteristics (PPCs) are technical documents that define the preferred attributes of diagnostic products for regulatory purposes, policy, and programmatic implementation. This WHO PPC will be a timely publication to promote the development of diagnostic products using emerging technologies and ensure that these will not only exhibit optimal clinical performance but also be relevant to different populations, affordable and available to those who need it.

The WHO is seeking feedback on the draft PPC from experts in the industry, product developers, the scientific community, people with lived experience and clinicians currently involved in the diagnosis and management of AD. Details of the PPC can be found below (please use the file 'table for feedback' to provide your inputs). You are welcome to provide comments as an individual or as a representative of a group:

[Preferred product characteristics \(Context and background\)](#)

[Draft Preferred product characteristics \(Table for feedback\)](#)

Proposed revisions arising from the public consultations will be considered by the PPC working group before it is finalised. The final PPC will guide the development and implementation of blood-based biomarkers for the diagnosis of AD.

If you have any comments, please send them using the 'table for feedback' file and use the email subject line AD blood-based biomarkers PPC feedback and submit it to: brain-health@who.int

<https://www.who.int/news-room/articles-detail/call-for-public-consultation--preferred-product-characteristics-of-blood-based-biomarkers-for-the-diagnosis-of-alzheimer-disease>

SCIENCE WATCH

24 MARCH

New study highlights global burden of disorders affecting nervous system



On 24 March 2024, The Lancet journal published the results of a landmark global study, a systematic analysis of people with disorders affecting the nervous system from 204 countries and spanning 31 years. The focus of this study was to assess the global, national and regional burden of nervous system disorders.

orders.

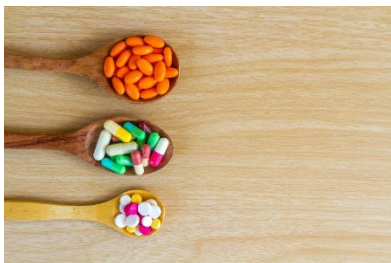
Of the 37 nervous system disorders studied, Alzheimer’s disease (AD) and other dementias was second on the list of disorders in terms of DALYS (disability-adjusted life-years) for people over 60 years, second only to stroke. When looking at the age-standardised DALY rates, AD and dementia were fourth overall in terms of impact. The global burden of disorders affecting the nervous system has increased during the study period and now represents the greatest overall disease burden in the world.

The authors call for effective prevention, treatment and rehabilitation strategies for these disorders, stating that “Resources for nervous system conditions should therefore span the entire care continuum, including prevention, diagnosis, treatment, rehabilitation, long-term care, and palliation.”

[https://doi.org/10.1016/S1474-4422\(24\)00038-3](https://doi.org/10.1016/S1474-4422(24)00038-3)

1 APRIL

New statistical analysis approach identifies “time saved” for participants in the LipiDiDiet clinical trial



A brief communication, published last month in the Journal of Prevention of Alzheimer’s Disease (JPAD), has used a new statistical analysis approach to show

that 24 months of treatment with a multinutrient supplement may be linked to a 9-10 month “time saving” in terms of cognitive decline.

LipiDiDiet was a double-blind, multi-centre randomised clinical trial designed to assess the safety and efficacy of a multinutrient supplement, Fortasyn Connect, compared to a control

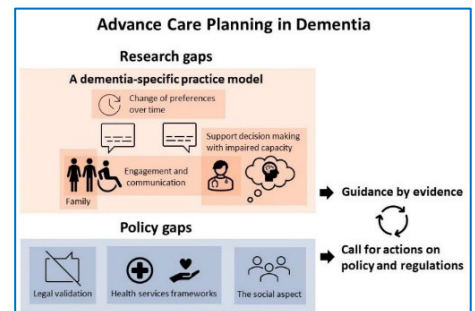
product, for people with prodromal Alzheimer’s disease (AD) or mild cognitive impairment. Fortasyn Connect, also known as Souvenaid, is a commercially-available multinutrient supplement that contains a number of vitamins and minerals. A 24-month analysis of LipiDiDiet data showed improvements on the Clinical Dementia Rating Sum of Boxes (CDR-SB) scale, but no improvement on the Neuropsychological test battery (NTB) scale. The study also evaluated changes in brain structure, using MRI scans.

Assessment of meaningfulness in clinical trials for Alzheimer’s disease is challenging, particularly in early disease. Converting clinical outcomes to disease progression time can help people to understand the value of an intervention on a scale that is meaningful to many people with Alzheimer’s disease: time. In the newly-published study, which was led by statisticians Susanne Hendrix and Samuel Dickson, a statistical analysis technique known as a “Time Component Test” (or TCT) was applied to the results of the LipiDiDiet trial. This approach can be applied to multiple outcome measures, combining the results across measures to compute the “time saved” by an intervention. Dr Hendrix and Dr Dickson applied the TCT technique to results from the CDR-SB and NDB scales, and the MRI measurements of hippocampal volume, for participants receiving Fortasyn Connect for 24 months. When the three domains were combined, an average time saving of 9 months with Fortasyn Connect was computed, when compared to the scores for individuals in the placebo arm of the trial.

9 APRIL

Consensus recommendations on future policy and research for advance care planning in dementia published by international Delphi panel of European Association for Palliative Care

To progress advance care planning (ACP) with people with dementia and their family has been a goal of the European Association for Palliative Care



taskforce ACP in dementia. A Delphi study with panellists from 33 countries across the globe reached a consensus on how ACP is defined to include persons with dementia in all stages

of their disease and their family caregivers, and on policy and research gaps.

