

# ALZHEIMER EUROPE NEWSLETTER

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## WELCOME



Firstly, congratulations to our members for all their hard work this World Alzheimer’s Day (21 September). The ongoing coronavirus pandemic has put up so many roadblocks in the work we all do, but our

members found new and creative ways to carry out their all-important awareness-raising and fundraising activities. It is so heartening and inspiring to see how resilient and hardworking everyone is in the dementia field. You can read more in our “World Alzheimer’s Day” section.

For our part, we marked the occasion with a social media campaign, calling attention to the damage COVID-19 is doing to dementia research, and asking for urgent action to address this.

MEPs Hilde Vautmans (Belgium) and Christophe Hansen (Luxembourg), both of whom are Vice-chairs of the European Alzheimer’s Alliance (EAA), submitted written questions to the European Commission this month. They asked about the place of dementia and cognitive disabilities in the forthcoming European Disability Strategy, and in the future research priorities of the EU, including within Horizon Europe. We look forward to the Commission’s responses. The EAA has also gained a new member, Chrysoula Zacharopoulou MEP (France). We welcome her and look forward to working together.

In other EU news, ahead of debates in the European Parliament on the EU’s forthcoming stand-alone health programme,

the EU4Health Civil Society Alliance has published a position statement, outlining key principles and points that should underpin the future Health Programme.

On the research front, it has been announced that a Phase II clinical trial of semorinemab, an anti-tau monoclonal antibody in early Alzheimer’s disease, did not meet its primary efficacy endpoint. It is always disappointing to read about failed trials, but there are many other studies underway and the field of dementia research continues to explore possible treatments, prevention, care and cure. Alzheimer Europe is fully committed to supporting research and for this reason, I am pleased to inform you that the Luxembourg Ministry of Research has accredited us for five more years, as a Luxembourg non-profit organisation in the field of research, allowing us to continue to participate in projects with the EU Joint Programme – Neurodegenerative Disease Research (JPND) or The Active and Assisted Living Programme (AAL). It also allows us to receive funding from the “Fonds national pour la recherche”.

October sees our 1<sup>st</sup> ever virtual conference, running from 20 to 22 October. Register by 19 October, for what promises to be an exciting and interactive event! While it is our 1<sup>st</sup> online conference, it is our 30<sup>th</sup> Annual Conference, marking 30 years since Alzheimer Europe began. We will dedicate a special section of the October edition of Dementia in Europe magazine to celebrating our 30<sup>th</sup> anniversary. Watch this space!

**Jean Georges**  
Executive Director

## COVID-19 SITUATION

### 17 September: Bengt Winblad gives TouchNEUROLOGY the Swedish geriatric neurologist perspective on COVID-19



TouchNEUROLOGY was honoured to have the opportunity to catch-up with Bengt Winblad (Karolinska University Hospital and Karolinska Institutet, Stockholm, Sweden), world

renowned researcher in Alzheimer's disease and member of the TouchNEUROLOGY Editorial Board. He discussed several topics including his perspective on the COVID-19 pandemic as a Swedish geriatric neurologist.

Watch the interview, here:

<https://bit.ly/3ieGn3f>

### 24 September: Comparative analysis identifies key lessons learned from different COVID-19 lockdown exit strategies



On 24 September, the Lancet published a health policy article that analysed the different lockdown exit strategies employed in Europe and the Asia Pacific region, identifying key lessons learned.

At the time of writing, the COVID-19 pandemic has claimed over 900,000 lives worldwide, with almost 23 million confirmed cases. In their article, first authors Emeline Han and Melisa Mei Jin Tan compared and contrasted the lockdown exit measures taken in 9 high-income countries and regions: Hong Kong, Japan, New Zealand, Singapore, South Korea, Germany, Norway, Spain and the UK. Using a comparative framework that included indicators of infection status, community engagement, public health capacity, health system capacity and measures for border control, they described the measures implemented in each of the 9 countries. For example, Japan, Germany, Norway, Spain and the UK have been reporting estimates of the COVID-19 reproduction number (R), while Hong Kong has based its analyses on a real-time R, which is harder to calculate but more accurate.

The authors also highlight the fact that countries and regions have varied in their ability to implement effective systems to test, trace and isolate people with, or at high likelihood of having, COVID-19. The analysis emphasizes the importance of community engagement, and identifies several examples where political leaders have struggled to secure public trust.

Lessons learned include the importance of establishing robust systems to monitor the infection situation, similar to countries such as Hong Kong and South Korea. Lockdown exit strategies that are clear, transparent and use a staged or phased approach are commended, as are those that implement effective contact tracing and isolation systems. Finally, the authors emphasise the importance of regularly reviewing and optimizing their processes, based on up-to-date knowledge of epidemiological, public and community health parameters.

The incidence rate of a disease measures the frequency with which it occurs over a specified time period, and is linked to the risk of developing the disease in question. Assessment of the incidence rate of dementia is complicated by the fact that many population-based cohort studies don't have a sufficiently large number of participants to accurately quantify changes in incidence over time. To address this issue, the ACC investigators analysed the data from 7 different EU and US cohorts, totalling 49,202 individuals aged 65 years and above. At least 15 years of follow-up data was available for each participant, including detailed clinical information and whether they had been diagnosed with Alzheimer's disease or dementia.

[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)32007-9/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)32007-9/fulltext)

### Sponsors of the month

Alzheimer Europe would like to express its gratitude to two new sponsors for its 2020 activities.

Read more about sponsorship opportunities here:

<http://bit.ly/sponsorAE>



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## ALZHEIMER EUROPE

### 1 September: Alzheimer Europe research accreditation renewed for five years



THE GOVERNMENT  
OF THE GRAND DUCHY OF LUXEMBOURG  
Ministry of Higher Education and Research

On 1 September 2020, the Luxembourg Ministry of Research accredited Alzheimer Europe as a Luxembourg non-profit organisation in the field of research. This accreditation was first granted to us in 2015, for a five-year period.

The renewal of this accreditation, which is for five more years, allows us to continue to participate in projects with the EU Joint Programme – Neurodegenerative Disease Research (JPND) or The Active and Assisted Living Programme (AAL). It also allows us to receive funding from the national funding agency “Fonds national pour la recherche” (FNR).

### 8 September: European Working Group of People with Dementia says farewell to Thomas Maurer



Due to different circumstances, members of the European Working Group of People with Dementia (EWGPWD) did not have the opportunity to say farewell to Thomas Maurer, the

group’s member from Switzerland, in person and to present him with his EWGPWD plaque.

Instead, Director for Projects Dianne Gove and Project Officer Ana Diaz coordinated with members of the Swiss Association to send the plaque and a card signed by all members of the EWGPWD to the people in charge of the Swiss dementia working group.

Together with Dianne and Ana, Vice-Chairperson of the EWGPWD Chris Roberts was invited to join the final part of one of the regular meetings of the Swiss group, which was also attended by Thomas. Chris and Dianne thanked Thomas for his contribution to the EWGPWD, on behalf of the group and of Alzheimer Europe respectively.

We wish Thomas all the best and thank him for his contributions to the group between 2018 and 2020.

### 10 September: TauRx Therapeutics and BrainMind launch new educational materials on the role of tau in AD



On 10 September, TauRx Therapeutics and BrainMind launched new educational materials on the role of tau in Alzheimer’s disease (AD) at a meeting organised by Alzheimer Europe and attended by 24 of its national member organisations. The illustrations are the result of the peer-reviewed, published science, developed by BrainMind through an educational grant from TauRx, with an aim to explain to doctors and their patients how abnormal tau aggregation affects the brain and how this could be treated.

TauRx’s goal in providing these materials first to Alzheimer Europe and its members, is to help people understand how its lead compound, hydromethylthionine, works and how it might benefit the research participants currently enrolling in its ongoing LUCIDITY clinical trial. The purpose of this study is to determine the safety and efficacy of hydromethylthionine in the treatment of people with Alzheimer’s disease. The trial has already started recruitment in France, Italy, Poland, Spain, UK and US. Results are expected to be available by mid-2022.

“People living with Alzheimer’s disease, their families and carers, as well as Alzheimer’s associations are closely following research developments in the hope of better treatment and prevention possibilities. Alzheimer Europe aims to provide easy-to-understand information on ongoing clinical trials and we are therefore very grateful to TauRx for presenting their phase III programme to our members. The educational material and visuals launched at our meeting will be very useful in explaining the important role of tau in the development of Alzheimer’s disease to a non-scientific audience”, said Jean Georges, Executive Director of Alzheimer Europe.

**16 September: Paper on ethical and social implications of using predictive modelling for AD prevention is published**



On 16 September Alzheimer Europe received word that the paper “Ethical and Social Implications of Using Predictive Modeling for Alzheimer’s Disease Prevention: A Systematic Literature Review” had been published in the Journal of Alzheimer-s Disease (JAD).

The authors include Director for Projects Dianne Gove.

<https://www.j-alz.com/vol76-3>

**21 September: On World Alzheimer’s Day, Alzheimer Europe calls for urgent action to support dementia research**



9.78 million people are currently living with dementia in Europe, with numbers set to double by 2050, which will place greater pressure on care and support services. We need better ways of treating and preventing dementia, if people with dementia and carers are to receive the high-quality and person-centred care they need. Without research, this cannot happen.

On 21 September 2020, Alzheimer Europe marked World Alzheimer’s Day with a social media campaign, calling attention to the damage COVID-19 is doing to the field of dementia research, together with a call for urgent action to address this.

“We urge all governments, funding bodies and research institutions to work together to ensure that the negative impacts of the pandemic are mitigated and that dementia is re-prioritised with the necessary resources and funds to improve our understanding of the underlying causes of dementia and our ability to provide the highest quality care and support”, said Jean Georges, Executive Director, Alzheimer Europe.

The campaign was based on the organisation’s recent position paper on this topic (28 July 2020), and called for:

- greater support and flexibility for existing dementia research projects, to allow them to conclude their crucial research
- economic responses to COVID-19 (e.g. the EU Recovery Instrument), to support research institutions and researchers
- research funders and governments to ensure that dementia research funding is not significantly diminished as a result of the pandemic
- a dedicated focus on dementia in the forthcoming Horizon Europe programme (2021-2027).

The campaign ran on Twitter, Facebook and LinkedIn and was supported by Alzheimer Europe’s national member associations, members of the European Alzheimer’s Alliance and representatives of European research projects, among others. You can read the position paper, here:

<https://www.alzheimer-europe.org/Policy/Our-opinion-on/Dementia-Research-and-COVID-19>

And the related press release, here:

[bit.ly/COVIDimpactsDementiaResearch](https://www.alzheimer-europe.org/Policy/Our-opinion-on/Dementia-Research-and-COVID-19)

**29 September: The 30<sup>th</sup> Alzheimer Europe Conference is nearly here – register now!**

The 30<sup>th</sup> Alzheimer Europe Conference (#30AEC) is fast-approaching, with only three weeks to go! The conference will take place online for the first time, from 20-22 October, and registrations will close on 19 October. At the time of writing, we have 572 registered delegates from 39 countries across the world and many more are still expected.



Conference registration gives you admission to all sessions, access to poster presentations, to chat rooms and to all conference videos after the event. Special rates are available for people with dementia, students, and members of Alzheimer Europe.

