I am pleased to be able to kick off 2021 with positive news in a number of areas. On the research front, January has seen an announcement from pharmaceutical company Eli Lilly, that its Phase II clinical trial TRAILBLAZER-ALZ evaluating donanemab in Alzheimer’s disease (AD) has met its primary endpoint. Donanemab is an investigational anti-amyloid therapy, targeting a modified form of beta amyloid called N3pG. In addition to this trial, Lilly is running a second Phase II trial, TRAILBLAZER-ALZ 2, to evaluate the safety, tolerability and efficacy of donanemab in people with early AD. This trial is currently listed in our Clinical Trials Watch service, to which we have just added two other Phase II trials this month. For more information, see the research section of our website.

There is plenty of dementia-related research happening across Europe, including a number of EU-funded projects in which Alzheimer Europe is a partner. The newly-launched LETHE project is one such initiative. LETHE is a personalised prediction and intervention model for early detection and reduction of risk factors causing dementia, based on AI and distributed Machine Learning. We look forward to collaborating with the other partners on this exciting new four-year project. On the subject of EU projects, it was announced, as part of the new EU-UK Trade and Cooperation Agreement, that the UK will retain access to the Horizon Europe research programme (2021-2027), however, its access will be less favourable compared with its previous access to Horizon 2020 when it was a Member State of the European Union.

Staying at the European level, I would like to thank the members of the European Alzheimer’s Alliance (EAA), who have shown their support following the publication of our report, “Dementia as a European Priority – A Policy Overview”. EAA Vice Chairs, Christophe Hansen MEP and Hilde Vautmans MEP, as well as EAA members Martin Brglez MEP and Chrysoula Zacharopoulou MEP, have spoken out about why they believe dementia must be prioritised across the health, social and research policies of the EU, including EU4Health and the Horizon Europe research programme.

At a national level, congratulations are in order for our friends at Federazione Alzheimer Italia, who have been instrumental in securing funding for Italy’s National Dementia Plan. While Italy’s Plan has been in place since 2014, it had no associated funding to allow its implementation. The news of specific funding will allow the country to start transforming objectives into concrete actions to support people with dementia.

One final piece of good news I want to share with you, is that the on-demand content from the virtual 30th Alzheimer Europe Conference #30AEC is now freely accessible. You can find out more in the Alzheimer Europe section of this newsletter.
COVID-19 SITUATION

5 January: US Alzheimer's Association launches the CNS SARS-CoV-2 Consortium, to study the long-term neurological consequences of COVID-19

On 5 January, in a Perspective article published in Alzheimer's & Dementia, the US Alzheimer's Association announced the launch of a global study to evaluate the long-term neurological consequences of COVID-19. The CNS SARS-CoV-2 study will be led by a global consortium from 30 different countries, receiving technical advice from the World Health Organisation (WHO), and focusing on the link between the coronavirus and cognitive decline, Alzheimer's Disease (AD) and dementia.

In the article, lead author Prof. Gabriel de Erausquin and colleagues outline what we currently know about SARS-CoV-2 - the coronavirus that causes COVID-19 - and the central nervous system (CNS). Describing evidence which suggests that coronaviruses can directly infect brain cells, they outline how SARS-CoV-2 may enter endothelial cells (specialised cells that line the inside of our blood vessels) by binding to ACE2 receptors, kicking off an inflammatory cascade that culminates in vascular dysfunction and disease. COVID-19 infection in older people is associated with several neurological symptoms, including delirium, loss of taste, altered behaviour and cognition. However, it is not yet known whether these symptoms are due to direct effects of COVID-19 on the brain - or indirect, systemic effects on other body systems. In particular, the authors highlight the established link between vascular disease and cognitive decline, suggesting that the increased incidence of stroke and vascular problems after COVID-19 infection may also contribute to an elevated long-term risk of dementia in recovered individuals.

To better understand the long-term consequences of SARS-CoV-2 on the brain, cognition and dementia, the CNS SARS-CoV-2 study will link study teams from many different countries worldwide, which together have reported over 22 million cases of COVID-19. With participants already enrolled in dementia research studies, the CNS SARS-CoV-2 consortium will study how people with or without COVID-19 progress following diagnosis, aiming to enrol around 40,000 COVID-19 survivors in total. Specific measures to be evaluated include cognition, behaviour and, where possible, brain volume - as measured using MRI scans. The study will initially be funded by the Alzheimer's Association, with researchers also seeking funding from their respective countries.


