We held a number of online meetings during February, including a European Parliament Workshop, chaired by Deirdre Clune, MEP (Ireland) Vice-Chairperson of the European Alzheimer’s Alliance (EAA). Our European Parliament lunch debates and workshops bring together national and European policymakers, with representatives from national Alzheimer’s associations, pharmaceutical companies, as well as researchers and members of the European Working Group of People with Dementia. By hosting and attending these events, MEPs in the EAA are helping to make dementia a European priority and we are very grateful to them for their invaluable support.

Our latest workshop examined the use of digital data for dementia research and innovation. It featured presentations from speakers working in the field of dementia, at Alzheimer Europe and for the European Commission. During this event, we were delighted to launch a new e-publication: a report on data sharing, funded by Gates Ventures. Unfortunately, research on dementia has historically received less funding than other disease areas, so there is an urgent need to maximise the utility of data from dementia research. Data sharing represents an important step towards meeting this need, and could help increase our understanding of dementia. However, there is still much to do to improve data sharing in dementia research. Taking this as a starting point, our report reviews recent changes in EU research policy and sets out a number of recommendations to improve data sharing.

At another online meeting, our public affairs meeting with national member associations, we launched our latest e-magazine. The 35th edition of Dementia in Europe magazine, features interviews with the Norwegian Health Minister Bent Høie and with French Health Minister Olivier Véran about their respective countries’ strategies on dementia and neurodegenerative diseases. It also provides updates on various EU-funded dementia research projects and on different aspects of the impact of COVID-19, on people living with dementia, on human rights and on research. I invite you to download our new publications, via the Alzheimer Europe website.

In Portugal, the Government has revealed its new recovery and resilience plan, and our friends at Alzheimer Portugal were delighted to see that funding has been included to help implement the country’s Dementia Health Regional Plans. February has also seen some interesting developments on the research front, with the FDA deciding to extend the review period for Biogen’s Alzheimer’s disease drug aducanumab until 7 June 2021. Also on the research front, we are pleased to be involved in the new EU-funded project, Al-Mind project, which will focus on artificial intelligence for dementia prevention.

I hope you enjoy our newsletter!

Jean Georges
Executive Director
COVID-19 SITUATION

9 February: Study of >61 million US electronic health records reveals that people with dementia are at significantly increased risk of COVID-19

On 9 February, a team of researchers led by Prof. Rong Xu of Case Western Reserve University (Cleveland, USA) published a study in Alzheimer’s & Dementia, evaluating the risk of COVID-19 in people with dementia and their unaffected peers. The results of this study indicate that people with dementia are, on average, twice as likely to get COVID-19 compared to their unaffected peers.

This case-control study employed the electronic health records of 61.9 million adults in the US, aiming to assess how race and other demographic factors such as age and sex affect the risk of COVID-19 in people with different types of dementia. Over 1 million adults in the population analysed had a dementia diagnosis, including over 350,000 with Alzheimer’s disease and 117,000 with vascular dementia. Focusing on the risk of COVID-19 in people with different types of dementia, the highest risk was observed in people with vascular dementia, who were over 3 times as likely to have COVID-19 compared to peers without dementia (an average Odds Ratio of 3.17). In comparison, the Odds Ratio for COVID-19 risk in people with Alzheimer’s disease was 1.86, indicating that their risk of COVID-19 was similar to the broader dementia population. Overall, the researchers estimated that people with dementia had double the risk of COVID-19, corresponding to an average Odds Ratio of 2.00.

Focusing on race and ethnicity, Black people with dementia were almost three times more likely to be affected by COVID-19 compared to their White peers, even after adjusting for age, sex and other COVID-19 risk factors. COVID-19 hospitalisation rates were also much higher for Black people with dementia, with over 73% requiring hospitalisation compared to 53.8% of white people with dementia. A higher proportion of Black people with dementia died from COVID-19 (23.08%) compared to their White peers (19.23% dying from COVID-19). Overall, mortality risk from COVID-19 was substantially higher for people with dementia (20.99% mortality rate) compared to people unaffected by dementia (4.81%).

Together, these results consistently identify a significantly increased risk of COVID-19 in people with dementia, especially those who are Black. This highlights the need to protect people with dementia during the COVID-19 pandemic, to ensure their risk of COVID-19 morbidity and mortality is minimised.


23 February: The Alzheimer Society of Ireland calls on Irish Government to designate family carers of people with dementia as priority group for COVID-19 vaccination

The Alzheimer Society of Ireland (ASI) is actively highlighting and lobbying the Irish Government about the importance of family carers of people with dementia being included as a priority group in the roll out of the COVID-19 vaccination programme. Unlike other European countries, where family carers are being prioritised, they are not recognised as an at-risk or high-priority group or category in Ireland’s COVID-19 vaccination plan.

There is a real urgency and importance to this issue and The ASI is concerned by the lack of any mention of family carers as a specific group, and by the vaccination schedule, given their very real vulnerabilities in relation to COVID-19.

Currently, family carers are not only shielding their loved ones from COVID-19, but are living in fear of what would happen if they themselves got sick and were unable to perform their...
The Alzheimer Europe Board met online on 22 February 2021. The meeting agenda included various financial and operational matters, including details concerning the 31st Alzheimer Europe Conference and membership-related decisions. The Board approved the 2020 accounts and also discussed the progress of the organisation’s 2021 Work Plan. The next Board meeting will take place online, on 7 April.

23 February: Alzheimer Europe hosts online Company Round Table meeting

On 23 February, Alzheimer Europe hosted an online Company Round Table meeting, attended by representatives from Biogen, Eisai, EFPIA, Grifols, Nutricia, Roche and TauRx. Also in attendance were: 7 members of the Alzheimer Europe staff, including Executive Director Jean Georges; 19 representatives of Alzheimer Europe member organisations from 16 different countries; and 1 representative of the European Working Group of People with Dementia (EWGPWD).

Project Officer Cindy Birck gave an overview of recent developments with regards our Clinical Trials Watch database. Policy Officer Owen Miller shared some recent policy developments at the WHO and EU levels on WHO Non-Communicable disease activities, WHO Global Action Plan on Dementia EU4Health Programme and Horizon Europe. Audrey Wolf and Thomas Allvin, two representatives from EFPIA, then presented the EU Pharmaceutical Strategy with general principles and opportunities for Alzheimer’s medicines. Finally, Jean Georges updated sponsors and other delegates on Alzheimer Europe’s activities. We would like to thank our

ALZHEIMER EUROPE

10 February: Alzheimer Europe updates website with information on national dementia strategies

Following a number of changes in the development and implementation of dementia strategies across Europe, Alzheimer Europe has updated its website to reflect the current position in each country.

Each country’s section has been updated to create a uniform approach, including:

- An introduction about when the strategy was launched and background information to its development.
- A brief overview of the content and structure of the structure, highlighting specific objectives or goals set out in the document.

In addition, each section includes downloadable copies of the country’s strategy (and past strategies where a country has had more than one), as well as providing links to further information on the strategies and their implementation within countries. You can access the updated section here: https://www.alzheimer-europe.org/Policy/National-Dementia-Strategies

18 February: AE adds new trials to its Clinical Trials Watch

Alzheimer Europe continues to develop and improve its Clinical Trials Watch (CTW), an innovative online resource providing up-to-date accessible information on clinical trials currently recruiting participants in a least one European country. The service provides information on phase II and III clinical trials that are investigating drugs for the prevention and treatment of dementia and/or Alzheimer’s disease (AD). In February 2021, five new trials have been added to the service:

- ANAVEX*2-73-AD-004 Phase III trial (Anavex Life Sciences Corp)
- ACI-35.030 Phase II trial (AC Immune)
- ALZ-801 Phase II trial (Alzheon Inc)
- Brainshuttle AD Phase II trial (Hoffmann-La Roche)
- TRAILBLAZER-ALZ 2 Phase II trial (Eli Lilly).

Further information about the CTW is available on: http://www.alzheimer-europe.org/Research/Clinical-Trials-Watch

22 February: Alzheimer Europe Board approves 2020 accounts and discusses progress of 2021 Work Plan

The Alzheimer Europe Board met online on 22 February 2021. The meeting agenda included various financial and operational matters, including details concerning the 31st Alzheimer Europe Conference and membership-related decisions. The Board approved the 2020 accounts and also discussed the progress of the organisation’s 2021 Work Plan.

23 February: Alzheimer Europe hosts online Company Round Table meeting

On 23 February, Alzheimer Europe hosted an online Company Round Table meeting, attended by representatives from Biogen, Eisai, EFPIA, Grifols, Nutricia, Roche and TauRx. Also in attendance were: 7 members of the Alzheimer Europe staff, including Executive Director Jean Georges; 19 representatives of Alzheimer Europe member organisations from 16 different countries; and 1 representative of the European Working Group of People with Dementia (EWGPWD).

Project Officer Cindy Birck gave an overview of recent developments with regards our Clinical Trials Watch database. Policy Officer Owen Miller shared some recent policy developments at the WHO and EU levels on WHO Non-Communicable disease activities, WHO Global Action Plan on Dementia EU4Health Programme and Horizon Europe. Audrey Wolf and Thomas Allvin, two representatives from EFPIA, then presented the EU Pharmaceutical Strategy with general principles and opportunities for Alzheimer’s medicines. Finally, Jean Georges updated sponsors and other delegates on Alzheimer Europe’s activities. We would like to thank our
sponsors and members for participating in this meeting and we look forward to welcoming them to the next Company Round Table meeting, on 16 June 2021.

**23 February: Alzheimer Europe co-hosts European Parliament Workshop on “Digital data for dementia research and innovation”**

On 23 February, Alzheimer Europe co-hosted an online European Parliament workshop with Charité – Universitätsmedizin Berlin, entitled “Digital data for dementia research and innovation”. Chaired by Deirdre Clune MEP (Ireland), Vice-Chairperson of the European Alzheimer’s Alliance (EAA), the workshop featured presentations from speakers working in the field of dementia, at Alzheimer Europe and for the European Commission.

