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ALZHEIMER EUROPE NEWSLETTER

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WELCOME



I want to start by saying how sorry I was to learn of the passing of Marc Wortmann. He was an integral part of the European and global Alzheimer's family and we are deeply saddened by this news.

As every year, this edition of our newsletter covers news from both July and August. One of our main objectives as an organisation is to help change perceptions and combat stigma and we are pleased to include news emerging from Pride Month, which took place at the start of summer. These include a new LGBTQI+ dementia café in Ireland, our Board member Karin Westerlund's participation in a Pride Week parade in Sweden, and a new LGBTQI+ Dementia Advisory Group. Still with this objective in mind, we launched our "Anti-Stigma Award" to recognise an outstanding initiative aimed at combating stigma and promoting a positive image of people living with dementia. 48 applications were received before the deadline and are now being reviewed. The winner will be announced at our Annual Conference, taking place from 17 to 19 October in Bucharest. Speaking of the conference, please don't forget to book your spot soon, as places are filling up fast!

Another of our objectives is raising awareness of brain health and prevention and we were interested to learn that the WHO has launched a position paper on brain health, setting out the importance of brain health optimisation throughout the life

course. The paper highlights that one in three people will develop a neurological disorder at some point in their life, making this the leading cause of disability and the second leading cause of death.

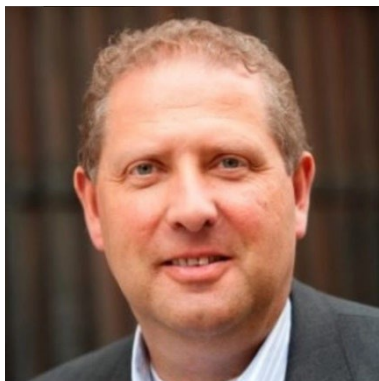
On the research front, a number of noteworthy developments were announced during the Alzheimer's Association International Conference and we report on some of these in the "AAIC watch" section of this newsletter. At a European level, the Horizon Europe-funded eBRAIN-Health project, in which Alzheimer Europe is partner, has been launched. eBRAIN-Health aims to develop a secure, trustworthy research platform that simulates complex biological phenomena of the brain, including the processes that drive the development of diseases such as Alzheimer's and Parkinson's disease. The project will run for four years. I am also pleased to announce that a paper on empowering interventions for people living with dementia has been published in the Journal of Advanced Nursing, co-authored by Alzheimer Europe.

Finally, I would like to congratulate our colleagues in Slovenia, where a Council for Dementia Management has been established by the President of the Republic of Slovenia on the initiative of Spominčica - Alzheimer Slovenia. This Council will serve as a consultative body to the President and to raise public awareness around the growing problem of dementia.

Jean Georges
Executive Director

IN MEMORIAM

15 August: In Memoriam Marc Wortmann, 1959 - 2022



We were very sad to learn of the sudden passing of Marc Wortmann, on 15 August, at the age of just 63.

Mr Wortmann was Executive Director of Alzheimer Nederland from 2000 until 2006, during which time he co-organised the Alzheimer Europe Conference in Maastricht, in 2002. He then became CEO of Alzheimer's Disease International (ADI), from 2007-2017. He was a strong advocate for people living with dementia, as well as their families and carers/supporters. His commitment continued in recent years, through involvement in a number of projects, both at a national level in the Netherlands and at an international level. He was truly an integral part of the European and global Alzheimer's family and we are deeply saddened by his passing.

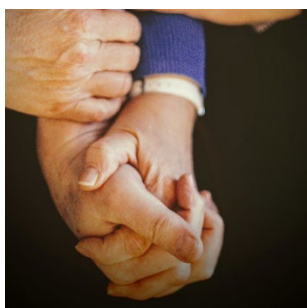
Our heartfelt condolences go out to his wife Corien, and to all of his family, friends and colleagues.



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COVID-19 SITUATION

15 July: New study explores the effects of the pandemic on dementia carers' wellbeing, mental health, and access to care



The pandemic has undoubtedly had a disproportionate impact on people with dementia, who have faced substantial barriers in accessing their usual care. But what has been the impact on their caretakers, with regards to mental wellbeing, health, and access to support?

A group of researchers sought to explore this, by synthesising the results of 36 studies that reported on the early impact of the pandemic on unpaid carers. These studies were conducted across 18 countries, including Greece, Italy, Poland, and the UK, and included quantitative, qualitative, and mixed method approaches. The findings were published in the journal *Aging & Mental Health*.

Findings indicate that, in general, unpaid carers, experienced a reduction in access to care and support during the pandemic. This applied to all forms of support, such as local day centres, memory cafés, support groups, and respite care. Caring responsibilities and time spent on caring also increased, with as much as one-third of carers indicating a severe degree of burden. Carers saw a strong decline in mental and social wellbeing, reporting more anxiety, stress, depression, social isolation, and loneliness.

Digital technology was noted as a way for some carers to stay connected or supported, for instance via online support groups. But digital support is not a panacea – many carers do not see it as equivalent to in-person connection and others might not have access to such technologies in the first place.

These findings highlight an important need for better and more targeted support for carers. This is essential for protecting their mental well-being and can also delay the time at which people with dementia enter a care home. The study authors recommend the development of appropriate policy measures to support carers' wellbeing and investigation into the long-term implications of carer needs.

<https://www.tandfonline.com/doi/full/10.1080/13607863.2022.2084510>

16 July: European Commission publishes COVID-19 and disabilities reports

The European Commission has published a series of reports examining the effect of the COVID-19 pandemic on persons with disabilities, including an overarching synthesis report, as well as individual reports on each Member State.



The reports reflect on initiatives undertaken at the EU level and draws on structured reports from the European Disability Expertise network about developments in their respective countries.

Some of the recommendations to the European Commission include:

- taking measures, including via European Semester and Social Pillar processes, to encourage Member States to ensure that relevant data is inclusive of people living in institutions

- focusing the implementation of the Strategy for the Rights of Persons with Disabilities 2021-2030 on addressing the underpinning social factors that have been shown to place people with disabilities at particular risk
- actively fostering the use of EU recovery funds on disability-specific initiatives and the embedding of disability-inclusive approaches in broader initiatives.

Some of the recommendations to governments in Member States include:

- reviewing and strengthening systems for disaggregating data on the basis of disability, to allow for a better understanding of the impact of COVID-19 and other events and factors on people with disabilities
- carrying out public health evaluations of care settings and the factors exposing residents to infection from COVID-19 and other communicable diseases
- identifying, maintaining and building upon ways of working introduced during the pandemic to ensure the accessibility of public services.

The synthesis paper and individual country reports can be accessed at:

<https://ec.europa.eu/social/main.jsp?catId=1540&langId=en>

24 August: European Patients' Forum invites patients and patient organisations to complete new survey on COVID pandemic impact on patients



The European Patients' Forum (EPF) conducted a COVID-19 survey between 18 September to 18 October 2020 (the report is available [here](#)). It aimed to gather more information on the lived experience and impact of the COVID-19 pandemic on patients and patients' organisations. As the COVID-19 pandemic is not yet over, and it continues to impact the daily life of many patients and patients' organisations, the EPF has decided to do a follow-up survey.

This time, the survey is presented as two separate questionnaires. One for patients' organisations and another for individual patients:

- The survey for patients' organisations (in English only) is accessible [here](#). EPF kindly asks that only one staff member per organisation completes the survey.
- The survey for individual patients (available in English, French, German, Spanish and Italian) is accessible [here](#). To change the language, simply select your preferred one in the top-right corner of the page.

For questions on any of these surveys contact EPF Policy Officer Juan Jose Fernandez Romero: juan.fernandez@eu-patient.eu

The survey for individual patients is done within the scope of the [Periscope project](#), of which EPF is a consortium member.

The deadline for both these surveys is 25 September at 23.59 (CEST).

Help us give a voice to people with dementia

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ALZHEIMER EUROPE

22 July: Alzheimer Europe co-authors new paper on empowering interventions for people living with dementia

Alzheimer Europe is delighted to have co-authored a new paper, "Empowering interventions for people living with dementia: a European survey", published in the Journal of Advanced Nursing on 22 July 2022.

The authors of the paper, including Alzheimer Europe Executive Director Jean Georges, Director for Projects Dianne Gove and Project Officer Ana Diaz, aimed to identify existing empowerment interventions for people living with dementia and to explore which used interventions and projects were considered empowering and why.

In total, 73 people participated in the online survey. Their responses mentioned a total of 98 interventions that they considered to be empowering. There were 90 unique instances of interventions, as some interventions were mentioned more than once.

Detailed questions about a specific intervention were answered for 69 of these interventions, whilst for 21 interventions, only basic information was provided.

You can read their published paper, here:

<https://onlinelibrary.wiley.com/doi/10.1111/jan.15385>



31 August: Places are filling up fast for the 32nd Alzheimer Europe Conference - Register now, to avoid disappointment!



The 32nd Alzheimer Europe Conference (#32AEC) will take place under the banner “Building Bridges, from 17 to 19 October. We are really excited about our first hybrid conference which is being held in person in Bucharest, with some carefully selected sessions broadcast for our online audience. Spots for the in-

person conference are filling up quickly, so please book your place soon, to avoid missing out! <https://www.alzheimer-europe.org/conferences/2022-bucharest/online-conference-registration>

View the agenda, here: <https://www.alzheimer-europe.org/conferences/2022-bucharest/detailed-programme>

You can find out more about all the keynote speakers, here: <https://www.alzheimer-europe.org/conferences/2022-bucharest/keynote-speakers>

Keep an eye on <https://www.alzheimer-europe.org/Conferences> and on our social media accounts (Twitter, Facebook, LinkedIn) for more information about the virtual conference platform, and all other aspects of the conference, as the time approaches. Join the online conversation, before and during the event, using the hashtag #32AEC.



Alzheimer Europe networking

- On 1 July (Barcelona, Spain) Angela Bradshaw and Chris Bintener participated in the final Neuronet meeting.
- On 5 July, Angela attended the BBMRI-ERIC Stakeholder Forum.
- On 8 July, Owen attended an online stakeholder event hosted by the European Commission on the EU4Health programme.
- On 11 July, Dianne, Daphne and Ange participated in the kick-off meeting for the eBRAIN-Health project.
- On 11 July, Jean attended the Health Advisory Board of GSK.
- On 14 July, Jean met with a representative of the US National Task Group on ID & Dementia Practices.
- On 14-15 July (Sankt Augustin, Germany), Soraya, Ana and Chris participated in the ADIS project kick-off meeting.
- On 15 July, Angela attended a joint meeting of the EMA PCWP and FDA Patient Engagement Collaborative.
- On 2 August, Kate had an online meeting with Flavia Topan from the European Patients' Forum to discuss mutual support on communications activities.
- On 4 August, Gwladys had an online meeting with speakers of the AAA on Intellectual disabilities.
- On 8 August, Jean had an introductory call with UCB.
- On 9 August, Jean met with Clariness.
- On 11 August, Gwladys had an online meeting with Roche about their participation to the 32AEC.
- On 14 August, Owen attended the online launch of the WHO's position paper on brain health.
- On 18 August, Jean met with EFPIA to discuss the EU pharmaceutical strategy.
- On 23 August (Kuopio, Finland), Alzheimer Europe Board member and European Alzheimer's Alliance Chairperson Sirpa Pietikäinen MEP attended the Kuopio Alzheimer Symposium and gave a speech on patient involvement, self-determination and empowerment, as well as on Alzheimer Europe's priorities in its work with memory-disabling diseases.
- On 23-25 August (Kuopio, Finland) Ana participated in the 9th Kuopio Alzheimer Symposium and 3rd Nordic Memory Clinic Conference.
- On 24 August, Jean had an exchange with Korian Foundation.
- On 25 August, Angela met with the EPND Project Management Team.
- On 28 August, Gwladys had an online meeting with our Slovak member organisation about the 34AEC.
- On 29 August, Cindy and Jean attended the Pattern-Cog Executive Management Board.
- On 31 August, Angela participated in a meeting of the EMA Advisory Group on Raw Data.



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EU PROJECTS

1 July: Neuronet members hold final meeting with Scientific Coordination Board



On 1 July, representatives of Neuronet's partner organisations and members of its Scientific Coordination Board (SCB) came together in Barcelona (Spain) to compile and evaluate the achievements of Neuronet at a final meeting. This meeting has also served as an opportunity to share and evaluate lessons learned.

Members of the SCB present at the meeting were, AMYPAD Leader – Gill Farrar, EPAD Chief Investigator – Craig Ritchie, Mobilise-D & IDEA-FAST representative Kirsten Emmert, MOPEAD representative – Marta Marquie as well as ROADMAP Coordinator – John Gallacher.

