

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 pandemic has inevitably impacted the work we all do,

but our members continue to find new and creative ways to carry out their awareness-raising and fundraising activities and it is so inspiring to see how resilient and hardworking everyone is. You can read more in our "World Alzheimer's Day" section, starting on page 15 of this newsletter.

Aside from supporting the efforts of our members this month, we have co-authored a paper on identifying relevant outcomes in Alzheimer's disease progression and contributed to a new book on "Management of Patients with Dementia".

We have also organised and attended a number of meetings, including an online session of our popular Alzheimer's Association Academy, focusing on advocacy and working with policymakers. We also organised the latest edition of our online European Parliament Workshop series, looking at "The Innovative Health Initiative: Building on the success of the Innovative Medicines Initiative".

Other notable meetings attended by team members included the WHO's 71st Regional Committee for Europe (RC71) and the launch of WHO Europe's new Pan-European Mental Health Coalition. Alzheimer Europe is delighted to have been invited to join this coalition and I was honoured to attend the launch event in Brussels which was opened by HM Queen Mathilde of Belgium, Hans Kluge the Regional Director of WHO and

Stella Kyriakides, European Commissioner for Health and Food Safety. At RC71, we submitted joint statements with other NGOs calling on the inclusion of dementia in mental health policies. We were delighted as well that WHO Europe renewed our recognition as an accredited non-state actor.

The WHO has also published a "Global status report on the public health response to dementia", which provides an overview of the implementation of the Global dementia action plan 2017-2025. It takes stock of actions thus far by Member States, the WHO and civil society, as well as highlighting barriers to its implementation (including COVID-19). The key conclusion of the report is that whilst some progress is being made, work is urgently required in order to meet objectives by 2025.

It is really heartening to see the WHO putting so much focus on dementia and working so closely with us. It is also encouraging to see that G20 Health Ministers have published a declaration on the future of health, which includes the need for a specific focus on dementia and healthy ageing.

On a less positive note, we have not yet had a satisfactory response from DG Santé and Commissioner Kyriakides, regarding our concerns about the decision to exclude operating grants from the 2021-2022 EU4Health Annual Work Programme. This decision continues to put key activities of European health NGOs in jeopardy, and this during a global public health crisis. We continue our campaign together with a coalition of health NGOs, and hope that this disastrous decision will be revoked.

Jean Georges
Executive Director

Sponsor of the month

Alzheimer Europe would like to express its gratitude to a new sponsor for its 2021 activities.

Read more about sponsorship opportunities here:

<http://bit.ly/sponsorAE>



ADDI
Alzheimer's Disease
Data Initiative

Similar patterns of increased risk were observed for the likelihood of hospital admission due to COVID-19.

It is hoped that the new QCovid algorithms will help support public health policy and prioritise patients for targeted, early interventions to avoid COVID-19 mortality and hospital admission after vaccination.

<https://www.bmj.com/content/374/bmj.n2244>



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ALZHEIMER EUROPE

13 September: Alzheimer Europe supports joint statements at WHO Europe RC 71

Alzheimer Europe has joined with other international and European non-governmental organisations (NGOs) in submitting joints statements to the World Health Organization's (WHO) 71st Regional Committee for Europe, held between 13 and 15 September.

The first statement, signed by World Federation of Occupational Therapists (WFOT), Alzheimer Europe, EuroHealthNet and Mental Health Europe (MHE), focuses on the WHO's Mental Health Coalition programme, making a number of calls, including the importance of a psychosocial approach to treatment and management, the need to embed the economy of wellbeing in systems and mobilising funds for mental health reforms. Importantly, it also calls for Alzheimer's disease and dementia to be recognised within the programme (as they fall within the remit of mental health in the WHO).

Alzheimer Europe also supported a statement led by the European Public Health Association (EUPHA), and signed by 25 NGOs, thanking the WHO for the renewal of recognition of Non-State Actors (NSAs), as well as highlighting the constructive role of NSAs in contributing to the work of the WHO.

The joint statement on the Mental Health Coalition can be found here:

https://www.euro.who.int/__data/assets/pdf_file/0006/511728/ai7-MHE-joint-statement.pdf

The joint statement on re-accreditation can be found here:

https://www.euro.who.int/__data/assets/pdf_file/0018/511731/ai12-EUPHA-joint-statement.pdf

COVID-19 SITUATION

17 September: New research published in the BMJ identifies patient groups at higher risk of COVID-19 related death after vaccination, including people with dementia



The original QCovid tool was developed to inform policymakers on the risk of COVID-19-related death or hospital admission for different groups of people, and to help identify patients at

high risk of severe COVID-19 outcomes. In their BMJ (British Medical Journal) article, the team of researchers behind QCovid publish two new risk algorithms, QCovid2 and QCovid3, which estimate the risk of COVID-19 related mortality and hospital admission in UK adults after one or two doses of COVID-19 vaccination.

The new risk algorithms were developed based on data from the second pandemic wave in England, analysing data on people who received a vaccination between early December 2020 and June 2021. In total, data from 6,952,440 people were analysed, 74% of whom had received two doses of COVID-19 vaccination. Of 2031 COVID-19 deaths that occurred during the 6-month period, 81 deaths (4%) occurred two weeks or more after the second vaccination dose. People who had received two vaccine doses were over 80% less likely to die from COVID-19 compared to people who had only received one dose.

Closer evaluation of the data showed that particular groups may be at higher risk of COVID-19 mortality and hospital admission after vaccination, in particular people with Down's Syndrome (12.7-fold higher risk), people who had received kidney transplants (8.1-fold higher risk) and people living in care homes (4.1-fold higher risk). Dementia was also associated with a 2.2-fold higher risk of death from COVID-19 after vaccination.



14 September: Alzheimer Europe hosts Alzheimer's Association Academy session focusing on advocacy initiatives and working with policy makers



On 14 September 2021, Alzheimer Europe held an online session of its popular Alzheimer's Association Academy series. These Academy sessions have been running since December 2015, and have been online since the start of the COVID pandemic. The theme for the session of 14 September was "Advocacy initiatives and working with policy makers".

There was a total of 39 participants at the Academy: 6 Alzheimer Europe staff members, including Executive Director Jean Georges who chaired the meeting; 23 representatives of Alzheimer Europe national member associations from 15 different countries; 8 industry representatives; and 6 expert speakers.

The first speakers were Nils Dahl, Ministry of Health, Germany and Sabine Jansen, Deutsche Alzheimer Gesellschaft (DAIzG) - the German Alzheimer association, who gave a joint talk on "The German Alzheimer's Association, a key partner for the development and implementation of the German Dementia Strategy". Mr Dahl gave the background about the strategy itself and said that Germany is now in the first phase of implementation. He also mentioned the creation of an alliance for people living with dementia and said that one of the most important aspects of implementing the strategy is the partnership with the DAIzG. Ms Jansen then spoke about this partnership and about the role of her organisation in four of the working groups carrying out some of the 27 aims and 162 measures set out in the strategy. These four working groups in which DAIzG plays a role are on dementia inclusive communities and carers, with two of them working on improving support for people with dementia and carers (professional and voluntary support), a third looking at advanced care and long-term care and the fourth on dementia research.

Other actions include Germany's version of the Dementia Friends programme, called "Demenz Partner", which includes a course of around 90 minutes. Federal Minister of Health Jens Spahn is a dementia friend, and working together with him and other Ministries, allows the DAIzG to reach more people and encourage them to think about dementia and about being more inclusive. Currently, the Demenz Partner programme is working on training 10,000 transport workers throughout Germany, which should also help make everyday life easier for people

with dementia, she said. Finally, she mentioned working with various sports teams, including ice hockey team the Berlin Ice Bears and the women's national football team. This is another way to reach more people and also to ensure that people with dementia can participate in sports. In closing, Mr Dahl took the (virtual) floor again, emphasising another area of cooperation of their two institutions, which is around measures from the fourth aim of the strategy, focused on research, i.e. promoting more participation of people with dementia in research. The first example he gave was a project called "PraWiDem", aiming to "close the gap". The second is a project on Dementia Care Management called "RoutineDeCM". A "care manager" is a professional caregiver, he noted. Both of these projects are funded by the Ministry of Health.

Lorène Gilly from France Alzheimer, was up next, with a presentation on "Alzheimer as a political priority in France: ups and downs of public engagement". Things have changed for the worse in France, in recent months, with regards political engagement in the area of dementia and France Alzheimer is having to fight hard, in the context of the pandemic, due to the tight budget available to engage in concrete action. She mentioned repeated national consultations on the subject of autonomy to announce a long-awaited reform, which will now not see the light of day, before the end of the current presidential term. This announcement was a huge disappointment. With the presidential race beginning and elections taking place next April, it is a difficult time to get the government to commit to anything. Ms Gilly also emphasised the launch of a new neurodegenerative diseases roadmap 2021-22, which was unfortunately only launched midway through the first of its two-year period and falls far short of what France Alzheimer had hoped for. Since the end of the former plan 2014-2019, France Alzheimer has created an informal collective, with stakeholders such as France Parkinson and Multiple Sclerosis associations, with the aim of fighting together to boost the engagement of the government in building a new strategy/plan, but it has not been willing to start a new strategy the year before the election. The roadmap was launched instead, through work with the ministry of health and the ministry of autonomy. Overall, Ms Gilly said that France Alzheimer is not satisfied with the roadmap, as it lacks ambition, the budget is unclear, there is no agenda for implementation and there are no details on evaluation either. Health Minister Olivier Véran told France Alzheimer that he wants to complete the first version of the roadmap, with complementary measures to be set up in 2023 and 2024, but due to next year's election, this does not alleviate France Alzheimer's fears, as it may not be the same government in place. The presentation highlighted some of the real difficulties faced in the areas of advocacy and working with policymakers, in the "in-between" period when a government is in its final months before a general election. It also stressed, however, that France Alzheimer is not giving up, but rather is reaching out, working with some of the main services of the Ministry of Health on three measures from the roadmap, developing a plan of action, reaching out to MEPs,

raising awareness among the public and trying to involve everyone in this battle. Their aim is for the current roadmap to count and to hopefully be a transition to a greater strategy.

Clodagh Whelan from The Alzheimer Society of Ireland (ASI) was next, with a talk about "Using elections and the budget submission as key campaigning opportunities". She began by saying that her main focus would be on how to talk to policymakers. Ireland, she noted, is famous for its storytelling, and this is something she brings into her policy work, which helps convey messages to policymakers and the general public in an engaging and clear manner. Our organisations and academics need a reason to come together, and opportunities to do so, she stressed, and these national opportunities are really important. At the ASI, they have found that personal stories coupled with evidence work best. Making it personal makes it harder to say no. In Ireland politics is local and people want to know what is happening in their area. The ASI therefore sends local politicians data about their area, so that they are well-informed. She also stressed the importance of "keeping it simple", and laid out some actions taken before, during and after each campaign. Before: Gather evidence and create reports. A lot of smaller government departments don't have time to do this, so bringing this to them is helpful. The context is important too, for instance COVID is the obvious context, just now. Considering the context of the policymakers themselves and of their parties is important too, she noted. During: Most people want to help and we need to help them to do that. Giving them straightforward and accessible ways to do so, being upfront and honest about where we are and what we need, usually works well, she said. Keeping the story going is also hugely important, for example if a campaign is taking place over a few weeks, they try to have several outputs throughout. After: The ASI reviews its work to see what went well and what didn't. They ask people with dementia, carers and organisations for feedback, as well as asking politicians during their "downtime" (i.e. not during the run-up to an election). She particularly stressed asking policymakers if there is a reason they are saying no that you are unaware of, as this helps to shape future campaigns and approaches. She also highlighted the importance of engaging with "grassroots" and thanking them for their support. In closing, she conceded that this straightforward approach will not always get you what you want and things certainly don't move quickly, but said that "taking the incremental wins" and focusing on the progress made is the best way to keep up hope. Dementia is a huge political and social issue, and it will not be solved with one single campaign.

Following these three presentations at a national level, the final one was given by Melissa Mitchell and Susan Wile Schwarz of the Global Coalition on Ageing (GCOA), USA. They gave delegates a preview of the GCOA's upcoming publication, "The Alzheimer's Innovation Readiness Index", and looked at ways in which it might be used as a tool to effect change at national level. The publication will be out in late October, so we cannot

share the details at this time, but will report on the launch when it happens, so watch this space!

Jean Georges complimented all the speakers on their informative and engaging presentations and on the interesting initiatives mentioned and advice given on how we can all work better together and with policy makers. Our next Academy session will take place on 13 October 2021 and will look at dementia-friendly initiatives.