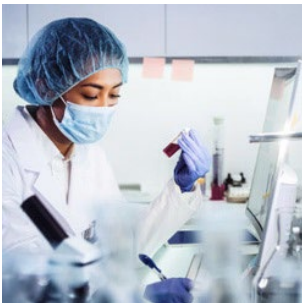
The most recent paper, published on 9 April in The Lancet Healthy Longevity, addresses recommendations for policy and research. Eleven recommendations concern the regulation of advance directives, equity of access, and dementia-inclusive approaches and conversations to express patients' values. Identified research gaps included the need for an evidence-based dementia-specific practice model that optimises engagement and communication with people with fluctuating and impaired capacity and their families to support decision making, while also empowering people to adjust their decisions if their goals or preferences change over time. Policy gaps included insufficient health services frameworks for dementia-inclusive practice.

The results highlight the need for more evidence and policy development that support inclusive ACP practice models. The consensus-based recommendations and identification of research and policy gaps provide key starting points for discussion across multiple stakeholders including people with dementia.

[https://doi.org/10.1016/S2666-7568\(24\)00043-6](https://doi.org/10.1016/S2666-7568(24)00043-6)

11 APRIL

Roche receives FDA breakthrough device designation for AD blood test



On 11 April, Roche announced that its blood test, Elecsys pTau217, has been granted breakthrough device designation from the US Food and Drug Administration (FDA) for earlier diagnosis of Alzheimer's disease (AD).

The blood test, which is being developed in collaboration with

Eli Lilly, works to identify the presence or absence of amyloid pathology, a pathological feature of AD. Elecsys pTau217 is intended to be an in-vitro diagnostic immunoassay for the quantitative determination of the protein pTau217 in plasma from people aged 60 years and older. According to the press release, pTau217 is a phosphorylated fragment of the protein tau, used as a biomarker to distinguish AD from other neurodegenerative disorders.

A positive Elecsys pTau217 result indicates a high likelihood of having a positive amyloid positron emission tomography (PET)/cerebrospinal fluid (CSF) result, while a negative Elecsys pTau217 result indicates a high likelihood of having a negative amyloid PET/CSF result. The pTau217 result should be used in the diagnostic pathway in conjunction with other clinical information, the company said.

If approved, the test will aid healthcare providers in identifying amyloid pathology. Both companies believe that the test could

help broaden and speed access to diagnosis and appropriate care, including participation in clinical trials and access to approved disease-modifying therapies.

The Breakthrough Devices Program is a voluntary program for certain medical devices that provide for more effective treatment or diagnosis of a life-threatening or irreversibly debilitating disease or condition. This program is designed to expedite the development and review of these medical devices.

<https://diagnostics.roche.com/us/en/news-listing/2024/roche-granted-fda-breakthrough-device-designation-ptau217-blood-test-support-earlier-alzheimers-disease-diagnosis.html>

15 APRIL

Recent study addresses major gaps and outlines solutions for Lewy Body Dementia

A recent paper by Kanishka Agarwal and colleagues aims to address and bridge the major gaps in Lewy Body Dementia (LBD) by mapping the current landscape based on ex-



pert interviews, literature and database analysis, and desk research. The main areas of focus were:

advocacy and awareness

funding

research

pharmaceutical and biotechnology industry activity

patient impact.

The research team identified critical gaps across the board with particularly important gaps in LBD research. To close the gaps they suggest the development of standardised and validated assessment and diagnostic tools, and the introduction of consistent metrics and outcome measures to ensure accurate early diagnosis. Furthermore, the authors outline the importance of establishing reliable diagnoses for LBD, by understanding the disease progression and its patterns of co-morbidity with Alzheimer's dementia and Parkinson's disease, creating accessible biomarkers, and increasing longitudinal patient studies to transform the LBD therapeutic landscape and patient experience. Increasing funding and public awareness campaigns to support advancements in LBD research is another factor that was highlighted in the viewpoint paper, that might enable innovation in the field.

These recommendations for change could lead to enhanced clinical research, facilitate more effective therapeutic trials, likely accelerate the development of treatments, and ultimately lead to improved patient care, awareness, and advocacy. The study was published in the journal Alzheimer's & Dementia. To learn more about the paper by Agarwal et al. follow the link:

<https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.13674>

15 APRIL

AviadoBio initiates Phase I/II trial for AVB-101 in frontotemporal dementia



On 15 April, the UK-based biotechnology company AviadoBio announced the initiation of its Phase I/II ASPIRE-FTD trial evaluating AVB-101 in people with frontotemporal dementia (FTD) with progranulin (GRN) gene mutations.

AVB-101 is a potential one-time therapy designed to stop disease progression by delivering a functional copy of the GRN gene to restore appropriate progranulin levels to affected areas of the brain. The open-label and multi-centre trial aims to evaluate the safety and efficacy of AVB-101, which is administered directly to the part of the brain called the thalamus.

AVB-101 was administered to the first participant in the ASPIRE-FTD trial at the Interventional Neurotherapy Center at Mazowiecki Szpital Bródnowski Hospital in Warsaw, Poland. Clinical trial sites are currently open in Poland, Spain and the Netherlands. The company plans to expand the trial to additional countries, including the US.

In November last year, AVB-101 received fast-track designation from the US Food and Drug Administration (FDA). Fast Track is a process designed to facilitate the development and expedite the review of new drugs to treat serious conditions and fill an unmet medical need. AVB-101 has also received orphan drug designation by both the FDA and European Commission.