The event was attended by 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 meeting was also attended by EAA Chairperson, Sirpa Pietikäinen MEP (Finland), and EAA member Tsvetelina Penkova MEP (Bulgaria). Additionally, Isabel García Muñoz MEP (Spain) attended the meeting, as did representatives from the offices of Martin Brglez MEP (Slovenia) and Hilde Vautmans MEP (Belgium).

Petra Ritter, BIH Johanna Quandt Professor for Brain Simulation at Charité – Universitätsmedizin Berlin and leader of the Virtual Brain Cloud project, outlined the project’s goal of developing personalised prevention and treatment for dementia, supporting this through the integration of data from large cohorts of patients and healthy controls to create a multi-scale brain simulation. As part of this outline, the technical and legal challenges in relation to the use and sharing of personal data in brain simulations were explained to attendees.

Paweł Świeboda, Director General of the Human Brain Project and CEO for EBRAINS, introduced these two programmes of work, outlining how they were addressing the challenges in infrastructure and interoperability related to the sharing of data in brain health research, as well as addressing issues of collaboration and scale. Looking towards the forthcoming work of the EU in relation to a European Health Data Space, it was suggested that there is a strong case to be made for a dedicated Brain Health Data Space embedded within this work.

Tetsuyuki Maruyama, Executive Director, Alzheimer’s Disease Data Initiative (ADDI), introduced the ADDI and ADDI’s AD Workbench, explaining that both the organisation and initiative are relatively early in their development. It was explained that ADDI’s aims include developing a data sharing platform and associated data science tools to provide researchers with access to data from dementia research, as well as connecting data globally to allow access for researchers working in the dementia field. Launched in November, the AD Workbench aims to increase data sharing and support the development of new tools and analytics for researchers, with over 700 users globally using the platform so far.

Angela Bradshaw, Project Officer, Alzheimer Europe, launched Alzheimer Europe’s new report “Data Sharing in dementia research – the EU landscape”, which outlines the legal and policy context that dementia researchers working in the field must navigate. The report identifies that whilst open access and data sharing is widely agreed upon in principle, practices vary widely between sectors and Member States, with the General Data Protection Regulation (GDPR) also not fully delivering on its aim of facilitating research data sharing. Key recommendations within the report include the development of pathways for faster, secure sharing of research data between sectors and across borders, support for researchers to maintain datasets and platforms after projects end, and embedding academic reward systems that place a greater value on data sharing and transparency.

Saila Rinne, Head of Sector for policy, Unit H.3 eHealth, Wellbeing and Ageing, DG CONNECT, provided a focus on some of the different work being undertaken by the European Commission in relation to digital health and ageing. Much of this work is built around three points: secure access and exchange of health data; health data pooled for research and personalised medicine; and, digital tools and data for citizen empowerment. In addition, to projects and work which has been undertaken so far in relation to digital health and ageing, future workstreams with relevance for better sharing and use of data for health research were highlighted, including Horizon Europe, EU4Health and the Digital Europe programmes.

Concluding the workshop, Iva Holmerová, Chairperson of Alzheimer Europe, noted the importance of data, highlighting that the process of meta-analysis in research, beginning with the Cochrane process in clinical research decades ago, had built a foundation for the current context. In addition, she thanked the speakers for their presentations, Deirdre Clune MEP for hosting and the Ms Pietikäinen and Ms Penkova for their contributions, as well attendees for joining the event.

**23 February: Alzheimer Europe sets out recommendations to improve data sharing in dementia research**

At an online European Parliament workshop hosted by Deirdre Clune MEP (Ireland), on 23 February, Alzheimer Europe launched a new report “Data Sharing in Dementia Research”, which reviews recent changes in EU research policy and sets out recommendations to improve data sharing in dementia research.
In this report, Alzheimer Europe evaluates the legal and policy landscapes that dementia researchers have had to navigate since the launch of Horizon 2020 in 2013. The report identifies key barriers and enablers for data sharing. It maps the Horizon 2020 dementia research portfolio, assessing the scale of EU investment in dementia research and the use of clinical research data. Finally, it reviews recent surveys of researchers, research participants and patients, collating their perceptions and concerns regarding data sharing.

Key findings:
- To date, over EUR 570 million has been invested through Horizon 2020 in dementia research projects, many of which involve the use of clinical data
- Although Open Access principles have been widely adopted, the uptake of Open Data practices varies between sectors and Member States
- The General Data Protection Regulation (GDPR) has not yet fully delivered on its aim of facilitating research data sharing, due to a perceived lack of clarity and regulatory divergence between Member States
- Researchers face technical, financial and motivational obstacles to data sharing, with the loss of privacy being the most frequently-cited concern for research participants.

Key recommendations to improve data sharing:
- Developing pathways for faster, secure sharing of research data between sectors and across borders, including GDPR codes of conduct and standard contract clauses
- Supporting researchers to maintain datasets and platforms after projects end, and embedding academic reward systems that place a greater value on data sharing and transparency
- Increasing digital literacy in the general population, ensuring that older adults and vulnerable groups are not left behind
- Involving people with dementia in the design and conduct of research, as well as in data governance.

Commenting on the launch of the report, Alzheimer Europe’s Executive Director, Jean Georges, stated: “The number of people with dementia in Europe is likely to double by 2050, increasing from 9.78 to 18.8 million in the wider European region. Unfortunately, research on dementia has historically received proportionately less funding than other disease areas. As a result, there is an urgent need to maximise the utility of data from dementia research. Data sharing represents an important step towards meeting this need, and could help increase our understanding of the causes, treatment, prevention and care of dementia. However, there is still much to do to improve data sharing in dementia research. To ensure people with dementia benefit from the progress made in recent years, we need to work together to overcome the remaining obstacles to data sharing, and maintain dementia research as a priority for EU research programmes.” To download (PDF):


Alzheimer Europe gratefully acknowledges the support of Gates Ventures for its report on “Data sharing in dementia research – the EU landscape”.

24 February: Dementia in Europe issue 35 published as an e-magazine

Alzheimer Europe has published a new edition of its “Dementia in Europe” policy magazine, in an electronic format.

The first section of the magazine looks at some of the key work our organisation has been involved in, over the past few months. The opening article recaps the European Parliament Workshop held online in December. We then move on to an overview of the suite of policy and ethics publications that Alzheimer Europe launched in the latter part of 2020. In the following article, we introduce the new European Working Group of People with Dementia (EWGPWD) and meet its members – we look forward to working with them during their term!

Turning to research projects in which Alzheimer Europe has been involved, the co-leads of the European Prevention of Alzheimer’s Dementia (EPAD) project, Craig Ritchie and Serge Van der Seyten, reflect on the achievements of the project as it reaches its conclusion. We then hear from the leads of the recently-finished Patients Active in Research and Dialogues for an Improved Generation of Medicines (PARADIGM) project, Nicola Bedlington and Magda Chlebus. A brief update on the launch of the Neuronet Knowledge Base follows and finally, we hear from Charlotte van Corven about the SPAN+ project, which focuses on empowering people with dementia.

In the Policy Watch section, we are delighted to have an interview with the Norwegian Minister for Health and Care Services, Bent Høie, who introduces the country’s new dementia strategy, whilst Secretary General for the Norwegian Health Association (Nasjonalforeningen for folkehelsen), Mina Gerhardsen, shares her reflections on this important development. We are then pleased to present an interview
with French Minister for Solidarity and Health, Olivier Véran, who outlines the future of dementia policy in France, with President of France Alzheimer, Joël Jaouen, providing his organisation’s perspective. Staying at the national level, Avril Easton from The Alzheimer Society of Ireland discusses the organisation’s campaign in the lead-up to the Irish budget and shares their success in securing additional funding for dementia services.

At a European level, Alzheimer Europe presents some of the latest developments in EU policy, examining the future budget of the EU and the implications for health and research policies. In addition, we summarise the latest meeting of the European Group of Governmental Experts on Dementia, which met online in December 2020, to discuss recent dementia policy developments across Europe.

The Dementia in Society section opens with a focus on COVID-19, with members of the EWGPWD writing about how the measures to control the spread of the virus have affected them. This is followed by an article in which our member associations outline how the human rights of people with dementia and their carers have been affected during the pandemic, in their respective countries.

As part of our work supported by Gates Ventures, Alzheimer Europe Project Officer Angela Bradshaw shares insights into the perspectives of research participants and patients, on data sharing, highlighting some of their key concerns. Following this, Alzheimer Europe spoke to six early stage researchers (ESRs) working on two EU-funded research projects, to gain a better understanding of what drew them to the field of dementia research and to ask how COVID is affecting their work. We then go “Behind the Headlines”, with Alzheimer Europe Project Officer Cindy Birck and Tobias Hartmann of the European LipiDiDiet project, to examine the effect of a multinutrient intervention (Souvenaid) on cognitive and functional decline in early Alzheimer’s disease.

The last article in this section is our “Dementia in the Arts” feature in which we speak to Gina Martin, Founder and Executive Director of the Bob and Diane Fund, who shares her motivation for creating this annual photography award for visual storytelling about Alzheimer’s and dementia. She also discusses the winning project for 2020.

To round off this edition of the magazine, we take a look back at the 30th Alzheimer Europe Conference (#30AEC), which was held virtually for the very first time, in October 2020. The event was co-moderated by Kim Coppes from Live Online Events, and Jean Georges, Executive Director of Alzheimer Europe. Despite the unusual circumstances, the conference was a great success, with almost 800 participants, from 42 countries, as well as 260 speakers and 100 poster presentations. We revisit some of the key presentations, special sessions and symposia held during the event, including those organised by the EWGPWD, and the Neuronet and VirtualBrainCloud projects. You can download the PDF, here:

http://bit.ly/DementiaInEurope35

24 February: Alzheimer Europe hosts online Public Affairs meeting

On 24 February, Alzheimer Europe hosted an online Public Affairs meeting. 25 representatives from member associations, 9 Alzheimer Europe staff members and 2 members of the European Working Group of People with Dementia (EWGPWD) were in attendance. Chairperson Iva Holmerová led the meeting. The agenda focused on:

- Feedback and follow up, on discussions from company round table meeting of 23 February - Prevalence of dementia, aducanumab update (Jean Georges)
- The 2021 Dementia in Europe Yearbook: Dementia-friendly initiatives (Ana Diaz and Owen Miller)
- National campaigning activities and dementia-friendly initiatives (11 presentations by representatives of member organisations)
- Towards a new strategic plan of Alzheimer Europe (Jean Georges).