Neuronet (Efficiently Networking European Neurodegeneration Research) is a three-year coordination and support action that began in March 2019, approaching the end of its funding period at the end of August 2022.

Its main aim was to set up an efficient platform to boost synergy and collaboration across the Innovative Medicines Initiative (IMI) projects of the Neurodegenerative Disorders (ND) portfolio, assisting in identifying gaps, multiplying its impact, enhancing its visibility and facilitating dovetailing with related initiatives in Europe and worldwide.

Neuronet is steered by Synapse Research Management Partners S.L (read the interview with Coordinator Carlos Díaz [here](#)) and led by Janssen Pharmaceutica NV (read the interview with Project Leader Lennert Steukers [here](#)). Main pillars of Neuronet are to focus on the development of tools and services to support the dissemination of project results, as well as the promotion of synergies between projects.

Up until today, Neuronet already supports more than 20 projects in IMI's ND portfolio through multiple activities, including its working groups on data use and sharing, support and interaction with regulatory agencies and Health Technology

Assessment bodies, on ethics and patient privacy, and sustainability.

In addition to this, Neuronet convened ten meetings with the representatives of the individual projects discussing areas of common interest, alignment of communication activities, best practice, shared challenges as well as approaches to overcome them. The group also organised three annual networking and communication events involving the IMI ND projects, relevant external experts and stakeholders.

Tangible results

At the last meeting, the Consortium reflected on the tangible results and innovations of the project, with a special emphasis on its [Knowledge Base](#) – The Neuronet Asset Map to provide a comprehensive overview of the assets from the IMI ND portfolio, categorised by R&D stage (non-clinical, clinical, regulatory and Real-World Evidence) and type, including its [Asset Map](#) and [Decision Tool](#) for engagement with Regulatory and Health Technology Assessment bodies.

Alzheimer Europe representatives present at the meeting were Angela Bradshaw and Christophe Bintener.

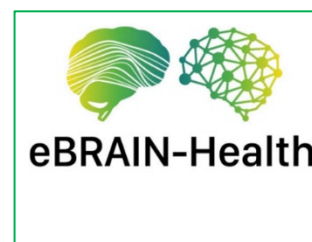
Alzheimer Europe co-leads the communication and dissemination Work Package of Neuronet with the following goals:

- promoting synergy across the individual dissemination and communication activities of the different IMI neurodegenerative diseases projects to maximise their visibility and impact, and optimize use of resources;
- fulfilling Neuronet's 'ambassador' role by reaching out to relevant stakeholders and initiatives worldwide.

<https://www.imi-neuronet.org/>

11 July: eBRAIN-Health project hosts online kick-off meeting

On 11 July, the Horizon Europe-funded eBRAIN-Health project hosted its kick-off meeting online. eBRAIN-Health aims to develop a secure, trustworthy research platform that simulates complex biological phenomena of the brain,



including the processes that drive the development of diseases such as Alzheimer's and Parkinson's disease. The project involves 20 partners, including Alzheimer Europe and EBRAINS AISBL, the coordinating body of the EU flagship Human Brain Project. The project will run for four years from July 2022, with a total budget of almost 13 million EUR, and is coordinated by Prof. Petra Ritter, Johanna Quandt Professor of Brain Simulation at Charité University Hospital, Berlin.

Petra launched the kick-off meeting with an overview of the vision, structure and objectives of the project. eBRAIN-Health is built around the concept of "digital twins", defined as virtual representations that can serve as real-time digital counterparts of individuals. Based on health data and developed using

artificial intelligence (AI), digital twins have the potential to support more accurate and personalised decision-making, for example by allowing clinicians to simulate the possible outcomes of treatment options.

Petra went on to explain that in eBRAIN-Health, a large variety of information will be brought together in a GDPR-compliant research platform, to support the development of digital twins of the brain. This information includes brain imaging studies, behavioural studies and lifestyle surveys, as well as clinical data from thousands of patients and healthy peers. The data is combined with biological information from scientific knowledge databases and made available for research purposes. The resulting "digital twins" of the brain will allow a large number of researchers to conduct innovative research within a powerful digital platform. In addition, the complex, individualised brain simulations have the potential to improve our understanding of brain function and disease; improve diagnosis and risk prediction, and optimise potential therapies.

After Petra's introduction to the project, leaders and partners from the ten work packages of eBRAIN-Health described the work they will be undertaking over the next four years. Wide-ranging activities in eBRAIN-Health will span the integration of diverse sources of data; legal and ethical compliance; creation of a cloud-based platform; generation of knowledge graphs for disease mechanisms; development of multi-scale brain simulations; design of clinician and patient interfaces and apps; and activities to support exploitation and dissemination. Following a presentation from Lukas Faymann (University of Vienna) on the legal and ethical framework for eBRAIN-Health, Daphné Lamirel (Project Officer, Alzheimer Europe) provided an introduction to public involvement in research, showing how public involvement will ensure the needs, perspectives and values of people affected by dementia are reflected in the research being carried out in the project. Dianne Gove and Angela Bradshaw also represented Alzheimer Europe at the meeting. After a discussion session between attendees, Petra closed the eBRAIN-Health kick-off meeting by thanking all partners and wishing them continued success and effective collaborations over the next four years.

20 July: Arrest AD project shows how heparan sulfates fit into the Alzheimer's disease puzzle and shares why its researchers are hopeful about future treatments

The ArrestAD programme, funded by the European Commission (FET-OPEN H2020 737390) and evaluated by Iva Holmerová, Chairperson of Alzheimer Europe, set out with the aim of understanding the central role of complex sugars called heparan sulfate (HS) in the puzzle of cascades leading to Alzheimer's disease (AD). Since the 1990s, HS were seen abnormally accumulated inside the AD-damaged neurons. However, their roles in the disease were disregarded, possibly because of their unknown functional specificity in neurons. In



2015, a discovery of paramount importance was made by L'Université Paris-Est Créteil (UPEC), France, coordinator of ArrestAD, which showed that the HS accumulation in vulnerable neurons can induce the protein phosphorylation and aggregation observed in AD. Based on this central discovery, a completely new mechanism-based hope for preventing and arresting AD was born, with a new class of drug candidates and new blood diagnosis tools.

After five years of research, the ArrestAD project has concluded that "this new approach seems to afford the missing piece of the AD puzzle", with three main outcomes:

- the discovery of neural HS biosynthetic enzymes as new drug targets for arresting AD and tools to discover related drugs
- several unrevealed mechanistic steps by which HS trigger protein aggregation from the synapse, until the cell dies
- a raft of diagnostic tools in blood, from the detection of HS in cells to miRNA measurement in plasma.

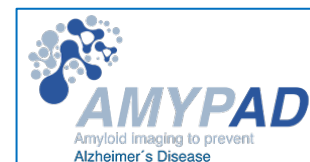
The researchers say that the approach they have taken in ArrestAD "fits together all known neurodegeneration cascades and affords hope for efficiently treating AD in the future". It aims to do this with the involvement of the UPEC-issued company Glycanix, which aims to bring the ArrestAD concept to patients.

Find out more about ArrestAD, via the project website:

<https://arrestad.wordpress.com/>

21 July: AMYPAD completes the last patient visit in its Prognostic and Natural History Study

On 30 June, the members of the Amyloid Imaging to Prevent Alzheimer's Disease (AMYPAD) project announced the completion of the last patient



visit in its Prognostic and Natural History Study (PNHS). All sites have been done with the recruitment and scanning of participants, which represents an important milestone.

The PNHS study is an open-label, prospective and multi-centre cohort study aiming to understand the role of amyloid PET

imaging in the earliest stages of Alzheimer's disease (AD). The first participant was recruited in Amsterdam, The Netherlands, in October 2018. The study succeeded in recruiting 1,321 participants. The final scans were performed in June and the number of prospective scans collected within AMYPAD PNHS is 1,419 (1,192 baseline and 227 follow-up). At this moment, the AMYPAD team is focused on the close out of the sites and the last closure visit is scheduled for September 2022.

8 August: AI-Mind launches an educational social media campaign



On 8 August, the AI-Mind consortium has launched an educational social media campaign that runs over six weeks on the project's [Twitter](#), [Facebook](#) and [LinkedIn](#) accounts. Every week more people with mild cognitive impairment (MCI) join the [AI-Mind study](#) to help develop

and validate artificial intelligence (AI)-based tools to predict who is likely to develop dementia. The project's team has kicked off a series of "educational posts" dedicated to sharing knowledge on dementia and other aspects related to brain health. Every week the project's team posts on its social media platforms information dedicated to a specific topic and provides a fresh dose of daily "facts" on Twitter. These include MCI symptoms, forms of dementia and its risk factors, how the disease affects people worldwide, ways for dementia prevention and more. Through this journey, AI-Mind aims to

increase awareness and arm people with knowledge related to brain health as much as encourage discussion with different groups. Follow AI-Mind on social media to keep yourself updated and for more information, visit the AI-Mind website:

<https://www.ai-mind.eu/blog/take-care-of-your-brain-health-ai-mind-educational-campaign/>

26 August: Interdem and ISTAART survey seeks to examine the needs for support in early career researchers based in Europe - answer it today!

Are you a researcher or scientist? Are you working in the field of dementia?

Do you self-identify as an "early-career researcher"? Are you based in Europe? If yes, this survey is for you.

As an early career researcher, you make valuable contributions to dementia research, but what can organisations like INTERDEM (Academy) and ISTAART do to support you in this work? And what kind of support do you need?

Please take a moment to share your thoughts and priorities via this questionnaire (10-15 min): <https://cutt.ly/pZnWpiQ>

The results will be discussed during the INTERDEM Academy symposium at the 32nd Alzheimer Europe Conference #32AEC (session P22, 19/10/22, 10:45-12:00).

Thanks in advance on behalf of INTERDEM and ISTAART's Professional Interest Area to Elevate Early Career Researchers (PEERs).



EU project acknowledgements



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

AI-Mind – grant agreement 964220

AMYPAD – grant agreement 115952

eBRAIN-Health – grant agreement 101058516

Neuronet – grant agreement 821513

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



Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at **91**, 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); Ruža Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D). **Czech Republic:** Tomáš Zdechovský (EPP). **Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe); **Finland:** Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France:** François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). **Greece:** Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE-NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraiki (EPP); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland:** Barry Andrews (ALDE); 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); Pierfrancesco Majorino (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:** Vilija Blinkeviciute (S&D). **Luxembourg:** Marc Angel (S&D); Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Isabel Wiseler-Lima (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). **Poland:** Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP). **Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Clàudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D). **Romania:** Cristian-Silviu Busoi (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtasun (Greens/EFA). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (ECR).



EU DEVELOPMENTS

5 July: European Parliament adopts report on the future of care in Europe

The European Parliament has adopted a resolution, "Towards a common European action on care", following the adoption of the report by the Employment and Social Affairs (EMPL) and

Women's Rights and Gender Equality (FEMM) Committees in June 2022.

The report calls on the European Commission and Member States to fund all types of care services more effectively, as well as using structural and investment funds to invest in childcare, care for older people and others in need of support.

The MEPs stress that legislative measures and investment are needed at the EU level to promote decent working conditions and to make work in the care sector more attractive. In

addition, it calls for Member States to develop training for informal and formal carers to prevent and combat care-related violence and harassment.

The report calls for a robust and future-proof European Care Strategy that targets and responds to the needs of people at critical periods throughout their life, including investment in high-quality public care for every child in the EU. The full report is available at:

https://www.europarl.europa.eu/doceo/document/TA-9-2022-0278_EN.html

6 July: European Parliament adopts report on inclusion and the social economy



The European Parliament has approved a report outlining its key recommendations on the EU Action Plan for the Social Economy.

The report highlights that social economy contributes to social integration and quality job creation, including for persons with disabilities. It therefore calls for legal and policy frameworks to be strengthened, including in relation to the provision of guidance on access to EU support mechanisms.

The report welcomes the European Commission's commitment to introducing a recommendation on developing social economy framework conditions, whilst also calling for the establishment of a statute for European cross-border associations and non-profit organisations.

Furthermore, the report highlights the role of the social economy in the integration and employment of disadvantaged workers, especially persons with disabilities. Additionally, it reemphasises that the Public Procurement Directive allows contracting authorities to use public procurement to pursue social objectives, including the inclusion of persons with disabilities in the workforce. The full report can be accessed at:

https://www.europarl.europa.eu/doceo/document/TA-9-2022-0288_EN.html

12 July: European Parliament Committee adopts report on Accessible EU Centre

The European Parliament's Internal Market and Consumer Protection Committee (IMCO) has passed a report outlining the Parliament's position in relation to the AccessibleEU centre, a flagship initiative of the European Disability Rights Strategy 2021-2030.