<https://aviadobio.com/first-patient-treated-in-aspire-ftd-clinical-trial/>

16 APRIL

Recent study explores possible link between HSV-1 (Herpes Simplex Virus) and dementia



A recent study published in the Journal of Alzheimer's Disease (issue 97, 2024) entitled "Herpes Simplex Viral Infection Doubles the Risk of Dementia in a Contemporary Cohort of

Older Adults: A Prospective Study" explored the possible link between HSV-1 (Herpes Simplex Virus) and dementia, stating that a serum presentation of anti-HSV IgG is associated with a doubled risk of developing dementia. This study also looked at HSV-2 and CMV (cytomegalovirus) but found no link. Of the cohort of 1,002 Swedish people over the age of 70 without

Alzheimer's disease or dementia who were followed for 15 years, 4% developed AD and 7% (69) developed other dementias. Lead author Erika Vestin pointed out that, although this study confirms results of prior studies, it is not yet sufficient to establish causality.

The incidence of dementia is increasing worldwide and is currently affecting more than 55 million people. HSV-1, which results in cold sores and remains in the body for life, is prevalent in up to 80% of the population by retirement age, but the possible link between the two needs to be explored further, in order to glean enough evidence to assess causation.

The study, published in the Journal of Alzheimer's Disease, can be viewed, here: <https://content.iospress.com/articles/journal-of-alzheimers-disease/jad230718>

17 APRIL

New analysis of biomarker data from the AHEAD study shows that amyloid levels differ across ethnic groups, which may affect participant diversity in clinical trials

A new study, published in the Alzheimer's & Dementia journal, shows that people from certain ethnic groups may be ineligible for Alzheimer's disease clinical trials because they have lower levels of amyloid protein at early stages of the disease – underscoring the importance of adapting eligibility criteria to maximise inclusion and diversity.

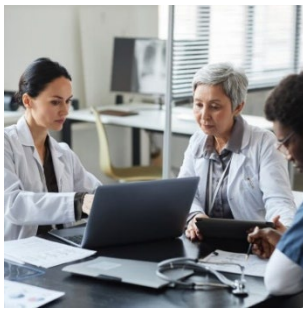


It has long been recognised that some of the groups most likely to get dementia, such as people from minority ethnic groups, are greatly underrepresented in clinical trials. Underrepresentation of these groups in trials can limit the translation of study findings in the real world, as interventions may not benefit all populations at risk. Amyloid biomarker measurements are increasingly being used to determine eligibility for clinical trials, however differences in levels of amyloid biomarkers between ethnic groups could contribute to the inadvertent exclusion of these groups from studies. To understand this issue in the context of a real-world clinical trial, researchers turned to the AHEAD 3-45 study, which is designed to assess the safety and efficacy of lecanemab in preclinical (pre-symptomatic) Alzheimer's disease. Biomarkers play a particularly prominent role in recruitment for these studies, at a stage of Alzheimer's disease when symptoms are not yet present. Researchers from the Keck School of Medicine (Los Angeles, USA) collected blood tests and brain scans from 4,905 participants, ages 55 to 80, from a wide range of ethnic groups. Based on blood tests designed to detect levels of amyloid,

non-Hispanic Caucasian groups were most likely to meet eligibility cut-offs for clinical trials. People who identified as Hispanic Black, Hispanic white, non-Hispanic Asian and non-Hispanic Black were significantly less likely to be eligible for studies based on amyloid levels in the blood when compared to non-Hispanic white counterparts. Participants who were eligible based on blood tests also underwent brain PET scans that are used to directly measure amyloid build-up in the brain. Among those who met the blood test cut-off, individuals from all ethnic groups were equally likely to be eligible to participate based on PET scan data. According to the authors, This suggests that the cut-offs for eligibility are adequate, but also point to a paradox where some groups may have a higher risk of dementia but lower levels of amyloid. As a result, treating those groups may require a different approach.

17 APRIL

Biogen continues to advance BIIB080 in early Alzheimer's disease



Earlier this year, the global biotechnology company Biogen announced its decision to discontinue development and commercialisation of aducanumab for early Alzheimer's disease (AD), continuing to advance lecanemab and accelerating BIIB080, an antisense oligonucleotide (ASO) targeting

tau. BIIB080 is the first tau targeting ASO to enter human AD clinical trials.

Findings from a Phase Ib trial in people with AD showed that BIIB080 was generally well tolerated with favourable trends on multiple exploratory endpoints of cognition and activities of daily living in AD, building upon prior results which showed a reduction of tau protein in the cerebral spinal fluid (CSF t-tau) and tau positron emission tomography (PET) across brain regions.

These findings support further investigation of BIIB080 in the ongoing CELIA phase II trial evaluating its efficacy, safety and tolerability in people with mild cognitive impairment (MCI) due to AD or mild AD dementia. The company plans to enrol 735 participants aged 50-80 years who will receive either a low dose or high dose of BIIB080, or a placebo, as an injection into the fluid around the spinal cord once every 12 weeks or 24 weeks. The primary outcome is the dose response in change of CDR-SB from baseline after 76 weeks. Secondary measures include ADCS-ADL-MCI, ADAS-Cog 13, MMSE, iADRS, ADCOMS and adverse events. After 76 weeks of treatment, eligible participants will move in the Long-Term Extension Period, where all participants will receive the drug for

an additional 96 weeks. The trial is being carried out in around 140 sites across North America, Europe and Asia.