15 January: Scientific seminar on COVID-19 and physical exercise held by Panhellenic Federation of Alzheimer's Disease and Related Disorders

Since early 2020, the Coronavirus (COVID-19) has been spreading quickly through over 100 countries around the world and millions of people have been infected during 2020. The outbreak of the pandemic has brought relentless challenges to human health and it is still raging on. To cope with the crisis, many countries have taken urgent measures to safeguard their people, while researchers in a variety of scientific areas have been engaged in finding a solution.

In this environment, the Panhellenic Federation of Alzheimer's Disease and Related Disorders decided to organise a scientific seminar in the field, called "Guidelines for therapeutic physical exercise - COVID-19". The online seminar was held on 15 January 2021, with over 80 participants. The event focused on the worldwide circumstances during the COVID-19 pandemic; how the disease affects people's lives from different aspects; sharing important information and data to help the world fight COVID-19 and especially for people with dementia and their carers.

The speakers were Magdalini Tsolaki MD, PhD. Professor of Neurology, Christos Savvopoulos MD, PhD, Professor of Pathology, Charalampos Tzorbatzoudis PhD, Professor of the Department of Division of Human Studies TEFAA, Dr Vasiliki Garopoulou M.Sc.’s., PhD., P.D. Adapted Physical Education & Sports and Dr Christos Mouzakidis M.Sc., PhD., Physical Education & Sports. They addressed the following topics:

1. General Principles - Sources transmission of the virus
2. Antihypertensive treatment and Covid-19
3. Why Coronavirus Causes Serious Disease in Certain Population Groups
4. Individual Protection Measures and Health protocols
5. Mental health tips - Covid in Alzheimer's disease
7. Safe physical exercise during the Covid-19 period
8. Prevention and protection measures
9. Special adjustments of physical activity - therapeutic physical exercise
At the end, the participants had the opportunity to discuss with the speakers and ask them questions.

21 January: Alzheimer Slovenia organises online workshops and Alzheimer Cafes to ensure continued support for people with dementia and their families during COVID-19 pandemic

Spominčica (Alzheimer Slovenia) organises various online workshops for people with dementia and their families, on a weekly basis. Due to the COVID-19 pandemic, traveling outside municipalities in Slovenia is restricted, since late October 2020, and the majority of public life is shut down, including daycare/activity centres and schools. With online activities, Spominčica enables people with dementia and their carers to maintain contact, and their cognitive and social skills. Moreover, the association provides them with social support and counselling. Online workshops include training, information and resources about meaningful activities, maintaining the daily routine and using serious games. Spominčica aims to empower the relatives and carers of people with dementia, by sharing information about non-pharmacological interventions that can help maintain autonomy, reduce cognitive and behavioural decline and improve the quality-of-life of whole families affected by dementia.

Spominčica also organised online Alzheimer Cafes during this difficult period. In January, experts at these events spoke about how life has changed for people living with dementia or Parkinson’s disease, and about how their relatives’ lives have changed, too, during COVID-19. The challenges faced by these groups of people are difficult to manage even in “normal” circumstances, and the COVID-19 period has added a number of other problems.

The President of the Commission for Medical Ethics of the Republic of Slovenia, Dr Božidar Voljč, discussed the ethical aspects of the COVID-19 vaccination. "In the case of people with dementia, special consideration should be given to the ethical principle of free decision-making about vaccination. Through vaccination, each individual contributes to the health and security of society as a whole."

Dr Milica Gregorič Kramberger, Head of the Centre for Cognitive Disorders, presented the impact of COVID-19 on the management of neurodegenerative disorders. "Many outpatient appointments have been cancelled or replaced with telephone consultations, and hospital and therapeutic treatments cannot be performed due to limited options and adjustments to health care during the epidemic."