15 September: Alzheimer Europe re-accredited by WHO Europe

During the 71st session of the WHO Regional Committee for Europe, which took place online from 13 to 15 September 2021 a



resolution re-accrediting 19 existing regional non-State actors (NSAs) not in official relations with WHO, to attend future Regional Committee sessions was unanimously adopted. Alzheimer Europe is delighted to be one of those re-accredited, allowing us to continue to develop a closer collaboration with the Regional Committee and contribute more actively to the implementation of the global dementia plan at a European level. The resolution also accredited six new NSAs.

<https://apps.who.int/iris/handle/10665/343234>

28 September: Alzheimer Europe hosts European Parliament Workshop on "The Innovative Health Initiative: Building on the success of the Innovative Medicines Initiative"



On 28 September, Alzheimer Europe hosted an online European Parliament Workshop with Neuronet, entitled "The Innovative Health Initiative: Building on the success of the Innovative Medicines Initiative" looking at the future public-private partnership between the EU and industry partners. Alzheimer Europe Chairperson Iva Holmerová chaired the event, which was attended by 65 people, including EU policymakers, representatives from national Alzheimer's associations, national health ministries, pharmaceutical companies, researchers and members of the European Working Group of People with Dementia.

The opening presentation was made by Pierre Meulien, Executive Director, Innovative Medicines Initiative (IMI), who outlined the successes of IMI programmes-funded research projects focused on dementia. He explained that the public-

private partnership model had been of particular value for dementia and other neurodegenerative diseases, due to the complexity of the conditions and the high drug attrition rates. As such, over EUR 315 million has been invested in research into brain disorders thus far by IMI, including projects which had changed our understanding of Alzheimer's disease, as well as creating resources and infrastructure to facilitate future research in the field. The collaborative nature of the projects in IMI was identified as a particular strength of the IMI approach, including the involvement of patient organisations such as Alzheimer Europe. Looking to the future, the importance of enabling technologies at a pre-competitive phase and pan-European consortia were singled-out as key elements for future research collaborations in the Innovative Health Initiative (IHI).

Carlos Diaz, Neuronet project leader, Synapse, presented on lessons learned from IMI-funded projects and how the work of the Neuronet project, which includes 20 different IMI neurodegeneration projects, was trying to find synergies across the neurodegeneration portfolio. He highlighted some of the Neuronet work to date, including its Knowledge Base, a dashboard which allows people to more easily search IMI neurodegenerative projects, their deliverables and tools. In addition, the creation of asset maps and network diagrams have allowed for visual representations of the different resources, as well as identifying potential research areas not addressed by existing projects. Some of the challenges with existing funding mechanisms and collaborations were highlighted, including the sustainability of activities beyond the life of projects, as well as a perceived disconnect between decision-makers and principal investigators. As such, he argued that there is an evident need for a systems leadership approach to these types of projects, as well as the need for a shift from a focus on projects to assets.

Nicolas Creff, Senior Manager Research Partnerships, Science Policy & Regulatory Affairs, European Federation of Pharmaceutical Industries and Associations (EFPIA), presented on the forthcoming IHI, outlining the new collaboration between both pharmaceutical and pharma technology partners and highlighting that the new focus for the partnership will increasingly be on cross sector opportunities which make better use of data, drugs and medical devices. Furthermore, there will be a move towards broader themes of public health priorities, rather than specific diseases areas, however, there will be a consideration of aspects such as the prevalence of disease, high economic impacts and the transformational potential of research. It is expected that the legislative basis for the partnership should be completed by the end of the year, with calls potentially being issued as early as the first quarter of 2022.

Susan Wile Schwarz, Director of Communications, Global Coalition on Aging, presented an upcoming report, the Alzheimer's Innovation Readiness Index, jointly written with Alzheimer's Disease International. The report compares 10 European countries across 5 different domains: strategy and commitment; early diagnosis and detection; access to care;

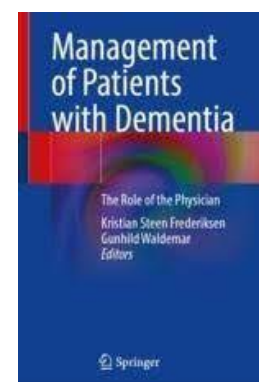
awareness and monitoring, and; care standards and settings. The report demonstrates that whilst there is some progress in countries, there remains significant variation across Europe, with many long-standing issues related to diagnosis, access to care and provision of adequate resources and funding, meaning that there are still significant difficulties for people with dementia and their carers across Europe. The report will be launched later in October 2021.

Concluding the Workshop, Iva Holmerová thanked presenters and participants for their contributions during the meeting and expressed hope that the next meeting would be in person. Videos from the event will be available on Alzheimer Europe's YouTube Channel:

http://bit.ly/AlzheimerEurope_YouTube

29 September: Alzheimer Europe and European Working Group of People with Dementia contribute to new book on "Management of Patients with Dementia"

A book on "Management of Patients with Dementia" has recently been published in electronic and print format. This book provides an overall introduction to the medical management of dementia, with chapters dedicated to specific topics such as pain, epilepsy, vascular risk factors in dementia and review of medication, which are often not addressed in books on the subject, and thereby filling a gap in the field.



This book is aimed at clinicians of different specialties (mainly neurology, psychiatry, geriatric medicine and general practice/family medicine) who manage patients with dementia on a regular basis, and thus provides useful guidance to be used in the clinic.

Jean Georges, Executive Director, Dianne Gove, Director for Projects and Ana Diaz, Project Officer, Alzheimer Europe, contributed a chapter on "Diagnosis and Support of Patients with Dementia: A Patient Perspective on Current Goals and Practice". Members of the European Working Group of People with Dementia also contributed a number of testimonials, to a different chapter of the book.

[Management of Patients with Dementia - The Role of the Physician | Kristian Steen Frederiksen | Springer](#)



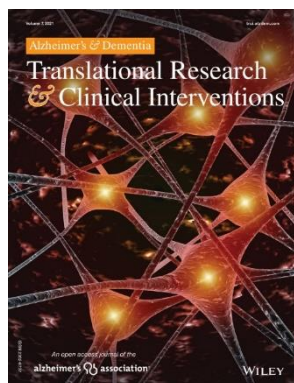
Alzheimer Europe networking (online)

- On 2 September, Owen and Ange attended the WHO launch of the Global Status Report on the public health response to dementia.
- On 3 September, Ana and Dianne attended the EWGPWD meeting.
- On 6, 8 and 9 September, Ana and Cindy participated in the EU-FINGERS Advisory Board meetings.
- On 7 September, Dianne and Ana attended the INTERDEM taskforce meeting on use of technology during the pandemic.
- On 8 September, Dianne attended the RADAR-AD extension meeting.
- On 8 September, Gwladys had a meeting with LOE preparing for 31AEC.
- On 10 September, Dianne presented on Public Involvement at the DZNE participatory research conference.
- On 10 September, Jean attended a European Economic and Social Committee hearing on the status of European associations.
- On 10 September, Owen attended a European Commission webinar on the responses to the EU4Health programme consultation.
- On 13 September, Jean joined a consensus meeting on MCI criteria.
- On 13-15 September, Owen attended the virtual 71st WHO Regional Committee for Europe.
- On 14 September, Jean met with the European Academy of Neurology.
- On 14 September, Alzheimer Europe organised an Alzheimer's Association Academy on "Advocacy initiatives and working with policy makers".
- On 14 September, Ange attended a meeting on public engagement, organised by the PRIME project.
- On 15 September, Ange attended an EFPIA Patient Think Tank meeting.
- On 15 September, Jean met with the EFPIA AD Platform.
- On 16 September, Jean participated in an AD Delphi virtual consensus meeting on outcomes and scales in dementia.
- On 16 September, Ange attended a virtual General Assembly meeting of the TVB_Cloud project.
- On 17 September, Jean met with a representative of Alnylam.
- On 17 September, Ana, Cindy, Chris, Dianne and Angela attended the AI-Mind General Assembly Meeting.
- On 20 September, Jean presented on Alzheimer Europe's public involvement activities at a Roche workshop "Advancing Healthcare Together with Patients".
- On 21 September, Jean presented on the impact of COVID-19 on dementia care and research at the World Alzheimer's Day conference of Spominčica, Slovenia.
- On 21 and 22 September, Ange attended a meeting of the EMA PCWP/HCPWP.
- On 23 September, Chris and Owen attended a webinar entitled "Alzheimer's Disease: Preparing for the "Silent Epidemic" in Europe", hosted by The Financial Times in partnership with Biogen and EU40.
- On 23 September, Ana attended the RADAR-AD Steering committee meeting.
- On 23 and 24 September (Amsterdam, Netherlands), Cindy attended the PRODEMOS General Assembly and Jean participated online.
- On 27 September, the Alzheimer Europe Board met.
- On 28 September, Alzheimer Europe organised a European Parliament workshop "The Innovative Health Initiative: Building on the success of the Innovative Medicines Initiative".
- On 28 September, Alzheimer Europe convened a company round table with its corporate sponsors.
- On 28 and 29 September, Ange attended sessions of the Digital Health Europe summit.
- On 30 September (Brussels, Belgium), Jean attended the launch of the pan-European Mental Health Coalition.
- On 30 September, Gwladys had a meeting with LOE preparing for 31AEC.



EU PROJECTS

20 August: Alzheimer Europe co-authors paper on identifying relevant outcomes in AD progression, together with ADDITION and ABOARD projects



On 20 August a paper called "Identifying relevant outcomes in the progression of Alzheimer's disease; what do patients and care partners want to know about prognosis?" was published in the journal *Alzheimer's & Dementia: Translational Research & Clinical Interventions*. Alzheimer Europe Director for Projects Dianne Gove and Project Officer Ana Diaz were co-authors of this paper, with research being led by the Alzheimer Center Amsterdam.

Prognostic studies in the context of Alzheimer's disease (AD) have previously mainly predicted time to dementia. However, it is questionable whether onset of dementia is the most relevant outcome along the AD disease trajectory from the perspective of patients and their care partners. The researchers therefore aimed to identify the most relevant outcomes from the viewpoint of patients and care partners, using a two-step, mixed-methods approach.

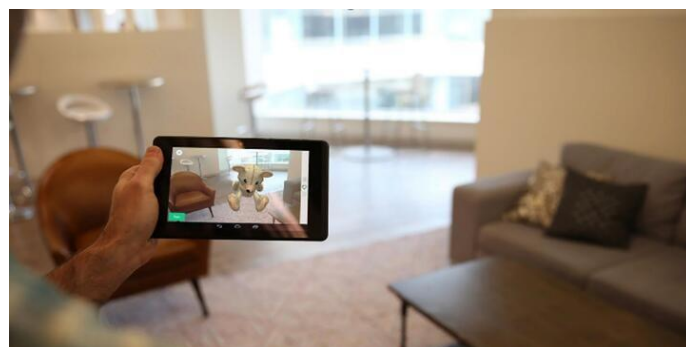
They conducted four focus groups in the Netherlands, followed by a survey conducted across Europe, eventually identifying a core list of outcomes and found that prognostic information related to cognitive decline, dependency, and physical health were considered most relevant by patients and their care partners.

Their findings have implications for research and clinical practice. Given that information on individual disease trajectories can support patients, care partners, and health-care providers to plan and organise care, the researchers are currently collecting patient-reported outcomes (PROs) in the context of the European ADDITION JPND project and Dutch ABOARD project, with the ambition to integrate these PROs into a disease progression model. Read the study, here:

[Identifying relevant outcomes in the progression of Alzheimer's disease; what do patients and care partners want to know about prognosis? - Mank - 2021 - Alzheimer's & Dementia: Translational Research & Clinical Interventions - Wiley Online Library](#)

25 August: Preliminary results from RADAR-AD were presented at this year's Alzheimer's Association International Conference

The RADAR-AD study aims at leveraging different combinations of wearables and smartphone applications in three different settings: during a lab assessment visit, at home and in a fully equipped digital smart home. To achieve this goal, the RADAR-AD consortium has selected wearable devices and built

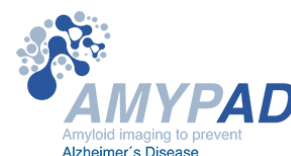


applications that can collect digital biomarkers for critical functional domains in people living with Alzheimer's disease (AD). The preliminary results from the use of some of these devices and apps (gait measured via the Physilog, cognition via the Altoida app, the ability to measure finances via a Banking app) were presented at this year's Alzheimer's Association International Conference (AAIC), which was a hybrid event, taking place in Denver, Colorado, USA and online, between 26 and 30 July 2021. The preliminary results are promising and the RADAR-AD consortium will continue investigating whether remote monitoring technologies are able to provide sensitive measures to detect functional decline in the early stages of AD.