To ensure our event is as engaging and interactive as possible, you will also have:

- the unique opportunity to interact with over 280 confirmed speakers who are giving 158 oral presentations, 60 quick oral presentations and 94 poster presentations
- the chance to meet other conference delegates in discussion forums, and to interact with the sponsors and exhibitors at their virtual booths
- the ability to arrange online meetings with speakers, delegates, sponsors and exhibitors.

You can find out more about all the keynote speakers, here:

<https://www.alzheimer-europe.org/Conferences/30AEC-2020/Keynote-Speakers>

See here for more information about registration:

<https://www.alzheimer-europe.org/Conferences/30AEC-2020/Conference-registrations>



## Alzheimer Europe networking (online)

On 2 September, Ange and Owen attended a meeting with Gates Ventures

On 7 September, Cindy and Ange attended a meeting of the Neuronet Communications Experts' Community

On 8 September, Dianne and Ana participated in a meeting of Alzheimer Switzerland to say farewell to EWGPWD member Thomas Maurer

On 9 September, Dianne and Ana participated in the RADAR-AD PAB meeting

On 10 September, Alzheimer Europe organised an information meeting with TauRx

On 10 September, Jean attended the Management Team of the Dementia Panel of the European Academy of Neurology.

On 10 September, Ana and Ange attended a session of the Patient Engagement Open Forum

On 11 September, Jean attended a WW-Fingers meeting

On 14 September, Dianne and Ana presented at the DISTINCT academy

On 15 September, Jean had an introductory meeting with Brain Health Scotland.

On 16 September, Dianne and Ana had a meeting with members of Alzheimer Portugal

On 17 September, Owen attended the online meeting hosted by Incisive Health on the future of Brain Health in the EU

On 17 September, Owen attended an online meeting of the EDF's Group of European Non-Government Organisations

On 18 September, Ange presented at a VirtualBrainCloud meeting "Bridging the gap between new technologies, health research and the protection of personal data"

On 21 September, Jean attended a PAVE (Project Alzheimer's Value Europe) project meeting

On 23 September, Ange attended a European Medicines' Agency (EMA) workshop on the application of the GDPR in the area of health and secondary use of data

On 23 September, Ana attended the IEEPO Global Webinar

On 24 September, Jean attended a Biogen Expert Panel: Planning for the Next Phase in Alzheimer's disease

On 28 September, Dianne presented at, and Owen attended a meeting organised by the European Foundation Initiative on Dementia: "Addressing dementia among people with a migration background – From diagnosis to EU policy action"

On 29 September, Ange and Cindy attended a meeting of the Neuronet Working Group on Data Sharing

On 30 September, the Alzheimer Europe Board met.

On 30 September, Cindy attended the EPAD General Assembly Meeting.

## EU PROJECTS

### 4 August: ROADMAP researchers publish systematic literature review on the ethical and social implications of using predictive modelling for AD prevention

On 4 August, members from the ROADMAP project published a research paper on the ethical concerns and social

implications generated by predictive modelling in Alzheimer's disease (AD) in the Journal of Alzheimer's Disease.

The team carried out a systematic review using a variety of databases, also complementing the outputs with grey literature. They then analysed the publications through a thematic analysis technique. Through that, they were able to identify thirty-one ethical issues as well as social concerns that correspond to eight ethical principles:



- respect for autonomy,
- beneficence,
- non-maleficence,
- equality, justice, and diversity,
- identity and stigma,
- privacy,
- accountability, transparency, and professionalism, and
- uncertainty avoidance.

The team stressed that a lot of the literature notes that the development of a disease-modifying treatment would be necessary in order to justify for the assessment of AD risk while there seem to be little debate about upcoming “challenges in providing equitable access to it, establishing long-term treatment outcomes and social consequences of this approach, e.g., medicalisation.” The article can be found here:

<https://doi.org/10.3233/JAD-191159>

### 24 August: MOPEAD project publishes a paper in the journal of Clinical Medicine



On 24 August, a team of researchers from the Models of Patient Engagement for Alzheimer’s Disease (MOPEAD) project published a scientific article in the journal of Clinical Medicine. In the published paper, scientists focused on a prospective observational study performed only in one centre (Vall d’Hebron University Hospital (HVH), Barcelona, Spain).

It was previously published that people with Type 2 diabetes (T2D) have more risk of developing Alzheimer’s disease (AD) than the non-diabetic population.

The objectives of this study were to evaluate the results of pre-screening for mild cognitive impairment in people with Type 2 diabetes (T2D) and evaluate the applicability of the Diabetes Specific Dementia Risk Score (DSDRS) as a screening tool for people with T2D and cognitive impairment. A total of 112 T2D research participants were recruited. Authors found a high prevalence of cognitive impairment in TD2 participants older than 65 years who attended a third-level hospital. In addition, the clinical DSDRS score was found to be a useful screening tool to predict value of cognitive impairment.

This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under Grant Agreement No 115985. This Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and the European Federation of Pharmaceutical Industries and Associations.

<https://doi.org/10.3390/jcm9092726>

### 27 August: New ROADMAP publication on valuing AD drugs: a health technology assessment (HTA) perspective on outcomes

On 27 August, scientists from the ROADMAP project published a literature review of studies that analysed decisions in HTAs in the journal Cambridge University Press.



**CAMBRIDGE  
UNIVERSITY PRESS**

The literature review focusses on decisions made across disease areas in three European countries (England, Germany, and The Netherlands). The team carried out case studies of technology assessments that were conducted for Alzheimer’s disease (AD) drugs in these countries.

In their paper, the researcher’s report that they found that outcomes measured using clinical scales had an overall stronger influence on decisions respectively recommendations about whether or not to fund AD drugs. Furthermore, they add that processes did not include early discussion and agreement on what would constitute appropriate outcome measures and cut-off points for effects.

The article can be found here:

<https://doi.org/10.1017/S0266462320000574>

### 1 September: ROADMAP project publishes a paper on health outcome prioritisation in Alzheimer’s Disease

On 1 September, an international team of researchers from the public-private ROADMAP project published a new paper on the ethics of health outcome prioritisation in Alzheimer’s disease (AD) in the Journal of Alzheimer’s Disease.



In their paper, the scientists focus on the ethical landscape related to health outcome prioritisation. In the context of the project, outcome prioritisation relates to ranking disease-related objectives and their associated cost or risk. In order to better understand the landscape, the team conducted a narrative review of literature that was published since 2007. In doing so, they identified eight areas of ethical salience for outcome prioritisation:

- Public health and distributive justice,
- Scarcity of resources,
- Heterogeneity and changing circumstances,
- Knowledge of treatment,
- Values and circumstances,
- Conflicting priorities,
- Communication, autonomy and caregiver issues, and
- Disclosure of risk.

Concluding, the team stated that the emerged eight areas highlight the difficult balance when allocating resources, measuring and prioritising outcomes and when seeking individual preferences.

The full article has been published open access and can be read here:

<https://doi.org/10.3233/JAD-191300>

**8 September: DISTINCT project researcher Golnaz Atefi was “Rolling for Dementia” this World Alzheimer’s Month**



During World Alzheimer’s Month, dementia researcher Golnaz Atefi rollerbladed 200km from Maastricht to Witten, to raise funds for the Adoption Project at Alzheimer Centrum Limburg, where she is a PhD student. The project organises for pupils from primary schools to visit people with dementia on a regular basis, interacting with them and doing activities together.

Golnaz is also an EU funded Marie Curie Fellow in the DISTINCT training network which supports fifteen Early Stage Researchers (ESRs) across Europe, who are carrying out research projects aiming to improve the lives of people with dementia and their carers, through technology: <https://www.dementiadistinct.com/>

On 8 September, Golnaz, who originates from Iran, embarked on her 5-day, 200km rollerblading journey, following three months of intensive training. She has a very personal reason for undertaking this challenge and for choosing dementia research as a career:

"You’ve had a great childhood if you had a chance to be around your grandparents. With their pure love, they have a glorious, magical way of making you believe you really are something special. My grandpa had dementia and my grandma was a dedicated caregiver, yet they remained the most supportive grandparents that anyone could ask for. As a kid, I was the happiest when I had my skates on and my grandparents beside me.

"When I grew older, watching my grandpa dealing with dementia, caregiving responsibilities for the family, social and emotional issues around it, all led me to create greater

understanding of the disease. It eventually shaped my future career as a researcher in the field of dementia." View a video about her fundraising challenge, here:

<https://www.youtube.com/watch?v=7VeLvjNXimQ>

Visit the fundraising website, here:

<https://www.actiealzheimeronderzoekfonds.nl/project/skaten-voordementie>

**9 September: RADAR-AD Patient Advisory Board participates in an informative meeting**

The first virtual meeting of the RADAR-AD Patient Advisory Board (PAB) took place on 9 September. All members of the core PAB were present and the meeting was also attended by four colleagues from the project.



The aim of the meeting was to provide members of the PAB with an update on the impact COVID-19 has had on the project, and to discuss the future work of the PAB. Researchers referred to the delay of the planned trials but also explained that some of the countries were starting to recruit participants.

The presentations were followed by a very lively discussion, all of which was facilitated by Alzheimer Europe Director for Projects Dianne Gove and Project Officer Ana Diaz.

The presentations were followed by a very lively discussion, all of which was facilitated by Alzheimer Europe Director for Projects Dianne Gove and Project Officer Ana Diaz.

**11 September: EPAD project publishes a new paper on cognitive dispersion**

On 11 September, an international team of researchers from the European Prevention of Alzheimer’s Dementia (EPAD) project published



an article in the journal of Alzheimer’s disease entitled “Cognitive Dispersion is not Associated with Cerebrospinal Fluid Biomarkers of Alzheimer’s Disease: Results from the European Prevention of Alzheimer’s Dementia (EPAD) v500.0 Cohort”.

The main aim of this study was to examine whether higher cognitive dispersion was associated with cerebrospinal fluid (CSF) levels of amyloid-β, total tau, phosphorylated tau and amyloid positivity in a cohort of older adults at various severities of Alzheimer’s disease (AD). A secondary aim was to explore which AD risk factors were associated with cognitive dispersion scores. Findings showed that dispersion was not associated with AD pathology, but was associated with age and years of education, highlighting individual differences in cognitive aging.

<http://dx.doi.org/10.3233/JAD-200514>

**11 September: Neuronet launches its social media campaign “The value of public-private collaboration & findings highlights”**



The Neuronet project is setting up an efficient platform to boost collaboration across research projects focusing on neurodegenerative diseases. Currently, the Neuronet initiative comprises 18 projects.

The Neuronet communication team and its community of communication representatives from the Innovative Medicines Initiative projects on neurodegeneration are pleased to announce that they are celebrating the great people behind their projects through an annual Neuronet campaign on social media. The campaign will highlight some of the great findings, interesting activities and tools, none of which would have been possible without public-private collaboration. It starts on September to capitalise on the increased public attention on neurodegenerative diseases during World Alzheimer’s Month. The social media campaign will conclude on 20 October, in time to build up awareness towards Neuronet’s yearly event, to be held during the Alzheimer Europe conference.

Follow them on Twitter so that you can keep up to date with the campaign.

<https://www.imi-neuronet.org/neuronet-campaign-launches-on-social-media-the-value-of-public-private-collaboration/>

**14 September: Alzheimer Europe participates in DISTINCT school**



On 14 September Dianne Gove, Ana Diaz and Chris Roberts (Vice Chair of the European Working Group

of People with Dementia - EWGPWD) took part in a session of the DISTINCT project “school”, on involving people with dementia in research, as advisors.