27 January: INTERDEM holds meeting of the task force on technology use during the pandemic

On 27 January, the INTERDEM task force on the use of technology by and for people with dementia and carers during the COVID-19 pandemic held its second online meeting, which was chaired by Laila Øksnebjerg. The group discussed the scope and possible approaches to the topic, and shared initial ideas on the methodology. Dianne Gove is participating in this working group.

ALZHEIMER EUROPE

15 January: Access on-demand content from the 30th Alzheimer Europe Conference for free!

If you didn't get a chance to participate in the virtual 30th Alzheimer Europe Conference last October, you can now access some of our on-demand content from the event, free of charge.

You will be able to view videos of plenary and parallel presentations, as well as quick oral presentations and posters. All details can be found on our webpage: Click here for full details

The programme and abstract book of our virtual conference can be found on our website. Click here

18 January: AE adds two 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 January 2021, two new Phase II trials have been added to the service:

- The purpose of the GRADUATION study is to evaluate the effects of once weekly administration of Gantenerumab in participants with early (prodromal to mild) AD.
The VIVIAD study is aiming to evaluate the safety, tolerability and efficacy of PQ912 in people with mild cognitive impairment and mild dementia due to AD.

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

28 January: EWGPWD holds zoom meeting

On 28 January, the EWGPWD members had a zoom meeting to discuss upcoming work. The group was pleased to welcome two Early Stage Researchers, namely Simone Felding and Beliz Budak, who are doing secondments at Alzheimer Europe in the context of the DISTINCT project. Simone and Beliz introduced themselves to the group and briefly explained the topic of their research. The group agreed on additional communication channels to use during the pandemic, exchanged information on the technical resources available to them and briefly discussed some of the upcoming projects, as well as Alzheimer Europe’s ethics work, with a view to determining levels of interest and desired involvement. Ana Diaz and Dianne Gove facilitated the meeting.

Alzheimer Europe networking (online)

On 6 January, Jean had an introductory call with Lundbeck.
On 8, 11 and 19 January, Ana and Cindy participated in the informative meetings of the EU-FINGERS Advisory Board.
On 8 January, Dianne took part in the pre-Interim review meeting for the RADAR-AD project.
On 14-15 January, Dianne and Ana took part in the RADAR-AD interim review.
On 15 January, Gwladys attended the High Impact Virtual Engagements webinar series.
On 19 January, Jean and Cindy attended the PRODEMOS General Assembly.
On 20 January, Jean met with representatives of the Global Coalition on Ageing.
On 20 January, Dianne participated in the social robotics webinar hosted by the Alzheimer’s Society of Ireland.
On 20 January, Ange, Jean and Cindy attended the launch meeting of the AI-MIND project.
On 20 January, Ange and Jean attended the General Assembly of the VirtualBrainCloud project.
On 20 January, Owen met with the E4Health Civil Society Alliance to discuss the future work programme of the group.
On 21 January, Jean had a call with Biogen.
On 25-26 January, Ana, Chris and Jean attended the kick-off meeting of the LETHE project.
On 26 January, Ana, Chris and Jean attended the kick-off meeting of the LETHE project.
On 27 January, Dianne attended the Miriade project check meeting.
On 27 January, Jean had a call with Roche.
On 27 January, Jean and Cindy attended the National Institute for Health Research (NIHR) webinar on recruiting and retaining research participants.
On 27 January, Gwladys attended an event on Think sustainably - the new era of events.
On 27 January, Gwladys attended the Budapest virtual FAM.
On 27 January, Dianne attended the zoom meeting of the INTERDEM AT Taskforce - subgroup Covid19.
On 28 January, Dianne and Ana participated in the meetings of the EWGPWD.
On 28 January, Owen met with the European Non-Government Organisations Group, hosted by European Disability Forum.
On 29 January, Gwladys attended the Brussels European Association Forum.
On 29 January, Jean attended a Biogen AD Steering Committee meeting.
Professor Miia Kivipelto was awarded the Ryman prize by the Right Honourable Jacinda Ardern, Prime Minister of New Zealand, at a special ceremony in Auckland, New Zealand. Due to the COVID-19 pandemic Professor Kivipelto joined the ceremony via video-link.

The Ryman Prize is an annual USD 250,000 international award for the best work carried out anywhere in the world that has enhanced quality of life for older people. The prize was established to create the equivalent of a Nobel Prize for people working in the field of the health of older people.