Read more [here](#).

6 September: AMYPAD consortium congratulates two young researchers on successfully defending their PhD theses

Two AMYPAD early career researchers successfully defended their PhD theses in July 2021. On 1 July 2021, Lyduine Collij (Amsterdam UMC, Netherlands) successfully



defended her PhD thesis entitled "The AMYPAD project: Towards the next stage in amyloid PET imaging". This work was conducted in the context of the AMYPAD project and was the first AMYPAD PhD to be completed. In her thesis, Lyduine investigated the utility and potential of amyloid PET imaging in clinical and research settings within the field of Alzheimer's disease.

Gemma Salvadó (BarcelonaBeta Brain Research Center, Spain) defended her thesis entitled "Detection of early cerebral amyloid- β deposition by PET imaging and its downstream effects" on 9 July 2021. Her thesis focused on two main points relating to the study of the preclinical stage of Alzheimer's disease. In the first instance, she focused on the early detection of amyloid- β , which is one of the first to accumulate in the brain in Alzheimer's disease. In the second part of her thesis, Gemma investigated other possible mechanisms that are triggered in relation to this early amyloid- β accumulation.

The AMYPAD project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 115952. The Joint Undertaking receives support from the European Union's Horizon2020 research and innovation

programme and EFPIA. This article reflects the author's view and neither IMI nor the European Union and EFPIA are liable for any use that may be made of the information contained herein.

<https://amypad.eu/news/recent-news/two-amypad-researchers-successfully-defended-their-phd-thesis/>

9 September: EU-FINGERS Advisory Board participates in its second consultation



The EU-FINGERS project will advance the understanding of, and the interventions for, the prevention of cognitive decline and Alzheimer's dementia. The project aims to develop tools and methods for researchers working in the field of prevention of Alzheimer's disease and dementia. One of the tools will involve the design of an intervention promoting brain health in older adults.

EU-FINGERS has set up an Advisory Board in January 2021. The Advisory Board is composed of people with an interest on the topic of brain health and prevention of dementia from seven countries in Europe (Finland, Hungary, Luxembourg, Netherlands, Spain, Sweden, UK). Alzheimer Europe, in close coordination with the other partners in the project, is responsible for the coordination of the EU-FINGERS Advisory Board and the contribution of its members.

Members of the Advisory Board were split in three smaller groups and met online on 7, 8 and 9 September. The focus of the meeting was on interventions for brain health which combine changes in lifestyle and drugs. During the meeting, members discussed on how they feel about this type of interventions, possible benefits and concerns, and how potential participants in this type of interventions could be informed. All meetings were very interactive and lively and the feedback received was very valuable for the project. Project officers Cindy Birck and Ana Diaz participated in the different meetings.

EURO-FINGERS is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project. The project is supported through the following funding organisations under the aegis of JPND - www.jpnd.eu: Finland, Academy of Finland; Germany, Federal Ministry of Education and Research; Spain, National Institute of Health Carlos III; Luxemburg, National Research Fund; Hungary, National Research, Development and Innovation Office; The Netherlands, Netherlands Organisation for Health Research and Development; Sweden, Swedish Research Council.

10 September: ADAIR project adopts new logo



The ADAIR project (2020-2022) has adopted a new logo.

ADAIR is a multi-national collaboration between neuroscientists, environmental

scientists, clinicians, epidemiologists, informaticians, and non-

profit organisations, including Alzheimer Europe. It aims to provide crucial mechanistic insight about the effects of air pollutants on the brain in humans and discover biomarkers for air pollution and Alzheimer's disease (AD) risk prediction. ADAIR addresses a major societal challenge with wide health-related, environmental, economic, scientific, social, and political impact. Lowering the incidence of AD attributable to air pollution and contribution to the mitigation of climate change, are closely linked. The ultimate goal is to develop strategies for early identification of people at risk of AD, and to discover novel targets for preventive strategies in AD.

The ADAIR project is funded by the JPND, for a duration of 36 months. It started in January 2020 and will conclude in December 2022.

<https://adair-jpnd.eu/>

16 September: VirtualBrainCloud project hosts a virtual General Assembly meeting

On 16 September, the H2020-funded VirtualBrainCloud project (TVB_Cloud) held its quarterly General Assembly meeting online, summarising recent project developments and discussing upcoming plans.



VirtualBrainCloud

The TVB_Cloud project was launched in early 2019, and is developing a cloud-based platform to support personalised decision-making for neurodegenerative diseases such as Alzheimer's and Parkinson's disease. TVB_Cloud brings together partners based at 17 different institutions, hospitals, companies and organisations, including Alzheimer Europe.

Chaired by Prof. Petra Ritter of Charité University Hospital Berlin, the TVB_Cloud meeting was attended by over 45 project participants. TVB_Cloud workpackage leaders provided brief summaries of ongoing activities on data processing, disease progression models, computational brain simulations, and the software development that underlies these activities.

There have been a number of recent publications from the TVB_C consortium, presenting the results of TVB_C research in journals such as Alzheimer's and Dementia, Scientific Reports and GigaScience. TVB_C research has also been presented at a number of workshops and seminars, including a Summer School at McGill University, an Ars Aequi podcast at the University of Vienna, and an online Brain Connectivity workshop. The next General Assembly meeting will be held in December.

To find out more about VirtualBrainCloud:

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



17 September: AI-Mind project holds its General Assembly meeting



On 17 September, the H2020-funded AI-Mind project held its general assembly meeting as a hybrid event (online and in Oslo, Norway). The project kicked off in March 2021 and aims to facilitate a paradigm shift in clinical practice. AI-Mind will create intelligent digital tools for screening of brain connectivity and dementia risk estimation in people affected by mild cognitive impairment.

Ira Haraldsen (Oslo University Hospital, OUS, Norway) coordinator of the AI-Mind project, kicked off the meeting by welcoming more than 60 members from its consortium counting 15 partners, with 40 delegates participating in person.

The meeting divided between morning and afternoon sessions focused on the project's aim – how to tackle the challenge of dementia prediction with the use of innovative technologies. The event was as well an exceptional occasion to get insights from the AI-Mind advisory board of which members were present at the assembly, including Francesca Sofia, Hernando Ombao, Ole Petter Ottersen, James Rowe, Klas Pettersen, Richard Milne and Andreas Keller. All agreed that the AI-Mind project is an important initiative that can enhance a patient's diagnostic journey and consequently the quality of life of those affected by mild cognitive impairment or ones who are onset to dementia. The general assembly meeting concluded with parallel breakout sessions dedicated to the various work packages. Ira then drew the meeting to a close, thanking all the participants for their active contribution to the meeting.

Alzheimer Europe (AE) is involved in the ethics, Patient and Public Involvement (PPI) and communication activities of the project. Angela, Cindy, Dianne, Ana and Chris took part in the meeting.

The AI-Mind project is funded by Horizon 2020, for a duration of 5 years. It will conclude in February 2026. This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 964220.

21 September: RADAR-AD consortium publishes a paper which reviews the EMA's recent scientific advice and opinions

The RADAR-AD consortium recently published a paper which presents a review of the advice and opinions (i.e. qualification opinions, qualification advices and scientific advices) provided by the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency (EMA). The authors conclude that, although there is a trend towards an increased use of remote monitoring technologies (RMTs) over time, their use in registration trials (a type of research study) is still relatively rare. This type of work can provide a better understanding of the EMA's requirements regarding the use of RMTs in clinical trials for Alzheimer's disease (AD). Most importantly, taking these recommendations into account could contribute towards a more optimal development of RMTs which are acceptable for regulatory agencies, and might also indirectly benefit people living with AD and their supporters/carers.

Read the full news story [here](#).



23 September: PRODEMOS project holds its General Assembly meeting in Amsterdam



The Prevention of Dementia using Mobile phone Applications (PRODEMOS) project held its general assembly meeting from 23-24 September as a hybrid event (online and in Amsterdam, the Netherlands). The project is aiming to make an evidence-based dementia prevention strategy using mobile Health (mHealth), accessible to those at increased risk of dementia.

The meeting commenced with Edo Richard welcoming almost 40 delegates, including representatives from the 8 institutions and organisations that make up the PRODEMOS consortium. Following on from the introductory session, two sessions were dedicated to the platform and the trial in China. A very fruitful session took place on the trial practicalities. This was followed

up by an overview of the planning trial including the project's extension. The first day was brought to a close with a session on data collection and analyses.

The second day of the meeting started with Anders Wimo and Ron Handels who reported on the health economic aspects including the cost-effectiveness analysis. Next, leaders of the trial study in UK discussed the recruitment status, the measurements, the coaching and the reactions of participants. Following on from this presentation, Cindy Birck presented the news items that are published on the PRODEMOS application and adapted to the target population. Finally, dissemination and management activities were also briefly discussed. Edo Richard and Eric Moll Van Charante then drew the meeting to a close, thanking all the participants for their active contribution to the meeting.

Jean Georges and Cindy Birck attended the general assembly meeting on behalf of Alzheimer Europe (AE). AE is partner in the project and is involved in the coordination and management, crossing cultural barriers and dissemination and communication work packages of this project.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 779238 and the National Key R&D Programme of China (2017YFE0118800). Further information on the PRODEMOS project can be found here:

<https://www.prodemos-project.eu>

28 September: Survey to collect views on early diagnosis and prevention of Alzheimer's disease



The EU-FINGERS and LETHE projects have launched a survey examining the perspectives of European memory clinic clinicians who are involved in the diagnostic work-up for dementia. The survey is opened to physicians (e.g. neurologists, geriatricians, psychiatrists) and other health care professionals (e.g. nurses, psychologists, dietitians) working in memory clinics across all European countries, willing to share their thoughts and experiences on communicating about early diagnosis of Alzheimer's disease, biomarkers, dementia risk and prevention. The survey is available online and planned to run until 20 August. If you are interested in taking part, please click here: <https://vumc.datacoll.nl/ogyvwhbpj?l=en>

Your views are extremely important and will be much appreciated. If you have any questions about the survey, please contact Heleen M.A. Hendriksen at h.hendriksen@amsterdamumc.nl

EU project acknowledgements



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Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at **93**, representing **26** Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance (EAA):

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



EU DEVELOPMENTS

28 August: European Commission publishes Horizon Europe health cluster calls



Alzheimer Europe has submitted a response to the European Commission's consultation on the Annual Work Programme 2022 of the EU4Health programme.

Due to the character limits in the consultation survey, Alzheimer Europe submitted an additional paper, setting out its views on the priority areas for the Annual Work Programme for 2022. The consultation response:

- Briefly refers to the ongoing engagement of Health NGOs on the subject of Operating Grants
- Highlights the prevalence and mortality figures for dementia in Europe
- Notes the variation and insufficient level of services for people with dementia

- Highlights the international prioritisation of dementia, e.g. by the World Health Organization (WHO).

Following on from these points, Alzheimer Europe's submission calls for the reintroduction of Operating Grants for health NGOs, a dedicated programme of work of Alzheimer's disease and other dementias, and support for policy platforms such as the European Group of Governmental Experts on Dementia.

The full submission can be read at:

<https://www.alzheimer-europe.org/Policy/Our-opinion-on/2021-EU4Health-Annual-Work-Programme-2022>

1 September: DataSavesLives initiative launches public survey on health data sharing

Health data, gleaned from sources such as medical records and devices, represents a valuable resource for research, healthcare and policymaking. When used safely,

health data can enable faster diagnosis, more effective medical treatments and person-centred care. Increasing the accessibility of health data can also make healthcare services more sustainable, accessible and effective, empowering patients in the management of their conditions.



However, many people have concerns and questions about health data use and sharing. DataSavesLives, a multi-stakeholder initiative aiming to increase public awareness and understanding about health data, is developing new health data resources for patient groups, to help answer these questions and concerns.

To ensure these resources meet the needs of different patient communities, DataSavesLives has launched a public survey on health data sharing. Have your say, here:

<https://datasaveslives.eu/dslsurvey>

15 September: European Commission President delivers State of the Union address



On 15 September, European Commissioner President, Ursula von der Leyen, delivered her annual “State of the Union” speech to the European Parliament, in which she reflected on developments over the past year, whilst setting out the political priorities of the EU for the year ahead.

The speech had a significant focus on health matters, particularly in relation to actions taken in response to the COVID-19 pandemic. In addition, she emphasised the importance of the implementation of the European Pillar of Social Rights.