Dianne and Ana presented the work of Alzheimer Europe and the EWGPWD in Public Involvement (PI) and some examples of how the EWGPWD has been involved in research related to technology.

The students attending took part in two short Mentimeter surveys to share their own experiences and perspectives related to working with people with dementia in this way.

Chris then talked about his personal experience of taking part in PI. After the presentations, there was a very active Q&A session.

**16 September: RADAR-AD project develops dashboards to improve data quality and completeness for use by clinical teams**

The RADAR-AD technical and clinical teams have co-developed dashboards to support the work of clinicians when collecting data on participants’ behaviour within the study.



Further RADAR-AD features are planned to be added soon to the initial cohort dashboards, such as the function to filter by study sites.

Read full new item here:

<https://bit.ly/3jkoyRS>

**16 September: RADAR-AD project publishes parts four of its “Behind-the-scenes” researcher interviews**

In order to showcase the variety of work done in RADAR-AD, the project decided to publish a series of interviews with RADAR-AD researchers. Discussion topics include: the work they do for the project; what excites and challenges them the most, especially at times of the present COVID-19 pandemic; and how they see the impact of the project for the wider field of Alzheimer’s research.

Part four of this series of researcher interviews has now been published.

Read more here:

<https://bit.ly/3igDP4D>

**18 September: The VirtualBrainCloud project holds a one-day workshop on the GDPR and health research**

On 18 September, the Horizon 2020-funded VirtualBrainCloud project held a 1-day workshop on GDPR Impact, entitled “Bridging the gap between new technologies, health research and the protection of personal data: GDPR Impact”. The VirtualBrainCloud (TVB\_Cloud) project will develop a cloud-based brain simulation platform to support personalised diagnostics and treatments for neurodegenerative diseases, including Alzheimer’s and Parkinson’s disease. As such, data protection is an important concern for the project, as the platform will house clinical data from patients and research participants.



The GDPR workshop was hosted by the University of Vienna, which is leading activities on ethical and legal aspects of TVB\_Cloud. Moderated by Prof. Nikolaus Forgo and his team in Vienna, the workshop was structured around four sessions focused on: 1) privacy, data protection and ethics in healthcare; 2) GDPR and AI-related challenges; 3) data security and AI in the health sector and 4) technical, legal and ethical challenges of the TVB\_Cloud project. The approaches used by different EU countries to ensure patient privacy were presented by experts in the field, and issues with regulatory divergence were discussed in detail. Data security concerns (such as the risk of attacks on data systems) were addressed, as well as the topic of trust and public awareness.

The final session was focused on TVB\_Cloud, starting with a presentation of the project by Prof. Petra Ritter (project leader) and including a technical update on the progress of the platform, which aims to provide clinicians with personalised brain simulations to facilitate decision-making and diagnosis. Angela Bradshaw, representing Alzheimer Europe, closed the workshop by presenting an overview of the legal and ethical framework that is being developed for TVB\_Cloud.

<https://virtualbraincloud-2020.eu/tvb-cloud-main.html>

## 21 September: The MinD project is publishing its results and outcomes



Following the formal completion of the MinD project in February 2020, the team is now working on the publication of

its rich set of outcomes to make them available to the public. Outcomes include design and policy guidance, design tools as well as design solutions. Key publications so far include:

- the Policy Recommendations, which highlight the contribution that design can make to quality of life and the need to recognise and support this contribution
- the Design Guidelines Report, which offers an overview of the context, frameworks, methods and mindful co-design values that have guided the MinD team
- the Mindful Co-design Toolkit, which offers hands-on advice for designers and others wishing to engage in the co-design process with people with dementia.

The MinD design solutions developed with and for people with dementia focused on supporting a positive focus and quality of life after the diagnosis and to enable people living with dementia to maintain agency and to continue to be socially active and engaged.

The “Living the Life” booklet, which was presented to the European Working Group for People with Dementia in December 2019, is also now available in three languages: English, German and Spanish, and has already been used by the public and by professionals.

All of these publications are available on the project website:

[www.designingfordementia.eu](http://www.designingfordementia.eu)

The MinD team is now working to commercialise the “This is Me” board game, to make it publicly available. The team’s effort and the potential of the game have been recognised by being awarded access to the European Commission’s Dissemination & Exploitation Booster Scheme to help develop the game for publication.

## 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 and Innovative Medicines Initiative 2 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:

**EPAD** - grant agreement 115736

**MOPEAD** - grant agreement 115985

**Neuronet** - grant agreement 821513

**RADAR-AD** - grant agreement 806999

**ROADMAP** - grant agreement 116020

**VirtualBrainCloud** - grant agreement 826421

## Members of the European Alzheimer’s Alliance



Currently, the total number of MEPs in the Alliance stands at **95**, 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:** Monika Vana (Greens/EFA). **Belgium:** Petra de Sutter (Greens/EFA); 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 Alamestä (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); Chrysoula Zacharaopoulou (Renew). **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); Matt Carthy (GUE/NGL); Deirdre Clune (NI); Ciàran Cuffe (Greens/EFA), Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke 'Ming' Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Mairead McGuinness (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 Blinkevičiute (S&D). **Luxembourg:** Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Nicolas Schmit (S&D); 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, MEP (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Tanja Fajon (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estaràs 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).

## EUROPEAN ALZHEIMER'S ALLIANCE

### 15 September: Hilde Vautmans MEP submits written question on dementia



European Alzheimer's Alliance Vice-Chair, Hilde Vautmans MEP (Renew, Belgium), has submitted a written question to the European Commission asking about the place of dementia and cognitive disabilities in the forthcoming European Disability Strategy. The question submitted was as follows:

"Dementia is a progressive, life-limiting condition which affects almost eight million people in the EU, for which there is no cure and no disease-modifying treatment. It often affects memory. However, as a neurodegenerative condition, it can also affect cognitive skills, speech, mobility, etc.

In line with Article 1 of the United Nation's Convention on the Rights of Persons with Disabilities (CRPD), which recognises physical, mental, intellectual and sensory disabilities, the symptoms of dementia qualify it as a disability. Therefore, the following questions relate to the development of the next European Disability Strategy.

- Will the Commission ensure that the strategy recognises the CRPD definition of disability?
- Will the strategy take specific account of the unique nature of disabilities caused by progressive conditions such as dementia, as well as the need for focused policy responses, both by the Member States and in support provided by the EU?

- To what extent will the European Disability Strategy link to other EU and international policies, inter alia, the EU4Health Programme, the European Pillar of Social Rights and the CRPD?

The submitted question can be viewed here:

[https://www.europarl.europa.eu/doceo/document/E-9-2020-004837\\_EN.html](https://www.europarl.europa.eu/doceo/document/E-9-2020-004837_EN.html)

### 15 September: Christophe Hansen MEP submits written question on dementia

European Alzheimer's Alliance Vice-Chair, Christophe Hansen MEP (EPP, Luxembourg), has submitted a written question to the European Commission asking about the place of dementia and cognitive disabilities in the future research priorities of the EU, including within Horizon Europe. The question submitted was as follows:

"Dementia affects almost 8 million people in the European Union and the number is expected to double by 2050. Currently, there is no cure for dementia, there is no disease-modifying treatment and only four symptom-modifying drugs exist on the market. As such, research into new ways of detecting, treating and supporting people with dementia is vitally important:

- How much money has been allocated to dementia and Alzheimer's research projects as part of Horizon 2020 and does this result in an increase, decrease or plateau in the funding for dementia and Alzheimer's research in the forthcoming Horizon Europe research programme?
- Will research into dementia and Alzheimer's disease be identified as a specific priority as part of the Horizon Europe research programme?



- Does the Commission consider to prioritize dementia as a future “mission”, as was done for cancer?”

**22 September: Chrysoula Zacharopoulou MEP joins European Alzheimer’s Alliance**



Alzheimer Europe is delighted to welcome Chrysoula Zacharopoulou MEP (Renew, France) to the European Alzheimer’s Alliance, taking the number of MEPs in the Alliance to 95 members from 26 countries.

We look forward to working with Ms Zacharopoulou towards helping make dementia a European policy priority!



**EU DEVELOPMENTS**

**8 September: EU4Health Civil Society Alliance publishes position paper on EU Health Programme**



Ahead of debates in the European Parliament on EU4Health, the EU’s forthcoming standalone health programme, the EU4Health Civil Society Alliance has published a position statement outlining key principles and points which must underpin the future Health Programme.

The position statement has been shared with decision and policy makers in the EU, encouraging them to ensure that the following points are included in the final version of the programme:

- The EU4Health programme and its budget shall address not only the COVID-19 recovery, but a sustainable system able to cope with emergency situations and crises in the future
- Civil society health organisations are an essential resource in shaping health policy at national and European levels
- The role of health promotion, primary prevention and recovery support should be strengthened and prioritised
- The EU4Health programme shall include actions to support health literacy and digital health literacy improvements for people of all ages living in Europe
- The focus on cancer offers an exciting case study and template for what focused EU health cooperation can achieve, but attention should also go towards ensuring positive impact from the EU4Health programme is delivered for other disease areas.
- Special focus should be given to other non-communicable diseases and their risk factors

Ahead of debates in the European Parliament on EU4Health, the EU’s

- Coherence shall be ensured with other elements of the EU budget, such as Horizon Europe, Digital Europe, ESF+ and structural funds, to mobilise resources and to ensure more health investment and avoid duplication and inefficient spending
- Solid governance and dedicated coordination structure for the EU4Health programme will be key to ensure efficient, well-designed and thoroughly evaluated use of resources, also in coordination with the abovementioned EU programmes and policies
- Better harmonised data systems can play a crucial role in strengthening health systems, improving healthcare quality in Europe and promoting effective disease self-management
- Strengthening of EU agencies, in particular European Centre for Disease Control (ECDC) and the European Medicines Agency (EMA).

The full position paper can be found at:

<https://eu4health.eu/how-to-harvest-long-term-health-benefits-of-the-eu4health-programme/>

**15 September: WHO Europe holds 70<sup>th</sup> Regional Committee online**

On 14 and 15 September, the World Health Organization (WHO) Regional Committee for Europe held its 70<sup>th</sup>



session. During the meeting, ministers of health and public health leaders from the 53 Member States of the WHO European Region approved the European Programme of Work (EPW) for 2020-2025, setting out the next five years of work. Under the EPW, European Member States will work towards three core priorities:

- Guaranteeing the right to universal access to quality care without fear of financial hardship
- Protecting against health emergencies
- Building healthy communities, where public health actions and appropriate public policies secure a better life in an economy of well-being.

Under the EPW flagship programme on Mental Health, dementia is referenced as an example of one of the conditions which will be addressed by this programme. In addition, WHO Europe and the European Commission published a joint statement outlining five areas of common action:

- Health security against health emergencies and other threats
- Effective, accessible, resilient and innovative health systems
- A comprehensive response to non-communicable diseases with a focus on cancer
- Sustainable food systems and health

- Health cooperation with non-European Union countries in the WHO European Region.

You can read more about the 70<sup>th</sup> session of the Regional Committee at:

<https://bit.ly/3iiNpEq>

You can read more about the EPW here:

<https://www.euro.who.int/en/health-topics/health-policy/european-programme-of-work/european-programme-of-work>

## 16 September: EPF publishes statement on EU4Health programme



The European Patient's Forum (EPF) has published a statement calling for the EU's forthcoming EU4Health programme to be more patient progressive and patient-centred in nature.