Alzheimer Europe is looking forward to meeting with its national member organisations at the next Public Affairs meeting, in June.

Alzheimer Europe networking (online)

On 1 February, Jean met with the EFPIA Alzheimer’s disease Platform.
On 1 February, Gwladys attended the Brussels European Association Forum (BEAF).
On 3 February, Jean attended the ADAIR General Assembly.
On 4 February, Jean attended the Management Group of the Dementia Panel of the European Academy of Neurology.

On 4 and 8 February, Angela attended a Neuronet Task Force meeting.

On 5 February, Gwladys attended the EPF webinar on High Impact Engagements.

On 10 February, Owen attended an online session of EFPIA’s Patient Think Tank, focused on developing a conceptual framework for unmet medical need.

On 10 February, Ange and Owen met with Gates Ventures to discuss the data sharing report.

On 11 February, Ana attended a BIOGEN Patient Advocacy Group meeting.

On 12 February, Angela attended a Core Group meeting of the DataSavesLives initiative.

On 15 February, Jean Gwladys and Chris met with Eventsforce to have an exchange on recent updates of their online conference platform.

On 16 February, Jean attended the epidemiology working group of the PAVE project.

On 16 February, Cindy had a call with Janssen to discuss the Clinical Trials Watch.

On 17 February, Cindy participated in the EPAD Scottish meeting.

On 17 February, Gwladys attended the ICCA event “From resilience to revival”.

On 19 February, Ana and Kate took part in a planning meeting with bPRIDE project leaders.

On 22 February, the Boards of Alzheimer Europe and the Alzheimer Europe Foundation met online.

On 23 February, Alzheimer Europe organised a company round table meeting.

On 23 February, Alzheimer Europe and Charité organised a European Parliament workshop “Digital data for dementia research and innovation”.

On 24 February, Alzheimer Europe organised a public affairs meetings with its national member organisations.

On 25 February, Dianne took part in the Interdem Virtual Social Health Taskforce meeting.

On 25 February, Ana and Cindy took part in a consultation with the EU-FINGERS Advisory Board.

---

**EU PROJECTS**

1 February: New Al-Mind project will focus on artificial intelligence for dementia prevention

Al-Mind is a 5-year project funded by Horizon 2020, with the goal of facilitating a paradigm shift in clinical practice, starting on March 1, 2021. Al-Mind will create intelligent digital tools for screening of brain connectivity and dementia risk estimation in people affected by mild cognitive impairment.

During its lifecycle, two new artificial intelligence-based digital tools will be developed by Al-Mind. The Al-Mind Connector will identify dysfunctional brain networks, and the Al-Mind Predictor will assess dementia risk using data from the Connector, advanced cognitive tests, and genetic biomarkers. These two tools will be integrated into an intelligent diagnostics platform to identify both brain network disturbances and dementia risk, creating personalized patient reports for further intervention recommendations.

**Dementia affects tens of million worldwide**

Currently, there are over 50 million people living with dementia across the globe. By 2050 we can expect that number to reach 82 million. Besides time-consuming patient investigations with low discriminative power for dementia risk, current treatment options focus on late symptom management. This has numerous implications in terms of familial, medical, and care costs.

Delaying the decline dementia causes will significantly reduce the overall medical and social costs for patients and those of the pressure on insurance companies and healthcare systems. Studies have consistently shown that the average medical, non-medical, and indirect costs for individuals with dementia are higher compared to those without dementia. Many underestimate the overall economic burden of dementia as many non-trivial components of costs, such as direct non-medical costs and indirect costs, are not included in the cost estimates.

**Al-Mind enables earlier preventative therapies**

The risk of dementia can be reduced by adopting healthy lifestyle habits and managing treatable conditions such as diabetes and high blood pressure. Thanks to the Al-Mind tools,
the time to make a diagnosis, which can take several years with current technologies, could be reduced to only one week. This gives doctors and patients a window for preventive interventions, therapies, and rehabilitation measures early in the course of the disease.

With the currently available technology, many patients receive their diagnosis only after the onset of dementia. As a consequence, there might not be the opportunity to start preventive therapies. For people with mild cognitive impairment (MCI), the dementia risk is almost 30% higher than unaffected individuals. Therefore, we need effective diagnostic tools for early dementia risk assessment and intervention for people with MCI.

**The doctor’s new best friend: AI**

What are now complex, labour-intensive, costly, and poorly predictive screening methods for mild cognitive impairment (MCI) shall be replaced by automated diagnostic screening tools. These are driven by artificial intelligence to address the urgent need for early accurate diagnosis and risk prediction.

**About Al-Mind**

The Norwegian coordinated Al-Mind project has received substantial funding from the European Union’s Horizon 2020 research and innovation program under grant agreement No 964220. Al-Mind is a five-year Research and Innovation Action (RIA) that officially starts in March 2021, with a budget of EUR14 million.

Fifteen project partners, from eight European countries, including academic institutions, medical centres, SMEs and patient organizations, make up the Al-Mind consortium: Tallinn University from Estonia, Aalto University and Helsinki University Hospital from Finland, Oslo University Hospital, BrainSymph AS, DNV-GL, and Oslo Metropolitan University from Norway, Scientific Institute for Research, Hospitalization and Healthcare, San Raffaele Pisana, Neuroconnect Srl, Università Cattolica del Sacro Cuore from Italy, Radboud University Medical Center from the Netherlands, Alzheimer Europe from Luxembourg, Complutense University of Madrid (and Universidad Politécnica de Madrid as third party) and Lurtis Rules from Spain, and accelopment Schweiz AG from Switzerland. Al-Mind is a partner project of DigitalLife Norway. Supporting organisations: CLAIRE and NORA. 

https://www.ai-mind.eu/

**5 February: DISTINCT project researchers find there is still little evidence available to show that new technologies help people with dementia remain socially active**

Researchers in the Netherlands have found that until now, there is almost no high-quality scientific evidence that new technologies can help people with dementia remain socially active. In their new paper, published this week in a special issue of the Journal of Clinical Medicine, the researchers report that globally, only nine relevant randomised controlled trials – the gold standard for scientific evidence – have produced published results. Only one of those studies was of good quality: an evaluation of a Korean computer-based cognitive training programme.

This is bad news for healthcare system leaders. Because of the COVID-19 pandemic, investment in technologies which claim to help people with dementia is growing rapidly. Many people hope that technology might make up for reduced physical contact and strained resources. But with so little evidence, any investments remain a gamble.

The researchers recommend several ways of improving the quality of evidence in future, so that effective technologies can be recommended and rolled out confidently, on the basis of good evidence for their effectiveness.

In the meantime, they warn healthcare leaders to make decisions, about which technologies might help people with dementia, very carefully, on a case-by-case basis.

The research has been published online in a special issue of the Journal of Clinical Medicine. The full text can be found here: https://www.mdpi.com/2077-0383/10/4/604

**16 February: The RECOGNISED project hosts a mini-symposium on the progress of its clinical studies**

On 16 February, clinical partners in the RECOGNISED project hosted a mini-symposium updating on the progress and procedures of the RECOGNISED clinical research studies. Bringing together 21 project partners from academia, SMEs and patient organisations, RECOGNISED aims to evaluate whether non-invasive retinal tests could be used to identify people with type 2 diabetes (T2D) who are at a higher risk of developing mild cognitive impairment (MCI) and dementia. To do this, RECOGNISED has launched cross-sectional and prospective, observational longitudinal cohort studies, aiming to recruit over 200 participants from 11 study sites in 7 countries.

The mini-symposium provided an update on the progress and procedures for the RECOGNISED studies, to ensure good alignment between site investigators and inform the wider consortium. Noemi Lois of Queen’s University, Belfast, kicked off the mini-symposium by providing an overview of the recruitment processes and progress. Next, Lieza Exalto of UMC Utrecht provided an update of the cognitive testing strategy being employed in the RECOGNISED studies, which includes the MoCA (Montreal Cognitive Assessment) and CDR tests.

Finally, clinical partners discussed the impact of COVID-19 on recruitment, enrollment and follow-up, identifying potential strategies that could mitigate issues in relation to COVID-19 and confinement. To find out more about RECOGNISED: 
https://sites.google.com/view/recognised/
17 February: Local actions taken to keep the EPAD Longitudinal Cohort data collection going

On 17 February, EPAD held its first local community meeting among the Scottish research sites, collaborators, academics and scientists who have been involved in the EPAD Longitudinal Cohort Study (LCS) throughout the IMI funded period and now continue to contribute to the study locally. The first local EPAD community meeting focused on carrying on data collection within the established EPAD LCS network in Scotland, follow-on studies and open access for the large EPAD data including bio samples and imaging data. The community meeting also marked the launch of the first post-IMI EPAD local initiative which they hope will be one of many across Europe to carry on collecting longitudinal data from the participants who have already contributed valuable data over several years, as well as for the research community to share ideas.

The lead of the EPAD project Prof Craig Ritchie gave an overview of the post-IMI period including work already published and encouraging the research community to apply for the EPAD LCS data now freely available. Attendees also got an overview from the other speakers on how to access the biosamples, the collaboration between EPAD and GAP and many of the follow-on studies. Some of the follow-on studies include a limited version of the original EPAD study protocol as well as studies using retinal imaging and speech analysis. Alzheimer Europe Project Officer Cindy Birck, gave a presentation to remind that the EPAD communications tools are still active to share the current work to keep EPAD going.