Of particular interest was the commitment to the creation of a European Care Strategy, however, no details were provided on the exact nature of the strategy and its contents. The inclusion of this commitment in the speech follows a position paper by the European People’s Party, focused on a European Care Strategy, which was published in June 2020. You can read or watch President von der Leyen’s speech at:

https://ec.europa.eu/commission/presscorner/detail/ov/SPEECH_21_4701

You can read the EPP position paper at:

<https://www.eppgroup.eu/newsroom/publications/epp-group-position-paper-on-a-european-care-strategy>

15 September: EFPIA hosts meeting of its Patient Think Tank, addressing health data access, sharing and re-use



On 15 September, the European Federation of Pharmaceutical Industries and Associations (EFPIA) hosted a meeting of its

Patient Think Tank, its forum for an open exchange of ideas, information and perspectives between patient organisations and industry. The meeting was chaired by Nicola Bedlington of the European Patient’s Forum.

The afternoon sessions of the Patient Think Tank were focused on the DataSavesLives initiative, the European Health Data

Space and the Code of Conduct for Health Research. The DataSavesLives initiative is jointly led by EFPIA and the European Patient’s Forum (EPF), and involves a broad range of industry and patient stakeholders. Activities in 2020 and 2021 have focused on increasing public awareness of health data use and sharing, developing a range of communication tools including a new website, blog posts and twitter chats. Recently, DataSavesLives has been working on developing a toolkit for patient organisations, which will be launched during the EPF congress in October 2021.

A presentation on the European Health Data Space was delivered by Guillaume Byk (European Commission), explaining how it is being developed to facilitate better exchange and access to different types of health data. Next, Derick Mitchell of IPPOSI presented the outcomes of its Citizen’s Jury on access to health information, in which 25 citizen jurors were asked for their opinions on access to and use of health data. Key outcomes include a call for joined-up health records, access to a portal to view the information that is being shared, and protection against sharing information with employers, banks and insurers.

Closing the meeting, Brendan Barnes of EFPIA presented recent work on the EFPIA GDPR code of conduct, focused on the area of clinical trials and pharmacovigilance.

<https://www.efpia.eu/relationships-code/patient-organisations/efpia-patient-think-tank/>

20 September: Mental Health and Disability organisations welcome decision by European Court of Human Rights to reject request for its Advisory Opinion on the Oviedo Convention



The European Court of Human Rights has rejected the request by the Bioethics Committee of the Council of Europe to develop an Advisory Opinion on two provisions of the Convention on Human Rights and Biomedicine (Oviedo Convention) related to the forced treatment of persons with psychosocial disabilities.

In 2020, Mental Health Europe, Autism Europe, Inclusion Europe, the European Disability Forum and the International Disability Alliance, jointly submitted a Third-Party intervention calling for the Court to consider the international convention, reports and decisions, and to ensure its advisory opinion aligns

with those instruments. Their collective concerns were recognised and noted in the Court's opinion.

The Court rejected the request of the Committee on Bioethics (DH-BIO) based on an advisory opinion on the matter not being within its competence and referred to the need for international legal standards to be respected, including those enshrined in the Convention on the Rights of Persons with Disabilities (CRPD) as interpreted by the UN Committee on the Rights of Persons with Disabilities.

As this decision is final, Mental Health Europe and the European Disability Forum are now calling urgently for the DH-BIO Committee and Member States to immediately end the regrettable work which is continuing on the Oviedo Convention, emphasising that it "reflects an outdated, biomedically driven approach".

For several years, organisations representing people with lived experience and persons with disabilities, as well as United Nations (UN) experts and internal bodies of the Council have all strongly criticised the DH-BIO Committee's work on the Additional Protocol, and have urged for the withdrawal of the draft.

The call for the withdrawal of the draft additional protocol to the Oviedo Convention is set to be voted on by members of the DH-BIO Committee in November 2021 and later approved by the Committee of Ministers in 2022.

30 September: WHO Europe launches Pan-European Mental Health Coalition



On 30 September, the World Health Organization (WHO) Europe launched a new Pan-European Mental Health Coalition, dedicated to improving mental health across the WHO European Region in line with the priorities established by the European Programme of Work, 2020–2025. The Coalition is relevant for dementia policy, as dementia sits within the framework of Mental Health within the WHO.

The Coalition will target barriers to accessing high quality care and support by gathering national leaders, professionals, members of civil society, representatives of international organisations and experts to collaborate. Key priorities for the Coalition include transforming mental health services, as well as

promoting mental health and preventing mental ill health across the life course.

Focal areas of the collaboration include shifting mental health care away from psychiatric institutions to community-based care; scaling up the mental health workforce; protecting and preserving the mental health of children, adolescents and young people; and strengthening initiatives to promote healthy ageing among older adults.

These priorities will be supported by leadership-building and advocacy initiatives, mental health literacy programmes, and a mental health data lab that will amass data on key indicators of population mental health to better serve all European countries in providing timely, affordable access to health care.

Alzheimer Europe has been invited to be a part of the Coalition, with Executive Director, Jean Georges, attending the launch event on 30 September. More details on the Pan-European Mental Health Coalition can be found at:

<https://www.euro.who.int/en/health-topics/health-policy/european-programme-of-work/flagship-initiatives/the-pan-european-mental-health-coalition>

Pictured (Ltr): Regional Director of WHO Europe Hans Kluge, HM Queen Mathilde, EU Health Commissioner Stella Kyriakides



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POLICY WATCH

2 September: WHO publishes Global Status report on dementia

The World Health Organization (WHO) has published a "Global status report on the public health response to dementia", which provides an overview of the implementation of the [Global dementia action plan 2017-2025](#).

The report takes stock of actions by Member States, the WHO and civil society since the adoption of the global action plan in 2017, as well as highlighting barriers to its implementation (including the COVID-19 pandemic). Additionally, the report highlights areas where urgent, accelerated action is required to achieve the action plan's 2025 targets.

The report also provides updated estimates of the prevalence of dementia and global costs, based on the WHO's Global Health Estimates 2019 and the Global Burden of Disease study



2019. It also uses data submitted by 62 of WHO Member States to the Global Dementia Observatory.

The key conclusion of the report is that whilst some progress is being made towards implementing the global action plan's targets, work is urgently required in order to meet these objectives by 2025. The full report can be found at:

<https://www.who.int/publications/i/item/9789240033245>

The executive summary can be found at:

<https://apps.who.int/iris/handle/10665/344707>

6 September: G20 ministers publish declaration on health



On 5 and 6 September, a meeting of the Health Ministers of the G20 was held in Rome, Italy. During the two days, participants focused on multiple issues related to health, including examining the impact of COVID-19 on the sustainable development goals (SDG) of the 2030 Agenda, agreeing what should be done to prepared for future pandemics and identifying tools which allow countries to effectively counter the pandemic. At the conclusion of the meeting a joint declaration was published. Of particular interest for Alzheimer Europe and its members was the reference to dementia in paragraph 11 of the declaration, which stated:

"We commit to promoting a healthy and sustainable recovery which builds towards achieving and sustaining UHC by strengthening public health and focusing on primary health care, a vital front line and crucial link to the wider health system, and tackling the impact of the social, economic and environmental determinants of health. We recognise the need to adopt a renewed long-term vision embedding the achievement of UHC as the overarching goal of the health-related SDGs, including by paying attention to healthy ageing and dementia, in continuity with the G20 Health Ministers' Declaration 2019, Okayama, Japan." The fully declaration can be read at:

https://www.g20.org/wp-content/uploads/2021/09/G20_Italia_2021_Health_Declaration_final_05092021_OFFICIAL.pdf

A detailed position paper on implementing the declaration has also been published and can be read at:

https://www.salute.gov.it/imgs/C_17_pagineAree_5459_9_file.pdf

21 September: Davos Alzheimer's Collaborative announces major milestones in its fight against Alzheimer's Disease

“Alzheimer's disease recognizes no boundaries. Yet too often our response is fragmented — leaving patients, families and researchers to face this burden alone, especially in low- and middle-income countries.”



Dr. Margaret Chan
Emeritus WHO
Director General
and Founding Dean
of the Tsinghua Vanke
School of Public Health

**Davos
Alzheimer's
Collaborative**

On 21 September, the Davos Alzheimer's Collaborative (DAC) announced that it had completion of financing for its foundational phase, launching several key initiatives to advance Alzheimer's research, prevention and care.

The DAC is a multi-stakeholder, public-private partnership that was launched at the World Economic Forum meeting in January 2021, aiming to improve the diagnosis and treatment of a disease that affects more than 55 million families worldwide. Since its launch, the DAC has worked on linking, scaling and building on efforts to combat AD across healthcare systems and sectors. It is now headquartered in Switzerland, with IRS 501c3 affiliate status in the US, and has recently completed financing for its foundational phase, obtaining USD 25 million (EUR 21.5 million) commitments from a broad range of stakeholders.

To achieve its vision, the DAC has created a community of experts in six groups that cover three key focus areas: global cohort development, global clinical trial support platform, and healthcare system preparedness.

Working with the International One Hundred K+ Cohorts Consortium and other partners, the DAC has linked 12 cohorts spanning Africa, Asia and South America, part of its bid to build a global cohort of one million people who reflect the diversity of AD. To reduce the time and cost, and increase the quality of clinical trials, DAC is working with the Global Alzheimer's Platform to link a network of 90 trial sites in North America with a number of trial sites in Europe, and surveying site capacity across the world. To improve the clinical care of people with or at risk of AD, the DAC is developing partnerships with healthcare systems in different countries, to pilot the use of blood-based biomarkers and technology-enabled methods in

the clinic. To build capacity and share learnings, the DAC is hosting "learning laboratories" where flagship healthcare systems can discuss good practice with other health systems, national health ministries and policymakers, supported by technical advice from the World Health Organisation.

George Vradenburg, CEO of the DAC, said "Now is the time to act on Alzheimer's. International bodies including the WHO, G7, and G20 have all made commitments in recent years that recognize the need to act together, act globally and act now to address this health crisis. DAC is a response to these calls for action, bringing the speed and scale that has too often been lacking in previous efforts."

<https://www.davosalzheimerscollaborative.org/additional-articles/davos-alzheimers-collaborative-world-economic-forum-announce-major-milestones-in-the-global-fight-against-alzheimers-disease>



WORLD ALZHEIMER'S DAY

6 September: Federazione Alzheimer Italia releases World Alzheimer's Month campaign song "Don't forget to love me" to raise awareness and invite more people to become Dementia Friends



Federazione Alzheimer Italia inaugurated a national campaign on the occasion of the World Alzheimer's Month. "Don't forget to love me" ("Non dimenticarti di volermi bene") is the name of this campaign launched on 6 September 2021 with the aim of raising awareness and encouraging more and more people to become Dementia Friends. They hope to create a group of citizens in Italy who are aware and informed about dementia, in order to break down the stigma that surrounds the disease and create a more inclusive society for all those living with dementia and for their families.

Thanks to the organisation's meeting with Lorenzo Baglioni, a singer-songwriter from Florence, a collaboration was born that led to the idea of communicating to everyone the importance of not forgetting those with dementia. Lorenzo wrote a new song entitled "Don't forget to love me" ("Non dimenticarti di volermi bene"). He involved Paolo Ruffini, a famous Italian actor, and together they sang this song and produced a video to raise public awareness and invite as many people as possible to become Dementia Friends. The two artists chose to donate the song to Federazione Alzheimer Italia and from this gesture the campaign #Nontiscordaredivolermibene was born.

"Music is fundamental in the emotional relationship between the person with dementia and his past because it helps to awaken memories and emotions that the disease tends to keep hidden. The first time I listened to 'Non dimenticarti di volermi bene' I was very impressed by the delicacy with which it talks about the progressive loss of memory and how to find a way to continue speaking to the heart of the person with dementia. We are therefore extremely happy that these artists have decided to be by our side by becoming Dementia Friends and inviting, with their concrete example, more and more people to be so", commented Gabriella Salvini Porro, President of Federazione Alzheimer Italia.

The campaign's call to action goes beyond using the song and directs the audience to visit the website www.nontiscordare.org (meaning "don't forget") which contains information on the disease and from there it is possible to start a training course (video and text) to become Dementia Friend.

"Non dimenticarti di volermi bene" achieved great success on social media, thanks to a massive online presence and a series of influencers who joined forces, and during World Alzheimer's Day it was also brought to national television (Rai), reaching millions of people.

Find out more about the wider Dementia Friends campaign and about the song, in the upcoming "Dementia in Europe" magazine for October 2021.