The statement opens by noting that with the programme due to commence in 2021, there is little time remaining to finalise the details of the programme. Whilst the programme itself is welcomed, the statement expresses regret at the decision of the European Council to cut funds from the EU4Health programme.

However, the statement notes that the programme continues to have the potential to deliver enhanced European coordination to protect the health of EU citizens, calling on the Council, Parliament and Commission to consider the proposals of the EPF, as the negotiations continue.

In particular, the EPF calls for greater involvement of patient organisations and civil society, including within the governance and implementation of the EU4Health programme. You can read the full statement here: <https://www.eu-patient.eu/news/latest-epf-news/2020/epf-proposes-a-progressive-and-patient-centred-eu4health-programme/>

## 16 September: European Commission President delivers State of the Union Address



On 16 September, President of the European Commission, Ursula von der Leyen, delivered her State of the Union Address, reflecting on the current policy

context at an EU level and setting out her policy priorities for the future.

Noting the ongoing pandemic and the continuing EU budget discussions, President von der Leyen highlighted the importance of common European actions, particularly in relation to health. She further noted that the NextGenerationEU was a once in a lifetime opportunity to make change happen, focusing on issues such as:

- Protecting lives and livelihoods in Europe, the health of citizens and the stability of economy

- Leading the digital transformation, particularly on data, technology and infrastructure
- Continuing to support global work towards an affordable and safe vaccine against COVID-19.

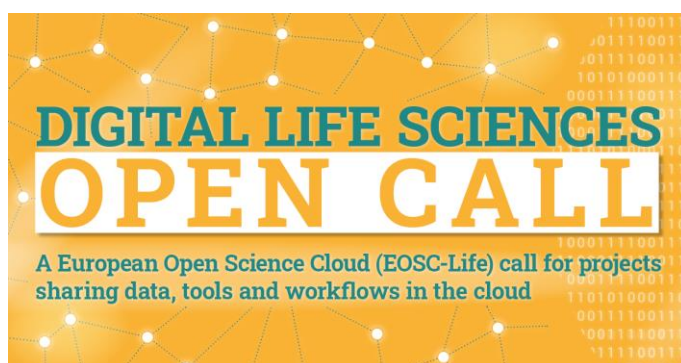
President von der Leyen also sent a Letter of Intent to David Sassoli, the President of the European Parliament, and German Chancellor Angela Merkel, as the Presidency of the Council, in which she detailed the actions the Commission intends to take in the following year by means of legislation and other initiatives, including:

- A legislative proposal on a Data Act
- An Action Plan on the European Pillar of Social Rights (and other areas)
- Legislative proposals to extend the remit of the European Medicines Agency and the European Centre for Disease Control
- A legislative proposal on a European Health Data Space.

You can read and watch the State of the Union here:

<https://www.eu-patient.eu/news/latest-epf-news/2020/epf-proposes-a-progressive-and-patient-centred-eu4health-programme/>

## 16 September: EOSC-Life launches a call for projects sharing data, tools and workflows in the cloud



On 16 September, the European Open Science Cloud-Life (EOSC-Life) initiative announced the launch of a funding call for projects aiming to share data, tools or workflows via the Cloud. EOSC-Life brings together the 13 European life science research infrastructures which were established by the EU to facilitate access for scientists to high-end technologies and services. The European Research Infrastructure Consortia (ERIC) include organisations such as EATRIS, BBMRI and ELIXIR, which address translational research, biobanking and life science data management, respectively.

The new EOSC-Life call, which is open to researchers in academia or Industry, is designed to support the development of projects that will contribute to the development of an open digital space for life science data, tools and workflows. The overall goal is to make life science research data publicly available in a Findable, Accessible, Interoperable and Reusable (FAIR) way. The call offers funding for the project team (equivalent to 1 full-time salary for a year), training and technical expertise from the EOSC-Life consortium, as well as

assistance in “cloudifying” the data, tools or workflows that are the subject of the application. The application deadline is 5pm on December 22, 2020, prior to which applicants should have consulted the EOSC-Life experts on the design and aims of their proposals.

<https://www.eosc-life.eu/services/open-call/>

**21 September: EFPIA urges European leaders to make dementia a priority of healthcare policy**



On 21 September, World Alzheimer’s Day, the European Federation of Pharmaceutical Industries and Associations (EFPIA) published a paper urging European leaders to make dementia more of a priority.

“We are at a turning point in our fight against dementia and Alzheimer’s disease. Long-awaited new therapies are on the horizon. To ensure we translate these breakthroughs into results, Europe must prepare”, stressed EFPIA.

The newly-published paper, “Alzheimer’s Disease Health System Readiness – The Time to Act is Now” can be read, here:

<https://efpia.eu/publications/downloads/efpia/alzheimer-s-disease-health-system-readiness-the-time-to-act-is-now/>



**WORLD ALZHEIMER’S DAY**

**31 August - 1 September: Bosnian Alzheimer association publishes “Statement of Experts” at World Alzheimer’s Month conference**



In Bosnia, World Alzheimer’s Month began with a conference on “Dementia Care and Policies of the extended Danube Region”, held as a virtual

meeting.

The conference had 34 lecturers (experts from various professions, researchers, Ombudsman for Human Rights, government representatives, etc.) from across the whole of the Danube Region. It was supported by the World Health Organization (WHO), Alzheimer Europe and Alzheimer’s Disease International (ADI).

The event was very constructive and looked at: the position of people living with dementia and older adults; their human rights; their exclusion from society; housing problems; and the need to adjust societies and create dementia/age-friendly societies which meet the needs of people with dementia.

As a conclusion to the event, a “Statement of Experts” was published. It describes, identifies and lists problems in the whole Danube Region and looks for solutions with which the Region can enter into a decade of healthy ageing for 2020-2030.

Download the Statement, here (free):

<https://www.demencija.org/Članci/.c/članci-articles>

**18 September: Association Luxembourg Alzheimer launches video called “Dementia, let’s talk about it”**



Talking about dementia, and breaking the taboo, is the focus of Association Luxembourg Alzheimer (ALA) ’s World Alzheimer’s Day events this year and with this in mind, it has produced a video called “Dementia, let’s talk about it” (in Luxembourgish).

The video, which was launched via YouTube on 18 September, brings together testimonies from the Minister of Families, the President of ALA, members of the Executive Board and staff, as well as from a person living with dementia and a member of his family.

“Dementia, let’s talk about it” can be seen on the ALA Facebook page and on its website:

<https://ala.lu/fr/2020/09/18/demenz-kommt-mir-schwätzen-driwwer-de-video-3/>

**19-23 September: Fahy families push themselves to the limit for virtual Alzheimer’s Memory Walk in Ireland**

The Fahy families pushed themselves to the limit as they undertook an epic 125 km five-day self-titled “Irish Camino” adventure as part of the first ever virtual Alzheimer’s Memory Walk, to raise much-needed funds for The Alzheimer Society of Ireland (ASI)

Chief family organiser, Marian Purcell, from Broadford, Co Limerick, left her local village with her family on Saturday, 19 September and arrived in Kilfenora, Co Clare on Wednesday,



23 September, completing their own 5-day Alzheimer's Memory Walk.

Dementia is very close to Marian Purcell's heart and she was inspired to organise this adventure by her mother, Kay Fahy, who lived with dementia for 7 years and sadly passed away in 2014. The whole family has come together to walk in her honour and to keep her memory alive.

Ever since the passing of their mother, Kay Fahy, on Christmas Day 2014, the family has continued to raise funds for The ASI, but due to COVID-19 restrictions this year, they have been unable to organise any of the usual fundraising events, so, as a family they undertook this walk instead.

Well over 2,500 walkers around Ireland made every step count, raising over EUR 100,000 for The ASI's first ever Virtual Alzheimer's Memory Walk, proudly supported by Iceland stores. For more information, see: [www.memorywalk.ie](http://www.memorywalk.ie)

*Pictured: Memory Walk - Ciara, Marian, Ali, Emma & Chris Purcell*

**21 September: Spominčica marks World Alzheimer's Month with a variety of events, including its 9<sup>th</sup> Memory Walk**



Spominčica – Alzheimer Slovenia marked World Alzheimer's Month with its 9<sup>th</sup> Memory Walk, unfolding in various locations throughout Slovenia. In Ljubljana the walk was adapted due to COVID-19.

A cultural event was also held at the Slovenian National Gallery in the centre of Ljubljana. To support Spominčica's cause, they were honoured by famous Slovenian rock and pop musicians who were also Eurovision contestants.

On the same day, the National Gallery of Slovenia became the 222<sup>nd</sup> Dementia friendly spot (DFS) in Slovenia. The new DFS was officially opened by the Director of the National Gallery of Slovenia, Dr Barbara Jaki, and the President of Spominčica – Alzheimer Slovenia, Štefanija L. Zlobec. The event was held under the honourable patronage of the Mayor of Ljubljana, Zoran Jankovič.

**21 September: NGO Futura in Montenegro marks World Alzheimer's Day with campaigning activities and a screening of "Still Alice"**



On World's Alzheimer's Day, NGO Futura in Montenegro joined the campaign "Let's Talk About Dementia", run by Alzheimer's Disease International (ADI). It also joined with the capital city of Podgorica and the Secretariat for Culture and Sports, to organise screening of the movie "Still Alice", held on 21 September at 8pm in the amphitheatre near Moscow Bridge (pictured). All measures of the national coordinating body were respected so that all those present could take refreshments and snacks in safety, during the pandemic situation.

On the same day, volunteers at NGO Futura distributed informative flyers, badges and protective masks in Podgorica park.

**21 September: Association Luxembourg hosts "Memory Stay"**

Each year, in September, "memory walks" are organised by Alzheimer associations around the world, with the aim of informing and educating the general public about dementia, as well as raising much-needed funds.

This year, in view of the ongoing



coronavirus pandemic, the traditional Association Luxembourg Alzheimer (ALA) Memory Walk was replaced with a “Memory Stay”, on World Alzheimer’s Day. This virtual event provided information and a platform for discussion and questions, with the aim of increasing public awareness of dementia and reducing stigma.

“To break the taboo, you have to talk about a disease” writes the ALA, and as part of the Memory Stay, participants were asked to display and / or wear a “Dementia, let's talk about it - September 21, 2020 - World Alzheimer's Day” sticker (pictured) and to send in photos. These were then posted on Facebook and on the ALA website. The stickers were sent to members, ministries and various organisations, with the aim of creating a “buzz” and getting people to show solidarity with people with dementia. A hashtag was also created for the occasion: #memorystay2020.

**21 September: Spominčica holds press conference on World Alzheimer’s Day**



On World Alzheimer’s Day, Spominčica held a press conference at the Medical Chamber of Slovenia, to share the latest findings in the field of dementia.

Speakers at the press conference were: Zdenka Čebašek-Travnik, President of the Medical Chamber of Slovenia, Štefanija L. Zlobec, President of Spominčica, Tomaž Gržinič, Slovenian member of the European Working Group of People with Dementia (EWGPWD), psychiatrist Polona Rus Prelog, neurologist Zvezdan Pirtošek, and GP Dr Tatjana Cvetko.

**21 September: Bosnian Alzheimer association adapts World Alzheimer’s Month activities to pandemic situation**

Udruženje AiR, the Alzheimer association in Bosnia and Herzegovina, has adapted its activities during World Alzheimer’s Month (September), to work within the restrictions of the coronavirus pandemic. The association wanted to bring in new services and begin a new way of communicating with its service-users, which it calls “tele-health and tele-care”.