18 February: EU-FINGERS Advisory Board participates in its first meeting

The EU-FINGERS project will advance the understanding of, and the interventions for, the prevention of cognitive decline and Alzheimer’s dementia. An important outcome of this project will be the “Multimodal Precision Prevention Toolbox”. This Toolbox will include different sets of tools for researchers working in the area of brain health and prevention of Alzheimer’s dementia.

EU-FINGERS has set up an Advisory Board in January 2021. The Advisory Board is composed of 16 people with an interest on the topic of brain health and prevention of dementia from 7 countries in Europe (Finland, Hungary, Luxembourg, Netherlands, Spain, Sweden, UK). Alzheimer Europe (AE), 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.

The first virtual meeting of the EU-FINGERS Advisory Board took place on 18 February. 13 members of the Advisory Board were present and the meeting was also attended by eight colleagues from the project. The purpose of this social meeting was to get to know more about each member as the working meetings will split the group in small sub-groups. Each member had the opportunity to present their hopes for the Advisory Board, all of which was facilitated by AE Project Officer Ana Diaz. The first working meetings will be organised in February and March, where members of the Advisory Board will have the opportunity to provide feedback and advice to the EU-FINGERS researchers about different topics and issues linked to the project. From AE, Ana and Cindy participated in the social meeting.

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; Luxembourg, National Research Fund; Hungary, National Research, Development and Innovation Office; The Netherlands, Netherlands Organisation for Health Research and Development; Sweden, Swedish Research Council.

19 February: bPRIDE project aims to generate and validate blood tests for early and specific diagnosis of major types of dementia

Alzheimer’s dementia, Lewy body dementia, and frontotemporal dementia (FTD) are amongst some of the most common forms of dementia. Each type is caused by different
biological factors and therefore requires a specific treatment which targets these factors. To develop effective treatments, it is important to correctly diagnose each dementia type, at the earliest possible stage.

The bPRIDE project (blood PRotein Identification to Discriminate dEmentias) aims to generate and validate blood tests for early and specific diagnosis of the major dementia types. To successfully achieve these aims, bPRIDE will analyse more than 1,000 blood proteins in over 1,000 patients, who are at different stages of these different dementias. This will be done using novel, extremely sensitive technologies.

The hope is to empower people with dementia by giving them specific and early/timely diagnoses, and to assign the most suitable novel treatments to the right people, whilst also increasing the potential for the successful development of potential therapies.

Alzheimer Europe is contributing to this project by supporting its dissemination plan and on 19 February, a communications planning meeting was held with project leaders, attended by Alzheimer Europe Project Officer Ana Diaz and Communications Officer Kate Boor Ellis.

You can find out more about the bPRIDE project, here:

bPRIDE.pdf (neurodegenerationresearch.eu)

19 February: The PRODEMOS trial has started!

In January 2021, the PRODEMOS randomised controlled trial began recruitment in the United Kingdom (UK). This trial studies the effectiveness and implementation of a coach-supported mobile health (mHealth) intervention to reduce dementia risk in people in the UK and China.

In this study, the PRODEMOS team (pictured) is investigating the effect of the use of a coach-supported, interactive mHealth platform, facilitating self-management of dementia risk factors in a total population of 2,400 participants. Participants are 55-75 years, are of low socio-economic status (UK) or from the general population (China), have ≥ 2 dementia risk factors, and use a smartphone. The main effectiveness outcome is change in dementia risk, measured with the CAIDE dementia risk score. Improvement of individual risk factors and cost-effectiveness will also be evaluated. Implementation outcomes include acceptability, adoption, feasibility, and sustainability of the intervention.

A six-week pilot of the project was conducted within the UK, in early 2020. The pilot study recruited 21 people and was evaluated through focus groups and individual interviews with pilot participants, coaches and research personnel. Based on their feedback the study logistics, the app and the platform were fine-tuned. A similar pilot study will be conducted, in March 2021, in China.

Alzheimer Europe (AE) is a partner in PRODEMOS, bringing its unique experience from three perspectives: Firstly, representing the patient perspective and bringing in extensive expertise in the field of qualitative research and ethical issues. Secondly, AE has a major impact on policymakers at the European level and can contribute to the efficient dissemination of the project’s results. Finally, AE contributes directly to the mHealth intervention, by writing news items on dementia risk reduction for the mHealth platform.

The trial is expected to be completed by the end of 2022 and the results will be published in an international peer-reviewed journal. The final aim of the PRODEMOS project is to implement the flexible, fully adaptable mHealth platform in a culturally appropriate form, in a range of healthcare settings across the globe.

Further information on the PRODEMOS project can be found here: https://www.prodomos-project.eu/

22 February: "I Do Service" builds on the work done in the MinD project

The IDoSService project aims to co-design tools which make it easier for people living with mild to moderate dementia to connect with relevant groups, charities or other activity groups. The objective is to support the wishes expressed by many people with mild dementia to have more opportunities for active participation in meaningful activities and to feel valued for any skills or expertise they might have to share.

Online focus groups were held, in February, with key stakeholder in the field of dementia support, activities and advocacy in Greater Manchester, United Kingdom, to gain insights into current services provision, barriers and opportunities. The focus groups’ first insights, perhaps predictably, highlighted the large impact which COVID-19 has on providing and accessing meaningful activities. People living with dementia, carers and service providers have had to adapt hugely to find ways to maintain social interactions and access to leisure activities. Information technologies were and are still very useful in many cases to keep contact and continue activities such as singing, crafts, physical activities, or support groups. However, even after providing tablets to people, online activities remain unsuitable for some people and some activities have to be completed using other, more traditional approaches, such as phone calls, or provision of information and other materials by post.
Remote interviews with people with dementia together with a care partner will begin in the coming weeks. They will provide an opportunity to follow up insights from the focus groups in more depth and to learn about first-hand experiences. The aim is to discuss the availability and accessibility of meaningful activities, and the needs and wishes of people in the early stages of dementia.

The IDoService project builds on the interdisciplinary participative design approach, ideas of empowerment and social engagement developed during the European project MinD (2016-2020).

You can find more information about the project here: https://www.art.mmu.ac.uk/profile/itournier/projectdetails/1074

For any questions or suggestions about access to meaningful activities, please do not hesitate to contact the research team on: idoservice@mmu.ac.uk

22 February: AMYPAD consortium has been published in EJNMMI

A new article from the AMYPAD consortium has been published in the European Journal of Nuclear Medicine and Molecular Imaging. The paper showed that visual assessment is able to detect early amyloid deposition and grade its extent using regional information. Lyduine Collij and Gemma Salvadó have been awarded the Junior Faculty Awards from the organizing committee of the 15th International Conference on Alzheimer’s and Parkinson’s Diseases for this work. Gemma will be presenting this work during the AD/PD™ conference on 12th March 2021. Read more here: https://amypad.eu/news/new-paper-published-in-ejnmmi/

22 February: AMYPAD reports on recent progress and future activities

The Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) project has reported the important advances that have been made during the past year. Despite the negative impact of COVID-19, the Diagnostic and Patient Management Study (DPMS) succeeded in recruiting 844 of the planned 900 participants when recruitment was formally ended on 30 October 2020. A total of 245 people with Subjective Cognitive Decline, 342 with Mild Cognitive Impairment and 258 with dementia had been enrolled across eight European sites and will continue to be followed as scheduled. The data cleaning process has been initiated and the results on the primary endpoint are expected in mid-2021.

In 2020, the Prognostic and Natural History Study (PNHS) saw great progress in the activation of all recruitment sites and the inclusion of additional Parent Cohorts. At this moment, the PNHS has 17 active sites and six cohorts have been actively enrolling into the study (EPAD LCS, EMIF-AD, ALFA+, FACEHBI, FPACK, UCL-2020-412), with two others confirmed to begin enrolment soon. In total, at the end of 2020, the AMYPAD PNHS had 754 participants consented of which 584 already underwent PET scanning. The data integration process (from all data sources) and quality check of data has been initiated.

In addition, the AMYPAD team has conducted a series of video interviews. Seven AMYPAD members explained the goal of each Work Package (WP) and the specific goals for 2021. Our project officer Cindy Birck was interviewed about the WP6 (Ethics, communication and dissemination) led by Alzheimer Europe. The video interviews can be found here. https://amypad.eu/news/recent-news/highlights-2020/

23 February: MOPEAD project publishes survey results on general practitioners’ attitudes towards early and pre-dementia diagnosis of Alzheimer’s disease

On 23 February, a group of researchers including the Executive Director of Alzheimer Europe Jean Georges, from the public-private MOPEAD project published a paper based on a survey about general practitioners’ attitudes towards early and pre-dementia diagnosis of Alzheimer’s disease (AD) in the journal Alzheimer’s & Dementia Diagnosis, Assessment & Disease Monitoring.

The paper is based on responses from 343 general practitioners’ who provided feedback on their general attitudes towards early diagnosis, diagnostic procedures, resources, and on present and future treatment options across five European countries. Looking at the results, the team noticed that the majority of general practitioners thought that an early diagnosis was of value. On the other hand, they also identified some barriers to an earlier diagnosis. These were mostly of logistic nature, such as a lack of time. Less than a third of the 343 respondents pointed out that they had sufficient time to manage a patient with very early dementia or Mild Cognitive Impairment (MCI). Looking at country variances, they found that there were strong differences with regard to reimbursement perceptions, but also regarding the knowledge about early diagnosis. About a third of the respondents did not feel confident in the diagnostic procedures for very early dementia or MCI.