14 September: Slovenian Ombudsman Peter Svetina makes World Alzheimer's Day video with Spominčica Alzheimer Slovenija



On 14 September, Slovenian Ombudsman Peter Svetina released a short video online, regarding dementia and World's

Alzheimer's Day. Spominčica Alzheimer Slovenija, who made the video with the Ombudsman, reminded us that the first "Dementia friendly Spot" in Slovenia was opened in 2017, at the offices of The Human Rights Ombudsman of the Republic of Slovenia. Link to the video (in Slovenian):

<https://youtu.be/J0MODa09F9k>



15 September: Czech Alzheimer Society re-opens mobile counselling centre during annual "Memory Week"



The Czech Alzheimer's Society re-opened its mobile counselling centre during "Memory Week", from 13 to 15 September. The mobile counselling centre was hosted by the Westfield Chodov shopping centre, and due to the growing pandemic, a stand was available in front of one of its entrances to make the visit as safe as possible. The counselling centre aimed to offer an easy way to obtain detailed information about dementia and to answer the basic questions that people have in connection with dementia, as well as pointing out possible methods for prevention.

17 September: Clinical research and theatre combine in Catalonia for World Alzheimer's Day



Can unifying clinical research and theatre work? Indeed, it seems, sometimes, it can, as demonstrated by "Pòsit", a show unveiled on 17 September in Figueres, Catalonia, by Festival Comic productions.

The idea was simple (not easy): coming up with a show that could contribute to a new method of healthcare attention and to a new way for society to view dementia care.

The story centres on a daughter preserving her life, her vitality, and love in the ever-changing world of dementia care, thanks to use of humour. A monologue performed by a talented actress playing with her thoughts, her memories, and beliefs using humour as both an emotional and a problem-focused coping strategy.

The show plays with those little pieces of paper we use to remind ourselves of things ("Post-it"), and the name of the show plays on the traces of memories that fade away but, nevertheless, remain in brains with Alzheimer's disease (in Catalan language).

This project was conceived by a geriatrician (Dr Maria del Mar Fernández-Adarve) from Figueres Hospital and a researcher (Dr Oriol Turró-Garriga) from the Girona Dementia Registry (ReDeGi). The writer, director, producers and technical staff then turned it into a reality, with support coming from Catalan Healthcare Service, Geriatric & Gerontology Catalan Society, researchers and physicians, and other social organisations.

The opening night of 17 September, scheduled to take place as close as possible to 21 September to mark World Alzheimer's Day, is the first of many showings, with many other cities, towns and centres starting to schedule the play, around the country.

The local Alzheimer's association added the "cherry on top" by opening an exhibition on the same day, celebrating portraits of older people laughing; perhaps some of them with Alzheimer's disease?

21 September: Documentary film "Sadan Hanım, An Istanbul Lady" launched in Turkey for World Alzheimer's Day



The premier of a documentary film called "Sadan Hanım: An Istanbul Lady", which was shot to draw attention to Alzheimer's disease and raise social awareness about the scientific consulting of the Turkish Alzheimer Association, was screened on 21 September, World Alzheimer's Day.

Alzheimer's disease (AD), which is becoming more and more widespread in the world, was the subject of the documentary film, which takes a look at the last five years of the life of a real person, from the time she was first diagnosed with AD, until her death.

In the film, director Göksel Gülensoy tells about Sadan Ünüvar's life in Turkey and abroad, from her childhood until her death. Famous actress Canan Ergüder, who met Sadan Ünüvar four years before she died, played the part of Sadan in the movie. Kenan Ece played Sadan's husband Ziyaeddin Ünüvar, who was a military attaché.

This is part of a six-year project with several stages, consisting of an art exhibition and a book presentation done last year,

while this year's stage includes the newly-launched film, in the "texture-drama" genre, which will continue to be shown to audiences throughout this year. The film both reveals the inspiring life of Sadan Hanım and draws attention to the importance of early diagnosis of the disease in Turkey, where it is predicted that one in three people will have AD in the near future, largely due to the longer life expectancy.

Director Göksel Gülensoy, who is also the son-in-law of Sadan Ünüvar, came up with the idea of making a documentary about seven years ago, when his wife introduced him to 8mm films shot by her father, Ziyaeddin Ünüvar. He explained that they decided to make the film based on historical videos containing images of Sadan Hanım from Kadıköy, Moda, Istanbul, Washington, Rome, Casablanca and many other places, shot 60 - 70 years ago. He said: "We had a unique video archive of approximately four-and-a-half hours due to the fact that her husband was a military attaché working in many different countries and was interested in shooting videos. At the time, when she was diagnosed with Alzheimer's, we talked to her doctor and the Turkish Alzheimer Association and with their support we filmed the stages of her disease using a scientific approach. Canan Ergüder, whom I reached out to because of her similarity to Ms Sadan and also the fact that they had met, became involved in the project since 2014. Kutsi Smart wrote the script and this movie, which we think is unique in the world, has emerged. Our film intends to draw attention to Alzheimer's, to provide guidance and motivation to people who are dealing with Alzheimer's themselves and to their relatives. I believe that our film will also convey the inspiring life of a republican woman who has lived a life to the fullest."

21 September: Alzheimer Athens runs awareness campaign and hosts fundraiser for World Alzheimer's Day



During World Alzheimer's Month September 2021, Alzheimer Athens ran an awareness campaign under the theme "Lost memories". The campaign was mainly digital, on social media and selected websites, for the whole month. More than 5,000 posters were pasted all over the Attica region and 60 giant posters were placed at bus and subway stops. According to Alzheimer Athens' data from the digital campaign, it engaged more than 120,000 people and the actual number appears to be much higher.

On 21 September, Alzheimer Athens threw a very interesting fundraising event at the garden of Byzantine and Christian Museum in Athens. During the event, the President of Greece, Katerina Sakellariopoulou gave a speech highlighting the difficulties that people with dementia and their families face in

Greece and praising Alzheimer Athens' excellent work. Dr Paraskevi Sakka, President of the Greek National Observatory for Dementia and Alzheimer's Disease and President of Alzheimer Athens, presented the newest data in the dementia field worldwide. Undersecretary of Health Zoe Rapti and Attica Regional Governor George Patoulis gave short speeches regarding the major issue of dementia in Greece. Politicians, members of the Greek scientific community, people with dementia and family caregivers also attended. Following the speeches, there was a screening of the film "The Father" featuring Oscar-winning Anthony Hopkins in the role of a man with dementia. A reception brought the evening to a close. Due to COVID-19 restrictions, the event hosted the allotted maximum of 200 people.

Informative material and the new issue of Alzheimer Athens' quarterly magazine was handed out to all the attendees, as well as an Awareness Memory Bracelet. The event attracted a lot of publicity from the media and all money raised from the event will go towards extra services for people with dementia and their families. For everyone at Alzheimer Athens, 21 September 2021 will be a day to remember!

21 September: Alzheimer Iceland holds special seminar on World Alzheimer's Day

Today, 55 million people worldwide have dementia and about 10 million new cases are diagnosed each year. There are no figures on how many people have dementia in Iceland, but it can be estimated that there are 5,000 people with dementia in Iceland and about 300 people are diagnosed under the age of 65, which is defined as early-onset dementia. The World Health Organization (WHO)

defines dementia as the seventh leading cause of death of all diseases and one of the leading causes of disability in the elderly, worldwide.

Alzheimer Iceland kicked off its autumn educational programme with a seminar on World Alzheimer's Day, 21 September. The title of the seminar was "Why Me?" Heredity - Research - Analysis. Kári Stefánsson, CEO of Icelandic Genetics, talked about heredity; Jón Snædal, geriatrician, discussed research and diagnosis; Ása Dýradóttir, cultural director, talked about art and about being a relative of a person with dementia; and musician Svavar Knútur played beautiful music at the end of the seminar.

The symposium was chaired by Ragnheiður Ríkhartsdóttir (pictured), Chairperson of Alzheimer Iceland. The seminar was



a hybrid event, with around 200 participants onsite and about 300 participants joining online.

"Contribute, spread knowledge about dementia, and help break down the prejudices that accompany diagnosis. Let us take an active part in helping people with dementia and their families to have a meaningful life where society treats all with respect, understands their problems and helps as much as possible, because with support it is possible to live a good life despite this illness" - this is the message conveyed by Alzheimer Iceland.

21 September: NGO Futura Montenegro promotes recently-opened day care centre for people with dementia, this World Alzheimer's Day



On the occasion of 21 September, World Alzheimer's Day, NGO Futura (Podgorica, Montenegro), together with the Public Institution Centers for Social Work

from Nikšić, Plužine and Šavnik, came together on the main square in Nikšić to promote a recently-opened day care centre for people with dementia. This centre opened in mid-June this year and has space for 15 users (currently, they already have 6 users).

The centre, which is located in the Nikšić settlement of Duklo, has two psychologists, a nurse, a caregiver and a driver who drives service users from their places of residence to the centre and back. It is open on weekdays from 7 am to 3 pm and the service is free. Users have access to psychological and social support and there is a counselling centre for them and their family members, who in some cases need it the most. One hot meal and refreshments during the day are provided for the centre users.

NGO Futura is partnering with the Nikšić Center for Social Work in the project which set up this day care centre for people with dementia.

As well as promoting this new centre, the Capital Podgorica showed solidarity with NGO Futura's campaign to provide support to people with dementia, by lighting the Millennium Bridge in purple, sending a message of support to people fighting the disease, as it has done in previous years.

21 September: Alzheimer Udruženje AiR organises round table meeting with key stakeholders in Bosnia for World Alzheimer's Day



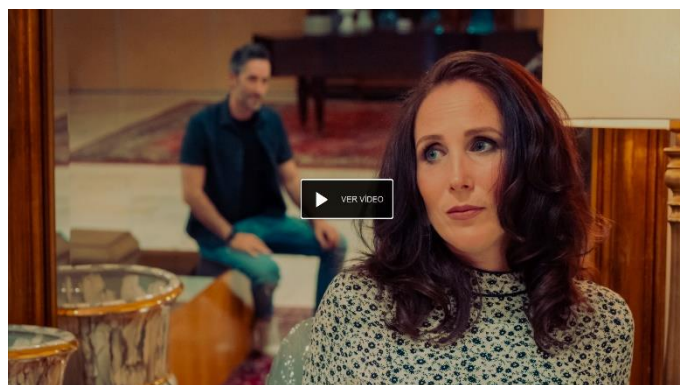
Marking World Alzheimer Day 2021, for the first time in the country's history and after nine years of activity for the association Alzheimer Udruženje AiR – Alzheimer BiH, key players from the Federation of Bosnia and Herzegovina (BH) were brought together around one table to meet and discuss "BH society in the context of dementia – how much we are an

empathic society". The goal was to bring together the relevant ministries – Ministry of Health, Ministry of Labour and Social Policy, Ministry of Justice, Ministry for Education and Ministry for Spatial Arrangement - as well as the Institute for Medical Expertise, the Public Health Institute, the Agency for Standardisation in the Medical Sector, and the Fund of Healthcare Insurance.

Alzheimer Udruženje AiR wanted to have an exchange of information about: dementia; the rights of people living with dementia and their needs; what is lacking in the health and social care systems; the deprivation of rights and position of people living with dementia in relation with other social groups; how bad the demographic picture is; and the impact of the emigration of younger people and experts on BH society in the context of older adults and people living with dementia. In that context, they discussed the need to set dementia in curriculums and the need for development of awareness among children, about people living with dementia and about creating a society that is more empathic to people living with dementia.

Participants identified many problems in all sectors and all agreed that taking action is not a choice, but that it is a necessity. In that context, they also agreed to organise an "Integrated Interdepartmental Group" with representatives from all mentioned entities, that will exchange information and create a common action for improving systems and creating a dementia-friendly community with people living with dementia, where they will not be so much included in society as they will be equal members of it.

21 September: Portuguese band the "Non Talkers" mark World Alzheimer's Day with a song and dedicate some of the proceeds to Alzheimer Portugal



On World Alzheimer's Day, the "Non Talkers", a Pop-Folk duo from Portugal comprised of Marco and Evita Brantner, released a new song called "You Don't Remember Anymore". Some of the proceeds from sales and streaming of the song will go to Alzheimer Portugal.