The University College London Hospitals NHS Foundation Trust (UCLH) has recruited the first participant in the UK into the CELIA trial. Dr Catherine Mummery is leading the trial which is taking place at the NIHR UCLH Clinical Research Facility. The recruitment for this study is also opened in Oxford. The CELIA study in Oxford is a collaboration between Oxford Health Clinical Research Facility (OH CRF), Oxford University Hospitals Clinical Research Facility (OUH CRF) and Oxford University Hospitals Pharmacy and Neurology departments.

<https://www.uclh.nhs.uk/news/uclh-trial-world-first-treatment-alzheimers-disease-progresses-larger-trial>

25 APRIL

Recent meta-analysis reports association between glucose metabolism and Alzheimer's disease-biomarkers

While epidemiological evidence suggests a link between diabetes mellitus and Alzheimer's disease, studies examining associations with Alzheimer's disease biomarkers report conflicting results. A recent meta-analysis study led by the Alzheimer Centre Limburg (Maastricht University), and published in the journal *Neuroscience and Biobehavioral Reviews*, examined associations between different measures of glucose metabolism and Alzheimer's disease biomarkers. The authors analysed and combined 37 studies examining type 2 diabetes status, levels of glycated haemoglobin and fasting blood glucose as well as insulin resistance in relation to amyloid beta and tau.



They found that, while a more impaired glucose metabolism was associated with higher levels of tau (as measured in cerebrospinal fluid and via PET scans), this was not the case for amyloid-beta. The authors concluded that diabetes mellitus may be associated with dementia via a different pathway than amyloid-beta. The full open-access article can be read here:

<https://www.sciencedirect.com/science/article/pii/S0149763424000733?via%3Dihub>

MEMBERS' NEWS

19 MARCH

Alzheimer Athens organises "Caregiver's day" 2024



There are 250,000 people living with dementia in Greece and more than 500,000 family caregivers. Compared to existing needs, services provided to them are still inadequate. In order to acknowledge and support the challenging role of caregivers, Alzheimer Athens established for the past 17 years an annual event called "Caregiver's day". This year's event was a whole

day conference with morning sessions for health professionals and afternoon sessions for family caregivers and took place on 19 March at Megaron Athens Concert Hall. The title of the conference was "There is care, there is hope". Both sessions opened with a lecture by Dr Paraskevi Sakka, President of Alzheimer Athens, titled "Dementia in Greece today" followed by the lectures of 14 distinguished health scientists who informed the participants about the latest scientific developments in the field of dementia, prevention methods, new pharmaceutical treatments, non-pharmaceutical psychosocial interventions and available services and interventions for patients and caregivers. They provided answers to questions and concerns, guidance and hope to the audience. The event closed with a concert by the music ensemble of the Department of Music Studies of the National and Kapodistrian University of Athens. It was a great success, more than 900 caregivers participated, and many new members joined the association. Alzheimer Athens is really happy and proud that many other Greek Alzheimer associations adopted "Caregiver's day" and organised similar events for caregivers of people with dementia during March 2024 all over Greece.

22 MARCH

Alzheimer's Association of Turkey invites you to complete "Dementia Awareness Questionnaire" as part of Turquoise Project: Bridge Between Community and Dementia Research

Türkiye Alzheimer Derneği, the Alzheimer's Association of Turkey is pleased to share details of a collaborative academic project being carried out by researchers at some of the top

universities in Turkey, and encourages Alzheimer Europe's newsletter readers to complete a survey linked to the project. This survey, the "Dementia Awareness Questionnaire", aims to help the researchers gather feedback from as many different nationalities and cultures as possible. It is being conducted within the scope of "Turquoise Project: Bridge Between Community and Dementia Research" by Assistant Professor Dr Didem Öz.

If you volunteer to participate in the study, you will be asked to fill out a demographic information form that will take approximately five minutes, as well as a Dementia Information Survey consisting of 20 questions. You will not be asked to give personal identifying information such as your ID number, name or surname. The information you provide will only be used for the scientific research project. This study is conducted with the collaboration of the American Alzheimer's Association, Dokuz Eylül University, Istanbul University and Koç University.

For more information about the project, visit: <https://doi.org/10.29399/npa.28152>

To complete the survey, visit:

<https://docs.google.com/forms/d/e/1FAIpQLScgQwL4gq48bA1cJezucub5C94EM3zyISQChXgcXopaT9png/view-form?vc=0&c=0&w=1&flr=0>

DEMENTIA AWARENESS QUESTIONNAIRE (google.com)

25 MARCH

Alzheimer's Care Armenia collaborates with Armenia National Institute of Health for ground-breaking conference on Alzheimer's disease

On 25 March, Alzheimer's Care Armenia in partnership with Armenia National Institute of Health successfully hosted a conference called "From early detection to end-of-life: An interdisciplinary approach to Alzheimer's Disease".

The event started with a moment of silence in honour of the late Professor Mikayel Aghajyanov, a distinguished scientist and former head of the biochemistry department at Yerevan State University.

"We are delighted to spearhead this vital initiative. With dementia affecting an increasing number of people worldwide, innovative solutions to raise awareness and address the needs of the adults with cognitive impairment are imperative," stated Dr Jane Mahakian, American-Armenian gerontologist and founder of Alzheimer's Care Armenia.

Dr Samson Khachatryan, Deputy Director of the National Institute of Health, underscored the significance of the conference in his opening remarks and highlighted recent advancements in Alzheimer's research, disease prevalence, and preventive measures.