The survey also focussed on their opinion on pharmacological treatment options that are currently available and the paper highlighted that the majority was of the opinion that they have no or low benefit for patients. The same time, results pointed out that the majority thought that non-pharmacological options do come with a benefit although results indicated that they are not sufficiently available. https://doi.org/10.1002/dad2.12130
A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon2020 or from the Innovative Medicines Initiative and Innovative Medicines Initiative 2 Joint Undertakings. The Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA. The projects in this newsletter are:

AI-MIND – grant agreement 964220
AMYPAD – grant agreement 115952
EPAD – grant agreement 115736
EU-FINGERS – INTER/JPND/19/BM/14012609
PRODEMOS – grant agreement 779238
RECOGNISED – grant agreement 847749

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 92, representing 26 Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer’s Alliance (EAA):

Austria: Monika Vana (Greens/EFA). Belgium: 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); Sergej 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: Alvina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Mia Petra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). France: François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjou (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 Zacharopoulou (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 Spyrou (EPP); Elissavet Vozemberg-Vrioni (EPP). Hungary: Tamás Deutsch (EPP); Ádám Kós (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 Blinkevičiute (S&D). Luxembourg: Marc Angel (S&D); Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Isabelle Wiseler-Lima (EPP). Malta: Roberta Metsola (EPP); Alfred Sant (S&D). Netherlands: Jeroen Lenaerts (EPP); Annie Schreijer-Pierik (EPP). Poland: Elżbieta Łukacijewska (EPP); Jan Olbrycht (EPP). Portugal: Sara Cerdas (S&D); José Gumsão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D). Romania: Cristian-Siüliu Busoi (EPP); Marian-Jean Marinescu (EPP). Slovakia: Ivan Stefanc (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 Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtasun (Greens/EFA). Sweden: Jytte Guteland (S&D); Peter Lundgren (ECR).

EU DEVELOPMENTS

2 February: European Disability Forum calls for COVID-19 residential settings investigation

The European Disability Forum (EDF) has called for the European Parliament to investigate the impact of COVID-19 on residential settings, highlighting how the pandemic has highlighted shortcomings and structural problems within both EU and national policies in relation to persons with disabilities.

During a public hearing organised by the European Parliament’s Employment and Social Affairs, and Civil Liberties Committees, EDF President Yannis Vardakastanis set out a number of asks to better protect and promote the rights of persons with disabilities:

• A Parliamentary investigation into the numerous cases of discrimination and human rights violations in residential institutions across the EU
• A strong commitment to support the right to independent living in the community
• Use of the EU Budget to support deinstitutionalisation
• Vaccine prioritisation of persons with disabilities
• Adoption of horizontal EU antidiscrimination legislation.

During the hearing, European Commission Vice-President of Democracy and Demography, Dubravka Šuica, and Commissioner for Equality, Helena Dalli, presented on the work of the European Commission in their respective areas, as well as responding to MEPs questions how the shortcomings would be addressed at an EU-level. This public hearing can be viewed at:


You can read more on EDF’s call at:


4 February: European Commissioner announces panel to reform European Research Area

On 4 February, the European Commission announced the establishment of an expert group to design the governance structure for the European Research Area (ERA), the EU’s planned single market for research (which was first launched in 2000).

The Commissioner for Innovation, Research, Culture, Education and Youth, Mariya Gabriel announced the launch of the new group at a joint press conference with Portuguese science minister Manuel Heitor. The objectives of the group in 2021 will be to:

• Provide recommendations on a new ERA governance framework, including the mandate and objectives of its different components and the interactions between them
• Cooperate on the development of the first ERA policy agenda and advance its work in line with the roadmap set out in the communication “a New ERA for Research and Innovation”
• Provide input for a new yearly ERA Scoreboard to monitor the progress in implementing the ERA.

As part of the work around the ERA, the Commission aims to encourage Member States to increase the average research and development spend to 1.25% of GDP, up from the current 0.8% (below the 3% target when the ERA was first launched in 2000). You can access more information on the ERA and the new expert group here:


19 February: European Commission launches process to adopt UK data adequacy decisions

On 19 February 2021, the European Commission launched the process towards the adoption of two adequacy decisions for transfers of personal data to the United Kingdom, one under the General Data Protection Regulation (GDPR) and the other for the Law Enforcement Directive.

The Commission has been assessing the UK’s law and practice on personal data protection, including the rules on access to data by public authorities and has concluded that the UK ensures an equivalent level of protection to the one guaranteed under both the GDPR and Law Enforcement Directive.

The draft decisions, once fully adopted, will be valid for period of four years, after which it will be possible to renew the adequacy finding, so long as the level of protection in the UK continues to be considered adequate.

The next steps in the process will be for the Commission to seek the the opinion of the European Data Protection Board, followed by a request to Member States’ representatives to approve the proposed decision. After this, the European Commission will be able to adopt the final adequacy decisions for the UK.

Until the adoption data of the adequacy decisions, the flow of data between the European Economic Area and the UK will continue as a result interim regime agreed as part of the EU-UK Trade and Cooperation Agreement. This interim period expires on 30 June 2021. You can read more about the launch of the process here:


11 February: Alzheimer Sweden interviewed by Sweden’s biggest evening paper

Karin Westerlund of Alzheimer Sweden has been interviewed by Sweden’s main evening paper, Aftonbladet. Journalist Katarina Frostensson spoke to Ms Westerlund and to Professor Kaj Blennow, whose scientific research is highlighted in the article. The piece was published on 11 February. This is a rough translation of the article (with thanks to Karin Westerlund):

A simple blood test can soon reveal if a person has Alzheimer’s disease, even at a very early stage. A promising medicine may also soon be on the market.

"We hope that the blood test can be up and running this year”, said Professor Kaj Blennow.

Swedish researchers in Gothenburg have, together with an American company, developed a simple blood test that can show even low levels of tau proteins.
"This means that the disease can be detected very early, and tau proteins are not found in other dementia diseases, either," said Kaj Blennow, professor and research leader at the Neurochemical Laboratory at Sahlgrenska University Hospital and one of the authors of the study.

"It is about developing biomarkers to detect levels that can be compared to a sugar cube in a large swimming pool", he commented. "We can now measure exact levels".

Even before Alzheimer's disease manifests itself in the form of memory loss, the patient has an increased proportion of tau proteins. "This test thus works early in the process and, together with a new type of antidepressant based on immunotherapy being developed, we believe that there may be relief of the disease within reach" stated Prof. Blennow.

The new drug is awaiting approval from the FDA, the US Food and Drug Administration.

"It is mainly focused on amyloid proteins, but we believe that if you succeed in stopping their development, the tau proteins will follow, he said.

Everyone who works with this has high hopes for this medicine. Even at Alzheimer Sverige (Alzheimer Sweden), people are hopeful.

"The blood tests are valuable, to be able to track the development during the entire progression of the disease", said Karin Westerlund.

About 70 percent of all people with dementia have Alzheimer's disease.

"Even though there are no disease-modifying treatments today, many people and carers want to get a diagnosis, and to have the opportunity to plan their lives and health in a more individualised way", she stated.

She also believes that increased knowledge about diagnosis among physicians will increase the demand for research for medical treatment.

"A more accessible and cost-effective biomarker for Alzheimer's disease can influence Swedish healthcare in the right direction", asserted Ms Westerlund.

18 February: Alzheimer Bulgaria presents e-LILY project at Panhellenic conference

On 18 February 2021, Alzheimer Bulgaria took part in the 12th Panhellenic Conference on Alzheimer's Disease and the 4th Mediterranean Conference on Neurodegenerative Diseases, the purpose of which is to present state-of-the-art research on dementia diagnosis, prevention, and treatment.

Angelina Kancheva, one of the volunteers of the association, presented the implementation of the e-LILY project in Bulgaria, made possible thanks to the tireless work of the Executive Secretary of Alzheimer Bulgaria, Irina Ilieva. The e-LILY project aims to improve the e-health literacy of dementia carers by providing class sessions and an e-learning course in countries with a low rate of health-related internet use, namely: Greece, Cyprus, Bulgaria, Italy, and Poland. One of e-LILY's main priorities during the COVID-19 pandemic is to also educate health professionals, people over the age of 65, and the carers of those affected by dementia, on the benefits of using digital tools and the internet in health-related decision-making.

During the conference, Ms Kancheva highlighted the need to transform the health and social care systems in Bulgaria, so that innovative digital technologies are developed, implemented, and disseminated across the country. All other e-LILY partners also presented their findings. Areti Efthymiou introduced the e-LILY programme and the need to improve the digital literacy among carers of people with dementia; Joanna Menikou presented the pilot results of the blended training course in Cyprus; Nikoletta Geronikola talked about the use of new technologies supporting carers in Greece; and Beata Mintus discussed sustainability issues regarding the implementation of e-LILY in all partner countries.

Alzheimer Bulgaria is grateful to the organizers of the conference for their invitation, and is looking forward to further work on e-LILY in 2021. To learn more about the project, visit: https://alzheimer-bg.org/novini/e-lily/
The Memory Barometer survey measures the status of memory work, i.e. services for people with dementia (or, as we say in Finland, people with memory-related diseases), in municipalities nationwide, and highlights areas for improvement. The response rate was 79% and the municipal coverage 82.7%. A total of 139 responses were received. The barometer was sent out at the end of May 2020, to the people responsible for the services for older people in municipalities and local government collaboration areas. The respondents were encouraged to answer the survey in working groups, with the idea that questions on different topics would be answered by people familiar with the services in question.

The aim of The Memory Programme was to build solidarity to create a memory-friendly (i.e. dementia-friendly) Finland. Advancement has occurred on several fronts over the last five years. However, certain important issues, such as supporting living at home and services aimed at relatives and loved ones, are lagging behind compared to other areas. Ensuring the availability of the necessary services comprehensively, throughout Finland, and supporting relatives and loved ones would be in line with the ideal of solidarity. Attitude-influencing work, the collection and utilisation of feedback, and the diversification of housing solutions for people with dementia are also among the issues that still require attention.