The AccessibleEU centre, due to be established in 2022, aims to support the implementation of EU accessibility legislation by facilitating access to relevant knowledge and resources.

The text calls for the European Commission to ensure the AccessibleEU centre facilitates cooperation among public administrations, economic operators, accessibility professionals and persons with disabilities and their representative organisations. In addition, it calls for the

Commission to ensure adequate financial and human resources to ensure the effective operation of the centre. The report specifies certain actions the centre should undertake, including:

- providing guidance and training, and inspiring policy developments and innovation at national and EU level, including through the identification and sharing of best practices
- providing advice, including guidelines, to relevant EU institutions and bodies and Member States on their internal accessibility policies
- identifying and helping to overcome gaps and inconsistencies in current legislation, providing policy recommendations for updating and developing accessibility laws
- supporting Member States to develop accessibility education programmes to increase the number of accessibility professionals, and providing training to EU and national public officials and to interested people
- playing a role in the standard-setting system when accessibility standards are being developed.

The full report can be accessed at:

https://www.europarl.europa.eu/meetdocs/2014_2019/plmrep/COMMITTEES/IMCO/DV/2022/07-11/14-Final_CAs_AccessibleEUCentre_EN.pdf

12 July: EMA launches pilot project on the use of raw data from clinical trials for regulatory decision-making

On 12 July, the European Medicines Agency (EMA) announced the launch of a pilot project to assess whether the analysis of 'raw data' from clinical trials by regulatory authorities improves the evaluation of applications for new medicines, or for post-authorisation applications. The pilot will also explore practical aspects of the submission and analysis of such data.



Raw data consists of individual patient data from clinical studies, stored in a structured electronic format that is directly accessible for analysis and visualisation. Examples of raw data include clinical laboratory results, imaging data, and patient medical charts, which are collected during the clinical research process. Currently, raw data is not routinely provided by organisations applying for the authorisation of new medicines, or applying to change the terms of an existing marketing authorisation.

The Human Medicines Committee (CHMP) is responsible for evaluating medicines that are submitted for marketing approval to the EMA. At the moment, during the evaluation process the CHMP receives patient data in an aggregated format, submitted by the applicant after statistical processing as clinical summaries or PDF listings. The CHMP scrutinises these summaries as part of the scientific evaluation of the benefits

and risks of new medicines. This process typically results in several rounds of questions, in which the Committee may ask the applicant for methodological clarifications, re-analysis of data, or additional data. Although it is not part of the routine process, raw data have been requested by the CHMP on several occasions in the past when it was considered that it would be helpful in the evaluation of a new medicine.

The raw data project stems from one of the ten priority recommendations issued by the joint Big Data Task Force of EMA and the Heads of Medicines Agencies (HMA) in 2020, which highlighted the need to strengthen the regulatory capability to analyse data collected at individual patient level to better inform regulatory decision making. There are several potential benefits the analysis of raw data might bring, including faster evaluation through fewer questions being put to applicants and a better definition of the target treatment population. Raw data analysis may therefore enable faster and better access to new medicines for patients. To help guide the pilot project, an Advisory Group was established in 2021, consisting of representatives of EMA committees and working parties, including Alzheimer Europe, which is a member of the Patients and Consumers' Working Party (PCWP).

Pilot participation is open to applicants that are about to submit marketing authorisation applications or post-authorisation applications to EMA. If selected, they will include raw data as part of their submissions. The pilot is expected to last up to two years and will include approximately ten regulatory procedures submitted to EMA from September 2022. The pilot will fully comply with data protection legislation requirements. Upon the completion of the pilot, EMA will organise a workshop with relevant stakeholders to discuss the learnings and will also publish a summary report.

More information on the pilot's objectives and on the terms of participation is available in the description of the pilot to industry, which can be found [here](#).

20 July: European Patients' Forum responds to European Commission's call for feedback on European Health Data Space



The European Patients' Forum (EPF) has published its response to the European Commission's call for feedback on the European Health Data Space (EHDS). The Commission will summarise all feedback received and present them to the European Parliament and the Council of the EU to inform the legislative debate.

The EPF response, drafted in collaboration with member organisations, welcomes this overarching framework for the exchange and sharing of health data while stressing the need for a European Health Data Space shaped with and for patients. This is a unique opportunity for EPF and its members to play an enabling role in data quality and trust, which should be reflected in the regulation.

As this call for feedback only allowed a limited response, EPF will develop a more extensive position statement on a patient-centred EHDS to engage with relevant stakeholders throughout the legislative process. Read the full response here:

<https://www.eu-patient.eu/globalassets/news/20220720-ehds-call-for-feedback---final.pdf>

21 July: EU Access City Award 2023 is open for applications



The Access City Award 2023 is open for applications until 8 September 2022 (23:59 CEST). Since 2010, this award has been recognising cities that are making significant efforts to become more accessible for persons with disabilities. The Access City Award 2023 is open to all EU cities of over 50,000 inhabitants, and to urban areas composed of two or more towns with a combined population of over 50,000 inhabitants, if they are in EU countries with fewer than two cities with over 50 000 inhabitants. Participating in the award is a unique opportunity to gain European recognition and visibility and winning cities also receive a financial prize:

- 1st prize: EUR 150,000
- 2nd prize: EUR 120,000
- 3rd prize: EUR 80,000.

Take a look at the website for further information:

<https://ec.europa.eu/social/main.jsp?langId=en&catId=88&eventsId=1977&furtherEvents=yes#navItem-1>

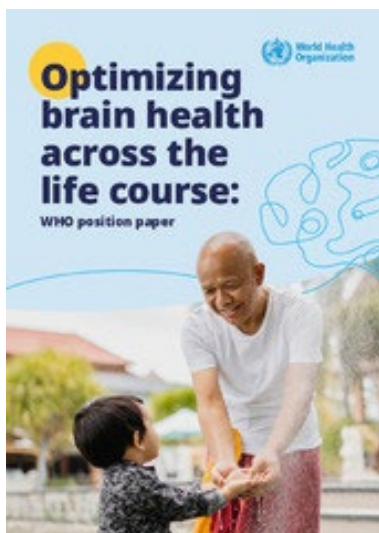
The most recent winner was Luxembourg City. For examples of initiatives taken by Luxembourg and by last year's runners-up and winners of special mentions, see the brochure:

<https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8462&furtherPubs=yes>



POLICY WATCH

9 August: World Health Organization launches brain health report



The World Health Organization (WHO) has launched a position paper on brain health, setting out the importance of brain health optimisation throughout the life course. The paper defines brain health as the state of brain functioning across cognitive, sensory, social-emotional, behavioural and motor domains, allowing a person to realise their full potential over the life course, irrespective of the

presence or absence of disorders.

The paper highlights that 1 in 3 people will develop a neurological disorder at some point in their life, making neurological disorders the leading cause of disability and the second leading cause of death. In addition, it notes that many determinants are known to impact brain health and continuous interactions between these determinants, as well as an individual's context, lead to lifelong adaptation of brain structure and functioning. Specifically, the paper addresses the following determinants:

- Physical health
- Healthy environments
- Safety and security
- Learning and social connection
- Access to quality services.

The paper explains that optimising brain health leads to multiple benefits including lower rates of many chronic health conditions – neurological, mental, substance use and physical – as well as improved quality of life and multiple social and economic benefits. Furthermore, it offers practical policy solutions and future directions for the field including specific actions for addressing brain health determinants, ongoing priorities in brain health research, and operationalising and measuring brain health. The full report is available at: <https://www.who.int/publications/i/item/9789240054561>



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31 August: Inaugural meeting of new Slovenian Council for Dementia Management takes place at Presidential Palace



On 31 August 2022, the inaugural meeting of the Council for Dementia Management took place in the Great Hall of the Presidential Palace, hosted by the President of the Republic of Slovenia.

On the initiative of Spominčica - Alzheimer Slovenia president Štefanija Lukič Zlobec and Prof. Dr Zvezdan Pirtošek, the President of the Republic of Slovenia, Borut Pahor, established the Council for Dementia Management as a consultative body to the President of the Republic of Slovenia.

The Council for Dementia Management, in addition to representatives of decision-makers, brings together mainly experts in the field of dementia. The Council's aim is to formulate positions, recommendations and proposals, to address them to the competent institutions and to raise public awareness around the growing problem of dementia, one of the major problems of modern society.

The inaugural meeting was attended by:

- Mgr. Tadej Ostrc, State Secretary at the Ministry of Health
- Andrej Grdiša, Director General of the Directorate for the Elderly and Deinstitutionalization at the Ministry of Labour, Family, Social Affairs and Equal Opportunities
- Mgr. Tamara Kozlovič, Chair of the Committee on Health in the National Assembly
- Dr Jože Rutar, Deputy Ombudsman
- Dr Božidar Voljč, Chairman of the Slovenian Medical Ethics Commission
- Štefanija Lukič Zlobec, President of the Association Spominčica - Alzheimer Slovenia
- Dr Nena Kopčavar Guček, general practitioner
- Dr Milica Gregorič Kramberger, neurologist
- Dr Zvezdan Pirtošek, neurologist
- Dr Polona Rus Prelog, psychiatrist
- Dr Mercedes Lovrečič, psychiatrist, National Institute of Public Health

- Denis Sahernik, Secretary of the Community of Social Institutions

The following people were appointed to the Council for Dementia Management under the President of the Republic of Slovenia:

- Danijel Bešič Loredan, Minister of Health
- Mr Luka Mesec, Minister for Labour, Family, Social Affairs and Equal Opportunities
- Ms Tamara Kozlovič, Chair of the Committee on Health in the National Assembly
- Mr Peter Svetina, Human Rights Ombudsman
- Dr Božidar Voljč, Chairman of the Slovenian Medical Ethics Commission
- Štefanija Lukič Zlobec, President of the Association Spominčica - Alzheimer Slovenia
- Dr Nena Kopčavar Guček, general practitioner
- Dr Milica Gregorič Kramberger, neurologist
- Dr Zvezdan Pirtošek, neurologist
- Dr Polona Rus Prelog, psychiatrist
- Dr Mercedes Lovrečič, psychiatrist, National Institute of Public Health
- Denis Sahernik, Secretary of the Community of Social Institutions

31 August: Alzheimer Portugal presents its Manifesto for a national, integrated approach to Alzheimer's and other dementias, "Pela Memória Futura"



After waiting more than two years for the approval of the Five Regional Dementia Health Plans, in Portugal, which have been ready since July 2019, the country's Minister of Health finally issued the Act (nº 12761/2021 of 29.12.2021) approving these plans, at the end of 2021. This happened in the framework of The Mental Health Reform and the Portuguese Recovery

and Resilience Plan.

For the assessment of the implementation of each Regional Plan an Executive Committee was created and Alzheimer Portugal is a member of this Committee, represented by Catarina Alvarez, Institutional Relations Officer, and Rosário Zincke, Vice Chairperson. The Committee is in charge of:

- assuring that the principles adopted in the Health Strategy for Dementia (Act of the Minister of Health nº 5988/2018) are followed (respect for the needs and preferences of people with dementia and for the ethical principles of care, informed consent and autonomy, community based care assuring their continuity, diversity, accessibility and equity)
- monitoring the implementation of each plan and the fulfilment of the defined milestones

- collecting and coordinating the information provided by each region, according to the report model defined by the WHO Global Dementia Observatory
- giving opinions on issues related to the health of people with dementia, namely in what concerns health promotion, disease prevention and planning and organisation of care
- drafting a semesterly follow-up report to be submitted to the Minister of Health and to the Mental Health Politics National Coordination board.

The first follow-up report has been finalised and was delivered to the Minister of Health at the end of July 2022.

The above-mentioned Minister of Health Act (Act nº 12761/2021 of 29.12) also states that the Directorate General of Health is responsible for the updating of the Norm nº 53/2011 on the Therapeutic Approach in Cognitive Changes. This work is done and only waiting for formal approval. This is a very important achievement as it establishes the diagnosis criteria to be followed at the National Health Service.

The same Act also defines that the ACSS, I.P. (Central Administration of the Health System) and the SPMS, E.P.E. (Shared Services of the Ministry of Health) are responsible for the creation of the framework necessary to make the mandatory informatic registration of the diagnosis (ICP2 and CID 10) at primary and hospital care. This will allow the identification of cognitive disorders and the improvement of the interoperability of information systems among the different levels of care. The final aim is to make possible the definition of an Individual Care Plan tailored to each person with dementia. This process is ongoing.

The implementation of the Regional Dementia Health Plans implies the creation, in each Health Region, of specific units, named "Unidades Coordenadoras Funcionais para as Demências" aiming to assure a better collaboration between the different levels of care and between these and people with dementia, family members and carers, in order to define the diagnosis and treatment pathways. These units exist already in the Five Regions but are still in the beginning of their implementation.