Guest speaker Dr William Shankle, Medical Director of the Shankle Clinic in Newport Beach (California) presented virtually on testing the Cytotoxic Aggregated Misfolded Polymorphic Structures (CAMPS) hypothesis.

Dr Kristine Galstyan, Chief Public Specialist at the Republic of Armenia Ministry of Health, emphasised the ministry's commitment to addressing dementia-related challenges. She highlighted the inclusion of dementia awareness initiatives within the National Dementia Plan aimed at enhancing public understanding of Alzheimer's disease and preventive measures.

The conference, tailored for primary care physicians, therapists, neurologists, and psychiatrists, featured presentations from various experts and international guests. The conference, which was also available on Facebook live, included 516 attendees. They gained insights into different approaches employed worldwide and had the opportunity to engage with experts, receiving answers to pertinent questions.



17 APRIL

A decade of impactful advocacy: 'The Dementia Carers Campaign Network' marks 10 years

On 17 April, The Dementia Carers Campaign Network (DCCN) marked a significant milestone as they celebrated their 10th Anniversary at an event in Dublin. Minister of State for Mental Health and Older People, Mary Butler TD, joined



The Alzheimer Society of Ireland's (The ASI) DCCN in honouring the advocacy group's decade-long commitment to advocating for those caring for people living with dementia. The event, kindly hosted by the Lord Mayor of Dublin, Daithí de Róiste, at the Mansion House, highlighted the impactful work of the DCCN since its inception in 2014.

The DCCN is a group of people who have experience caring for and supporting a person living with dementia. Established with the support of The ASI, the group aims to be a voice of, and for, dementia carers in Ireland and to raise awareness of issues affecting families living with dementia. Supported by Judy Williams, Advocacy, Engagement and Participation Officer at The ASI, the DCCN has become a powerful voice for those caring for people living with the condition. In the past decade, the DCCN has made significant strides in amplifying the lived experience of dementia carers in Ireland.

Through their work, the group brought the voices of dementia carers and supporters to the forefront, challenging stigma and driving increased funding for dementia supports. Members have contributed to national policy, most critically, to Ireland's 'National Dementia Strategy' and the 'Model of Care for Dementia' in Ireland. They have supported The ASI to develop resources, raise funds and undertake political advocacy. The DCCN has undertaken many media engagements to ensure carer voices are heard and it has contributed thousands of volunteer hours in research, policy, and practice development.

23 APRIL

Alzheimer Bulgaria is training students to work with people with dementia

In 2024, the "Non-medical therapies for maintaining cognitive ability in people with dementia project" was launched. It was funded by the TELUS International Public Board Foundation in Bulgaria and has a value of BGN 14,957 (Bulgarian currency). Its aim is to provide knowledge, skills and practical experience to 20 students from the Bulgarian cities of Sofia and Pleven who chose to qualify in the fields of psychology, social work and healthcare. The information sessions were launched in Sofia and Pleven.



In April and May, the students will undergo specialised trainings led by Alzheimer Bulgaria. By October, the participants will have the opportunity to apply the provided knowledge in residential care homes for people with dementia, and to be of assistance to selected families caring for their loved ones. The project includes adapted activities to 80 people with dementia and will help enhance their cognitive skills and emotional well-being.

29 APRIL

Alzheimer Hellas presents a project with dance and neuro-degenerative disorders at its heart



Tango Training started in March in the University of Bourgogne

A multidisciplinary team from France and Greece, joined by artists, health care professionals, psychologists, physiotherapists, therapists, and caregivers, shared their knowledge and energy to create the best interventions for patients with Alzheimer's Disease.

"Dance away your fears and embrace your hopes."

Weekly Lessons

Live Music: Greek Traditional Dances from Tango to Sirtaki

The second part of the project will be devoted to Greek Traditional Dances. French and Greek will embrace the Greek music and spirit.

After Research project aims to detect the positive effect of Dancing on a Cross-Cultural level.

The 2nd round starts in September 2024

1 Name: Alzheimer Hellas
2 Email: hellas@alzheimerhellas.org
3 Address: 2003 Athina, Greece | Contact: 00357 2103434343

ABB Reportages, an ERASMUS+ project, is a cross-cultural collaboration between France and Greece that sets dance and neuro-degenerative disorders at its heart. Through training, workshops, creation, and research, this project opens a pathway for seniors coping with neuro-degenerative disorders like Alzheimer's disease to become involved in a process of cultural creation based on

tango and Greek dance, that will be exposed to a wider public at The Seniors Tangueros Olympiads 2024. Both tango and Greek dances are recognised by UNESCO as intangible heritage. Furthermore, this is a creative project that culminates during the Olympiads where they will be able to meet and exchange with other seniors and healthcare workers from Greece

and beyond, enhancing international collaboration and a feeling of belonging.

The project started in March and the "therapeutic tango training" took place in France. A micro-credential was provided by the University of Bourgogne to the participants attending this four-day training, in order to autonomously perform tango for elderly people. On behalf of Alzheimer Hellas, two professionals received this training to implement the workshops in Thessaloniki, in line with the vision of the project.

The training was dedicated to professional caregivers, such as assistants in gerontology, nurses, neurologists, psychologists, art therapists, but also dancers, musicians, sports students of adapted sport, interns, volunteers, and families. It also welcomed different nationalities. This heterogeneous group then came together with elderly people and their own caregivers making it an inter-generational project combining different ages and backgrounds; creating and promoting learning opportunities among all citizens and generations.