20 February: NGO Futura reports on its recent activities to support people with dementia in Montenegro

In recent months, NGO Futura, Montenegro, has:

- established five counselling centres for people with dementia and their families, in five cities - Podgorica (capital), Bijelo Polje, Nikšić, Bar and Budva
- worked on the project “Living with dementia, but with dignity” co-financed by the European Union and the Government of Montenegro
- prepared for the opening of an NGO Futura day centre for people with dementia, within a home for the elderly, in Nikšić
- delivered eight thematic trainings for professionals on early detection, recognition of the first symptoms of dementia, prevention and education for proper treatment and care of the elderly and people with dementia, and Alzheimer’s disease, between 10 September 2020 and 20 February 2021
- provided trainings on adequate care and accommodation, as well as activities for people with dementia, techniques of adequate communication, overcoming stigma and prejudice related to dementia, basics of stress at work (these were attended by more than 80 professional associates)
- developed a handbook for carers who work with people with dementia
- made many media appearances in order to promote and provide better visibility of all topics related to dementia.

22 February: Alzheimer Hellas organises English lessons with the use of songs, for people with mild cognitive impairment

The Erasmus+ funded “English Lessons with the Use of Songs for People with Mild Cognitive Impairment” (E.L.So.M.C.I.) programme is a two-year pan-European initiative, which started in September 2020. It aims to develop an educational programme on teaching English to people with mild cognitive impairment (MCI), using English songs as a main tool for the teaching process.

The project coordinator is Alzheimer Hellas (Greece) and the partners are Alzheimer Valencia (Spain), Anziani e Non Solo (Italy), Spominčica - Alzheimer Slovenia (Slovenia) and University Psychiatric Hospital Vrapče (Croatia). All the consortium members come from Mediterranean countries that share some cultural similarities and where the first language is not English. For this reason, English will be used as a tool for the participants’ memory and attention improvement.

The methodology of this educational programme is based on innovative teaching approaches such as “Communicative Language Teaching” and “Natural Approach” and the method of “Neuro-linguistic Programming” (NLP). These methods place great emphasis on verbal communication, creation of a positive environment in class, reduction of stress and encouragement of learners to learn step by step in a natural and pleasant way.

The aims of the project are divided into the following objectives:
1. improving memorising skills of people with MCI, through the use of songs
2. supporting the teaching process with songs
3. reducing stress and increasing positive emotions
4. social contact for people with MCI and creating a sense of belonging to a group
5. improving quality of life and reducing stress, as well as sharing useful knowledge with people with MCI
6. dementia prevention
7. familiarisation with English language through phrases related to communication and verbal expression
8. exposure to British and American culture
9. improving knowledge regarding vocabulary, grammar, syntax and other aspects of English language using an enjoyable learning process.

You can find more information on the official website:
https://www.songsforcare.eu

22 February: Alzheimer Athens develops Greek dementia helpline

The Athens Alzheimer Association, with the support of the Greek Ministry of Health, Region of Attica and Hellenic Inter-Municipal Network of Healthy Cities (EDDYPPY), has developed the Greek Helpline for Dementia 1102.

The Helpline is staffed by specialised counsellors, neurologists, psychiatrists, psychologists and social workers, who provide immediate information, guidance, advice and liaise with dementia services.

The Helpline serves:
- people with memory problems
- caregivers – family & friends of people with dementia
- the general public
- healthcare professionals.

The services provided by the Helpline are:
- information on dementia and prevention strategies
- information on available services and programmes for people with dementia and their carers
- practical care tips for carers of people with dementia
- guidance for crisis management
- liaising with Alzheimer’s organisations operating in Greece
- networking with the dementia consulting centres that operate in collaboration with EDDYPPY (National Inter-Municipal Network of Healthy Cities - Health Promotion) all over Greece
- information about dementia issues for healthcare professionals
- information about memory clinics, municipal social services, insurance organisations, care units, dementia day-care centres, private and public hospital departments all over Greece.

Paraskevi Sakka, Chairperson of Alzheimer Athens and of the National Observatory for Dementia stated: “The ongoing COVID-19 pandemic has dramatically increased the need for help and support of people with dementia and their families. Alzheimer Athens created the Helpline 1102 which provides direct and specialised support and liaises with institutions and services for dementia throughout Greece. Our goal is for every person with dementia and every carer in Greece, wherever they might live, to be properly supported and informed”.

Helpline 1102 operates Monday to Friday 9:00-19:00. Alternatively, users can communicate via live webchat or send an email to 1102@alzheimerathens.gr and the specialised consultant will contact them as soon as possible. The service is free of charge.

More information on the website: www.alzheimerathens.gr

23 February: Alzheimer Slovenia continues to organise on-line Alzheimer Cafés and workshops

Alzheimer Slovenia (Spominčica) is successfully continuing with its successful series of online Alzheimer Cafés, where different professionals provide much-needed information to carers, family members and other professionals.

At the February 2021 Alzheimer Café, professionals from the Neurology Clinic Ljubljana together with professionals from nursing homes, expressed their concerns about observed deterioration in the cognitive abilities of older people, with or without a diagnosis of dementia during the pandemic. The largest Slovenian newspaper, "Delo" published a large article about the online Alzheimer Cafés, organised by Spominčica.

Maintaining an active and meaningful life is one of the key factors for maintaining quality of life, for people with dementia. During COVID-19, when everyone is facing significant changes in their daily routines, it is important to raise awareness among the public, about recognising the first signs of dementia and also how to maintain as active and as independent a life as possible.

During the COVID-19 pandemic, when people are mostly concerned about infection prevention measures, it is also important to pay attention to cognitive health. In case someone perceives changes in their own cognitive abilities that affect their daily life, it is important to consult a doctor as soon as possible. It is true that access to doctors is more difficult, but there are still many other options to talk to a
specialist who can help people access information about dementia and symptoms. To facilitate the accessibility to this vital information, Spominčica has strengthened its counselling service, using external professionals from various fields (neurologists, psychiatrists, psychologists, nurses, social workers, lawyers), all of whom have many years of experience working with people with dementia.

To help reduce the effects of social isolation, Spominčica’s trained volunteers maintain regular contact with people with dementia. Spominčica also continues to hold weekly meetings online with carers and people with dementia, and provides a helpline and a variety of activities via online workshops. “It is very good to talk to people with dementia, share memories, keep in touch, and also help relatives with advice and knowledge.” concluded Štefanija L. Zlobec, president of Spominčica.

The principal aim of the review was to recommend improvements to adult social care in Scotland, primarily in terms of the outcomes achieved by and with people who use services, their carers and families, and the experience of people who work in adult social care.

The Independent Review concluded at the end of January 2021 and its report, together with an accompanying short film, was published on 3 February 2021.

The recommendations and key points within the report are centred around three key points:

- Shifting the paradigm – changing the way in which social care and support is viewed
- Strengthening the foundations – creating step changes in the implementation of policy and the use of improvement methodology
- Redesigning the system – establishing a National Care Service and a change in the way in which services are planned and commissioned.

The full report can be accessed at: https://www.gov.scot/publications/independent-review-adult-social-care-scotland/

The short film about the review can be viewed at: https://youtu.be/_bEt9NwrTXE

17 February: Government of Portugal’s national recovery and resilience plan includes funding for implementation of Dementia Health Regional Plans

In the framework of the political agreement on the Recovery and Resilience Facility, the Government of Portugal has prepared its national recovery and resilience plan, to be assessed by the Commission and hopefully adopted by the Council. The plan was launched on 17 February and is under public discussion for 15 days thereafter.

It was with great happiness and hope that Alzheimer Portugal discovered, on pages 45 and 46 of this 147-page document, an investment of EUR 85 million to conclude “The Mental Health Plan Reform”, the objectives of which include the implementation of the “Dementia Health Regional Plans”.

The five Regional Dementia Plans are finished, since July 2019, but in spite of some reminders from Alzheimer Portugal to the Health Minister, nothing was happening, until now. This investment comes as a very pleasant surprise, during such turbulent and uncertain times.

In June 2018, the Portuguese Health Ministry launched the “Health Strategy for Dementia”, which is the result of the recommendations included in the “Bases for the Definition of Public Policies in the Field of Dementia”. The Strategy sets out the principles of care for people with dementia, criteria on prevention, early detection, availability of clinical and comprehensive diagnosis, therapeutic intervention at primary care level, hospital and specialised care, and a care pathway based on the ethical principles of proximity, availability, equity and continuity. The Regional Plans were built in respect of these guidelines.

It is also important to highlight other measures in the Portuguese recovery and resilience plan, that may contribute to promoting the quality of life of people with dementia, such
as: measures related to the reform of primary care and its articulation with other levels of care; the improvement of proximity services with special focus on home and community services and facilities; requalification and innovation at nursing and residential homes for the elderly, people with disabilities or with incapacity.

Finally, the implementation of the "National Strategy for the Inclusion of People with Disabilities 2021-2025" is planned. This Strategy will have a positive impact on people with diminished capacity, reinforcing the awareness of the importance of defining appropriate and flexible measures in the exercise of legal capacity.

Alzheimer Portugal will make every effort to ensure that the measures contained in this Plan come into effect as soon as possible, to ensure a better quality of life of people with dementia and their families.

19 February: There are 29% more people with dementia in Norway than previously thought, study finds

A study, carried out by the Norwegian National Advisory Unit on Ageing and Health and published in the Journal of Alzheimer’s Disease, has found that there are 101,118 Norwegians living with dementia, 29% more than had been previously estimated. Results were presented to the Minister of Health and Care Services, Bent Høie and Minister of Agriculture and Food, Olaug Bollestad during Norway’s annual "Demensdagene" - Dementia Awareness Days 2020.

In parallel, an interactive map of Norway was launched, based on the study and providing the number of persons diagnosed with dementia in each of Norway’s municipalities. It also predicts how their numbers will rise in the future.

"We are presenting, for the first time, a valuable tool that gives planners and politicians a solid foundation for smart decision-making. No one can excuse themselves in 2050, when the numbers with dementia have more than doubled, claiming ‘we didn’t know’," said Geir Selbæk, research director at the Norwegian National Advisory Unit on Ageing and Health and professor at the University of Oslo.

Until now, the prognoses were based on numbers from studies in other countries, and estimations ranged from 70,000 to 104,000 people living with dementia in Norway.