You can listen to the sing and watch the music video, via this link:

<https://www.publico.pt/2021/09/21/culturaipsilon/video/non-talkers-assinalam-cancao-dia-mundial-doenca-alzheimer-20210920-181042>

21 September: Spominciča Alzheimer Slovenija hosts national conference on World Alzheimer's Day



On World Alzheimer's Day, 21 September, Spominciča Alzheimer Slovenija held a national conference with international participation titled "The Situation and Challenges in the Field of Alzheimer's Disease in Slovenia." The conference participants included: Former Minister of Health Dr Božidar Voljč, Ph.D. med., President of Spominciča Štefanija L. Zlobec, Aige Rurane - a representative of the World Health Organization (WHO) in Slovenia, a representative of Alzheimer's Disease International (ADI), Mag. Nadja Čobal from the Ministry of Health, Mag. Janja Romih from the Ministry of Labor, Family, Social Affairs and Equal Opportunities, Dr Milica Gregorič Kramberger, Ph.D. med., spec. of Neurology, Prof. Dr Zvezdan Pirtošek, Ph.D. med., spec. of Neurology, Asst. Dr Polona Rus Prelog, Ph.D. med., spec. psych., Dr Mercedes Lovrenčič from the Institute of Public Health, Asst. Dr Barbara Lovrečič, member of NIJZ council and three Slovenian MEPs. Executive Director of Alzheimer Europe, Jean Georges was in attendance and delivered a presentation discussing the impact of the COVID-19 pandemic on people living with dementia.

21 September: Spominciča Alzheimer Slovenija hosts annual Memory Walk



September is Alzheimer's Disease Awareness Month and Spominciča Alzheimer Slovenija focused even more on raising awareness and educating people about dementia this year, as they do every year, to ensure that the campaign reaches as many people as possible, preferably those who need aid and

information the most. Diagnosis was the topic of this year's international campaign, as it is estimated that three in four people who have dementia have no diagnosis. Recognising the condition is crucial to maintaining the dignity of people with dementia, as well as for families, so that they can understand better how to interact with them know and that they can always turn to Spominciča for advice, said the association.

Spominciča Alzheimer Slovenija, in collaboration with Pošta Slovenije, therefore launched a campaign to increase dementia awareness "Into every Slovenian home" on 17 September 2021. Leaflets with essential information about the earliest signs of dementia and on how to communicate with persons with dementia, together with Spominciča's contact information were distributed to all homes in Slovenia and on 18 September, the association held its annual Memory Walk. The walk began at 10 a.m. in front of the National Gallery and passers-by were invited to take a stroll in support of persons with dementia, at the same time doing something positive for their health.

23 September: Panhellenic Federation of Alzheimer's Disease and Related Disorders meets to review the actions carried out in Greece for World Alzheimer's Day 2021

On 23 September 2021, the members of the Panhellenic Federation of Alzheimer's Disease and Related Disorders carried out an online meeting on the topic "Report of the Actions for the Celebration of World Alzheimer's Day".



As part of the celebration of World Alzheimer's Month, a series of events were organised by the members of the Panhellenic Federation in different cities across Greece. This is a list of the actions which took place during September, to reflect and raise awareness about Alzheimer's disease in Greece:

- 1) Screening of the films "The Father" & "Remind me" (Athens, Chania, Heraklion)
- 2) Memory Walks (Larisa, Thessaloniki)
- 3) Informative outdoor events in main squares of cities: (Chania, Larisa, Patra, Serres, Thessaloniki, Xanthi,)
- 4) Online events - lectures: (Karellio-Athens, Patra, Thessaloniki)
- 5) Caregiver's personal history: (Chania)
- 6) TED- Show about Alzheimer's disease: (Serres)
- 7) T-shirts printed & badges: (Serres)
- 8) Music events: (Serres)
- 9) Excursions: (Chalkida, Serres)
- 10) Open discussion to the general public: (Patra)
- 11) Awareness campaigns: (Patra, Serres)
- 12) Distribution of informative and awareness materials: (Athens, Chania, Larisa, Serres)
- 13) Lighting of monuments: (Patra)

- 14) Actors' participation in social messages: (Patra, Thessaloniki)
- 15) Educational games: (Chalkida, Patra, Thessaloniki)
- 16) Interviews on television and radio media: (Athens, Heraklion, Larisa, Patra, Rhodes, Thessaloniki, Serres)
- 17) Grand opening of a new day centre of dementia: (Ioannina)
- 18) Memory tests: (Karellio- Athens, Rhodes, Serres, Thessaloniki).

23 September: Alzheimer Bulgaria takes part in various events for World Alzheimer's Day



For World Alzheimer's Day, Alzheimer Bulgaria took part in various events to promote prevention, awareness-raising and advocacy.

On 23 September, the association participated in the final conference of a project called "Advocacy campaign for presenting, imposing and disseminating the concept of specialised daycare centres and other services in the community for people with Alzheimer's and other forms of dementia". Alzheimer Bulgaria partnered with Foundation Compassion Alzheimer (FCA) for this project, which was funded by the Active Citizens Fund. At the conference there were participants from Bulgarian ministries, national agencies, directors of residential care homes, a representative of the WHO and representatives of families affected by dementia.

During the meeting, Alzheimer Bulgaria and FCA shared the outcomes of the projects (a report of good practices in Europe and a concept of a daycare centre), as well as the results. Participants also discussed the policy-related problems that hinder people with dementia in benefiting from the daycare services.

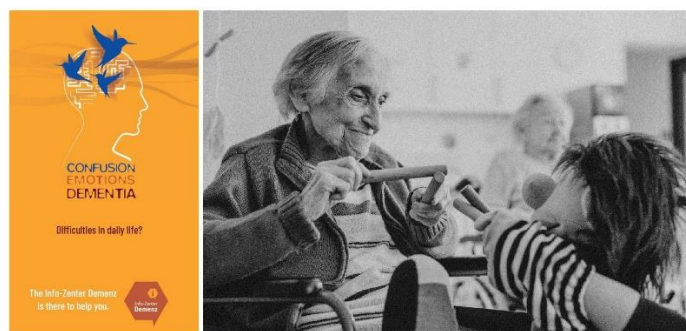
Alzheimer Bulgaria also prepared an online social media campaign, sharing the personal stories of relatives of people with dementia. Positive posts were shared with photos and personal stories and feelings, poems, and inspiring words.

The last initiative that Alzheimer Bulgaria prepared was the annual run for World Alzheimer's Day, in collaboration with "5krun". On 2 October, in one of the parks in Sofia, the association will take part in a regular Saturday 5km run, for the 3rd year in a row, in order to spread the word about preventive healthcare through sport. The slogan of the event is "Let's outrun dementia together". Each year more and more

participants take part in the run and learn more about dementia. All participants receive T-shirts stamped with the Alzheimer Bulgaria slogan.

The association continues to develop its initiatives, in order to raise awareness and make the Bulgarian population more engaged with the problems of people affected by dementia. World Alzheimer's Day is a great opportunity to popularise the idea of a dementia-friendly society.

23 September: Info-Zenter Demenz organises conference on "Music for a better quality of life with dementia"



On 23 September, marking the occasion of World Alzheimer's Day, the Info-Zenter Demenz, the national information centre on dementia in Luxembourg, organised a conference on the topic "Music for a better quality of life with dementia", with Prof. Dr Theo Hartogh. The Info-Zenter Demenz sent us this report about the event.

One of the symptoms of dementia is increasing memory impairment. New information can no longer be stored and remembered well. Memory loss starts with recent events and, as the disease evolves, gradually progresses to memories from earlier years, such as experiences from youth and young adulthood, which are the last to disappear. Researchers have found, however, that memories of music are partially unaffected by this forgetting. Dementia actually seems to spare the long-term memory for music.

The power of music is huge, whether it is being listened to or whether people are actively playing music themselves. Music has many positive effects - for everyone, not only for people with dementia.

Music is generally considered the ultimate way to reach people with dementia. It awakens memories and makes it possible to express feelings. Even where language is limited or no longer available, communication is possible thanks to music.

For many people affected by dementia, music is a bridge to their own past, which evokes emotional memories. Music strengthens their identity: suddenly they realise "this is me", "I feel like myself", "I have a connection to this song". People affected by dementia can suddenly "wake up". Only music works this way.

Another aspect is participation. Making music together is a positive activity for people with dementia. It promotes the exchange with others, sociability and self-confidence.

For people with dementia, music seems to be literally unforgettable. When playing music with them it becomes clear that human beings are more than just their brain functions, their minds. Music definitely contributes to a better quality of life for people living with dementia.

The Info-Zenter Demenz is the national information and counselling centre in Luxembourg for all questions related to the topic. The team is available Monday to Saturday and can be reached by phone (+352 26 47 00) or email (mail@i-zd.lu).

25 September: Association Luxembourg Alzheimer hosts its 20th annual Memory Walk



On 25 September 2021, the Association Luxembourg Alzheimer (ALA) organised its 20th Memory Walk on the Place de l'Europe in Luxembourg-Kirchberg.

From 11:00 am to 5:00 pm, visitors were able to learn about ALA's services and about Alzheimer's disease and other forms of dementia, from information booths. In this relaxed atmosphere, they had the opportunity to meet great people and take part in many discussions.

Alongside food and information stands, various activities were offered, including a concert by Luxembourg singer Serge Tonnar. The Memory Walk meanwhile allowed participants to show their solidarity with people with dementia. This walk, accompanied by a tour guide, took participants to Fort Thüngen where they could enjoy a breathtaking view of the old town and the fortress.

The theme for this year's Memory Walk was "Dementia, Pay Attention". When dementia is diagnosed, we tend to see only the disease and no longer the person. But people with dementia still have capacities and they want to participate in everyday life. In order to integrate them, you need to be attentive: there may be a need to speak more slowly, to seek out contact, to choose simpler words and to be patient. People with dementia and their loved ones need to feel that they are part of society despite the illness.

The Minister of Families, Corinne Cahen (pictured, centre), also showed her support by gracing the Luxembourg Memory Walk with her presence. After a virtual edition of this event in 2020,

the ALA was delighted to be able to celebrate this 20th anniversary face-to-face with a 'real' audience.

28 September: Alzheimer Larissa uses World Alzheimer's Month to make "A purple reconnection"

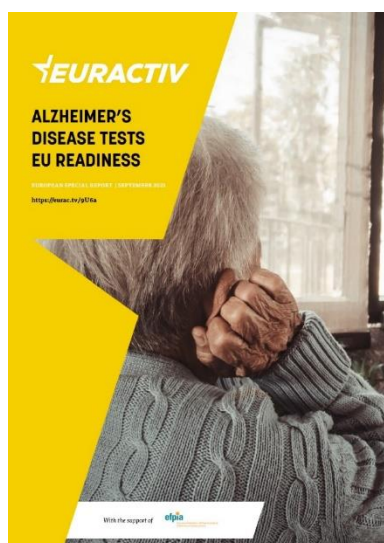


Despite not being directly affected by COVID-19, the activities of Alzheimer Larissa were frozen due to the strict preventive measures. Since March 2020, no activities have been allowed in the Association's premises. Communication has been limited to phone calls to members, and only a few group activities took place. Alzheimer Larissa therefore aimed for September 2021 to be an opportunity for reconnection and to demonstrate COVID-19 safe conduct in the fight against dementia.

So far, the Association has organised 17 open-air meetings in various neighbourhoods within Larissa, hosting small groups of people with a valid COVID-19 certificate. At each meeting, the 10 signs of dementia were presented, questions were addressed and the need for motivation and socialisation, regardless of occasional mobility restrictions, was underscored. Participants were given a purple balloon, a purple face mask and an informative leaflet.

World Alzheimer's Day was marked by the 3rd "Mnemosyne" Memory Walk through Larissa city centre, along the purple lit "Sculptured river" fountains, ending at city hill. The event was supported by the Municipality of Larissa, and the Laboratory of Social Nursing, University of Thessaly. Many officials showed up for the walk, which was led by the Larissa Philharmonic Orchestra, playing parade tunes and paying tribute to the composer Mikis Theodorakis at regular stops. The legendary syrtaki (dance) of Zorba the Greek lifted the parade's spirits and attracted onlookers sitting at nearby cafés. Some dared to dance and some joined the line to walk. On 23 September, the Association visited the Philharmonic's premises at Papa's Mill, to highlight the cognitive benefits of music. People living with dementia showed their support to the musicians that had to rehearse separately for a very long time; they offered rosemary plants, known as the "memory elixir", and advised them to take care of the plants as a reminder of lifelong mental and cognitive care.

28 September: Alzheimer Europe contributes to World Alzheimer's Month report by EURACTIV



Alzheimer Europe Executive Director Jean Georges has contributed to a special report for World Alzheimer's Month by EURACTIV, called "Alzheimer's Disease Tests EU Readiness". The report includes six articles, the first of which Mr Georges contributed to and which looks at the importance of ensuring Alzheimer's disease and dementia are European priorities.