According to guidelines defined by "The Conclusion of the Mental Health Reform and Implementation of the Dementia Strategy" each Region, bearing in mind its own specificities, defined a training plan on dementia to healthcare professionals and informal carers. There will be a common online training platform built by SPMS, E.P.E. (Shared Services of the Ministry of Health).

Alzheimer Portugal, as a training entity recognised by the Governmental Department for Training Certification, will be involved in the delivery of training sessions having already being invited by the different Regions. This means that they will have the opportunity to share best practices and very specific knowledge and experience on dementia. The training is to be financed by funds from the Portuguese Recovery and Resilience Plan. Although training on dementia is obviously very important and needed, as it will enable healthcare professionals and

informal carers to know more about dementia and to be more prepared to diagnose, treat and care for people with dementia, the reality is that, in Portugal, especially in inner and rural areas, people are not as aware as they could be about what dementia is and how to interact with a person with dementia. For this reason, and as a member of the Committee, Alzheimer Portugal stressed the importance of fighting against stigma and ignorance associated with dementia, and proposed the launch of a national awareness campaign led by the Government. This will, Alzheimer Portugal believes, significantly increase understanding and knowledge in the field of dementia. According to the organisation's proposal, part of the funds earmarked for the training programme will be allocated to this campaign. The awareness campaign will be launched by the end of this year. This is particularly good because it will not happen at the same time as Alzheimer Portugal's September awareness initiatives, for World Alzheimer's Day.

Alzheimer Portugal is very happy to be involved in the implementation of the Regional Dementia Health Plans. Its involvement is not only at national level, being a member of the Committee, but also at regional level, being also represented in the Algarve and in the Lisbon Health Regions. The organisation is aware that the process of really recognising dementia as a national priority in Portugal has been too slow and is far from being a complete reality. However, the ongoing implementation of the Regional Dementia Health Plans is nonetheless a very important step forward.

Many achievements are yet to happen. That is why Alzheimer Portugal has written a manifesto for a national, integrated approach to Alzheimer's and other dementias, named "Pela Memória Futura" (For the Future Memory). It has four main axes: To prioritise (dementia has to be recognised as a national social and public health priority); to make it happen ("Concretizar" – turn ideas and politics into action); to create awareness (develop campaigns to make every stakeholders aware about dementia); and to connect (between the different stakeholders: health, social affairs and municipalities, among others, in order to reach a holistic approach to dementia care).

This Manifesto has already been presented to the Members of the Parliament from the different parties of Portugal. The parties from the opposition showed interest in putting questions to the Government about the implementation of the Regional Dementia Plans, namely about the July 2022 report and when it will be published. Alzheimer Portugal's conversation with the Government's party was focused on what it thinks is the main gap – connection between the Ministry for Health and the Ministry for Labour and Social Affairs.

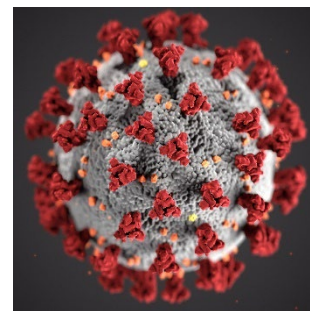


AAIC WATCH



1 August: New findings show that loss of smell due to COVID-19 and intensive care unit hospitalisation may increase the risk of cognitive impairment

During this year's Alzheimer's Association International Conference (AAIC), researchers presented new findings about COVID-19 and its link to cognitive impairment. A first study, looking at 766 adults aged 55 to 95, reported that two-thirds of individuals who had been infected with COVID-19



exhibited functional memory problems. In particular, impairments were identified in memory for 11.7% of the individuals, in attention and executive function for 8.3%, and in multiple domains (i.e., memory, learning, and attention) in 11.6%. An important finding of the study was that persistent loss of smell was a better predictor of cognitive impairment than the severity of the COVID-19 infection.

A second study revealed that intensive care unit hospitalisation was associated with a 71% higher likelihood of developing dementia over a follow-up period of 7.8 years on average. In people with vascular problems, other types of chronic health conditions and functional disabilities, the associated risk of all type-dementia was 120% higher.

The final study, conducted in both the US and Latin America identified several life changes and demographic characteristics associated with cognitive impairment during the first stages of the pandemic. Female gender, lack of employment, lower socioeconomic status, and negative life changes (e.g., economic difficulties and low social contact), were all independently associated with a higher risk of cognitive problems. Nonetheless, the experience of one positive life change during the pandemic, such as spending time with friends or in nature, was identified as a way of limiting the negative consequences of these negative life changes or demographic characteristics on cognition.

These findings open new avenues for identifying and developing prevention methods to limit the impacts of COVID-19 infections and lockdowns on cognitive status and dementia.

https://aaic.alz.org/releases_2022/covid-19-dementia-risk.asp

1 August: Alzheimer's Association Global Workgroup publishes recommendations for blood-based biomarker tests in Alzheimer's disease



Biomarkers are nature's indicators: measurable molecules that reflect processes happening inside our bodies. In Alzheimer's disease, brain imaging scans and cerebrospinal fluid (CSF) tests which measure the amyloid biomarker form part of the diagnostic pathway in several

countries. Researchers have also spent many decades working on biomarkers for Alzheimer's disease that can be measured in blood samples, which can be easily obtained without undergoing invasive spinal tap procedures or costly PET scans.

In their new article, just published in the *Alzheimer's and Dementia* journal, and launched at the 2022 Alzheimer's Association International Conference (AAIC), the Alzheimer's Association Global Workgroup provides recommendations for the appropriate use of blood-based biomarkers in clinical practice and trials. Highlighting that 25-30% of patients with a clinical diagnosis of Alzheimer's dementia are misdiagnosed, and citing the lack of tools for predicting disease progression, the authors explain that blood-based biomarkers may be a feasible, cost-effective and accessible option for use in primary care. However, they caution that most studies of blood-based biomarkers in Alzheimer's disease have been performed in the clinical research setting, which does not always capture the diversity present in wider society.

As a result, the Workgroup calls for more studies on blood-based biomarkers in diverse, primary care populations prior to implementation in this setting, explaining that care must be taken to avoid doing more harm than good. The article identifies a number of research priorities from the Workgroup, which span technical developments to more in-depth, longitudinal research on biomarkers; as well as work on implementation, interpretation of results, and communication of these to doctors and patients.

Although blood-based biomarkers are not yet ready for use in primary care, the Workgroup recommend their use in clinical trial recruitment and screening, where they could help identify participants with Alzheimer's disease pathological changes who could benefit from trials of disease-modifying therapies. As a starting point towards implementing blood-based biomarkers

in clinical practice, they recommend using them as part of the diagnostic progress in specialised memory clinics, alongside established methods such as brain PET imaging and/or analysis of CSF.

Prof. Charlotte Teunissen (VUmc, the Netherlands), senior author of the article, explained: "The implementation of blood-based biomarkers in primary care will likely take a much longer time because there are very few relevant and high-quality research studies on Alzheimer's-related biomarkers conducted in this setting - but more prospective studies are expected to launch in the coming years."

https://aaic.alz.org/releases_2022/blood-biomarkers-appropriate-use-recommendations.asp

1 August: Racism and discrimination are associated with poorer cognition outcomes

According to new findings reported at the Alzheimer's Association International Conference (AAIC), experiencing racism and/or discrimination is associated with worse cognition in mid and late life, especially among Black individuals. A first study, looking at nearly 1,000 middle-aged Black, Latino and White people, assessed experiences of interpersonal, institutional, and structural racism. Research showed that Black individuals are the most likely to be exposed to racism, civil rights violations and discrimination throughout their lives. While these experiences led to a lower memory score in Black participants, structural racism was associated with lower episodic memory (memory of previous experiences) among the three groups included in the study.



A second study revealed that lifetime experiences of discrimination worsen the semantic memory (memory of general knowledge) in late life. 468 old-aged participants with an average age of 93, from diverse racial and ethnic groups (Asian, Black, White, Latino and multiracial), reported experiences of major lifetime discrimination via questionnaires. Based on their responses, participants were classified into three groups. Group 1 referred to workplace discrimination and was reported by mostly White men. Group 2 was composed of White women and Asian, Black and Latino old-aged adults who reported little to no discrimination over their lifetime. Group 3 referred to non-White participants who experienced discrimination across workplace, housing and financial domains.

One of the major findings of the study was that participants in group 3 (i.e., those reporting lifetime major discrimination) had worse semantic memory at baseline compared to the participants who reported little discrimination or no

discrimination at all. However, no difference in cognitive decline was reported over time (after 1.2 years) among the three groups.

The researchers said that their findings highlight that wide-ranging discrimination and exposure to racism during one's life are associated with poorer cognitive health in old age. Addressing inequities in socioeconomic status, and access to education, healthcare, and healthy food may therefore contribute to reducing dementia risk, in particular in groups who are at higher risk of experiencing discrimination.

https://aaic.alz.org/releases_2022/racism-cognitive-decline.asp

4 August: Dr Claire Sexton shares some highlights from AAIC with touchNEUROLOGY



The Alzheimer's Association International Conference (AAIC) is the largest and most influential meeting dedicated to advancing Alzheimer's and dementia research.

Each year, it gathers researchers to share discoveries that can lead to methods of prevention and treatment, as well as improvements in the diagnosis of Alzheimer's disease.

Dr Claire Sexton is the Senior Director of Scientific Programs and Outreach at the Alzheimer's Association, and she joined touchNEUROLOGY to discuss some of the highlights at this year's AAIC, 29 July to 4 August 2022.

<https://touchneurology.com/alzheimers-disease-dementia/conference-hub/claire-sexton-highlights-of-aaic-2022/>

15 August: TouchNEUROLOGY discusses experiences of discrimination on cognitive function and ageing in the over 90s, with Dr Kristen George at the AAIC conference



The LifeAfter90 (LA90) study aims to understand what cognitive ageing and dementia look like among individuals aged 90 and above. In an interview conducted by

touchNEUROLOGY, Dr Kristen George (University of California Davis School of Medicine, University of California, Davis, CA, USA) discussed what the study found in terms of the effect of discrimination on the cognitive function of this population.

The poster, entitled "Experiences of Discrimination on Cognitive Function and Aging among the Oldest Old: LifeAfter90 (LA90)

Study", was presented at the annual Alzheimer's Association International Conference (AAIC), 31 July – 4 August 2022. You can view the full interview, here:

<https://touchneurology.com/alzheimers-disease-dementia/conference-hub/kristen-george-aaic-2022-experiences-of-discrimination-on-cognitive-function-and-ageing-among-the-oldest-old-the-lifeafter90-la90-study/>

SCIENCE WATCH

21 June: TouchNEUROLOGY discusses major risk gene for Alzheimer's disease with Elisabeth Hendrickx at the European Academy of Neurology Congress 2022



ABCA7 is a major risk gene for Alzheimer's disease (AD), and rare premature termination codon and missense mutations are

enriched in people with AD. Elisabeth Hendrickx Van de Craen (VIB-UAntwerpen, University of Antwerp, Antwerp, Belgium) spoke with touchNEUROLOGY about the findings of her study with participants presenting with cerebral amyloid angiopathy (CAA) and AD, and how this emerging evidence could be used in practice to optimise care for people with AD.

They discussed rare loss-of-function variants in ABCA7, originally described in a Belgian person with AD and whether these mutations are associated with disease progression; the findings in people presenting with CAA and AD; and how this emerging evidence could be used in practice to optimise care for people with AD.

The abstract titled "Belgian Carriers of Rare ABCA7 Mutations Present with Pronounced Cerebral Amyloid Angiopathy and Alzheimer's Disease" was presented at the European Academy of Neurology Congress 2022, which took place from 25 to 28 June 2022. You can watch the full interview, here:

<https://touchneurology.com/alzheimers-disease-dementia/conference-hub/elisabeth-hendrickx-van-de-craen-ean-2022-rare-abca7-mutations-and-alzheimers-disease/>

1 July: Research study shows that long-term high fat diet aggravates depression and memory problems in an Alzheimer's disease mouse model

Tau is a protein mainly involved in the stabilization of the neuronal skeleton. The function of tau is regulated by the attachment of phosphate groups (phosphorylation) that occur in specific sites of the protein. In Alzheimer's disease (AD), neuronal tau protein is hyperphosphorylated and aggregates to form one of the major pathological features of the disease, the neurofibrillary tangles (brain tangles). Previous studies have shown that chronic obesity and diabetes are associated with AD and may impair the central nervous system function. Difficulties



in effective insulin use (i.e., impaired glucose absorption by the cells) have also been found in post-mortem brains of people with AD and could be associated to the phosphorylation state of neuronal tau protein. However, the impact of fatty foods on cognitive function and mood in a mouse model for AD predisposed to memory problems and pronounced tau hyperphosphorylation is still unknown.