The tango workshops are based upon the Dinzel method adapted to the needs and capacities of older people, specifically those affected by Alzheimer's. This approach aims at rehabilitating elderly people by stimulating their motor capacities, but reaches further as it encompasses both the didactic and the therapeutic aspects, tackling both physical and mental health, and well-being.

The expertise of Alzheimer Hellas in research concerning ageing is extremely important to this project. The wide variety of adapted activities it offers, promoting learning and well-being for older people with neuro-degenerative issues, lead to great field experience which is necessary to this project.

LIVING WITH DEMENTIA

3 APRIL

Pia Knudsen, member of the European Working Group of People with Dementia features in national Danish magazine SØNDAG



SØNDAG is a Danish language weekly lifestyle magazine which is headquartered in Copenhagen, Denmark. Launched in 1921 it is one of the oldest publications in the country. In late 2023, an article appeared in the publication, featuring Pia Knudsen, who is a member of the European Working Group of People with Dementia. She was diagnosed with Alzheimer's disease in 2021, during the COVID-19 pandemic and joined the group in 2022. She was 57 years old at the time.

The article in SØNDAG highlights how Pia came to be diagnosed and how she is coping with life now. It stresses that life can still be good, with dementia, but also mentions some of the difficult things Pia has experienced, such as losing her beloved teaching job, and her partner leaving.

When things began to re-open after COVID, Pia began attending "The Dementia Corner" (DemensHjørnet), which is a training offered by Aarhus Municipality, for people in the early stages of dementia. She also joined and the Dementia Community East Jutland, which is open to people with dementia and their relatives. Three times a week, she goes to physical and cognitive training to slow the progression of the disease, as well as participating in several of the Dementia Association East Jutland's activities. She continues to enjoy her life, despite Alzheimer's,

spending free time socialising and walking in the great outdoors, as well as doing activities and advocacy work for people with dementia, including with the EWGPWD.

16 APRIL

Former family carer and Public Patient Involvement representative Carmel Geoghegan shares her involvement in recent mySupport study and subsequent newly-launched In-Touch trial

The mySupport study

In 2020, I became a member of the Public Patient Involvement representatives on the EU Joint Programme for Neurodegenerative Disease (JPND)-funded mySupport study. The main aim was to adapt, implement and evaluate a previous study intervention, Family Carer Decision Support (FCDS), in six countries. As a former primary carer who cared for my mum who lived with mixed dementia (I cared for her till end of life) this is a very important subject. My mum was refused palliative care by a general practitioner because she had not been diagnosed with cancer.

The Comfort Care booklet and Question Prompt List were developed in Canada in 2005, by family physician Marcel Arcand who practiced in nursing homes. He noticed how families struggled to come to terms with what is good care for their loved ones near end of life. The booklet was devised from research, practical and personal experience. It was a core part of the mySupport study, as it had been identified as an area that needed highlighting and some structural guidance. Palliative care was not readily available to residents diagnosed with dementia and the booklet highlights that dementia is a terminal disease and that a palliative approach to care is therefore appropriate. It provides information about the trajectory of the disease and possible complications, options to manage issues such as feeding difficulties and pneumonia, symptom management and comfort care, the decision-making process, the dying process and grief. The aim of the booklet is to inform family caregivers of the disease progression, to help them actively participate in conversations regarding their relative's care needs.

The findings from FCDS were:

- **Adapt** the Comfort Care Booklet and a Question Prompt List for each country participating in the study.
- **Implement** the Comfort Care Booklet with Question Prompt List in nursing homes for people with advanced dementia using Family Care Conferences or meetings.
- **Evaluate** the impact of the intervention on family carers and nursing homes.

This work was all carried out during COVID-19, so all our communication was through Zoom and emails. I feel this experience has strengthened our collaboration and shown that it is possible to achieve very important research through the power of technology. Find out more about the mySupport study: <https://mysupportstudy.eu/>

The In-Touch trial

The University College Cork (UCC) School of Nursing and Midwifery recently hosted a kick-off event for the In-Touch trial, which has been granted EUR 7.5 million in funding from Horizon Europe. In-Touch will run over five years, from 2024 to 2028, and the intervention being explored in this trial builds on the work of the mySupport study. I was delighted to attend the kick-off meeting in my capacity as a Public Patient Involvement representative, alongside Helen Rochford Brennan, who is living with dementia and is also a Public Patient Involvement representative.



The ambition is that In-Touch will enhance the lives of people with dementia living in care homes through a multisensory care programme approach to improve their dignity and quality of life, whilst also supporting their families in decision making. In-Touch is coordinated by UCC Principal Investigators Professor Nicola Cornally (School of Nursing and Midwifery) and Professor Suzanne Timmons (School of Medicine). It has an international consortium of partners from across the EU, UK, and Canada. Representatives from all partner organisations, as well as patient and public representatives of people with dementia and family members. Director of Namaste Care International, Rishi Jawaheer, and Dr Hanneke Smaling, were invited to share insights on Namaste that will be part of the overall intervention. In-Touch hopes to enhance care spanning 56 care homes across seven countries and its primary objective is to mitigate social isolation by orchestrating tailored, group-based, multi-sensory activities based on Namaste’s approach for individuals with advanced dementia and their families. It will provide an opportunity to discuss prognosis and fundamental aspects of care.