This article, called "EU unprepared to tackle

Alzheimer's disease as new treatments progress", can be read in English, here:

<https://www.euractiv.com/section/health-consumers/news/eu-unprepared-to-tackle-alzheimers-disease-as-new-treatments-progress/>

The special World Alzheimer's Month report also includes articles on:

"More research, better diagnosis: what France can improve in the fight against Alzheimer"

"Germany urged to boost early testing to tackle Alzheimer's disease"

"More data and awareness needed to fight Alzheimer's disease, Czech experts say"

"Early detection of Alzheimer's a wish, not yet a reality in Slovenia"

"Italy delays €15 million 'dementia fund' while disease costs billions"

The publication, which is also available in French, German, Czech, Slovenian, and Italian, received support from the European Federation of Pharmaceutical Industries and Associations (EFPIA). You can see all versions of the full report, as well as the individual online articles, via this link:

[Alzheimer's disease tests EU readiness](#)

MEMBERS NEWS

23 September: Alzheimer Iceland aims to open a new service centre in 2021



Alzheimer Iceland was founded in 1985 and works, among other things, to promote the interests of people with dementia with support,

counselling and education. Its role is also to increase the knowledge of the general public, relatives, professionals and the government about the tasks that a person with dementia and relatives have to deal with. Membership in the association is open to all who are interested in and concerned about the issue of dementia.

Alzheimer Iceland's long-held dream of establishing a service centre for people with dementia is coming true. At the end of the year (2021), it is estimated that the association's service centre will open on the 3rd floor of the "Quality of Life Center" in Hafnarfjörður. The service centre is intended for individuals with mild symptoms of dementia and their relatives, and is intended as the first port-of-call after diagnosis, before specialised day training. The activities are intended to meet the needs of this group, with individual emphasis, and to maintain physical, mental and social aspects as well as to promote independence and increased activity.

The facility is about 340m² and the association will also move its offices, education and support groups to these premises. The service centre's activities are based on the ideology of occupational therapy, where the emphasis is on working with the individual's strengths, creating conditions for them to be able to pursue their occupation and strengthen their social connections. The service centre will have various professionals, such as an occupational therapist, a psychologist, assistants, as well as volunteers. Alzheimer Iceland also intends to recruit a social worker, a speech pathologist, a physiotherapist and other professionals to join them, so that the range of services is as diverse as possible.

You can follow their progress regarding the opening of this new service centre, scheduled for the end of 2021, via:

www.alzheimer.is

23 September: Alzheimer Switzerland and Swiss Memory Clinics intensify their collaboration



Alzheimer Suisse (Alzheimer Switzerland) and Swiss Memory Clinics have decided to intensify their collaboration. The aim is to strengthen health care for people with dementia and improve the quality of life for those who are ill and those who are close to them.

Around 145,000 people currently have Alzheimer's or some other form of dementia in Switzerland. There are no medicines that can cure these conditions yet, and age is considered the main risk factor. Considering the demographic evolution, it is estimated that 315,000 people could be confronted with this type of diagnosis by 2050. Dementia also affects the entourage which gradually takes on more administrative, support or care tasks.

In order to improve the support for people with dementia and their families, Alzheimer Switzerland and Swiss Memory Clinics

signed a cooperation agreement on 8 September 2021, allowing them to strengthen their existing collaboration and their common commitment in terms of policy, health and public relations.

To promote access to quality care throughout Switzerland, it is necessary to establish, in terms of pricing and social policy, a framework that meets the needs of people with dementia and those around them who participate in the accompaniment. These needs include a sufficient number of well-trained health workers, whose services are adequately funded by compulsory health insurance. Optimizing care information, advice and support play a central role for patients and their loved ones. This is why Alzheimer Switzerland and Swiss Memory Clinics aspire to better networking of their existing and new offers.

People with dementia and their loved ones want to feel included and accepted in society. It is therefore essential that the population be informed and made aware of the disease. To this end, Alzheimer Switzerland and Swiss Memory Clinics will also step up their public relations work.

24 September: The Alzheimer Society of Ireland launches its Pre-Budget Submission



On 24 September 2021, The Alzheimer Society of Ireland launched its Pre-Budget Submission, "Dementia; The Continuing Crisis". Over 50 members of the Irish Parliament heard

powerful testimony from people living with dementia and those who care for and support them.

The organisation engaged in a public consultation with 338 people, evaluated dementia services and undertook extensive research on the impact of COVID-19 on people affected by dementia, to prepare the submission. This evidence, combined with current research and personal stories, was presented to politicians in an event chaired by Helena Quaid, Chair of the Dementia Carers Campaign Network.

The Alzheimer Society of Ireland CEO Pat McLoughlin welcomed the continuing engagement with the Department of Health, in particular Minister for Older People and Mental Health Mary Butler who has shown a huge interest in the lived experience of dementia. Pat McLoughlin presented the current funding requests with a strong focus on capital investment in dementia services and the urgent need in communities throughout Ireland.

Pictured: Pat McLoughlin, Jacinta Dixon (Irish Dementia Working Group) and Paddy Crosbie (DCCN) at Leinster House.



SCIENCE WATCH

25 August: Cortexyme presents new analyses of its GAIN Phase II/III trial for AD

On 25 August, Cortexyme, a clinical-stage pharmaceutical company developing novel treatments for altering the course of Alzheimer's disease (AD) and other neurodegenerative disorders, presented new data of its GAIN Phase II/III trial at the virtual Annual Biomarkers for Alzheimer's Disease Summit.

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 Alzheimer's disease (AD).

COR388 is an oral small-molecule inhibitor of gingipains, which are proteins that are released by bacteria species (*p.gingivalis*) that commonly reside in the mouth. Previous studies have shown that people with bacterial gum disease have a higher risk of developing AD and that people with AD have elevated levels of gingipain in their brains.

The GAIN trial has been enrolling since the second quarter of 2019 at sites in the US and Europe and recruited 643 participants. Top-line results are expected by mid-November 2021.

Analyses presented showed that approximately 84% of the participants had high levels of well-established AD biomarkers, such as amyloid-beta and tau, in their cerebrospinal fluid (CSF). All participants analysed at the beginning of the study who had CSF available data (472 participants), were positive for antibodies against *p.gingivalis*, suggesting an infection by *p.gingivalis* in the central nervous system.

In addition, the company recently announced the initiation of a Phase I trial with its new drug candidate COR588. 64 healthy participants will receive either placebo or COR588. COR588 is a second-generation small-molecule lysine-gingipain inhibitor differentiated from COR388 by its improved pharmacokinetic properties and anticipated once daily oral administration.

<https://ir.cortexyme.com/news-and-events/presentations>

31 August: AC Immune announces top-line results from LAURIET, their Phase 2 trial of semorinemab

On 31 August, AC Immune announced the first top-line results from LAURIET, their Phase 2 trial of semorinemab, showing an improvement in cognitive decline but no effect on functional decline for participants with mild-to-moderate Alzheimer's disease.



Semorinemab is a monoclonal anti-tau antibody that was co-developed by AC Immune and Genentech, part of the Roche group. LAURIET is a placebo-controlled Phase 2 study of semorinemab that started recruiting participants with mild-to-moderate Alzheimer's disease (AD) in January 2019, with study centres based in the US, France, Poland and Spain. Semorinemab is delivered as an intravenous infusion every 2-4 weeks, and the two primary endpoints in LAURIET are changes in cognitive function as measured by ADAS-Cog11 (Alzheimer's Disease Assessment Scale, Cognitive Subscale, 11-item version), and changes in activities of daily living as measured by ADCS-ADL (Alzheimer's Disease Cooperative Study - Activities of Daily Living).

In their announcement, AC Immune stated that participants with mild-moderate AD who received semorinemab during the year-long, double-blind period of the trial had a significant reduction in cognitive decline of 43.6% compared to participants receiving the placebo. There was no effect on the co-primary endpoint of functional decline, or on the secondary efficacy endpoints on the MMSE (Mini-Mental State Examination) or CDR-SB scales (Clinical Dementia Rating - Sum of Boxes).

Further analyses and top-line data will be presented at the CTAD conference in November. The open-label extension part of the LAURIET study is still ongoing.

<https://www.globenewswire.com/news-release/2021/08/31/2289102/0/en/AC-Immune-Announces-First-Positive-Cognitive-Results-for-a-Tau-Targeting-Monoclonal-Antibody-in-Alzheimer-s-Disease.html>

1 September: New research in JAMA Neurology explores the impact of sleep duration on amyloid accumulation and cognitive performance



A detailed analysis of data from the A4 study has shown that self-reported sleep duration in adults without cognitive impairment may influence amyloid accumulation and

performance in cognitive tests.

The Anti-Amyloid Treatment in Asymptomatic Alzheimer's Disease (A4) study is currently being conducted across 67 sites in the US, Canada, Australia and Japan, testing whether a new antibody treatment, solanezumab, can slow memory loss caused by Alzheimer's disease (AD) in cognitively normal individuals aged between 65 and 85. In their JAMA Neurology article, a team of researchers led by Dr Elizabeth Mormino at the Stanford University School of Medicine performed a cross-sectional analysis of data from 4417 A4 participants, aiming to understand whether self-reported sleep duration might influence amyloid accumulation in the brain, and performance in tests of cognitive and executive function.

When they compared the levels of amyloid accumulation in the brain (as measured by amyloid-PET brain scans) in people

reporting different amounts of nightly sleep, they found that people who reported sleeping 6h or less ("short sleep") had higher levels of brain amyloid, and reduced performance in memory domains of cognitive tests. On the other hand, people who reported sleeping 9h or more ("long sleep") had lower performance on a test of executive function, which controls behaviour, attention and task management. The researchers also found associations between lifestyle factors such as alcohol consumption, depressive symptoms and body mass index and self-reported sleep duration.

Together, these results suggest that there might be a "sweet spot" for sleep, with both short and long sleep durations being associated with worse outcomes for older adults.

<https://jamanetwork.com/journals/jamaneurology/fullarticle/2783664?resultClick=1>

2 September: Gabriel de Erausquin discusses impact of COVID-19 on long-term cognitive dysfunction and acceleration of AD symptoms

TouchNEUROLOGY

interviewed Gabriel de Erausquin (UT Health San Antonio, Texas, USA), during the 2021 edition of the Alzheimer's Association International Conference (AAIC21). Their discussion was around the Alzheimer's Association-led Global SARS-CoV-2 Consortium and the links between long-term cognitive dysfunction, acceleration of Alzheimer's disease (AD) symptoms and COVID-19. The interview was published online on 2 September:

[Gabriel A de Erausquin, AAIC 2021: The Alzheimer's Association-led Global SARS-CoV-2 Consortium - touchNEUROLOGY](#)



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<https://touchneurology.com/>

7 September: Alpha Cognition receives FDA approval to proceed with the clinical development of Alpha-1062 for AD

On 7 September, Alpha Cognition, a bio-pharmaceutical company committed to developing novel therapies for neurodegenerative diseases such as Alzheimer's disease (AD) and amyotrophic lateral sclerosis (ALS), announced that the US Food and Drug Administration (FDA) has accepted its

investigational new drug application for its lead candidate, Alpha-1062, to proceed with the pivotal clinical phase of the development program for mild to moderate AD. The company plans to start enrolment in Q3 2021.

Alpha-1062 is being developed as a new generation of acetylcholine esterase inhibitor for the treatment of dementia of the Alzheimer's type.

<https://www.alphacognition.com/investors/news/alpha-cognition-announces-the-acceptance-of-its-us-fda-investigational-new-drug-application-ind-for-lead-candidate-alpha-1062-for-mild-to-moderate-alzheimers-disease>

13 September: New study by Women's Brain Project finds clinical trials in Alzheimer's disease enrol less women than expected and less than in the past



The proportion of women involved in trials of experimental drugs for Alzheimer's disease (AD) is significantly lower than the proportion of females in the general population affected by AD, as well as being lower than the proportion of women included in older trials for already approved drugs,

according to a new study published by Women's Brain Project (WBP) in the Journal of the American Medical Association (JAMA) Network Open.

Most publications did not report treatment outcomes by sex and the WBP study launches a call to action for the development and implementation of strategies to ensure optimal representation of both sexes in clinical trials and publication of sex-stratified results. In the new publication "Proportion of women and reporting of outcomes by sex in clinical trials for Alzheimer Disease: A systematic review and meta-analysis," a pool of researchers led by WBP has conducted a systematic review and meta-analysis of 56 randomised clinical trials for AD, with the aim of describing the current sex proportion and consideration of sex differences in clinical trials.

The randomised clinical trials examined included a total of 39,575 participants, 59% of those being women. The proportion of women differed across studies, though; in fact, the randomised clinical trials for AD which led to drug approval had a proportion of 67.3% female in contrast to 57.9% for experimental drugs.