In a new study published in the journal *Metabolic Brain Disease*, the team of researchers led by Jing Xiong and Xin-Fu Zhou from the University of South Australia (Adelaide, Australia) found a clear association among long-term high fat diet and the exacerbation of cognitive decline.

To understand the impacts of fatty food on cognitive function, the researchers of the study used a mouse model for AD with a pronounced phosphorylation of tau protein. Mice were either fed a standard diet or a high fat diet for 30 weeks. Variations in food energy intake, body weight, glucose levels and insulin tolerance were measured. Anxiety, depression, memory, and tau phosphorylation state were also assessed at different intervals of the study. The researchers showed that long-term high fat diet enhances body weight gain and caloric intake, that are larger in the AD mouse model. Fatty food induces obesity, impaired insulin sensitivity and altered glucose absorption. It also aggravates anxiety and depression, as well as tau hyperphosphorylation, and cognitive impairment in mice with memory problems and pronounced tau pathology.

These findings reveal that a high fat diet not only induces obesity, but also leads to diabetes, cognitive impairment and behavioural changes in mice predisposed to brain tangles and cognitive decline. The study also highlights the effects of metabolic syndromes and tau pathology on mood and cognitive behaviour, and points towards a mouse model that may be beneficial to study the link between and mechanisms of AD, diabetes and obesity.

<https://link.springer.com/article/10.1007/s11011-022-01029-x>

5 July: Eisai and Biogen drug, lecanemab, is accepted for priority review by the US FDA under their accelerated approval pathway

On 5 July, the Tokyo-based pharmaceutical company, Eisai, together with partners at Biogen, announced that the US Food and Drug Administration had accepted their biologics licence application (BLA) for lecanemab, under the accelerated approval pathway.

Lecanemab, also known as BAN2401, is an antibody that targets amyloid protofibrils, which build up in harmful amyloid plaques within the brain during the development of Alzheimer's disease

(AD). Clarity AD, a phase 3, randomised, placebo-controlled trial of lecanemab, is currently evaluating the efficacy of the drug in participants with mild cognitive impairment or mild dementia due to AD. Ongoing analyses indicate that lecanemab is efficient at clearing amyloid plaques from the brain when delivered fortnightly at a 10mg/kg dose via intravenous infusion. Clarity AD completed enrolment in March 2021, recruiting 1,795 participants, with primary endpoint results expected in late 2022. The FDA has agreed that the Clarity AD trial, when completed, can serve as the confirmatory study to verify the clinical benefit of lecanemab.

Acceptance of the lecanemab BLA by the FDA under the accelerated approval pathway means that a decision is expected early in 2023. In their press release, Eisai stated that, depending on the results of the Clarity AD study, they will submit a traditional application for FDA approval by March 2023. They expect to file concomitant applications for approval with the European Medicines Agency and the Japanese Regulator, Pharmaceuticals and Medical Devices Agency (PMDA).

<https://eisai.mediaroom.com/2022-07-05-THE-U-S-FDA-ACCEPTS-AND-GRANTS-PRIORITY-REVIEW-FOR-EISAI-BIOLOGICS-LICENSE-APPLICATION-OF-LECANEMAB-FOR-EARLY-ALZHEIMERS-DISEASE-UNDER-THE-ACCELERATED-APPROVAL-PATHWAY>

5 July: New research shows effects of noradrenergic treatment in AD

In a new study, researchers showed that a class of drugs, called noradrenergic drugs, commonly used to treat attention deficit hyperactivity disorder (ADHD) and depression might have some benefits when used in people with Alzheimer's disease (AD). Findings were published in the *Journal of Neurology Neurosurgery & Psychiatry*.

Scientists collected data from 19 studies involving 1,811 people with either AD or mild cognitive impairment. They first looked the results of 10 studies including 1,300 people in which noradrenergic drugs had been used to potentially improve cognitive or neuropsychiatric symptoms in people with neurodegenerative diseases.

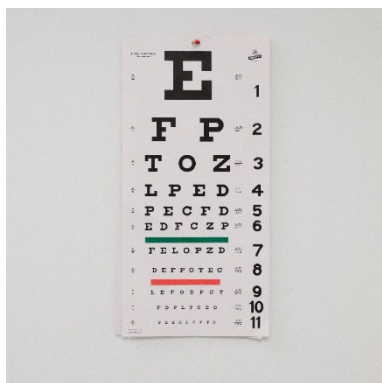
They found a small but significant positive effect of noradrenergic drugs on overall cognition in people with AD, compared with placebo, as measured using the Mini-Mental State Examination or Alzheimer's Disease Assessment Scale — Cognitive Subscale. These drugs were also shown to improve apathy, which is a common symptom of AD. No effects were found for other symptoms, including attention, memory or agitation.



Overall, this study shows evidence that noradrenergic drugs may improve cognition and decrease apathy in people with AD. However, authors raised study's limitations as this was not an experimental study and underlined the strong rationale for further targeted clinical trials. Data came from studies targeting particular groups and doses used in current licenced applications of the drugs.

<http://dx.doi.org/10.1136/jnnp-2022-329136>

15 July: Visual impairment may be a risk factor for cognitive problems and dementia



According to Alzheimer's Disease International (ADI), cognitive issues affect 50 million people in the world, and this number is predicted to triple by 2050. To tackle this challenge, it is important to identify the modifiable factors that are associated with cognitive problems, so that

appropriate prevention strategies targeting such factors can be implemented.

Previous studies indicate that visual impairment may be among the risk factors that contribute to the development of cognitive problems. To further elucidate the link between cognitive and visual impairment, a group of researchers examined data from studies on this topic and published their results in the journal *Aging & Mental Health*.

The researchers identified 16 studies that reported on the relationship between cognitive and visual impairments. These studies examined individuals at a single point in time or over a certain period. In total, this amounted to 76,373 study participants included in their analysis.

Their quantitative analyses uncovered a significant association between visual impairment and cognitive problems. In particular, the researchers found that individuals with visual impairment at the starting point of the studies had a 137% higher rate of developing cognitive impairment and dementia (regardless of whether it was objectively or subjectively assessed). People who had a visual impairment at the study start point had a 41% higher risk of experiencing cognitive problems and a 44% higher risk of developing dementia, compared to individuals with no visual issues.

According to the authors, these findings prompt the need for more research to determine whether treatment for visual disturbances (for instance, wearing glasses or cataract surgery) can be useful for reducing the risk of cognitive problems. Regular eye check-ups may also serve as a preventative measure/tool for dementia in older adults.

<https://www.tandfonline.com/doi/full/10.1080/13607863.2022.2077>

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18 July: People with several dementia risk factors could exhibit brain changes equivalent to up to 20 years of aging

A new study published in the journal of the Alzheimer's Association, "Alzheimer's and Dementia: Diagnosis, Assessment and Disease Monitoring" marks the largest study thus far to investigate the risks associated with cognitive decline, over the life course.



The researchers looked at data from 22,117 people aged between 18 and 89 years old and assessed their cognition levels. They also asked about several modifiable risk factors for dementia: low level of education, hearing loss, traumatic brain injury, alcohol or substance abuse, hypertension, smoking (currently or in the past four years), diabetes, and depression.

The findings revealed that having just one of these modifiable risk factors could decrease cognition levels by the equivalent of up to three years of ageing. And each additional risk factor led to the same amount of cognitive decline.

The researchers describe these results as very "encouraging" - they indicate that individuals have the power to significantly alter their risk of cognitive decline and dementia, at any age, by making changes to their lifestyle.

A few differences, however, were found between younger and older adults. In middle-aged and older adults, the effect of risk factors on cognition was stronger than in younger participants. This might be because young people have more protection against the effects of cognitive decline, or more "cognitive reserve".

The prevalence of risk factors also varied across ages. Older adults had more risk factors than the young and the types of risk factors varied as well. Young adults are more likely to smoke and experience depression, while older adults are more prone to hypertension and hearing loss. This prompts the need to tailor prevention strategies according to one's age group.

<https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/dad2.12337>

19 July: Roche AD biomarker test panel granted breakthrough device designation by FDA

On 19 July, Roche announced that the US Food and Drug Administration (FDA) had granted a Breakthrough Device Designation to its Elecsys Amyloid Plasma Panel. The Roche panel is the first blood-based biomarker test for Alzheimer's disease (AD) to receive this designation from the FDA, which opens the door to accelerated discussions and priority review by the regulator.

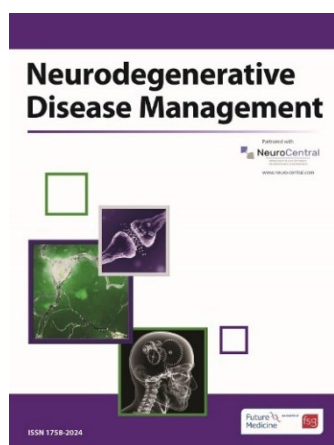


The goal of the FDA Breakthrough Devices Program is to provide patients with timely access to these medical devices by speeding up their development, assessment, and review. Breakthrough Device Designation means that manufacturers can obtain regular feedback on device development,

and receive prioritised review for future regulatory submissions. Roche has previously been granted this FDA designation for two diagnostic tests that can be used to analyse biomarkers for AD in cerebrospinal fluid samples, which are obtained using lumbar punctures of the spine.

Conversely, the Elecsys Amyloid Plasma Panel is designed to be used for analysis of plasma samples, obtained via a minimally-invasive blood draw. The test panel measures pTau181, a protein that accumulates in the early stages of AD, and APOE4, which is the most common genetic risk factor for AD. The FDA Breakthrough Device Designation is for the use of this blood test in the treatment of symptomatic patients being assessed for AD and other causes of cognitive decline.

22 July: Plain Language Summary of study on use of lumbar puncture and safety recommendations in Alzheimer's disease is published



Future Science Group, a publisher of peer-reviewed medical and scientific journals has recently begun publishing a new type of article called Plain Language Summaries of Publications. These articles provide a concise overview of a published, scientific journal article written in non-technical language. These summaries enable a wide audience, including non-specialist healthcare professionals and

patient audiences, such as patient advocates, patients and their caregivers, to be able to access and understand the research being discussed. They have recently published "The use of lumbar puncture and safety recommendations in Alzheimer's disease: a plain language summary". You can read it, here:

<https://www.futuremedicine.com/doi/10.2217/nmt-2022-0012>

More information on their plain language summaries can be found at:

<https://www.plainlanguagesummaries.com/>

5 August: New study sheds light on reasons for and against the disclosure of a dementia diagnosis

Previous research shows that the majority of people have a preference for disclosure of an Alzheimer's disease (AD) diagnosis but information about how preferences may have changed over time is lacking. In this study published in the journal *Aging & Mental Health*, researchers at the Queensland University of Technology (Brisbane, Australia) sought to analyse current AD disclosure preferences and their evolution in the past 20 years.



The present study included a sample of 229 educated participants aged between 18 and 77, including 66.7% of them aged 18 to 25 and 57.6% with at least 12 years of education. Demographic characteristics, dementia exposure and knowledge were measured. Using the "reasons for wanting to know" questionnaire, the researchers also collected information about the reasons for and against disclosure of a dementia diagnosis for oneself and for one's relative.

The study found that most people were in favour of disclosure for themselves and for their relatives, with older participants (aged over 35) being significantly more likely to want to know about their own diagnosis than younger people.

The most common reasons cited for wanting to know about one's own AD diagnosis included planning, and the right to know, accounting for the preferences of more than 90% of participants in both groups. Regarding disclosure of diagnosis to a relative, more than 90% of participants cited their reasons as being the desire to support their relative, and the right to know. The most common reason against disclosure for oneself was concern about depression and agitation and the desire to live "normally". For relatives, these included fear of upsetting them, potential suicide, and desire to protect the relative.

Most participants expressed reasons for and against disclosure, showing that people can hold a range of different and sometimes contradictory preferences. When asked whether anything would alter their position on the subject, participants' responses were varied, with 10 different reasons being given overall.

These results indicate that preferences for disclosure differ across individuals, and may be more influenced by age and values than knowledge or exposure to dementia. This research also shows that the most common reason for favouring AD disclosure is the right to know indicating that autonomy is highly valued.