Helen Rochford-Brennan commented: “It was an honour to participate in the follow-up session of the mySupport study, now recognised as In-Touch, at University College Cork last week. The intersection of Palliative Care and dementia is an area which I feel is often overlooked, making this experience particularly enlightening for me as an individual living with Alzheimer’s. Engaging with researchers from seven different countries allowed for a comprehensive discussion on the challenges inherent in implementing research findings to effect meaningful change in long-term care settings. The potential positive impact on the quality of life for those receiving palliative care can be profound. Personally, I am deeply appreciative of the opportunity to contribute the perspective of someone living with dementia to the research process and collaborate with such esteemed researchers.” For more on this story, see:

<https://palliativeprojects.eu/in-touch/>

Twitter: <https://twitter.com/InTouchEU>

LinkedIn: <https://www.linkedin.com/company/in-touch-horizon-europe/>

Pictured: Dr Irene Hartigan (leading the In-Touch co-design and development of education across the seven implementation sites), Carmel Geoghegan, Helen Rochford-Brennan and Pam Halliday (PPI representative from Canada on the mySupport study)

DEMENTIA IN SOCIETY

24 APRIL

World Joint Artificial Intelligence Network Challenge awards prototype and full-fledged product aimed at supporting people with dementia and their carers

On 9 April, the finalists of the World JAIN Challenge (WJC) were broadcast, and on 23 April the winners were announced after the finalists went through a few rounds of revisions by an

international jury including members from Alzheimer Europe’s European Working Group of People with Dementia (Kevin Quaid, Lieselotte Klotz, Angela Pototschnigg and Věra Ryšavá) and European Dementia Carers Working Group (Sonata



Mačiulskytė, Peter Banda, Paddy Crosbie and Barry Northedge).

The main purpose of the WJC is to form the international learning community who are developing technology solutions for people with memory problems or dementia, informal carers and family, healthcare professionals, and healthcare institutions, which:

- increase self-reliance and quality of life of people with memory problems or dementia and informal carers
- extend the time that people with memory problems or with memory problems or dementia can live in one's own living environment
- support informal carers, family, and healthcare professionals
- reduce costs within healthcare promoting affordable healthcare.

The WJC 2024 is a public competition for developed or prototyped technical products and services based on Artificial Intelligence. It concerns technology solutions that support the quality of life and self-reliance of people with memory problems or dementia and their informal carers and that will support professional and informal carers in providing optimal care. On 9 April, the WJC programme included a series of presentations including an opening by Dr Franka Meiland (Chair of the WJC 2024), followed by a presentation from Dr Arlene Astell (University of Toronto). After that, the six finalists, three in each category (prototypes and full-fledged products), presented their technology solutions in the form of pitches. The three finalists in the "prototype" category were:

- **GG Care:** A virtual elderly and dementia care guide powered by Amazon Alexa's Automatic Speech Recognition (ASR) technology.
- **The Empathic Coach:** A virtual, human-shaped, assistant that helps people with cognitive problems or dementia with different tasks, such as organising schedules, and providing medication reminders and instructions on how to take medication. **HELP-ICE:** A wearable badge clip, designed for vulnerable individuals, including people living with dementia, which helps bystanders or healthcare providers to access important information about a person in case of an emergency.

This was followed by the three finalists in the "product" category, which were:

- **Calendar Clock:** It helps individuals maintain a sense of continuity by allowing the person to differentiate day and night, to anticipate daily activities and to engage in a more structured routine.
- **Memory Lane:** A smart photo frame that stimulates memories, promotes safety and independence, and reduces feelings of isolation, while features like video calls and lifestyle monitoring promote connectivity and quality of life.
- **D-Time:** A screen that detects restlessness and helps experts and close ones to stay connected with each other, understand how to provide the most effective support to the person with dementia, and closely monitor the effectiveness of the support provided.

On 23 April, the WJC award ceremony took place. The ceremony started with an introduction from Thomas Arnold. This was followed by a presentation from Vijay Karwal (Chief Executive Officer of AffaMed Therapeutics) about "Recent investment trends and strategic considerations in global Alzheimer's care". After this, Dr Meiland explained the judging and selection processes of the WJC international independent jury. Following this, the winners were announced:

- The prototype winner of the 2024 WJC is GG Care (by David Grey).
- The winner in the category of full-fledged products is Memory Lane (by Rudolf Wolterbeek).

[Winners World JAIN Challenge 2024 \(youtube.com\)](https://www.youtube.com/watch?v=...)

25 APRIL

Winner of 2023 REGIOSTARS award Fundació Pasqual Maragall receives visit from European Commission

On 25 April 2024, Fundació Pasqual Maragall (Pasqual Maragall Foundation), winner of the 2023 REGIOSTARS award, received a visit from representatives of the European Commission.



Monika Hencsey, Director for Budget, Communication and General Affairs of the Directorate-General for Regional and Urban Policy at the European Commission led the delegation that visited the Foundation building, to mark the occasion of the 2023 REGIOSTARS award that the Pasqual Maragall Foundation received, in the category "A Competitive and Smart Europe".

During the visit, Ms Hencsey stressed that "When the funding brings together great stories and great projects, great things can happen." Furthermore, she added: "At the Pasqual Maragall Foundation you often say 'We will beat Alzheimer's disease'. It is a bold statement, but it is the kind of boldness that Europe needs to face present and future challenges. Especially if, as in this case, boldness goes hand in hand with concrete and tangible results. In 2022, 21% of the EU population will be 65 years of age or older, and the figures for Spain are similar. We need our elderly, who continue to grow in number, to enjoy the best possible health."