All residents of Nord-Trøndelag County over the age of 13 were asked to participate in this renowned study, and upwards of 10,000 in the age group 70+ were examined. The study was based on the Trøndelag Health Study (HUNT4), using questionnaires and clinical examination. People attended designated stations or were visited by the researchers, to undergo physical and cognitive tests. Taking this approach in their study, which is one of the largest studies of its kind in the world, Prof. Selbæk and his colleagues were able to achieve a far more accurate assessment of the numbers.

Prof. Selbæk gave further details on the methodology of the study:

“Data from the examinations as well as results from interviews with a family proxy were sent to the country’s leading clinicians in this medical field and they diagnosed the participants. The experts worked in pairs and a third colleague was asked to help out in cases when they didn’t concur on a diagnosis. Eventually, they reached a consensus on all the diagnoses. The findings from Nord-Trøndelag were then extrapolated for the entire Norwegian population, with help from the Norwegian Institute of Public Health.”

In addition to quantifying the dementia population in Norway, the Norwegian National Advisory Unit on Ageing and Health launched its "dementia map" to also indicate the prevalence of cases on the county and municipal levels. The numbers were achieved using population projection figures provided by Statistics Norway.

The map shows that the share of persons over age 90 with dementia – the group with the largest health and care needs – will increase sevenfold by 2050. "This means we not only have to ratchet up the resources and care models we have today, but also have to really reconsider the ways we could provide good services for dementia patients in the future," stated Prof. Selbæk.

Government Ministers Bent Høie and Olaug Bollestad attended the presentation of the study in connection with the launch of the Dementia Plan 2025 at Demensdagene 2020.

The interactive map can be found at: demenskartet.no

The study can be found at: https://pubmed.ncbi.nlm.nih.gov/33427745/

Pictured: Olaug Bollestad (left), speaking with Norwegian National Advisory Unit on Ageing and Health Manager Kari Midtbø Kristiansen (centre) and Research Director Geir Selbæk (right) at the Norwegian National Advisory Unit on Ageing (Photo: Bente Wallander, Ageing and Health)
SCIENCE WATCH

11 January: TauRx completes enrolment of its Lucidity Phase III trial for AD

On 11 January, the company TauRx Therapeutics Ltd announced it has completed the patient enrolment of its Lucidity Phase III trial for the treatment of Alzheimer’s disease (AD).

The Lucidity trial is a randomised, double-blind and placebo-controlled study evaluating the safety and efficacy of hydromethylthionine in people with AD encompassing mild cognitive impairment due to AD in US, Canada and Europe. Hydromethylthionine acts by blocking abnormal accumulation of Tau protein in the brain. Lucidity is the only late-stage study targeting the tau pathology of AD.

More than 500 research participants have been enrolled. They are receiving oral capsules (8 or 16mg/day of hydromethylthionine or placebo) twice daily for 52 weeks. The primary outcomes of the study are progression of cognitive decline and functional impairment over 12 months measured by standard clinical scales. Results are expected to be available by mid-2022.

http://bit.ly/2Oiqz6c

29 January: FDA extends review period for Biogen’s AD drug aducanumab

Aducanumab, a monoclonal β-amyloid antibody, has been evaluated in several clinical trials on mild Alzheimer’s disease (AD) and mild cognitive impairment, including the ENGAGE, EMERGE and PRIME trials. Since 7 August 2020, Aducanumab has been under priority review at the US Food and Drug Administration (FDA).

On 29 January, Biogen and Eisai have announced that the FDA has extended the review period by three months for the biologics license application for aducanumab. The decision by the FDA on the drug application was expected on March 7, but is now delayed until June 7, 2021.

“We are committed to working with the FDA as it completes its review of the aducanumab application,” said Michel Vounatsos, Chief Executive Officer at Biogen. “We want to thank the FDA for its continued diligence during the review.”

http://bit.ly/3kC0Z8s

2 February: Cassava Sciences announces interim results from its open-label study of simufilam in mild-to-moderate AD

On 2 February, the biopharmaceutical company Cassava Sciences announced results of an interim analysis from its open-label study of simufilam (formerly PTI-125) in Alzheimer’s disease (AD). Simufilam is a small molecule drug targeting the altered form of filamin A found in the AD brain to restore its normal shape and function.

This one-year, open-label and multi-center study is evaluating the long-term safety and tolerability of simufilam (100mg twice daily) in 100 people with mild-to-moderate AD. This study was initiated in March 2020 and is now approximately 80% enrolled.

The pre-planned interim analysis was conducted with data of the first 50 participants who have completed at least 6 months of treatment. Results showed that participants who received simufilam had improved cognition and behaviour scores. Simufilam was found to be safe and well-tolerated. Adverse events were mild and transient.

Based on these results, the enrolment target for this open-label study will be increased by up to 50 additional participants, to a total target of approximately 150 participants. In addition, the company plans to initiate a Phase III clinical program with simufilam in AD in 2021.


14 February: Hearing aids may protect against progression to dementia, study finds

An international team of scientists has found that people with mild cognitive impairment (MCI), who use hearing aids have a significantly lower risk of developing dementia and experience a slower cognitive decline.

The new paper, published in the journal Alzheimer’s & Dementia: Translational Research & Clinical Interventions on 14 February, is the first to investigate the link between hearing aids and progression to dementia in individuals with MCI.

The research team was led by Dr Magda Bucholc of Ulster University and used data from the National Alzheimer’s Coordinating Center (NACC). The researchers analysed a sample of more than 2,000 people over the age of 50 with hearing impairments, whose cognitive status ranged from MCI to dementia.

MCI involves decline in cognitive abilities greater than normal age-related changes but not severe enough to meet diagnostic criteria for dementia. Many individuals with MCI do not
progress to dementia and may even regain normal cognitive ability.

The study also looked at how participants’ scores in a standard cognitive test for dementia changed over time. Researchers found that the mean annual rate of decline in cognitive scores for non-hearing aid users with MCI was nearly 30% higher than the average rate of change for hearing aid users.

It is not yet known with certainty why hearing loss is associated with increased dementia risk. Potential explanations include a reduction in people’s ability to engage socially, resulting in higher rates of depression or loneliness, and/or changes to the brain associated with the impact of sensory deprivation. There is also the possibility that hearing problems require greater use of cognitive resources when individuals are engaged in listening.

Dr Sarah Bauermeister of Dementias Platform UK (DPUK) co-authored this new study. You can find out more about it, on the DPUK website:


15 February: Reduction of cardiovascular risk factors in mid-life may help protect against dementia in older age

On 15 February, Dr Marta Cortes-Canteli, Prof. Valentin Fuster and colleagues published an article in the JACC journal, evaluating the link between cardiovascular risk factors and subclinical atherosclerosis with alterations in brain metabolism that may predict dementia decades before the typical age of symptom onset.

Studies have conclusively shown that cardiovascular risk factors such as high blood pressure and smoking can also increase the risk of developing dementia. However, questions still remain about the specific contribution of mid-life atherosclerosis (which describes the deposition of fat-rich plaques that cause the narrowing of arteries) to dementia risk. In their study, Dr. Cortes-Canteli sought to address some of these questions, by evaluating atherosclerotic plaque burden and brain markers of neurodegeneration in middle-aged participants in the Progression of Early Subclinical Atherosclerosis (PESA) study. The PESA study includes asymptomatic 40 to 54-year old staff members of the Banco Santander in Madrid, who were invited to undergo cardiovascular risk factor assessment, 3D vascular imaging scans (to quantify atherosclerotic plaques in different arteries) and FDG-PET brain scans (to quantify brain hypometabolism, a marker of neurodegeneration that may predict dementia onset in later life). Evaluating data from 547 PESA participants, the researchers found that the amount of atherosclerotic plaque in the carotid arteries of participants was associated with a greater amount of brain hypometabolism, as measured using FDG-PET. They also identified strong associations between Framingham Risk Score (a generalised cardiovascular risk score), hypertension and brain hypometabolism, indicative of neurodegeneration. Looking at different areas of the brain, Dr. Cortes-Canteli and colleagues saw that cerebral areas showing hypometabolism included those known to be affected by neurodegeneration in dementia.

Together, these results underline the importance of controlling and mitigating cardiovascular risk factors early in life, to increase cognitive reserve and reduce the risk of dementia in later life.


15 February: Cortexyme provides update on its development program for COR388 in AD

On 15 February, Cortexyme, a clinical-stage pharmaceutical company developing novel treatments for altering the course of Alzheimer’s disease (AD) and other neurodegenerative disorders, announced that a partial clinical hold has been placed on its drug candidate COR388 by the US Food and Drug Administration (FDA).

The fully enrolled GAIN Phase II/III trial will continue as planned, participants with mild to moderate AD will continue to receive the study drug at their assigned dose, with top-line results expected in the fourth quarter of 2021. The GAIN trial protocol also includes an open-label extension study in the US. Following the institution of a partial clinical hold, the company has stopped enrolment and dosing in this open-label extension.


16 February: Researchers identify high gait variability as a marker of cognitive dysfunction

On 16 February, researchers from the Canadian Consortium on Neurodegeneration in Aging published an article on gait variability across neurodegenerative and cognitive disorders in the journal Alzheimer’s & Dementia. The study that led to the results involved 500 older adults with various forms of cognitive impairments as well as a group of controls.
The team assessed participants’ gait as well as their cognitive performance. Following on, they identified four independent gait domains (rhythm, pace, variability and postural control), these were then compared to cognitive performance. Looking at the results from the statistical analyses, the team found that high gait variability correlated with lower cognitive performance and helped to differentiate between Alzheimer’s disease and other forms of cognitive conditions.

The scientists therefore concluded that gait variability could be used as a marker of cognitive-cortical dysfunction, which can help to identify Alzheimer’s disease dementia.


17 February: SciSparc plans to conduct a Phase II trial with SCI-110 in AD

On 17 February, SciSparc Ltd., a clinical-stage pharmaceutical company focusing on the development of cannabinoid-based treatments, announced it has signed an agreement with The Israeli Medical Center for Alzheimer’s to conduct a phase II clinical trial in Alzheimer’s disease (AD).