<https://www.tandfonline.com/doi/full/10.1080/13607863.2022.2107174>

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25 August: Older dogs are at higher risk of dementia – but regular exercise could help



Increasing age is one of the main risk factors for developing dementia in humans. The same is thought to be true for dogs, who can develop a condition called “Canine Cognitive Dysfunction” (or CCD) which has symptoms such as memory problems, loss of spatial awareness and disrupted sleep. In their new study, published in Scientific Reports on 25 August, a team of researchers from the Dog Aging Project have conducted the largest analysis of CCD in companion dogs to date. The US-based Dog Aging Project cohort study was launched in 2018 and is currently composed of over 27,000 companion dogs, enrolled by their owners. Owners complete multiple surveys at different timepoints in the study, and it is this data that was analysed by the research team, aiming to understand the prevalence and other factors linked to CCD. In total, 15,019 dogs were included in the study of CCD. Of these, 19.5% were classified as being in the last quarter of their anticipated lifespan. 1.4% of all dogs were classified as having CCD based on survey responses from their owners. Statistical analyses revealed that over the age of 10, dogs have a 52% increased risk of developing CCD for each additional year of life – even when correcting for factors such as breed, gender and geographic location.

Interestingly, dogs who had a history of neurological, ear or eye disorders had higher odds of CCD. Also, among dogs of the same age, health status and breed, those who were not physically active were more likely to have CCD compared to their more active counterparts. However, researchers cautioned that this association may be due to cognitive decline leading to reduced activity, rather than the other way around. More research is now needed to see whether screening programmes or measures that increase physical activity can help the diagnosis and prevention of CCD.



MEMBERS NEWS

27 July: Fujitsu and the Alzheimer Society of Ireland Launch their collaborative project the Virtual Dementia Hub



In October 2021, Fujitsu proudly partnered with the Alzheimer Society of Ireland (ASI) as its primary charity partner. As a leading global technology company, the Fujitsu team eagerly shared their technical skills with the ASI. Together, they embarked on a Digital Inclusion project to empower people living with Dementia through technology. In March 2020, The ASI’s day care centres closed nationwide due to COVID-19 and the charity began distributing paper activity packs to keep their service users entertained and stimulate the brain to slow down the onset of dementia.

The ASI presented Fujitsu with an idea to create a platform where the activity packs could be accessed online independently by people living with dementia and their carers. Fujitsu recognised the value in this and invited several stakeholders from the ASI to participate in Co-Creation Innovation sessions using Fujitsu Human Centric technology. To better understand the end-user, the ASI facilitated consultation with the Irish Dementia Working Group and Dementia Carers Campaign Network - groups that advocate for better services, supports and policies for those impacted by dementia. This consultation was invaluable as it enabled Fujitsu to build a concept with them in mind – the Virtual Dementia Hub (VDH).

<https://virtualdementiahub.ie/>

22 August: Comedian Neil Delamere and beauty expert and entrepreneur Pamela Laird are supporting The Alzheimer Society of Ireland Memory Walk 2022



Comedian Neil Delamere and beauty expert and entrepreneur Pamela Laird invite the public to make every step count for the third successive Alzheimer's Memory Walk proudly supported by Irish Life, which is taking place nationwide on Sunday 18 September, during World Alzheimer's Month 2022. The Alzheimer Society of Ireland (ASI) Alzheimer Memory Walk is a family-friendly event suitable for all ages and abilities to unite together with their families and communities to raise awareness and funds for dementia supports. The ASI hopes that 3,000 walkers across Ireland will help them raise EUR 250,000 for vital services that help to support many people with dementia and their family carers across Ireland. An estimated 64,000 people live with dementia in Ireland, which will more than double in the next 25 years to over 150,000 by 2045. Walk Together on 18 September to help support them.

Walk with your household, family, friends and pets; it's guaranteed to be a fun event. You can choose where you walk, whether your back garden or the local park. There are only a few weeks left for participants to receive their packs. Family-friendly prices are EUR 8 for kids and EUR 20 for adults.

Let's Walk Together! You can learn more about Memory Walk at: <https://alzheimer.ie/get-involved/fundraising-events/alzheimer-memory-walk/>

26 August: Alzheimer Larissa organises special beauty event to mark Mothers' Day

Earlier this year, on the occasion of Mothers' Day, Alzheimer Larissa (EENAL) held a beauty event in honour of mothers, in collaboration with the beauty and fashion department of IEK Dimitra. The festive atmosphere was opened by the president of EENAL, Eleni Nifli, who spoke about the contribution of mothers, in the family, in the arts, in science, culture, etc.

Spilioti Vassiliki spoke about the positive effect of personal grooming on the soul and the human body. She also presented new techniques, materials and colours, for beautiful hands and



nails. Her presentation evoked memories in some of the participating women, who shared old techniques and wanted to learn more about nail art and painting.

This was followed by hand and nail treatments, given by the students of the nail department, in a nice atmosphere. The students, in collaboration with the women participating in the event, chose the colours of the nail varnish, as well as painting them. The result was amazing, as the participants felt that they had received a beautiful gift.

The event continued, with the offer of tasty treats, juice cocktails and the exchange of thanks and wishes. The staff of EENAL also gave out pots of red and white begonias, to the mothers and the women of IEK Dimitra, as a sign of love and remembrance. The participants were thrilled and had their photographs taken. The event closed with a song by Antonis Kalogiannis, "open the window, let in, the coolness of May ..."

30 August: UK Alzheimer's Society publishes important information about improving life for LGBTQI+ people affected by dementia



The Alzheimer's Society (UK) has published its latest "Dementia Together" magazine, for August-September 2022, which includes an article sharing important information about improving life for LGBTQI+ people affected by dementia. The article features members of the LGBTQI+ Dementia Advisory Group, Dáithí Clayton, Chris Maddocks and Mike Parish (pictured, right with his husband Tom). They aim to help improve life for people affected by dementia who identify as lesbian, gay, bisexual, trans, queer plus.

The LGBTQI+ Dementia Advisory Group is a group of individuals who are passionate about improving the lives of all people affected by dementia who identify as LGBTQI+. The group believes that the key to successfully effecting positive change is to bring together like-minded people to share ideas,

knowledge, and expertise. Members of the group aim to develop a network of people who will work together to achieve this common goal. They value the combined input of people with lived experience of dementia, people with experience of caring for or supporting people with dementia, and people who identify as LGBTQ+ with an interest in dementia.

You can find out more about the LGBTQ+ Dementia Advisory Group, here: <https://www.lgbtqdementiaadvisorygroup.net/home>

You can read the magazine article, on the Alzheimer's Society website:

<https://www.alzheimers.org.uk/get-support/publications-and-factsheets/dementia-together/creating-better-life-lgbtq-people-affected-dementia>

You can download the full Dementia Together magazine, containing the article, here:

https://www.alzheimers.org.uk/sites/default/files/2022-07/Dementiattogether_AugSept2022.pdf

LIVING WITH DEMENTIA

8 July: "I had to journey on a path I did not want" - Lieselotte shares her difficult experiences as a person diagnosed with early-onset dementia in Germany



"I had to journey on a path I did not want" - This is how I opened a digital experience exchange organised by the German Alzheimer Group in Rostock earlier this year. Fifteen people who work in caregiving met at this online event, to talk about their years of experience in the field. I was invited to join, to speak about my personal experiences and my point of view as a person diagnosed with early onset dementia.

I am 62 years old, a single mother of three children, and received my diagnosis of dementia five years ago. Back then, in 2017, I was the CEO of an IT company and responsible for upwards of EUR 3 million in profits and in charge of 200 people at the company.

But then, more and more mistakes started to creep in - the diagnosis "dementia" that followed forcefully plucked me from my successful career. The termination of my contract came quickly after: "An allegedly neurologically impaired CEO is not tolerable for the organisation." I was out! Within weeks, I was deemed ineligible and was expelled. I was no longer a person in tune

with the company's goals or with its philosophy of what was deemed as "functioning". I, who had always been right at the centre of things, went through the experience of people from my professional and personal life, either deliberately or out of uncertainty, withdrawing from me, as soon as they heard the word "dementia". Of course, I was angry and disappointed.

With increasing frequency, I was overlooked and not heard when at the doctor's or a government office, or even at support institutions. My conclusion is this: There is hardly any other illness, where people are talked about as much but almost never talked to directly. Our society does not yet hold acceptance for people with dementia. Especially, when it comes to the problems and situations faced by early stage patients, society is still largely under-equipped. There is too little room, in Germany, that would allow early stage dementia patients to share their experiences. Public and private institutions, unions, organisations, and charitable societies, as well as caregivers and doctors are still only at the beginning in their journey to a better approach to, and better support for, people with early-onset dementia. We are not yet old, we are just at the beginning of our dementia. Our shared online event did strengthen the group and myself. Encouraging each other is helpful. Experiences were exchanged and conveyed about topics such as: How to approach people who have an early stage dementia; How to bridge the gap between autonomy and caregiving; and How do we cope with saying goodbye to members of the group when the condition progresses? It is so important to still have a voice! And to be heard, because this illness will otherwise inevitably lead to an unintended and unwanted isolation of the affected person. The image of dementia in society must change - we all can and must contribute to that. I cannot and do not want to wait. I am still here, I still want to be involved, I want to be an active part of our society and I still have much to give! Now!

9 August: After a recent road trip with Helen Rochford Brennan, supporter Carmel Geoghegan shares her thoughts about driving after a dementia diagnosis

Carmel Geoghegan is friend and supporter to Helen Rochford Brennan, a member of the European Working Group of People with Dementia. She writes, here, about a recent road trip she took together with Helen and about the wider topic of driving after a dementia diagnosis:

For those of us who are not living with a dementia diagnosis, it is impossible to understand what it must mean to even consider never driving again. Driving is a lifeline, in particular in rural areas of any country where public transport is unreliable or non-existent and where neighbours may be some distance away.

In October 2021, I had the most exciting adventure when I was invited to accompany my friend and inspiration Helen Rochford Brennan on a road trip to Scotland. Helen lives in a rural village in Co. Sligo and I live in Connemara, Co. Galway, in the West of Ireland. Helen was eager to go and meet up with her dear friends who live in Scotland.

We drove to Belfast and took the ferry to Cairnryan, then drove to Ayr, birth place of Robert Burns the famous poet. Then, on to Glasgow where we met up with Agnes Houston, the amazing advocate and author of the leaflet “[Dementia & Sensory Challenges](#)”.

We then met with another strong advocate, [James McKillop](#) for coffee, and discussed the world’s happenings. We were delighted to also meet with our colleague Jim Pearson from Alzheimer Scotland for breakfast. Always a pleasure and we took the obligatory selfie!

We took off to go further north, through Stirling, but unfortunately due to COVID restrictions we didn’t get to visit Stirling University or meet with Professor Karen Watchman. That’s definitely another trip for the future!

It is important, at this stage, that I tell you how Helen had added me to her car insurance so I could share the driving but she was in full control and I got very little time behind the wheel. As we continued up to Cromarty, on the Black Isle, we stopped off at Loch Ness to see if the Monster was available for a selfie – no joy!

We spent a few days in the wonderful company of [Nancy McAdam](#), another selfless advocate for the rights of people with dementia. Nancy lives an amazing full life on the Black Isle, where her beautiful cottage is located in a very rural area and as she does not drive, she has to walk some distance to access public transport.

I was very privileged to have had the pleasure of Helen’s company for a week and to meet up with her great friends and colleagues. Just because someone gets a diagnosis this does not mean they can no longer live a full independent life. As a parting thought, I would say let us be non-judgemental and live with an open mind. I was reminded of the importance of this when we were meeting for coffee with another distinguished person who is a voice for rural ageing, but who assumed that I would be driving, not Helen!

Pictured: Carmel Geoghegan (left), Helen Rochford Brennan (centre) and Jim Pearson



25 August: Petri Lampinen discusses security and how it affects him as a person living with dementia



Petri Lampinen, a member of the European Working Group of People with Dementia, was recently invited to speak at a joint meeting of the divisions of the Finnish Customer and Patient Safety Association. They wanted to hear from people with dementia and about how security affects them. They had previously awarded him with a diploma and a badge of merit, in December 2021, for his work in this area and they now wanted him to speak at their event in Helsinki on 16 June 2022, at the meeting rooms of the Finnish Nurses’ Union (TEHY), which he was happy to do. This is what he shared with the audience, in his speech “Security, how does it affect me?”:

The safe running of things and avoiding various incidents; a life lived without too many fears; practicing and doing the things that you can still do safely yourself; leaving out more challenging tasks for yourself; the courage to ask other people for guidance and help - When I was a kid and young man, I didn’t pay any attention to these things. In retrospect, I am horrified by the dangers there were in childhood. A familiar family doctor lived next door to us at the time, and we little boys were referred to this doctor in the event of an

accident. They had a lot of medical work to do while off duty!

When I was working, I took care of the occupational safety of the people reporting to me. I paid particular attention to their proper orientation. I worked as a parish gardener in my working life.