The general director of the Pasqual Maragall Foundation, Dr Arcadi Navarro, highlighted the great contribution their building has made to the competitiveness of Europe in neuroscience, and also declared:

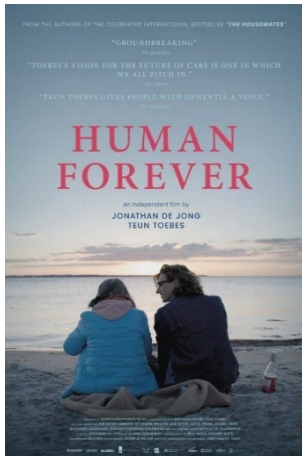
"We believe that a world without Alzheimer's is possible and that we are closer to it with the research we develop thanks to the contributions of the more than 80,000 people who support

us with their philanthropic donations. But we must insist, Alzheimer's can become a structural pandemic in the coming years due to its high incidence and only through science can we defeat it. For this reason, we must allocate even more resources and have more buildings like the Pasqual Maragall Foundation."

The European REGIOSTARS awards, which have been running since 2008, reward excellence, inclusivity, and impact on regional development from projects financed with European funds. 2023 was the first time that a Catalan proposal won this award.

30 APRIL

Documentary film "Human Forever" is a story about love for humanity told by people with dementia



24-year-old humanitarian activist Teun Toebes is on a mission to improve the quality of life of people living with dementia. He had been living in the closed ward of a nursing home for years when he decided to take his mission to the next level: In an adventurous three-year journey across four continents and through 11 countries, his documentary film "Human Forever" takes the viewer on a quest around the world in which he

looks for answers for the future.

"We want to show a more nuanced picture of dementia, told or shown by people with dementia themselves. Because in a world where the talk is now mainly about loss, there is still a world to be won", he commented.

Together with his good friend and filmmaker Jonathan de Jong, Teun Tobes explores how dementia is dealt with in other countries and what we can learn from each other to make the future more inclusive. "As the number of people with dementia doubles in the next 20 years, this quest is not a question, but a necessity", he asserts.

Human Forever premiered at a G20 summit in October 2023. It is currently breaking records in the Netherlands and is the most-watched human interest documentary ever in cinemas (70,000+ cinemagoers). The film is now showing in the Netherlands, Belgium and Germany and will later be released in other countries.

Talks are currently ongoing with other countries around the world, so if you are interested in bringing the film to your country as well, get in touch via social media or via www.humanforever.com (also to watch the trailer).

NEW PUBLICATIONS AND RESOURCES

17 APRIL

New open access book unlocks the world of science communication

On 17 April, the University of Luxembourg and the Luxembourg National Research Fund (FNR) have released a book entitled "50 essentials on science communication", as part of a book release event in Belval, Luxembourg. The textbook is dedicated to presenting, explaining and engaging people in research.



The book is aimed primarily at young scientists wanting to make their first steps in science communication and communication managers in research institutions.

The event was opened with brief introductory speeches, followed by World Cafés in which the attendees discussed different topics that are covered in the book, followed by networking opportunities.

The book is available for free download via: <https://www.degruyter.com/document/doi/10.1515/9783110763577/html>

17 APRIL

Scientific American and Davos Alzheimer's Collaborative publish special report on "The New Age of Alzheimer's"

A special new report, titled "The New Age of Alzheimer's" and published by Scientific American and the Davos Alzheimer's Collaborative, explores advances that could delay or possibly prevent dementia and shares intriguing new approaches to support brain health among the world's ageing population.



This special issue focused on Alzheimer's disease features contributions from Bill Gates, former NIH director Elias Zerhouni, and other global health and ageing leaders.

<https://www.scientificamerican.com/custom-media/the-new-age-of-alzheimers/>

AE CALENDAR 2024

DATE	MEETING	AE REPRESENTATIVE
2 May	Consultation with the ADIS Young Adults Advisory Board (ADIS YA-AB)	Soraya
3 May	Meeting with Vlaamse Alzheimer Liga (Luxembourg, Luxembourg)	Jean
6 May	eBRAIN-Health PPAG meeting	Dianne and Daphné
7 May	European Brain Health Summit (Brussels, Belgium)	Jean
8 May	Fondation Alzheimer Luxembourg (Luxembourg, Luxembourg)	Jean
11-12 May	European Disability Forum Annual General Assembly (Ljubljana, Slovenia)	Daphné
12-14 May	HOMEDEM consortium meeting (Milan, Italy)	Owen
13-15 May	PRIME General Assembly meeting (Bologna, Italy)	Ange
14 May	Multi-Memo Advisory Board online meeting	Ana, Cindy, Sarah
16 May	EFPIA Patient Think Tank	Owen
16-17 May	Euro-PAD scientific symposium (Amsterdam, Netherlands)	Cindy
22 May	Novo Nordisk CETA strategy summit	Ange
22-24 May	CPDP-ai Conference (Brussels, Belgium)	Daphné
28 May	Alzheimer's Association Academy "Collaborating with Researchers at European and national level"	AE members and staff
28 May	Online guest lecture (University of Vechta, Germany)	Chris

CONFERENCES 2024

DATE	MEETING	PLACE
28 July-1 August	AAIC 2024 – A global forum to advance dementia science, https://aaic.alz.org/	Philadelphia, USA and online
18-20 September	20 th 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	34 th Alzheimer Europe Conference – New horizons – Innovating for dementia	Geneva, Switzerland
29 October – 1 November	17 th Clinical Trials on Alzheimer's Disease (CTAD), https://www.ctad-alzheimer.com/	Madrid, Spain



34th Alzheimer Europe Conference

New horizons – Innovating for dementia

Geneva, Switzerland

8 - 10 October 2024 #34AEC

www.alzheimer-europe.org/conferences