The award recognises Professor Kivipelto for more than 20 years of research into the prevention, diagnosis and treatment of cognitive impairment, Alzheimer’s disease and dementia. She is leading the EU-FINGERS project, a JPND-funded consortium, which focuses on solutions for risk reduction of Alzheimer’s disease and dementia through a Precision Prevention approach.

Professor Kivipelto was delighted to win: “This is a great honour, not just for me, but for my team. I believe this will give us even more energy for what we do, which is more important than ever. We have kept going though COVID-19 and we are getting great results, and we will keep going.”

“The failure rate in Alzheimer’s disease drugs under development is 99.6% and there have been no new drugs approved since 2002. There is no miracle cure. Our research focuses on identifying who is at risk and finding ways they can reduce these risk factors. It is not just one solution – but there are a whole lot of things we can do to reduce the risk.”

Professor Kivipelto was singled out for this year’s prize for her tireless dedication to her research, and her far-reaching impact around the world.

“Our jury thought she was an outstanding candidate. Professor Kivipelto’s research is world leading, practical and influential. She leads a team of 100 researchers and clinical staff working on the challenge and her colleagues describe her as a very hard-working scientist who is absolutely dedicated to understanding disease and improving life for older people. She’s a great advocate for her field of research and there is no doubt she will use this recognition to her work. She is an inspiration, and this prize is a thank you for all the work she has done, and will no doubt continue to do.”, said David King, Ryman Prize Director.

https://www.rymanhealthcare.co.nz/the-ryman-prize/winners

13-15 January: ECR masterclass and general assembly meetings hosted by the H2020-funded PRIME project

Between 13-15 January, the PRIME project hosted a masterclass for early-career researchers (ECRs) and a two-day general assembly meeting. PRIME is a Horizon 2020-funded project that is studying dysfunctional insulin signalling in neurological conditions such as obsessive-compulsive disorder (OCD) and Alzheimer’s disease (AD).

Insulin is a key regulator of metabolism, promoting the uptake and processing of the sugars present in our food. Dysregulated insulin signalling is well-known as a driver of metabolic disorders such as diabetes. However new evidence points to a role for dysregulated insulin signalling in the brain as a contributor to neurological conditions such as OCD, autism spectrum disorders (ASD) and AD. The PRIME project is investigating whether disturbances in insulin signalling in the brain are linked to these conditions, using a wide range of preclinical and clinical approaches.

Alongside established researchers and clinicians, PRIME brings together a number of early-career researchers, defined as researchers who are currently doing or have recently finished, their doctoral studies. To make sure that the ECRs (who are based in several partner institutions) are actively involved and engaged with PRIME, Jeanette Mostert organized a day-long ECR masterclass, during which ECRs summarized their research and obtained feedback on presentations from members of the scientific and ethical advisory board.

During the PRIME GA meeting, which was chaired by Dr Janita Bralten (co-coordinator of PRIME), each of the work packages provided updates on progress over the past year. Despite the disruption caused by the COVID-19 pandemic, researchers have made good progress on addressing insulin mechanisms that may link the different neurological conditions that are the subject of PRIME. Between work package presentations, brainstorming sessions provided an opportunity for informal discussions of specific results, helping the consortium to refine the aims and objectives for PRIME in 2021 and beyond.

More information on PRIME can be found here:

https://prime-study.eu/
14 January: Two AMYPAD members have been awarded the AD/PD 2021 Junior Faculty Awards

Lyduine Collij, PhD student at the VU University Medical Center Amsterdam (VUmc, Netherlands), and Gemma Salvadó, PhD student at the Barcelona Beta Brain Research Center (BBRC, Spain) have been awarded the Junior Faculty Awards from the organising committee of the 15th International Conference on Alzheimer’s and Parkinson’s Diseases. The organising committee of AD/PD™ 2021 has recognized the top junior and trainee abstract presenters with Junior Faculty Awards. Eligible candidates for the Junior Faculty Awards were graduate students (PhD, MD) or junior scientists up to five years after the doctorate degree (PhD, MD). Recipients of this award are scheduled to give an oral presentation on their research during the conference (9-14 March 2021).