When I went on sick leave, before my diagnosis with a memory disorder, I lost my sense of security for the first time in my life. When I was at home, I was afraid of doing everyday activities. I often burned my hands when I was cooking. I flinched with even the slightest noises; I was afraid the appliances would be left on. The problem of functional/cognitive difficulties related to these activities made life exceedingly hard. Gradually, however, I began to trust myself and my ability to cope with everyday tasks. A very immense help in this situation, was my own activity, as well as developing my own means of assistance to support day-to-day tasks -not forgetting, of course, the support of loved ones.

The use of a whiteboard helped me remember things and reduce the amount of noise in everyday life. So, I did not have to go from room to room to check things out anymore. My wife was left alone at work, too, I did not have to check on her so often. In the initial stages of my illness, I called her all the time.

In neurological rehabilitation, I developed checklists to help me, so that no activity was left unfinished when I left the house. I also had lists with necessary items written on them, to remind me to take what I needed on any trip outside.

With the use of these developed aids, the daily visits from home-care staff were able to stop. Home-care gave me, in the initial stages of the illness, a sense of security. During the visits, home-care workers checked my safety. We were living in a detached house at the time, and it was not the safest place for someone with a memory disorder to live. Over the years, my wife and I have made joint decisions about where we live and about our type of housing.

I voluntarily gave up the right to drive, as I found myself a danger to others in traffic. I was having trouble with short-term memory, so while I may have thought I was paying attention to where I was going, sometimes I was not. I am happy with the information I have about my symptoms; it helps me to understand things that I can still do safely. Driving a car is no longer going well for me and I understand this perfectly. It is for my protection and for the protection of my fellow human beings!

A bicycle is good enough for me and since my diagnosis with a memory disorder, I have at least started wearing a bike helmet. Better late than never. Brain health should be nurtured in memory disorders.

It took me two years to get my diagnosis. This frontotemporal dementia is not easy to diagnose. Fortunately, over the years, there has been progress in this area. Great research has been carried out in Finland and around the world, but when I was first going to medical, I noticed problems with the flow of information between specialised medical units. I was seen by many units, some of which stayed connected with each other, while others did not. I noticed these things even more clearly, from the medical records I ordered afterwards. I had noticed the constant rush that doctors and nurses were in. It was only when we entered the room that they started looking for my medical records on the computer. Appointment times were short, and another problem was the ever-changing doctors.

Suddenly, in the middle of my journey to diagnosis, they just stopped seeing me, which was a shock. I felt that the quality of medical care was far from as good as it could be and certainly not like it is on the television show *Strömsö!* That is why I contacted the patient ombudsman. I fought for my rights and, with the ombudsman's help, sent a letter to the hospital's chief medical officer. I was not satisfied with his answer, so I then lodged a complaint with the Patient Injury Board. Their decision, which I liked, was that my appointments should not have stopped in the middle of my diagnostic journey. Sometimes, a little anger is good - you can take things forward in a stressful life situation. I am not bitter; I am not angry, because there is nothing to win in life by holding grudges. We all make mistakes, and we can learn from them. It is important not to worry but rather, to find positive things in life.

I prepared for medical appointments in advance. I had print-outs with me, my own lists of medicines, the latest study results, my blood pressure readings and the diagnoses received. I often received praise from the staff for helping their work in this way. I still use these lists today to help me with healthcare visits. Sometimes, I left my thick, self-collected patient file to be examined by a doctor in peace, especially when they needed more time to make an assessment. I have made a small addition to the lists, which I hope will lead to a better quality of treatment. I have also posted my health data on the Finnish health data website, Kanta: <https://www.kanta.fi/en/>.

By the time I arrive in the doctor's office, I have openly told staff that I have a memory disorder. I am open with them about my need for help, and I am not ashamed to ask them for support. I ask them to give me instructions in writing, especially if I do not have a supporter with me, as I do not always remember the instructions given, especially when it comes to medication. Information often comes so fast that I forget about it right away. I would also ask them to check that I remember to take all my things with me and that I am properly dressed. Impulsiveness can play tricks on you, sometimes. One time, when I was living in the previous town, I left the doctor's office without my shoes. The doctor shouted after me from the door that "your shoes stayed in the room, Petri." I would quickly have noticed the shoes were missing, but it was good to be reminded, nonetheless. I have also followed quite closely the health information that has been noted about me. A few times over the last two years, I have had to give feedback on inaccurate information. This information would have misrepresented my situation.

I have managed to take care of my mother's and my father's affairs in the last three years, despite my memory disorder. My mother passed away last summer, and I had problems running her affairs. She was moved from one unit to another and often I had to be a detective to see which unit she had been taken to. These things were influenced by the same thing that I mentioned earlier: The healthcare staff is in too much of a hurry. The nurses told me quite often that it was good that I was taking it upon myself to figure these things out. A few of the units called to say that my mother had been transferred to another unit, and I thanked them for the update. I reminded them of my mother's upcoming outpatient appointments, asking whether she needed to go to them or whether to remove these visits from her calendar.

Since my mother died, my father's condition has gotten worse. He has had two bad falls this spring. Unfortunately, there have been bone fractures both times. Together with the health care staff, I concluded that it was no longer safe for him to live alone at home. Short home visits from carers a few times a day do not guarantee a safe life for him. We also made sure that he understands

and accepts this, although of course it has been difficult for him. We have also been asked whether having a memory-impaired person in his close family is a security risk for my father. I have had to go through this, along with taking care of my parents' business. For example, I have had to fill out a questionnaire about my relative and when I have been open about my memory disorder, I have been asked, "Can someone else fill out the form?" In some units, the staff know me through experience and know they can rely on the correctness of the information I give. I understand that they question my ability to function, but we people with memory disorders must not all be put in the same category. People with young-onset memory disorders, who are of a working age, can still manage many things independently.

I am trying everything I can to take care of security. At home, I have smoke alarms, checklists, a whiteboard, a fire blanket and first aid supplies. I also have my patient data and information about my treatment in an envelope, ready. So, if I suddenly have a medical emergency at home, the paramedics will quickly receive the necessary information. I did this because some time ago, I watched a television programme which stated that the paramedics could not access the patients' database directly. Their superiors can, but this can take valuable time.

I have functional/cognitive difficulties, and problems with attention and concentration. I might be using the wrong product or object for the wrong situation. Last winter, we had to put distilled water in the humidifier of my CPAP (continuous positive airway pressure) device because the water where we live in Seinäjoki, is so chlorine-rich. I thought, in the store, that all the clear liquids were distilled water. When I woke up the next morning, I wondered about the whiteness of the humidifier and I felt stuffy anyway, so I went to the canister and checked the label of the product. I had accidentally bought diesel exhaust fluid. I had inhaled this all night. I was really scared and so I called the Poison Information Centre and got good instructions from them on this tricky situation. Since this event, my wife has been checking what liquid I use for my humidifier.

Similar errors may occur in healthcare, whether at the doctor's office, in a hospital or during a home-care visit. My father was given influenza and coronavirus vaccines on consecutive days, i.e. double doses. He had moved home from the inpatient ward of the hospital and the information on the vaccinations already received was not visible to the home-care worker. Or, perhaps the employee's haste affected this activity? Rushing and limited time for different things affects the feeling of security. Commotion and frightening situations in acute emergency care are exceedingly tricky situations for frail people and for people with memory disorders, as well as for the staff. I have been scared myself, sometimes as scared as a small child, even though I am an adult.

It has now been seven years since my diagnosis with a memory disorder. During this period, I have not had post-diagnostic care and support that normally comes with a memory disorder. This has not created security for me and for the people I care about. Apparently, it is because I was under sixty-five. Fortunately, however, things have changed for the better recently. In our area, South Ostrobothnia, a care pathway for people with memory disorders was introduced this year, in spring. It takes into account those of us who are still working-aged and have memory disorders, as well as our loved ones. I am an expert-by-experience for the Finnish Memory Association. I am not a healthcare professional. However, I believe that I can do my bit for customer and patient safety.

26 August: Driving is a lifeline for Helen Rochford Brennan, member of the European Working Group of People with Dementia

I am driving, while I still can. When I was diagnosed with early onset Alzheimer's, it never occurred to me that I might not be able to drive. I was not told so at my diagnosis. However, at a follow up with my consultant, he informed me that I must tell the road safety authority and my insurer, and that I must take an assessment. I was in a state of shock, as the thought of not driving would depress me. Of course, I quickly did what was necessary. I think doing a road assessment is a particularly good idea. I am responsible citizen and I would not drive without doing the assessment though I often feel many of those I encounter driving should perhaps resit their tests!

Driving is a lifeline for me as I live in a rural area with extremely limited public transport. During the COVID "cocooning" (lockdown), my late husband Sean and I planned to take a trip to Scotland to see some friends and for me to meet with my Alzheimer friends James, Agnes, and Nancy, but sadly we never got to take the trip.

I had given it much thought and spoke to my son Martin who encouraged me to go, but first to ask my travel support Carmel Geoghegan if she would like to join me. Since my diagnosis, I had driven from Sligo here in the Northwest of Ireland to London England, therefore, I was not concerned about the drive to Scotland. I always tell myself, "either you can drive safely, or you cannot and when in doubt STOP." Carmel was an amazing support in planning this trip with me. I love driving and Carmel only got to drive my car occasionally.



The GPS did not pick up closed streets in Edinburgh, which was a challenge, but Google maps on the phone sorted the route for us! We met a friend who participates in research and she was amazed I still drive, ten years after my diagnosis. It is upsetting to me that people still assume that we cannot drive, though from my many years of advocacy I do understand some of the reasons. Something I have heard over and over is “my partner told me not to”, or that side effects of medication prevent people from driving. Scotland was a joyful experience for me, meeting up with James McKillop and Agnes Houston in Glasgow, sightseeing in Edinburgh, which brought back great memories for me, and then driving to the Black Isle to see Nancy McAdam. They all have Alzheimer’s and are living such happy, productive lives, which encourages and inspires me.

It was also an immense pleasure to have breakfast with Jim Pearson from Alzheimer Scotland and get the usual selfie! Another highlight of the trip was having afternoon tea with Chris Lynch from Alzheimer’s Disease International. Two hours of bliss and laughter! Chris is so full of knowledge about beautiful Edinburgh and its places of interest. I have also just returned from my niece’s wedding in Calgary, Canada, where I also had the opportunity to drive. This was a new challenge, as it was the opposite side of the road.

Over the years, I have been told driving is about long term memory, that it requires multiple cognitive functions such as attention, spatial awareness, and memory. It is also about where we are on our own dementia journey, as we are all different.

As people with dementia, when taking trips, we should give ourselves lots of time, and on exceptionally long journeys take along someone for support if needed. We should also have an assessment annually and, if ever in doubt, reassess the situation, as safety of oneself and others is vital. Personally, I look forward to many more happy years of driving!



DEMENTIA IN SOCIETY

6 August: Swedish Federation for Lesbian, Gay, Bisexual, Transgender, Queer and Intersex rights participates in Swedish Pride week parade, together with its “seniors”



At the beginning of August, Karin Westerlund, Board member of Alzheimer Europe, was invited to the very start of Stockholm Pride Parade 2022 and proudly walked together with RFSL Sweden’s wagon 4 “RFSL Senior”. RFSL is the Swedish Federation for Lesbian, Gay, Bisexual, Transgender, Queer and Intersex rights and was started in 1950, making it one of the oldest surviving LGBTQI rights organisations in the world. One

of RFSL’s areas of focus is on issues for their “seniors”, older LGBTQI people.

Find out more about RFSL’s work with older people: <https://www.rfsl.se/en/organisation/senior/>

Each year, approximately 5,000 Swedish people take part in the parade in Stockholm, and there are more than 50,000 visitors following the annual two-hour parade through the city. There was a lot of joy, music, dancing and excitement in the air, as this was the first “real” live parade since the COVID-19 pandemic restrictions broke.

<https://www.stockholmpride.org/en/>

26 August: Alzheimer’s Care Armenia launches Brain Health Armenia project to help improve care and treatment of people with Alzheimer’s disease

The mission of Alzheimer’s Care Armenia is to raise awareness and offer solutions for the care and treatment of people with Alzheimer’s disease in Armenia. The organisation launched its Brain Health Armenia project in June, with a grant from the Davos Alzheimer’s Collaborative, the organisation leading an unprecedented global response to Alzheimer’s disease.

Alzheimer’s Care Armenia is very excited to announce that, during August, healthcare professionals working on this new project conducted early detection memory screening with several hundred people. As the leader in improving care services for people with Alzheimer’s disease in Armenia, the organisation’s team provided a “Dementia 101” course for



primary care physicians and nurses. A few dozen family members of people with dementia also attended the trainings for caregivers.