The purpose of the study is to evaluate the safety, tolerability and efficacy of SCI-110 in 110 people with AD and agitation. The primary objective of the study is the safety of SCI-110 and the secondary objective is the ability of the drug candidate to ameliorate agitation and other behavioural disturbances in people with AD. The company plans to initiate the trial immediately after receipt of all the required approvals.

http://prn.to/2PrCjdO

22 February: Alector initiates a new Phase II trial with AL002 for early AD

Alector, Inc., a biotechnology company developing immuno-neurology therapies for the treatment of neurodegenerative diseases, has recently initiated a new Phase II trial in early Alzheimer’s disease (AD). The first participant has been dosed in the INVOKE-2 Phase II trial evaluating the efficacy and safety of AL002 in slowing disease progression in people with early AD. The study will enrol approximately 265 participants in US, Australia and Canada.

In addition, the company provided an update on its INFRONT-3 Phase III trial evaluating AL001 in people at risk for or with frontotemporal dementia due to a progranulin gene mutation (FTD-GRN). The first participant was dosed in July 2020 and the company is currently enrolling participants in US, Europe and Australia. Approximately 180 participants will be randomised to receive AL001 or placebo intravenously every four weeks.


DEMENTIA IN SOCIETY

1 February: Legendary singer Tony Bennett is living with Alzheimer’s dementia

94-year-old singer Tony Bennett has been diagnosed with Alzheimer’s disease dementia. While the diagnosis was made back in 2016, he has now made it public in an article in AARP magazine, an American magazine focusing on issues around ageing.

Mr Bennett has won 19 Grammy awards during his career, which stretches back to the late 1940s. He is still making music, albeit with
more difficulty, and has just finished making a second album with singer Lady Gaga, due for release this spring. He has also collaborated with other popular artists in recent years, including Amy Winehouse, Mariah Carey and Michael Bublé. His wife Susan Benedetto, 54, is his primary caregiver.

NEW PUBLICATIONS & RESOURCES

5 February: Scottish Dementia Alumni group publishes "Dementia and GP services - a peer to peer resource"

This booklet was researched and written by the Scottish Dementia Alumni, a group of people living in Scotland who have a collective lived experience of almost sixty years with dementia. The group was created to inspire and support people with a new diagnosis of dementia, as well as to campaign for the human rights of people living with dementia. According to the experiences of the group members, there is a need for clearer communication around GP Practice services, because services vary from area to area and from practice to practice. The aim of the booklet is to provide clear information to empower people with dementia to access GP services, as is their right, and to do so with confidence. The booklet also highlights the kinds of issues encountered by people living with dementia in Scotland, to allow GP Practice teams to respond to these and to provide better support. The Scottish Dementia Alumni are: Agnes Houston, James McKillop, Nancy McAdam and Martin Robertson. You can download the booklet here: https://bit.ly/3rnTIQL

10 February: New touchNEUROLOGY video explores how to meet the needs of disease-modifying therapies in Alzheimer’s disease

How can we evolve to meet the needs of disease-modifying therapies in Alzheimer’s disease? Watch an expert neurologist discuss the importance of early diagnosis and the future use of disease-modifying therapies in Alzheimer’s disease. This activity is provided by touchME and provided by an independent medical education grant from Biogen.

17 February: Alzheimer Europe and Interdem co-author paper on the language of behaviour changes in dementia

A new paper on “The language of behaviour changes in dementia: A mixed methods survey exploring the perspectives of people with dementia” has been published (early view) in the Journal of Advanced Nursing (JAN). This study adopted a human rights approach and employed an online and paper-based questionnaire to collect data, between November 2019 and March 2020. In total, 54 people with dementia, including members of the European Working Group of People with Dementia (EWGPWD), completed the survey. Participants felt that the language we use to talk about changes in behaviour could influence how people with dementia are viewed and treated and how people feel about themselves. While there was no universal agreement on terminology, there was an overall preference for terms that reflect the unmet needs likely to underlie perceived changes in behaviour.

Authors include Alzheimer Europe Director for Projects Dianne Gove and Project Officer Ana Diaz, and members of the Interdem network.


20 February: February: New book on Down Syndrome and dementia aims to raise awareness and understanding among family members, health and social care professionals, and students

A book on "Down Syndrome and Dementia" - the first in a 'sharing good practice' series, by Bob Dawson - has been published by The Choir Press. It is primarily aimed at family members, health and social care professionals, and students. The publication aims to identify the main issues affecting individuals with Down Syndrome who develop dementia. It is an awareness-raising book aimed at stimulating discussions that will hopefully encourage the reader to find out more, using the websites provided. It takes the form of questions and answers, with all the questions raised being actual questions from training courses run by the author. Bob Dawson has worked in health and social care for over 40 years. The book can be purchased from bob_dawson@ymail.com or online, via https://amzn.to/3iZJXQ7
The Centre for Dementia Research at Leeds Beckett University in the United Kingdom (UK) is looking to recruit a post-doctoral researcher with expertise in dementia research to join its team as a Research Fellow. This is an exciting opportunity to build an academic career in applied dementia research in a supportive and developmental environment. The post is a permanent, full-time position.

The closing date is midnight on 21 March, with interviews conducted virtually on 8 April.

For an informal discussion about this post, please contact Claire Surr, Professor of Dementia Studies:

c.a.surr@leedsbeckett.ac.uk

The link to the job description and employee specification is below.

http://bit.ly/3q7tcVX

Contact Alzheimer Europe:

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

Alzheimer Europe Board:

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

Alzheimer Europe Staff:

Executive Director: Jean Georges; Communications Officer: Kate Boor Ellis; Conference and Event Coordinator: Gwladys Guillory; Director for Projects: Dianne Gove; Project Communications Officer: Christophe Bintener; Project Officers: Cindy Birck, Angela Bradshaw, Ana Diaz; Policy Officer: Owen Miller; Finance Officer: Stefanie Peulen; Administrative Assistant: Grazia Tomasini.
## AE CALENDAR 2021

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 March</td>
<td>Biogen roundtable on Alzheimer’s disease</td>
<td>Owen</td>
</tr>
<tr>
<td>2-3 March</td>
<td>EMA PCWP and HCPWP joint meeting</td>
<td>Angela</td>
</tr>
<tr>
<td>3 March</td>
<td>EFPIA AD Platform</td>
<td>Jean</td>
</tr>
<tr>
<td>3 March</td>
<td>PAVE coordination meeting</td>
<td>Jean</td>
</tr>
<tr>
<td>3 March</td>
<td>Consultation EU-FINGERS Advisory Board</td>
<td>Ana and Cindy</td>
</tr>
<tr>
<td>4 March</td>
<td>Interdem AT taskforce - subgroup Covid19</td>
<td>Dianne and Ana</td>
</tr>
<tr>
<td>5 March</td>
<td>Neuronet working group on data sharing</td>
<td>Cindy and Angela</td>
</tr>
<tr>
<td>8 March</td>
<td>Optional meeting with members of the EU FINGERS Advisory Board</td>
<td>Ana</td>
</tr>
<tr>
<td>9 March</td>
<td>PRIME meeting on dissemination and stakeholder engagement</td>
<td>Angela</td>
</tr>
<tr>
<td>10 March</td>
<td>Secondment meeting with ESR from DISTINCT programme</td>
<td>Dianne and Ana</td>
</tr>
<tr>
<td>11 March</td>
<td>AI-Mind kick-off meeting</td>
<td>Jean, Cindy, Ange, Chris</td>
</tr>
<tr>
<td>11 March</td>
<td>Consultation with the RADAR-AD Patient Advisory Board</td>
<td>Dianne and Ana</td>
</tr>
<tr>
<td>12 March</td>
<td>WW-Fingers Network meeting</td>
<td>Jean</td>
</tr>
<tr>
<td>16 March</td>
<td>Online Conference Systems Showcase Day – AAE</td>
<td>Gwladys</td>
</tr>
<tr>
<td>22 March</td>
<td>Neuronet Scientific Coordination Board meeting</td>
<td>Jean, Cindy, Ange, Chris</td>
</tr>
<tr>
<td>23 March</td>
<td>Alzheimer’s Academy Meeting &quot;Benchmarking and comparing national dementia responses&quot;</td>
<td>Alzheimer Europe staff and members</td>
</tr>
<tr>
<td>24 March</td>
<td>Virtual Helsinki for Meetings and Events</td>
<td>Gwladys</td>
</tr>
<tr>
<td>30-31 March</td>
<td>RADAR-AD Annual Meeting</td>
<td>Dianne, Ana and Jean</td>
</tr>
</tbody>
</table>

## CONFERENCES 2021

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Format/ Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>9-10 March</td>
<td>Dementias Online, <a href="https://www.dementiasconference.com/dementias-online">https://www.dementiasconference.com/dementias-online</a></td>
<td>Virtual</td>
</tr>
<tr>
<td>10 March</td>
<td>Liverpool Dementia &amp; Ageing Research Forum webinar: 'What really matters to people living with dementia?', <a href="https://www.eventbrite.co.uk/e/liverpool-dementia-ageing-research-forum-march-2021-tickets-136000253419">https://www.eventbrite.co.uk/e/liverpool-dementia-ageing-research-forum-march-2021-tickets-136000253419</a></td>
<td>Webinar</td>
</tr>
<tr>
<td>23-26 September</td>
<td>15th World Congress on Controversies in Neurology (CONy), <a href="https://cony.comtecmed.com/">https://cony.comtecmed.com/</a></td>
<td>Dubai, United Arab Emirates</td>
</tr>
<tr>
<td>26-29 October</td>
<td>Digital transformation of healthcare: the added value of patient partnerships (EPF), <a href="https://epfcongress.eu/">https://epfcongress.eu/</a></td>
<td>Virtual</td>
</tr>
</tbody>
</table>
31st Alzheimer Europe Conference
Building bridges
Bucharest, Romania
29 November to 1 December 2021
www.alzheimer-europe.org/conferences #31AEC