Lyduine and Gemma received this award for their work entitled “Visual assessment of [18F]flutemetamol PET images can detect early amyloid pathology and grade its extent”. This work was conducted within the Amyloid Imaging to Prevent Alzheimer’s Disease (AMYPAD) project. For further information on the AMYPAD project, visit www.amypad.eu

18 January: Alzheimer Europe Conference features 386 Million EUR Research Programme on Neurodegeneration

In 2019, the Neuronet Sessions introduced the projects of the Innovative Medicines Initiative (IMI) neurodegeneration portfolio to a broad audience composed of patients, caregivers, patient associations, researchers and clinicians.

This year, Neuronet expanded the focus of the event, titled “Working together to address common challenges for European neurodegeneration research”. Over the course of four parallel sessions, the programme showcased the work of IMI neurodegeneration projects on data sharing, ethics and regulatory/HTA interactions, and hosted presentations from early-career investigators working on these projects. In addition, it held a roundtable discussion, during which project leaders discussed the challenges experienced by public-private partnerships during the COVID-19 pandemic, and how research will evolve in the critical post-COVID period.

We are pleased to provide you with recordings of the 2020 Neuronet Sessions, which were held as part of the 30th Alzheimer Europe Virtual Annual Conference between 20-22 October, under the banner “Dementia in a Changing World”. Follow this link for to access the recordings: https://www.imi-neuronet.org/2020-virtual/

19 January: Three informative meetings for the EURO-FINGERS Advisory Board are held in January

EURO-FINGERS (EU-FINGERS) is a JPND funded project led by Karolinska Institute in Sweden. The work of EU-FINGERS started in 2020 and will continue for two more years. EU-FINGERS 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. The project has a Work Package dedicated to understanding and including in the project the views of people affected by Alzheimer’s and the general public. Part of this work involves setting up an Advisory Board composed of people affected by Alzheimer’s, people who have participated in prevention studies and lay people with an interest on this topic. This work is led by

Gove presented the Public Involvement work carried out by the Patient Advisory Board, as well as some of the earlier focus group work carried out in the UK, the Netherlands and Greece. The members of the PAB included people with Mild Cognitive Impairment, as well as people with dementia and their supporters from the European Working Group of People with Dementia.

On 15 January, there was an Interim Review of the RADAR-AD project. Ana Diaz and Dianne Gove presented the Public Involvement work carried out by the Patient Advisory Board, as well as some of the earlier focus group work carried out in the UK, the Netherlands and Greece. The members of the PAB included people with Mild Cognitive Impairment, as well as people with dementia and their supporters from the European Working Group of People with Dementia.
Alzheimer Europe in close collaboration with all project partners. The different organisations involved in EU-FINGERS identified in 2020 possible candidates for joining the Advisory Board. Three online informative meetings were organized on 8, 11 and 19 January. In these meetings, people interested in joining the Advisory Board received information about the project, the plans for the Advisory Board and were able to ask questions. The meetings were also attended by members of the EU-FINGERS team. A total of 15 people with an interest in the Advisory Board took part in these meetings. They will now be invited to formally join the Advisory Board. It is expected that the work of the Advisory Board will kick off in February 2021. From AE, Ana and Cindy participated in the informative meetings.

EURO-FINGERS is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project. The project is supported through the following funding organisations under the aegis of JPND - www.jpnd.eu: Finland, Academy of Finland; Germany, Federal Ministry of Education and Research; Spain, National Institute of Health Carlos III; 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 January: The PRODEMOS project holds its General Assembly meeting

On 19 January, the Prevention of Dementia using Mobile phone Applications (PRODEMOS) project held its General Assembly (GA) meeting online. The project is aiming to make an evidence-based dementia prevention strategy using mobile Health (mHealth), accessible to those at increased risk of dementia. The meeting commenced with Edo Richard welcoming more than 20 delegates, including representatives from the 8 institutions and organisations that make up the PRODEMOS consortium. During the GA, representatives from the different work packages in the project provided summaries on the work carried out to date and work planned for the coming months. Alongside, partners received an overview on the qualitative research work including pilot evaluations, an update on the recruitment and the mHealth platform.