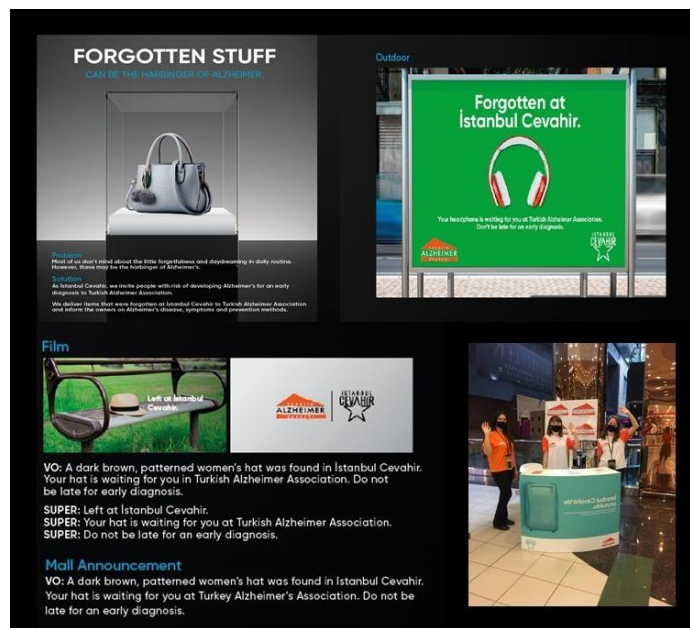
People with dementia can get the support they need at home, completely free of charge, via audio-video meetings. Udruženje AiR is thus able to give health advice, support for carers, psychological consultations and therapy to caregivers.

Every day, the association has many service users wanting to access information and online sessions, so much so that it is considering how to maintain these services for free, in the future.

*Pictured: A poster promoting the new services: tele-health and tele-care*



**28 September: Turkey launches innovative project “Forgotten Stuff” during World Alzheimer’s Month**



The most innovative event organised for the 2020 World Alzheimer’s Month in Turkey this year, was a project called “Forgotten Stuff”.

Türkiye Alzheimer Derneği (Turkish Alzheimer association) coordinated many events this year such as handing out masks with forget-me-not flowers embroidered, press releases, live online meetings bringing medical staff together with caregivers, publishing related posters and videos on social media, etc. However, the biggest surprise was triggered by “Forgotten Stuff”, organised by the management team of one of the major malls in Istanbul, partnering with a well-known public relations and advertising company and the Turkish Alzheimer association.

The event was planned around the fact that many visitors leave their belongings forgetfully in the shopping malls. Both

outdoors and indoors, publications were prepared with the slogan: “Forgotten Stuff can be a sign of Alzheimer’s”, drawing attention to “small” forgetful actions.

In addition to the visual reminders such as billboard posters and social media posts, announcements were made periodically inside the mall saying that an object was found and the owner of the object was directed to the headquarters of the association to collect their lost items. A different object was announced each time e.g. sunglasses or a hat or a cane, etc. Some of the announcements were not true, they were added to intensify the “flavour” of the event.

Furthermore, a stand was set up in the mall with representatives of the association attending and giving information verbally (due to the pandemic no brochures were handed out), both about the disease and the services provided by the Turkish Alzheimer association.

When the person who left an object at the mall arrived at the association they were given information about Alzheimer’s disease and its symptoms and were presented with informative leaflets, as well as being notified about pre-tests.

The aim of the activity was to make people reconsider their forgetfulness and realise the importance of early diagnosis.

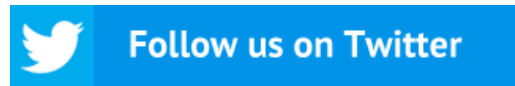
**28 September: Spominčica concludes World Alzheimer’s Month with two meetings, one with National Institute of Public Health and one promoting inter-generational links**



On 28 September, at the end of World Alzheimer’s Month, The National Institute of Public Health and Spominčica organised a meeting of professionals, titled “Situation and challenges in the field of Alzheimer’s disease in Slovenia”. Four Members of the European Parliament (MEPs) attended the round table meeting, which took place via video conference.

Spominčica also attended the event "Picnic under the trees", in Ljubljana, which aimed to promote multigenerational socialising. They used the opportunity to also celebrate the successes of Slovenian cyclists Roglič and Pogačar, for their double victory in the Tour de France.

Overall, this month, Spominčica’s events mainly highlighted the importance of physical activity, socialising and general well-being and of ensuring that these are prioritised, regardless of COVID.



**MEMBERS’ NEWS**

**2 September: Fundación Alzheimer España adapts internship programme during COVID-19, working remotely to compare approaches of European and US Alzheimer’s care groups**

Fundación Alzheimer España (FAE) has a tradition of inviting a pair of students from Tufts University (Boston, US), studying abroad for a semester in Madrid, to intern with them. Because of the spread of COVID-19, these students were sent back to the US by their university, but FAE adapted to the circumstances by continuing a remote collaboration with one of the students throughout the summer.



Part of the student’s role was to draw parallels between measures adopted by European and American Alzheimer’s care groups. From that investigation, the strategies implemented by the Alzheimer’s Foundation of America (AFA) were particularly interesting and might be helpful to other groups in Europe.

The AFA now provides a memory screening test easily accessible from its website. The test takes about five minutes, and the results of the test are followed by recommendations and resources for follow-up, which could help with the earlier detection of dementia. The AFA also provides a list of locations where people can do memory screening tests in person if they prefer. Making this test as accessible as the AFA does could be a great way to make it easier for people to test possible changes to their memory and get access to further assessments if needed.

The AFA also works as a hub of resources shared across different groups in the US by having a calendar of online events hosted by various Alzheimer’s groups in the US. Although Alzheimer Europe plays a similar role, its range is across an entire continent with different populations and languages. Having a similar calendar within a nation has the benefit of providing daily events for a clinic or foundation’s patients without putting the onus on a single group, and encourages collaboration among groups.

Enhancing the online presence of Alzheimer’s groups has become increasingly important. With uncertainty about the duration of the current pandemic and potential future outbreaks, being proactive about designing online resources

like those the AFA provides can be of great benefit to a large population of people with dementia and their families.

**14 September: Brain Health Scotland initiative developed in partnership with Alzheimer Scotland**



Brain Health Scotland, a new initiative developed in partnership with Alzheimer Scotland, and funded by the Scottish Government, was

launched on 14 September 2020.

Brain Health Scotland aims to inspire and empower people to protect their brain health and reduce their risk of diseases, including dementia. It will do this by providing:

- expert advice about brain health research, policy and healthcare
- promotion of positive brain health in collaboration with Public Health Scotland and other partners
- support to ensure health professionals in Brain Health Services can provide personalised protection plans
- opportunities to join brain health research programmes in Scotland.

Their work falls into two main strands. The first is focused on engaging the public with the concept of brain health. They are developing a suite of partnerships to embed positive brain health behaviours in all walks of life – including in nutrition, fitness, stress management and lifelong learning.

One of their first activities is to design educational resources for a variety of audiences from primary schools through to health care professionals so everyone can join the effort to better understand brain health and disease.

They are also working with supermarket and food producers to explore ways of providing clear advice about which foods keep brains healthy. A nationwide survey will shortly be launched, also, to help them to understand more about how people in Scotland think about their brain health.

Their other main strand of work will be to collaborate with healthcare partners and they are actively developing Scotland’s first brain health clinics, at which patients will be able to access the information and interventions they need to protect their brains. The Scottish Brain Health Register - a national register of people keen to join research programmes and trials of new treatments – is also underway.

The hope is that these Brain Health Services will help to detect and manage the most common brain health problem faced today – namely Alzheimer’s disease. The expectation is that in future fewer people in Scotland will develop Alzheimer’s disease, but for those who do, Brain Health Scotland will work to ensure they access the best assessments, treatments and care of anywhere in the world.

[www.brainhealth.scot](http://www.brainhealth.scot)

**21 September: Association Luxembourg Alzheimer publishes brochure to promote use of non-stigmatising language around dementia**

Produced by a collective of German-speaking Alzheimer’s / dementia associations (Austria, Switzerland, Germany, Luxembourg, Liechtenstein, Belgium and South Tyrol), a new brochure has been published (in German), advocating the use of language that does not stigmatise, but rather promotes understanding, inclusion and participation of people with dementia and which contributes to improving the quality of life for all those affected.



The “Sprachleitfaden Demenz” brochure aims to serve as a reference for people working in the health sector, in the media and in administrations, as well as helping inform and raise awareness among the general public.

It can be downloaded via the Association Luxembourg Alzheimer website:

<https://ala.lu/wp-content/uploads/2020/09/Sprachleitfaden-Demenz.pdf>

**21 September: Irish Dementia Working Group has a new Chair and Vice-Chair**



On World Alzheimer’s Day, The Alzheimer Society of Ireland (ASI) was delighted to make some exciting announcements to their Irish Dementia Working Group (IDWG) that does such amazing work bringing the voice of the lived experience to fore in our society.

The new Chair of the group will be Sean Mackell and the new Vice-Chair is Jacinta Dixon.

Sean Mackell was diagnosed with Alzheimer’s dementia in 2018 and says “being involved in the IDWG has been very good for me and hopefully I make a positive contribution to the work of The Alzheimer Society of Ireland. I always bring a ‘can do’ attitude with me I have fought for justice, fairness and people’s rights all my life and I am not going to stop now”.

Jacinta Dixon was diagnosed with dementia in 2016 and believes that there is a big stigma around dementia and this can only be broken down by members of the public finding out more information about the condition. Since joining the IDWG Jacinta says she has found a new purpose.

The ASI and the IDWG are delighted to have both of them on board, and would also like to wish former Chair and Vice-Chair, Kathy Ryan and Kevin Quaid respectively, all the best. Kathy Ryan has decided to take some personal time, and Kevin Quaid is embarking on an exciting new advocacy role. Watch this space!

**21 September: The Alzheimer Society of Ireland and Boots Ireland work together to support people living with dementia**



*Pictured: Fiona Foley from Understand Together (far right) with reps from Boots*

Boots Ireland has undertaken a significant step in supporting people living with dementia in communities across Ireland by providing training to all staff that will promote a dementia-inclusive environment across its 89 retail and pharmacy outlets. World Alzheimer’s Day on 21 September was a timely reminder about the need for society to nurture greater understanding and awareness of the challenges and experiences of those living with dementia.

The training, developed with the Dementia: Understand Together campaign, has been rolled out to over 2,000 staff members in all 89 boots stores across Ireland. Led by the HSE in partnership with the Alzheimer Society of Ireland and Age Friendly Ireland, the Dementia: Understand Together campaign is one of six key priorities of the Irish National Dementia Strategy.

The training modules were specifically modified for Boots staff and included testimonials from people living with dementia.

Staff were given insight into the ways in which they can recognise behaviours that could indicate that a person may have dementia and identify common challenges a person with dementia may encounter in a store environment, as well as a range of options they could consider in supporting them. Staff were trained on the ways they can modify the support given to customers to help overcome simple barriers they may experience.

Dementia: Understand Together is now supported by over 40 partner organisations across Ireland, including in the retail, transport, banking, health, voluntary and community sectors. These organisations, together with over 340 “Community Champions”, are leading the way in creating communities that actively embrace and include those living with dementia and their families.

Many businesses, from pharmacies to banks, along with sporting and cultural organisations, have taken steps to become dementia-inclusive. The first step is dementia training, which can be delivered online, to provide an understanding of life with dementia.