Thanks to its collaborators in Armenia and all over the world, Alzheimer's Care Armenia has an opportunity to extend its impact, by sharing best practices to improve awareness of Alzheimer's disease and other dementias.

<https://alzheimers.am/en/>

26 August: Engaging Dementia holds first Rainbow Virtual Café for members of the LGBTQI+ community living with dementia in Ireland

You are invited to the first meeting of our
Rainbow Virtual Café

Special Guest Speaker:
James O'Hagan
LGBT Champions Programme Manager

Topic: LGBT Ireland - Supporting Older LGBTQ+ People

Details: via Zoom on Fri 26th of August at 11am
(Last Friday of each month thereafter)

To sign up to attend email: virtualcafe@engagingdementia.ie

On 26 August 2022, Engaging Dementia, an Irish charity which provides training for carers of people living with dementia in nursing homes, day centres, hospitals or at home, held its first ever Rainbow Virtual Café, a dementia café for members of the LGBTQI+ community in

Ireland. Guest speaker James O'Hagan, LGBT Ireland Champions Programme Manager, discussed "LGBT Ireland: Supporting older LGBTQ People".

The café will continue to take place on the last Friday of each month from hereon in. If you would like to participate, please email virtualcafe@engagingdementia.ie

EDUCATION

7 July: Registrations are open for the Edinburgh Dementia Prevention Summer School 2022



Edinburgh Dementia Prevention are hosting a brain health summer school on Monday 26 September – Thursday 29 September 2022, at St Leonard's Hall, Edinburgh (UK). It is a 4-day interactive course

designed principally for trainee and qualified clinicians, nurses and allied health professionals working in (or with an aim to work in) brain health and Alzheimer's disease services. Post-graduate students with an interest in pursuing research in brain health and Alzheimer's disease will also be welcome, as are those interested in increasing their general knowledge of research in this area (for example public health workers).

An important aim of the course is to introduce students to approaches outside their current discipline with a view to

developing multi-disciplinary practice and research. The course will provide an overview of brain health clinical services and an exploration of the evidence base underpinning these. There will be a blend of lectures and interactive activities throughout the summer school to enhance learning.

Admission will be limited to 30 participants to maximise learning and networking opportunities! For more information about the programme and to enrol, visit:

<https://www.sdrc.scot/summer-school>

25 July: 8-week online course from the University of Worcester Association for Dementia Studies will look at "Championing physical activity for people affected by dementia"

This Autumn, the Association for Dementia Studies and Active Herefordshire and Worcestershire will be offering its popular, fully online course, "Championing physical activity for people affected by dementia". This is for colleagues supporting people affected by dementia, who are employed or volunteer in care, sport, leisure, housing, health, or community-based services.



The course will develop the knowledge and confidence of students to facilitate physical activity for people affected by dementia. There will be live and interactive sessions with the course tutors, as well as a multitude of resources to support learning and practice.

To find out more or to register, please contact Dr Chris Russell (tel. +44 01905 542635, email c.russell@worc.ac.uk)

Places are limited so please hurry!

JOB OPPORTUNITIES

21 July: The Pattern-Cog project seeks a Post-Doc

The Research Centre for Neurological Diseases Foundation offers a post-doctoral position at the Reina Sofia Foundation Alzheimer



Centre in Madrid, Spain. The successful candidate will work for the "Personalised aging pattern for early risk detection and prevention of cognitive impairment and dementia in cognitively healthy individuals (Pattern-Cog)" project, funded by the European grant initiative ERA-PerMed (Personalised Medicine). The Post-Doc will leverage data from an ongoing longitudinal study of a large cohort of healthy 70-85 year old, with particular emphasis on those individuals who later develop mild cognitive impairment and Alzheimer's disease.

Please contact Bryan Strange by email on bryan.strange@upm.es for further details. The deadline for submission is 30 September

2022. Ideally, the successful applicant will be able to start the position by 17 October 2022. For further information please visit:

<https://www.thestrangelab.org/positions/current-positions/>

1 August: Funded three-year Vice Chancellor Scholarship PhD in positive psychology approaches to dementia care available at University of Greenwich



A funded three-year Vice Chancellor Scholarship PhD opportunity has opened in the Faculty of Education, Health & Human Sciences at the University of Greenwich, London. The project will be in positive psychology approaches to dementia care. The closing date for applications is 2 September 2022.

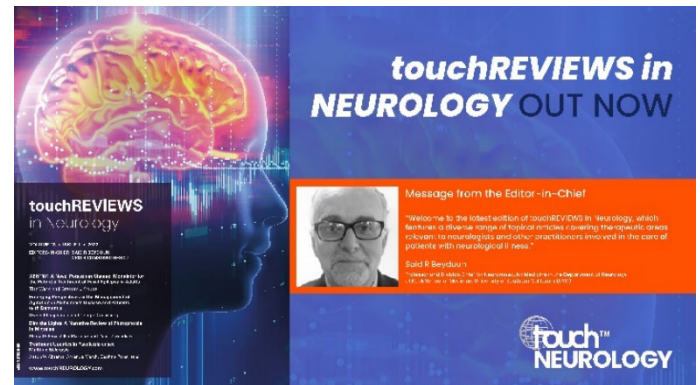
Find out more:

https://docs.gre.ac.uk/__data/assets/pdf_file/0027/292536/vcs-fehhs-02-22-web-advert-2022-07-08-09-49-11-472.pdf

Apply: <https://www.gre.ac.uk/research/study/application-process>

NEW PUBLICATIONS AND RESOURCES

1 August: touchNEUROLOGY publishes new edition of its journal touchREVIEWS in Neurology



Welcome to the latest edition of touchREVIEWS in Neurology which features a diverse range of free-to-view, topical articles covering therapeutic areas relevant to neurologists and other practitioners involved in the care of patients with neurological illness.

touchREVIEWS in Neurology would like to thank its expert authors for providing insightful and thought-provoking articles. They are also grateful to all organisations and media partners for their ongoing support and the members of the editorial board for their continued involvement and advice.

Explore the new edition of touchREVIEWS in Neurology journal, here:

<https://touchneurology.com/journals/touchreviews-neurology/touchreviews-in-neurology-volume-18-issue-1-2022/>



Reminder
LATE CALL FOR ABSTRACTS
September 15-30

November 29-December 2, 2022
San Francisco, USA

www.ctad-alzheimer.com
Email: ctad@ant-congres.com



11. KONGRESS DER DEUTSCHEN ALZHEIMER GESELLSCHAFT
vom 29. September bis 1. Oktober 2022 in Mülheim an der Ruhr
www.demenz-kongress.de

Contact Alzheimer Europe:

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

Alzheimer Europe Board:

Chairperson: Iva Holmerová (Czech Republic); **Vice-Chairperson:** Charles Scerri (Malta); **Honorary Secretary:** James Pearson (UK, Scotland); **Honorary Treasurer:** Marco Blom (Netherlands). **Members:** Stefanie Becker (Switzerland), René Friederici (Luxembourg), Sabine Jansen (Germany), Pat McLoughlin (Ireland), Sirpa Pietikäinen (Finland), Chris Roberts, Chairperson of the European Working Group of People with Dementia (United Kingdom), Karin Westerlund (Sweden), Maria do Rósario Zincke dos Reis (Portugal).

Alzheimer Europe Staff:

Executive Director: Jean Georges; **Communications Officer:** Kate Boor Ellis; **Conference and Event Coordinator:** Gwladys Guillory; **Director for Projects:** Dianne Gove; **Project Communications Officer:** Christophe Bintener; **Project Officers:** Cindy Birck, Angela Bradshaw, Ana Diaz; Daphné Lamirel, Soraya Moradi-Bachiller; **Policy Officer:** Owen Miller; **Finance Officer:** Stefanie Peulen; **Administrative Assistants:** Cristina Pencea, Grazia Tomasini.

AE CALENDAR

Date	Meeting	AE representative
1 September	IPA Webinar on New Promising Developments: Preventative Interventions in Dementia	Jean
2 September	Meeting to discuss proposal by Playlab Films regarding documentary "Captain"	Kate
5 September	Alzheimer Europe Membership Committee	AE Board and Jean
5-6 September	Site inspection 32AEC (Bucharest, Romania)	Gwladys, Cristina, Chris Roberts and Jayne Goodrick
6 September	AIM/AEIP event on European Care Strategy	Owen
6-8 September	General Assembly meeting of the PRIME project (Barcelona, Spain)	Angela
7 September	Lilly Multistakeholder Forum (Munich, Germany)	Jean
7 September	MinD network meeting	Dianne
8 September	Lethe Advisory Board meeting	Ana
9 September	Meeting with EFPIA AD Platform	Jean
11 September	Dinner with the European Federation of Neurological Associations (Luxembourg, Luxembourg)	Jean
12 September	General Assembly meeting of the RECOGNISED project	Angela
13 September	Alzheimer's Association Academy on intellectual disabilities and dementia	AE members and staff
14 September	Information meeting with TauRx	AE members and staff
15 September	Anti-Stigma Award Committee Meeting	AE Board and Jean
15 and 23 September	Joint Lethe and EU-FINGERS Advisory Board meetings	Ana and Cindy
16 September	Involving people with lived experience in neuroprogressive and dementia research (NHS, Edinburgh, UK)	Dianne (presenting virtually)
19-20 September	PRODEMOS Annual General Meeting (Luxembourg, Luxembourg)	Cindy and Jean
21 September	Meeting with Stella Kyriakides, EU Commissioner for Health and Food Safety	Jean with colleagues from EPF, EPHA and
21 September	Association Luxembourg Alzheimer Ethics Committee (Luxembourg)	Jean
22-23 September	AMYPAD General Assembly (Amsterdam, Netherlands)	Cindy
21-22 September	EMA PCWP/HCPWP meeting (Amsterdam, Netherlands)	Angela
26 September	Alzheimer Europe Board (Brussels, Belgium)	AE Board and staff
27 September	Company Round Table (Brussels, Belgium)	AE members, staff and sponsors

27 September	European Parliament lunch debate “The role of artificial intelligence and big data in dementia research” (Brussels, Belgium)	AE members, staff and sponsors
27 September	Alzheimer’s Association Academy on employment and dementia (Brussels, Belgium)	AE members and staff
28 September	Meeting with publishers Antilope de Bie (Duffel, Belgium)	Kate
27-28 September	EWGPWD meeting (Brussels, Belgium)	Dianne, Ana, Daphné and Soraya
29 September	RADAR-AD consortium meeting (Amsterdam, Netherlands)	Ana and Dianne
29 September	EPND workshop on sustainability (Monheim, Germany)	Angela
30 September	Webinar Interdem taskforce on primary prevention	Ana

CONFERENCES 2022

Date	Meeting	Place
8-9 September	International Dementia Conference 2022: Brave New World, https://www.dementiaconference.com/	Sydney, Australia
16 September	Neuroprogressive and Dementia Network conference 2022, https://www.eventbrite.co.uk/e/nrs-neuroprogressive-dementia-network-conference-2022-tickets-338227516607	Edinburgh, Scotland
20-22 September	Dementia Lab Conference - The residue of design, https://www.dementialabconference.com/	Leuven, Belgium
29 September - 1 October	11 th Congress of the German Alzheimer Association (Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz), “Dementia: Daring new ways”, www.demenz-kongress.de	Mülheim an der Ruhr, Germany
5-8 October	Croatian Congress on Alzheimer’s Disease with International Participation, CROCAD-22, http://www.alzheimer-croatia2022.com/	Supetar, Brač island, Croatia
13-15 October	In and Out of Your Mind conference, focusing on early intervention services for individuals experiencing a psychotic illness, co-organised by EUPHA Public Mental Health section, https://inandoutconference.com/	Zagreb, Croatia
17-19 October	32 nd Alzheimer Europe Conference “Building bridges”, https://www.alzheimer-europe.org/Conferences/2022-Bucharest	Bucharest, Romania
7-10 November	EMBO-EMBL Symposium on “The neurovascular interface”, https://www.embl.org/about/info/course-and-conference-office/events/ees22-11/	EMBL Heidelberg and Virtual
9-12 November	15 th European Public Health Conference 2022 “Strengthening health systems: improving population health and being prepared for the unexpected”, including EUPHA Public Mental Health section sessions https://ephconference.eu/	Berlin, Germany
29 November - 2 December	Clinical Trials on Alzheimer’s Disease (CTAD 2022), www.ctad-alzheimer.com	San Francisco, USA



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32nd Alzheimer Europe Conference

Building bridges

Bucharest, Romania

17 to 19 October 2022

www.alzheimer-europe.org/conferences

 #32AEC