While the overall proportion of women in experimental trials is still higher than that of men, this is significantly lower than the female prevalence of the disease in the real-world population with AD in both Europe and the US (between 62 and 68%), the paper showed. Read more: bit.ly/391Dfwf

20 September: Gates Notes post highlights the need for early diagnostics for Alzheimer's disease and dementia

On 20 September, Bill Gates published a Gates Notes post on recent progress in Alzheimer's disease (AD) research, highlighting how initiatives such as the AD Diagnostics Accelerator can support the development of new ways to diagnose AD during the early stages of disease.



Alzheimer's disease affects one in nine adults aged 65 or over, with a long presymptomatic phase that can last years or even decades. However, many people only receive a diagnosis when they already have symptoms of dementia. In his blog post, Bill Gates underlines the importance of early diagnosis to identify individuals who may benefit from clinical trials of novel treatments.

Cheap, minimally-invasive diagnostics could provide a way to diagnose people early, before their AD symptoms become more severe. The AD Diagnostics Accelerator was launched by the Alzheimer's Drug Discovery Foundation in 2018, aiming to support the development of new solutions for the early diagnosis problem. Since then, a number of additional philanthropic funders have joined the AD Diagnostics Accelerator, bringing additional resources and expertise to the initiative.

The Gates Notes blog post highlights some of the research that is currently being funded by the AD Diagnostics Accelerator, such as a new blood test being developed at the University of Gothenburg in partnership with Roche, and eye scans that spot tiny irregularities that may herald the development of AD. So far, 25 research projects have been funded through the Accelerator, encompassing diagnostics that use digital, wearable, blood and imaging scan data to identify early signs of AD that may otherwise go undetected. The blog post and accompanying video can be found here:

<https://www.gatesnotes.com/Health/New-breakthroughs-in-Alzheimers-diagnostics>

21 September: TouchNEUROLOGY discusses the approval of aducanumab for Alzheimer's disease, with two experts in the field



TouchNEUROLOGY was recently joined by Dr Marwan Sabbagh (Cleveland Clinic Lerner College of Medicine, Las

Vegas, NV, USA), to discuss the approval of aducanumab for Alzheimer's disease (AD). Aducanumab was granted accelerated approval on 7 June 2021, by the U.S. Food and Drug Administration (FDA).

Areas covered in this short interview video: include the clinical trial programme leading to the approval; the ongoing EMBARK study; why aducanumab has succeeded when so many other drugs have failed late stage clinical trials; some of the challenges and opportunities presented by this approval; and looking at what questions remain unanswered and what future studies are planned.

Dr Sabbagh is a board-certified Geriatric Neurologist and is the director of translational research at Cleveland Clinic Lou Ruvo Center for Brain Health.

The interview is available to view, here: [Marwan Sabbagh: Approval of Aducanumab for Alzheimer's Disease - touchNEUROLOGY](#) touchNEUROLOGY also spoke with Professor James Galvin (University of Miami Miller School of Medicine, Florida, USA) about the approval of aducanumab for the treatment of AD, and asked him what this recent accelerated approval might mean for future potential treatments.

Prof. Galvin is a Professor of Neurology and is the Founder and Director of the Comprehensive Center for Brain Health at the University of Miami Miller School of Medicine. His interview was published online on 21 September 2021:

[James E Galvin, AAIC 2021: Aducanumab for the Treatment of Alzheimer's Disease - touchNEUROLOGY](#)

DEMENTIA IN SOCIETY

21 September: Bob & Diane Fund invites applications for its USD 5,000 grant for photography projects related to Alzheimer's or dementia



Submissions for the Bob & Diane fund's annual USD 5,000 (EUR 4,300) grant are open. The fund is accepting photography projects (stills only) related to Alzheimer's or dementia. The deadline is 31 October 2021 and the Fund will announce its winner in November.

The grant is open to photographers worldwide.

Please apply here: www.bobanddianefund.org

To find out more about the Fund and its Visual Storytelling Grant, you can read our Dementia in Europe magazine article interviewing Founder and Executive Director, Gina Martin, and showcasing the 2020 winning project: <https://bit.ly/BobDianeFund>

NEW PUBLICATIONS & RESOURCES

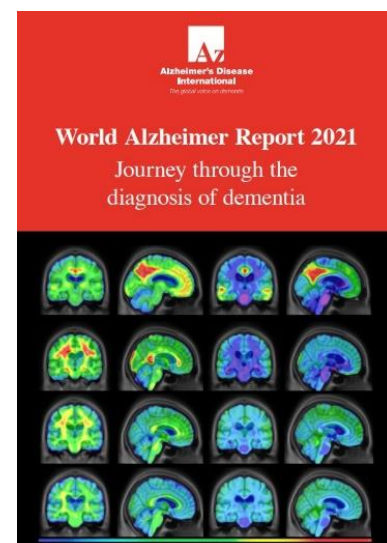
21 September: Alzheimer's Disease International publishes World Alzheimer Report 2021

On World Alzheimer's Day, 21 September, Alzheimer's Disease International published its World Alzheimer Report 2021. The topic for this year's report shines a light on the "Journey through the diagnosis of dementia".

The report contains over 50 essays from experts around the world, which are supported by findings from 3 global surveys, including 3,431 responses from clinicians, people living with dementia and carers and national Alzheimer and dementia associations.

The report also includes personal testimonies from people living with dementia and carers on their experiences of the diagnosis process, which have collectively formed recommendations for how systems can be improved. Read the report:

[World Alzheimer Report 2021 | Alzheimer's Disease International \(ADI\) \(alzint.org\)](#)



JOB OPPORTUNITIES

24 September: MIRIAD project has an open position for an Early Career Researcher (ESR)

The MIRIAD (Multi-omics Interdisciplinary Research Integration to Address Dementia diagnosis) project has an open position for an Early Career Researcher (ESR).

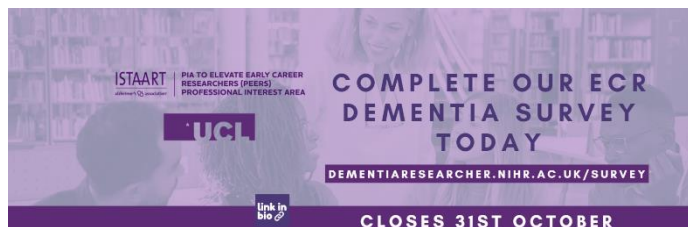
Position: PAR 2021/1189: <https://www.gu.se/om-universitetet/jobba-hos-oss/lediga-anstallningar>

Interested candidates can also get in touch via email: miriade@vumc.nl



EDUCATION

12 September: ISTAART launches global survey inviting early career dementia researchers to complete a survey exploring the challenges they face



Early career researchers face many challenges – from difficulties finding, funding, publishing and career progression to problems with research culture and individual forms of prejudice.

University College London and the Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment (ISTAART) Professional Interest Area to Elevate Early Career Researchers (PEERS) is working to better understand the challenges and what helps.

To inform the work, they are undertaking a survey aimed at early career dementia researchers, or those who have previously been an early career dementia researcher but have left the field. The survey asks questions about you and your research, how you are supported in your field, for your perceptions on how opportunities and support could be improved, and about the research culture that you work within (Please note, this does include some sensitive questions relating to gender / ethnicity, and asks some questions which may be upsetting e.g. Your experiences of certain types of bullying or prejudice etc.).

The results of this survey will be published to help institutions and research funders to understand the thoughts of early career dementia researchers. The results will also be used to guide the development of future ISTAART programmes and resources, and will be shared with the World Dementia Council. The closing date for this survey is 31 October 2021.

[Complete the Survey](#)



Contact Alzheimer Europe:

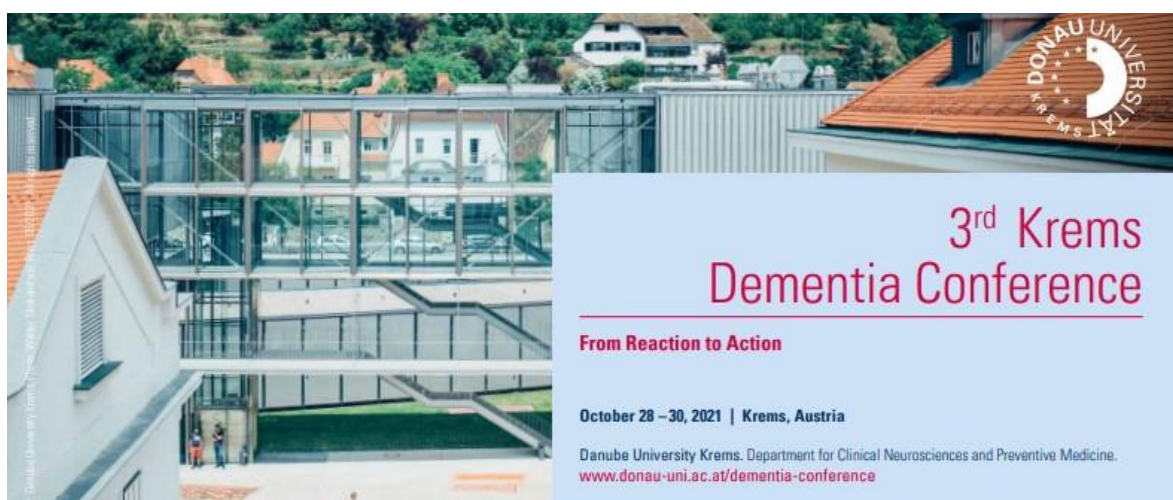
Alzheimer Europe: 14, rue Dicks (L-1417), Luxembourg; info@alzheimer-europe.org; www.alzheimer-europe.org

Alzheimer Europe Board:

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

Alzheimer Europe staff:

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



AE CALENDAR 2021

Date	Meeting	AE representative
4 October	EU4Health NGO coordination call	Jean and Owen
5 October	Fourth RADAR-AD Consortium Webinar on "Public Involvement"	Ana, Dianne
5 October	I~HD Virtual Plenary: scaling up the availability and reusability of big health data	Ange
6 October	EF – VCD and Conferences IO demo	Gwladys, Chris, Jean, Cindy
7 October	IMI online event on patient involvement	Dianne
7 October	EDF ENGO meeting	Owen
7-8 October	LETHE General Assembly	Ana and Chris
7-8 October	AMYPAD General Assembly Meeting	Cindy and Jean
11 October	BBMRI-ERIC Stakeholder Forum	Ange
13 October	EWGPWG Meeting	Dianne, Ana, Ange
14 October	Neuronet Working Group on data sharing	Cindy, Ange
19 October	Alzheimer's Association Academy on Dementia-friendly communities	AE Members and staff
19 October	ESCP International Virtual Symposium, "Clinical pharmacy, working collaboratively in mental health care"	Dianne
21 October	Neuronet SCB Meeting	Jean, Chris, Ange and Cindy
21 October	WDC global dialogue on non-amyloid targets for disease modification	Cindy
21 October	Workshop on communication & dissemination MIRIAD	Chris
21 October	EU-FINGERS informational meeting	Ana, Dianne
21 October	LOE catch up meeting 31AEC	Gwladys, Jean
24-27 October	ICCA Congress	Gwladys
25-26 October	Roche Global AD Patient Advisory Group	Jean
26 October	WDC global dialogue on psychosocial research	Dianne
28 October	DataSavesLives session at the EPF Congress	Ange

CONFERENCES 2021

Date	Meeting	Format/ Place
3-7 October	XXV World Congress of Neurology (WCN 2021), https://2021.wcn-neurology.com/	Virtual congress
6-7 October	Patient Engagement Open Forum 2021, https://patientengagementopenforum.org/	Virtual
6-8 October	Healthcare Clowning International Meeting, https://www.hcim2021.com/	The Hague, Netherlands
26-29 October	Digital transformation of healthcare: the added value of patient partnerships (EPF), https://epfcongress.eu/	Virtual
28-30 October	3 rd Krems Dementia Conference, 3 rd Krems Dementia Conference - Donau-Universität Krems	Krems, Austria
29 Nov-1 December	31 st Alzheimer Europe Conference, https://www.alzheimer-europe.org/Conferences/2021-Online	Virtual
15-20 March 2022	International Conference on Alzheimer's and Parkinson's Diseases and related neurological disorders (AD/PD 2022), https://adpd.kenes.com/	Barcelona, Spain
5-7 December 2022	32 nd Alzheimer Europe Conference, https://www.alzheimer-europe.org/Conferences	Bucharest, Romania



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31st Alzheimer Europe Conference

Resilience in dementia: Moving beyond the COVID-19 pandemic

Virtual Conference

29 November - 1 December 2021

www.alzheimer-europe.org/conferences

 #31AEC