**23 September: New Alzheimer Slovenia magazine features European Working Group of People with Dementia member Tomaž Gržinič**

In September, Spominčica (Alzheimer Slovenia) released a new issue of its magazine, featuring Tomaž Gržinič on the cover. Tomaž is a member of the European Working Group of People with Dementia (EWGPWD). The new issue was enriched with different articles written by professionals to help people with dementia and their carers. It is available via the Spominčica website [www.spomincica.si/](http://www.spomincica.si/)



**23 September: NGO Futura (Montenegro) is working on two new projects**



NGO Futura is currently working on two projects IPA II – Multi-annual Action Programme for Montenegro on Employment, Education and Social Policies (2015-2017), funded by the European Union (EU) and being implemented by the Ministry of Finance, the Ministry of Social Work and Care and the CFCU.

The first one, “Living with Dementia but with dignity” is about opening five counselling centres for dementia in Montenegro, in Bar, Budva, Podgorica, Bijelo Polje and Nikšic. Besides opening of the centres, NGO Futura will be filming a movie

about dementia, organising a lot of workshops and trainings for social workers and will also organise an international conference in Montenegro.

The second project is run by the Center for Social Work, in Niksic, and is also financed by the EU. NGO Futura is a partner in this project, which will include the opening of a day-care centre for dementia in Niksic.

**23 September: CEAFA introduces protocols for change towards a solidary and dementia-friendly society**



The Confederación Española de Alzheimer (CEAFA) has been able to verify the existence of a general lack of knowledge about dementia in Spain, which causes stigma, rejection and social exclusion for those who are living with the condition, either with a diagnosis themselves, or as family carers.

With an increasingly ageing population and a growing number of dependent people, today's society demands changes at a global level that support the needs of these people. It is necessary to make this reality visible and to generate a supportive and friendly future with dementia.

In the early stages of the disease, people with some type of dementia continue with their usual lives and are able to continue doing many of their daily activities, such as shopping, going for a walk, having a coffee, etc. Carrying out these activities constitutes the basis of their autonomy and quality of life, which is why it is recommended that they continue to carry these out for as long as possible.

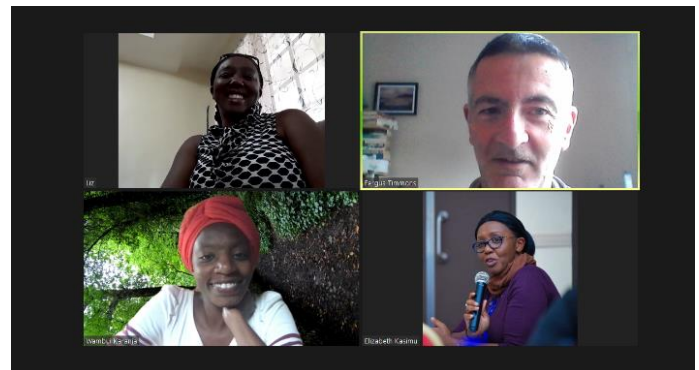
CEAFA has developed a project that aims to sensitise and inform society about dementia and how to detect warning signs, as well as providing guidelines for recognising, and for communicating effectively with, a person with dementia.

Through this project, CEAFA has developed action protocols aimed both at entities that provide services to society in general (public and private transport companies, local businesses, healthcare centres) and at local communities, so they know how to support people with dementia. These protocols aim to transform the perception, consideration, and acceptance of people with dementia and family carers.

Along with these protocols, CEAFA has also drafted letters of commitment that they want to make available to banks, notaries and insurance companies, encouraging them to contribute to the protection of people with dementia and their assets, through transparency in the information provided and the reinforcement of measures that favour professional ethics.

**23 September: The Alzheimer Society of Ireland and Alzheimer's and Dementia Organisation Kenya partner in new project**

Alzheimer's and dementia support organisations in Kenya and Ireland have come together to share and promote best



practice in developing and delivering online education programmes for family carers looking after a loved one with dementia. The new project is called Dementia Education Exchange Project Ireland Kenya (DEEPIK).

Alzheimer's and Dementia Organisation Kenya (ADOK) has received funding from the Atlantic Institute to work together with The Alzheimer Society of Ireland (ASI) on a short three-month project to design online carer education to be delivered in Kenya.

The project will adapt and translate The ASI's successful online family carer course "Home Based Care-Home Based Education", to make it relevant for the needs of people in Kenya.

Through working together with ADOK, the DEEPIK project will allow The ASI to gain a greater understanding of the needs of cultural minorities in Ireland. The ASI's External Learning and Development Manager, Fergus Timmons said:

"We are absolutely delighted to be in a position to work with our colleagues at ADOK, to use our course materials as a starting point for developing a high quality online learning experience for Kenyan family carers of people with dementia."

If you would like more information on the project contact [fergus.timmons@alzheimer.ie](mailto:fergus.timmons@alzheimer.ie)

*Pictured: Fergus Timmons with his colleagues from Alzheimer's and Dementia Organisation Kenya, at a recent meeting.*

**25 September: Alzheimer Slovenia organises 2<sup>nd</sup> "In the Rhythm of the Human Brain" conference**



On 25 September, Spominčica (Alzheimer Slovenia) held the 2<sup>nd</sup> edition of its conference, titled "In the Rhythm of the Human Brain". The event was held at the Faculty of Medicine - University of Ljubljana, under the honorary patronage of Slovenian President Borut Pahor. Six different neurological diseases were presented: Dementia, Parkinson's Disease, Multiple Sclerosis (MS), Huntington's Disease, Amyotrophic lateral sclerosis (ALS) and Spinal Muscle Atrophy.

**29 September: Alzheimer Scotland announces launch of a virtual dementia resource centre**

Alzheimer Scotland has announced the launch of its pioneering Alzheimer Scotland Virtual Resource Centre, which will provide much-needed online support for carers and people living with dementia.

The Virtual Resource Centre has a dementia-friendly design, taking into account adjustable lighting, carpeting and furniture and is modelled on the current interior of Alzheimer Scotland’s “bricks and mortar” Dementia Resource Centres, allowing visitors to “walk through” a Dementia Resource Centre. They are welcomed in the reception area by an “avatar” guide who is multi-lingual and able to respond to queries, as well as to direct people to the support they are looking for.

The first of its kind in the UK, the Virtual Resource Centre is currently under construction, and Alzheimer Scotland is calling on the public to back the rest of the build by supporting the Virtual Brick Appeal. The appeal calls for people to buy a virtual brick, and help raise the vital funds required for the completion of the digital centre, one brick at a time.

Whilst this project has been on the radar for some time, Alzheimer Scotland decided to accelerated its development due to the coronavirus pandemic, as a means to provide people living with dementia easy access to the help they need.

Alzheimer Scotland Chief Executive, Henry Simmons, said:

“The coronavirus pandemic has had an extreme impact on people living with dementia, as well as carers and loved ones, and we have reacted quickly to find new ways of supporting people. It is clear that there is urgent need and demand for a digital resource which can be accessed quickly and easily now and in the future.”

To support the Virtual Brick Appeal, visit:

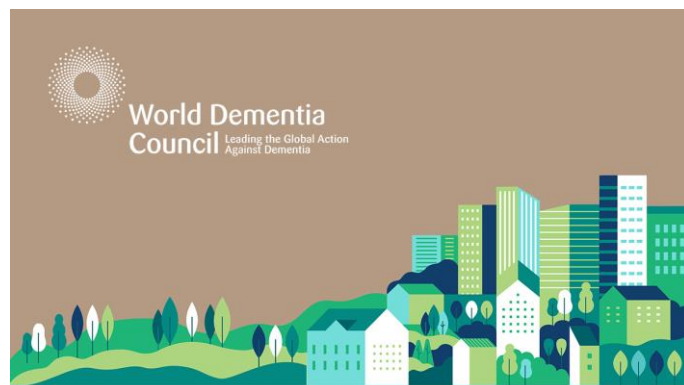
[www.alzscot.org/virtualbrick](http://www.alzscot.org/virtualbrick)



**REGISTER NOW!**  
Alzheimer Europe Conference

**POLICY WATCH**

**18 September: World Dementia Council launches 1<sup>st</sup> in series of papers looking at impact of dementia-friendly initiatives**



On 18 September 2020, the World Dementia Council (WDC) published the first paper to emerge from its dementia-friendly initiatives (DFIs) project. The project came out of a 2018 WDC summit in London, which brought together dementia experts from across the globe, to look at some of the challenges faced in reaching the 2025 goals on dementia, set by the G8 in 2013.

The WDC launched a year-long consultation in 2019, to gather international evidence on the design and delivery of DFIs and an evidence framework was designed to compare and synthesise a global evidence base, attempting to consider the variety of initiatives designed to have impact; the breadth of evidence likely to be submitted from countries around the world; and the range of voices that would contribute. A literature review, field survey and a number of consultation events informed the project.

A report was planned for summer 2020, but was postponed due to COVID-19 and is now being published as a series of papers over the autumn. You can find this first paper, here:

<https://worlddementiacouncil.org/DFIs>

**23 September: International Experience Exchange with Patient Organisations hosts Global Webinar on Personalised healthcare**



**International Experience Exchange with Patient Organisations**

The International Experience Exchange with Patient Organisations (IEEPO - funded by Roche) has organised a series of virtual events relevant to the patient community. The latest of these events was a Global Webinar on the topic of Personalised healthcare which took place on 23 September.

The webinar kicked off with a welcome speech by Sanja Njelic, Head of Global Patient Partnership at Roche. This was followed by a panel session where four patient advocates, from

different countries around the world, shared their real-life stories about personalised healthcare.

The next virtual IEEPO event will be in November 2020, and will examine key topics impacting the patient community from a global perspective. Project Officer Ana Diaz participated in this event. Find out more about this series of virtual events, here: <https://www.ieepo.com/en.html>

## SCIENCE WATCH

### 31 August: Axsome Therapeutics announces development status for AXS-05 in the treatment of AD agitation



On 31 August, the company Axsome Therapeutics, which develops therapies for the management of central nervous system disorders, confirmed the pivotal development status for its drug candidate AXS-05 for the treatment of Alzheimer’s disease (AD) agitation.

AXS-05 received the Breakthrough Therapy designation from the US Food and Drug Administration (FDA) earlier in the year. A Breakthrough therapy designation is a process to expedite the development and review of drugs for serious or life-threatening conditions. The Breakthrough therapy designation for AXS-05 in AD agitation was supported by positive results from the pivotal ADVANCE-1 Phase II/III study, which enrolled 366 US participants with agitation associated with AD. This trial met its primary endpoint by demonstrating a statistically significant improvement in AD agitation.

Following a recent successful Breakthrough Therapy meeting with the FDA, Axsome Therapeutics has announced confirmation of the pivotal development status for AXS-05. This means the company is ready to file a New Drug Application (NDA), which is a comprehensive document that must be submitted to the FDA in order to request regulatory approval for new drugs. Only one Phase III clinical trial will be needed to support the filing of this NDA. This Phase III placebo-controlled and randomised-withdrawal efficacy trial is on track for Q4 2020. In addition, the company plans to initiate a long-term safety trial of AXS-05 in AD agitation to supplement the existing AXS-05 database. This study is expected to start by the end of the year.

<https://bit.ly/2Gmkjqr>

### 1 September: ImmunoBrain Checkpoint will launch a Phase I trial of IBC-Ab002 in AD



On 1 September, ImmunoBrain Checkpoint, a biopharmaceutical company developing novel disease-modifying immune therapies to combat neurodegenerative diseases, has been awarded a grant from the Alzheimer’s Association’s under the 2020 Part the Cloud-Gates Partnership Grant Program. This USD 1 million award will support the company’s upcoming Phase I trial of IBC-Ab002 in Alzheimer’s disease (AD).

IBC-Ab002 is an antibody developed by ImmunoBrain Checkpoint, targeting to enhance the immune system and induce brain repair processes in people with AD. The company’s technology is based on studies by Professor Michal Schwartz at the Weizmann Institute of Science (Rehovot, Israel), who is now the company’s chief scientist. She pioneered the idea that the brain engages in a life-long healthy dialogue with the immune system for its maintenance and repair, and that this communication is compromised in aging and AD.

<https://bit.ly/2EOPHNR>

### 1 September: Cortexyme reaches milestone with 500 research participants enrolled in its GAIN Phase II/III trial of COR388 in mild to moderate AD



Cortexyme, a clinical-stage pharmaceutical company developing novel treatments for altering the course of Alzheimer’s disease (AD) and other neurodegenerative disorders, announced that it has reached a milestone after enrolling 500 research participants in its GAIN Phase II/III trial.

The GAIN Phase II/III study is a randomised, double-blind and placebo-controlled study assessing the efficacy, safety and tolerability of two dose levels (40 and 80mg) of COR388 oral capsules in people with mild to moderate AD. The company is aiming to recruit 573 participants who will receive COR388 or placebo for 48 weeks. The primary endpoint is the mean change in the activities of daily living at week 48, measured by the Alzheimer Disease Cooperative Studies- activities of daily living (ADCS-ADL) scale.

The GAIN trial has been enrolling since the second quarter of 2019 at sites in the US and Europe. The study's protocol includes an interim analysis, scheduled to occur after 300 participants reach 24 weeks of treatment with COR388, this is expected by the end of 2020. Top-line results from the study's final analysis are expected in the fourth quarter of 2021.

<https://bit.ly/3I3JTIR>

**1 September: New report identifies key barriers for Alzheimer's disease clinical trials**



A new report from Gates Ventures and the Schaeffer Center for Health Policy & Economics at the University of Southern California has identified seven key barriers hindering clinical trials in Alzheimer's disease (AD). Aiming to understand the patient journey to and through a typical AD clinical trial, the report is based on

interviews with 60 stakeholders and quantitative survey results from nearly 900 US-based respondents, including patients, caregivers, clinicians and researchers.

Co-authored by the Director of the Schaeffer Center, Gates Ventures and IQVIA, the report shows that Alzheimer's disease (AD) clinical trials are generally more complex, costly and slower than trials for other conditions. In part, this is due to higher screen failure rates, particularly for trials on prodromal AD (78% failure rate) or preclinical AD (88%): screening procedures for these conditions are time-consuming and costly, making it hard for study sites to recruit eligible participants. Moreover, AD trials often last longer than trials for other conditions, and the tests involved in monitoring participants during these trials can be extremely expensive (e.g. USD 8,000 for a PET scan in the US).

Barriers to AD clinical trial participation identified in the report include personal aspects such as limited awareness of early AD, and fear of an AD diagnosis due to stigma. AD patients in the US healthcare ecosystem find that these systems are often overstretched; that doctors may not diagnose AD until symptoms are more severe; that the lack of treatment options reduces the number of doctors perceiving a benefit from screening for AD; and that mild AD is often diagnosed using a process of elimination, due to the lack of inexpensive

diagnostics. For example, an estimated 65% of patients who undergo amyloid imaging tests pay for these tests out of their own pockets. The final barrier identified in the report is limited awareness of AD clinical trials; many healthcare providers lack reliable, accessible information on clinical trials and how to refer their patients to them.

<https://bit.ly/3cJP3h9>

**14 September: Cassava Sciences announces positive results of its Phase IIb trial of sumifilam in AD**

On 14 September, the biopharmaceutical company Cassava Sciences announced final results of its Phase IIb study of sumifilam (formerly PTI-125) in Alzheimer's disease (AD).

The Phase IIb trial was a randomised, placebo-controlled, double-blind and multi-centre clinical study of sumifilam in mild to moderate AD. A total of 64 US research participants received placebo or sumifilam (50 or 100mg) twice daily for 28 days.

Sumifilam was found to be safe and well-tolerated. Findings reported that participants treated with sumifilam showed statistically significant improvements in multiple biomarkers of AD pathology compared to those who received the placebo. In addition, research participants treated with sumifilam showed improvements in cognition compared to the placebo group.

The company is conducting a long-term, open-label, and multi-centre extension study of sumifilam (100 mg) twice daily for 12 months. The company reported that this open-label study is currently over 50% enrolled.

<https://bit.ly/3I6UV6P>

**17 September: Longitudinal study indicates that women with more fertile years may be at increased risk of dementia in old age**



Dementia risk is strongly age-dependent, with the largest numbers of diagnoses occurring in people aged over 80. In this age group, women are more likely to be diagnosed with dementia than men, with oestrogen exposure identified as a possible mechanism accounting for this difference. To assess the effect of long-term oestrogen exposure on dementia risk in

older women, the authors of an article in the September issue of Alzheimer's and Dementia analysed data from the Swedish Prospective Population Study of Women (PPSW), evaluating the rate of dementia diagnosis in women in relation to their reproductive periods. The reproductive period (in years) was estimated based on information collected in the PPSW study on the women's age at menarche and menopause, number of pregnancies, months of breastfeeding and use of oral contraceptives or HRT.

During the study period examined, 291 of the 1364 women developed dementia, at an average age of just under 80 years. Longer reproductive period and later menopause was associated with an ~7% increased likelihood per year of developing Alzheimer's disease (AD) and/or dementia. Those with the longest reproductive periods (>38 years) had the highest relative risk of dementia and AD, with almost twice the risk of developing dementia compared to women with shorter reproductive periods (<32.6 years). This may partly explain why women aged over 85 have higher dementia incidence than men of the same age.

<https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/alz.12118>

**21 September: Observational study suggests that dementia risk in people with type 2 diabetes varies depending on the type of dementia**



Type 2 diabetes is known to be a risk factor for developing cognitive impairment and dementia, with studies indicating that people living with the condition may be twice as likely to develop dementia compared to the general population. Findings presented at the Annual Meeting of the European Association for the Study of Diabetes (EASD) now suggest that the diabetes risk of people with type 2 diabetes varies depending on the type of dementia.

These new findings are based on an observational study that compared over 370,000 people with type 2 diabetes with almost 2 million matched controls, following them up over an average period of 7 years. Co-led by Prof. Naveed Sattar at the University of Glasgow and colleagues at the University of Gothenburg, the study indicated that people with type 2

diabetes have a 36% increased risk of developing vascular dementia, compared to a 9% increased likelihood of being diagnosed with non-vascular dementia. Interestingly, the risk of developing Alzheimer's disease dementia did not appear to be higher in those with type 2 diabetes compared to their unaffected counterparts, underlining the strong connection between diabetes and vascular health.

Blood sugar control was also shown to impact dementia risk: people with poorly-controlled diabetes had almost double the vascular dementia risk compared to people with good blood sugar control. Although the study authors emphasised that the absolute risk of developing vascular dementia was still low, they highlighted the importance of healthy lifestyle habits for dementia prevention and care.

<https://www.mcknights.com/news/clinical-news/type-2-diabetes-tied-to-vascular-dementia-risk-but-not-alzheimers/>

**21 September: New research investigates women's higher vulnerability to Alzheimer's disease**



In a recent paper published in the journal *Progress in Neurobiology*, a study conducted by a group of researchers of the Institute of Biochemistry and Cell Biology of the National Research Council proposes a new perspective to explain women's higher vulnerability to developing Alzheimer's disease (AD).

Previous studies found that menopause, which reduces oestrogen levels in a women's body, may be the reason more women are affected than men. In the published study, researchers worked to better understand the reasons that determine the greater diffusion of AD in women. They revisited many of the major findings and explored a novel hypothesis on the use of the hippocampus, the brain structure responsible for the formation of long-term memory and spatial orientation, and which is a region affected by AD. They reported that oestrogens tend to disadvantage the use of the hippocampus in women, which in turn makes them more vulnerable to the effects of ageing. In addition, authors proposed the use of behavioural treatments, which specifically train the brain network and favour the use of the hippocampus.

<https://doi.org/10.1016/j.pneurobio.2020.101895>

**23 September: The TAURIEL Phase II study evaluating semorinemab in early AD did not meet its primary efficacy endpoint**



On 23 September, the Swiss-based biopharmaceutical company AC Immune announced that its partner Genentech, a member of the Roche group, has reported top line results from a Phase II clinical trial of semorinemab, an anti-tau monoclonal antibody, in early Alzheimer’s disease (AD).

The Phase II TAURIEL study is a 73-week, double-blind and placebo-controlled trial evaluating the efficacy and safety of semorinemab in people with prodromal to mild AD. A total of 457 participants across 97 study centres in Canada, Europe and US received one of three intravenous doses of semorinemab or placebo.

Top line results showed that the safety endpoint was met. However, the study did not meet its primary efficacy endpoint of reducing decline on Clinical Dementia Rating scale Sum of Boxes (CDR-SB) scores compared to placebo. In addition, two secondary endpoints were also not met (ADAS-Cog13 and ADCS-ADL). Genentech is continuing to analyse data and plans to present the results at an upcoming conference.

<https://bit.ly/3jmOXOT>

**DEMENTIA IN SOCIETY**

**7 September: Dementia Research Chatathon Live takes place online**



It is no secret that charities’ incomes have been substantially affected by the corona virus pandemic. Across the world dementia charities are a substantial contributor to research, funding discoveries in all areas of science, care research and practical support for people living with dementia and their families. In the United Kingdom, Alzheimer’s Research UK and

Alzheimer’s Society have both suspended funding calls until early 2021, and as a result there will be fewer PhD Students and new Fellows this year.

Adam Smith, Programme Director within the UK NIHR Office of the National Director for Dementia Research decided to put his professional experience and connections to use personally, and help, creating the Dementia Research Chatathon Live.

On 7 September, Mr Smith hosted a marathon 12-hour live-stream session, talking with 56 researchers and four special guests. The aims of the event were to share information with the public on some of the important research taking place, and to raise much-needed funding for Alzheimer’s Research UK.

Throughout the day, over 2,000 visitors attended the session, to watch and ask questions via YouTube, Zoom and Periscope. Donations totalled GBP 3,800 (approx. EUR 4,180) and Mr Smith is continuing to work towards meeting his GBP 5,000 (EUR 5,500) target.

“Researchers are doing amazing work, and I wanted to give people a chance to see some of the wide range of research taking place. Looking at prevention, improving care, diagnosis, discovering what goes on in the brain, new treatments and research to improve care homes, and evidence how activities such as art can help”, said Adam Smith.

“I was able to group up the researchers, and talk in 30 minute segments on a massive range of topics, and recordings of each session are now available through the Chatathon website. I hope that people will watch these, and hopefully continue to donate to help meet our ambitious GBP 5,000 target”, he commented.

Those interviewed on the day included Chris Roberts, Vice-Chairperson of our own European Working Group of People with Dementia (EWGPWD). Chris gave his perspective on research, sharing a message on the important role that research and charities play.

Information on the event, the recordings and details on all the guests can be found at:

[www.chatathon.uk](http://www.chatathon.uk)

**21 September: Centre for Access to Football in Europe marks World Alzheimer’s Day**



On 21 September, marking World Alzheimer’s Day, the Centre for Access to Football in Europe (CAFÉ) published three articles aimed at spreading awareness of dementia and Alzheimer’s disease, dispelling myths and combatting stigma, as well as supporting fans with dementia and their families:

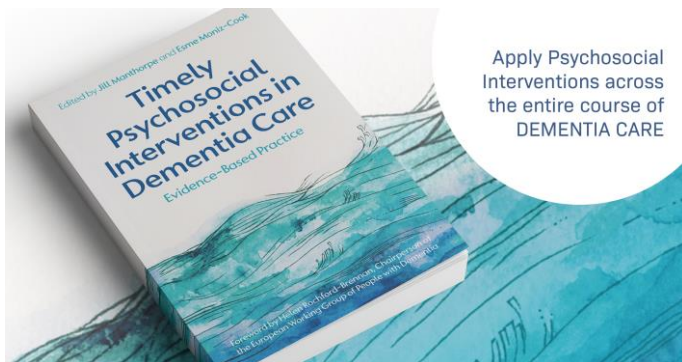
- an interview with Everton in the Community, the official charity of Everton FC, about its “Pass on the Memories” programme: <https://bit.ly/3n8IbOT>

- an interview with Hamburg SV about using football to support people with dementia: <https://bit.ly/3igrqOF>
- an article looking at stigma and stereotypes around Alzheimer's and dementia: <https://bit.ly/30nOLaA>



## NEW PUBLICATIONS & RESOURCES

**8 September: Book on “Timely Psychosocial Interventions in Dementia Care” is published, with a preface by Helen Rochford-Brennan**

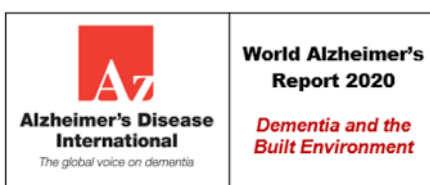


A recently-published book, “Timely Psychosocial Interventions in Dementia Care”, has been published, with a preface written by Helen Rochford-Brennan in her capacity as Chairperson of the European Working Group of People with Dementia (EWGPWD).

The book was coordinated by Jill Manthorpe and Esme Moniz-Cook (INTERDEM), with contributions from clinicians and researchers across Europe.

<http://www.jkp.com/jkpblog/2020/03/timely-psychosocial-interventions-in-dementia-care-evidence-based-practice/>

**21 September: Alzheimer’s Disease International launches World Alzheimer Report 2020**



On 21 September, World Alzheimer’s Day, Alzheimer’s Disease International (ADI) launched its 2020

report. The World Alzheimer Report 2020 takes an in-depth look at dementia-related design and the built environment, looking at progress to date, pioneers and innovators, design principles, application, regional and cultural contexts, the importance of including people with dementia in all aspects of design, and the role of design during the COVID-19 pandemic and beyond.

Across two volumes, including 84 case studies, the report looks at design in home/domestic settings, day and residential care, hospitals and public buildings and spaces. It concludes

that design for dementia is 30 years behind the physical disabilities movement. ADI calls on governments to embed design in their national dementia responses under the Convention on the Rights for Persons with Disabilities (CRPD).

**21 September: University of Vechta launches website with educational videos to help teach people with dementia play musical instruments as part of a collaborative project**



On 21 September, collaborators at the University of Vechta (Germany), who partake in the European project “ReKuTe – Partizipative Wissenschaft für Region, Kultur und Technik”, launched a new website.

The website offers about 80 videos in which website visitors can track violin lessons that were carried out with a person with mild-stage dementia and her teacher Anke Feierabend throughout a year. The length of each video varies between one to six minutes, each is accompanied by elaborate explanations. The website (German) can be found here:

[www.musikunddemenz.de](http://www.musikunddemenz.de)

**30 September: TouchNEUROLOGY has a new website**



TouchNEUROLOGY has a new and improved website, making it easier for healthcare professionals who regularly visit the site to find what they are looking for, with an improved user experience, new user features and a simpler structure. The new website also makes it easier for them to share congress and society videos:

<https://touchneurology.com/>

**Contact Alzheimer Europe:**

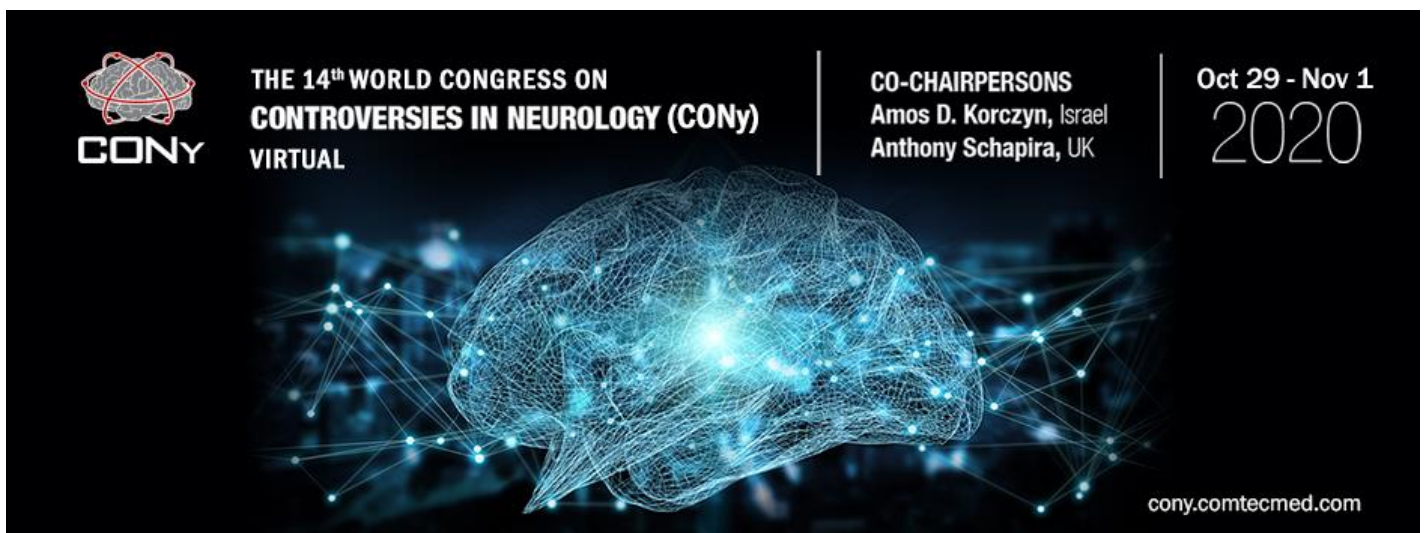
Alzheimer Europe: 14, rue Dicks (L-1417), Luxembourg; info@alzheimer-europe.org; www.alzheimer-europe.org

**Alzheimer Europe Board:**

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

**Alzheimer Europe Staff:**

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



**THE 14<sup>th</sup> WORLD CONGRESS ON CONTROVERSIES IN NEUROLOGY (CONy) VIRTUAL**

**CO-CHAIRPERSONS**  
Amos D. Korczyn, Israel  
Anthony Schapira, UK

**Oct 29 - Nov 1  
2020**

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**AE CALENDAR**

Date	Meeting	AE representative
1 October	EPAD General Assembly	Cindy and Jean
1 October	Neuronet Scientific Coordination Board	Jean, Ange, Cindy, Chris
1 October	EFPIA PTT meeting	Owen
2 October	Smart Ageing Prize second judging panel	Angela
2 October	MHE High Level Seminar	Owen
5 October	Alzheimer Europe Annual General Meeting	AE members, Board and staff
6 October	Neuronet Working Group on Ethics and Patient Privacy	Dianne, Angela and Jean
6 October	VirtualBrainCloud General Assembly meeting	Jean, Ange
7 October	Mini-meetings EWGPWD	Ana and Dianne
8-9 October	AMYPAD General Assembly	Cindy and Jean
12 October	Final meeting of the EWGPWD (2018-2020)	Dianne and Ana
13 October	EuropaBio Patients BioForum	Owen
20 October	INTERDEM Annual Meeting	Dianne and Ana
20-22 October	30 <sup>th</sup> Alzheimer Europe Conference "Dementia in a changing world"	AE members, Board and staff

<b>23 October</b>	European Medicines Agency training day	Ange
<b>26 October</b>	EU Coalition for Health Virtual Summit	Owen

## CONFERENCES

Date	Meeting	Place
<b>5-6 October</b>	21 <sup>st</sup> International Conference on Alzheimer's Drug Discovery <a href="https://meetings.alzdiscovery.org/alz-home/">https://meetings.alzdiscovery.org/alz-home/</a>	Virtual conference
<b>5-6 October</b>	Digital Tools for Patient Empowerment and Person-Centred Care – best practices that boost cooperation between patients and healthcare professionals, <a href="https://eupatient.wufoo.com/forms/k1udbtc51vuihc4/">https://eupatient.wufoo.com/forms/k1udbtc51vuihc4/</a>	Online workshop
<b>12 October</b>	Dementia care & Palliative care: during and beyond the COVID-19 pandemic	Webinar
<b>20-22 October</b>	30 <sup>th</sup> Alzheimer Europe Conference "Dementia in a changing world"	Virtual conference
<b>27 October</b>	JA CHRODIS PLUS Online Conference on Chronic Diseases	Online conference
<b>29 October – 1 November</b>	The 14 <sup>th</sup> World Congress on controversies in neurology, <a href="http://cony.comtecmed.com/">http://cony.comtecmed.com/</a>	Virtual conference
<b>4-7 November</b>	13 <sup>th</sup> Clinical Trials on Alzheimer's Disease (CTAD) <a href="https://www.ctad-alzheimer.com/">https://www.ctad-alzheimer.com/</a>	Boston, US
<b>16-18 November</b>	2 <sup>nd</sup> Krems Dementia Conference, <a href="http://www.donau-uni.ac.at/dementia-conference">www.donau-uni.ac.at/dementia-conference</a>	Krems, Austria
<b>10-12 December</b>	34 <sup>th</sup> International Conference of ADI "Hope in the age of dementia", <a href="https://adi2020.org/">https://adi2020.org/</a>	Virtual conference
<b>18-21 February 2021</b>	12 <sup>th</sup> Panhellenic Conference of Alzheimer's Disease (PICAD) and the 4 <sup>th</sup> Mediterranean Conference on Neurodegenerative Diseases (MeCoND), <a href="http://www.alzheimer-conference.gr">www.alzheimer-conference.gr</a>	Thessaloniki, Greece
<b>9-14 March 2021</b>	AD/PD 2021 - The 15 <sup>th</sup> International Conference on Alzheimer's & Parkinson's Diseases, <a href="https://aat-adpd.kenes.com/">https://aat-adpd.kenes.com/</a>	Barcelona, Spain
<b>26-29 June 2021</b>	Brain & Brain PET 2021, <a href="http://brain2021.scot/">http://brain2021.scot/</a>	Glasgow, UK
<b>29 Nov - 1 Dec 2021</b>	31 <sup>st</sup> Alzheimer Europe Conference	Bucharest, Romania

# 30<sup>th</sup> Alzheimer Europe Conference

## Dementia in a changing world

### Virtual Conference

### 20–22 October 2020

[www.alzheimer-europe.org/conferences](http://www.alzheimer-europe.org/conferences)

 #30AEC