The next PRODEMOS GA will be held during the summer. Jean Georges and Cindy Birck represented Alzheimer Europe (AE) at the PRODEMOS GA. AE is partner in the project and is involved in the coordination and management, crossing cultural barriers and dissemination and communication work packages of this project.

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

20 January: The VirtualBrainCloud project holds a General Assembly meeting online

On 20 January, the H2020-funded VirtualBrainCloud project (TVB_Cloud) held its General Assembly meeting online, chaired by Prof. Petra Ritter, who is leading the project. The meeting was attended by over 50 project participants, including representatives from the 17 institutions and organisations that make up the TVB_Cloud consortium.

The primary objective of TVB_Cloud is to create a decision support system for clinicians, formed around a cloud platform for personalised brain simulations based on high-quality, multidisciplinary clinical data, encompassing brain scans, -omics and blood-based biomarker data. This decision support system will enhance the early diagnosis, prognosis and personalised treatment of neurodegenerative diseases, with an initial focus on Alzheimer’s disease (AD).

Petra Ritter kicked off the TVB_Cloud General Assembly (GA) meeting by providing an overview of the key accomplishments since TVB_Cloud started in January 2019. These include the development of ‘Trusted Cloud’ principles, pathways for visualisation of brain imaging series, a virtual research environment platform, and a data protection framework for patient data. Providing further detail on these developments, leaders presented updates from the coordination, legal & ethical, technical and clinical data work packages. To close the meeting, members of the Ethical Advisory Board provided feedback to the consortium, congratulating them on their progress to date.

More information on TVB_Cloud can be found on the project website: https://virtualbraincloud-2020.eu/tvb-cloud-main.html
25-26 January: LETHE project holds virtual kick-off meeting

On 25 and 26 January, the LETHE project held its official kick-off meeting.

LETHE (A personalised prediction and intervention model for early detection and reduction of risk factors causing dementia, based on AI and distributed Machine Learning) is a four-year project funded under the Horizon 2020 research programme. It is aiming to provide a data-driven risk factor prediction model for older individuals at risk of cognitive decline building upon big data analysis of cross-sectional observational and longitudinal intervention datasets from 4 clinical centres in Europe including the 11-years analysis of the FINGER study. LETHE is set out to establish novel digital biomarkers, for early detection of risk factors, based on unobtrusive ICT-based passive and active monitoring. The aim is to establish a digital-enabled intervention for cognitive decline prevention based on the evolution of a successful protocol (FINGER) evolving into an ICT based preventive lifestyle intervention through individualized profiling, personalized recommendations, feedback and support (FINGER 2.0), well targeted on a population stratified by cost-effective biological biomarkers.

The LETHE solution will be tested in a feasibility study validating the achieved improvements.

The kick-off meeting was chaired by Project Coordinator Hanke Sten from Johanneum Research limited company and provided partners with the opportunity to introduce their organisations and involvement in the project as well as opportunities for cross work package collaboration.

Ana Diaz from Alzheimer Europe presented on Alzheimer Europe’s main involvements, namely:

- Leading on the set up of a Patient Advisory Board which will be composed of people affected by Alzheimer’s disease across the continuum.
- Leading on the communication to the dementia community leveraging on Alzheimer Europe’s extensive communication channels and the organisation of a symposium at an Alzheimer Europe conference. Furthermore, Alzheimer Europe will contribute to the overall communication, dissemination and exploitation of results.
- The meeting concluded with a General Assembly during which one representative from each partner institution shared their thoughts about the meeting and possible challenges with regard to the project.

26 January: MIRIADE holds project check meeting

On 26 January, the beneficiaries, partners and ESRs took part in a project check meeting. This was aimed at assessing progress with and fulfilment of recruitment procedures, training programmes and the various roles and responsibilities of the various fellows and host institutions. The ESRs each provided an overview of their work and this was followed by discussion. Dianne Gove attended the meeting on behalf of Alzheimer Europe.

1 February: The Neuronet programme releases Knowledge Base dashboard representing key information on 18 neurodegeneration research projects

On 1 February, the members of the Neuronet (Efficiently Networking European Neurodegeneration Research) programme announced the launch of a pan-European Knowledge Base which brings together key information about the 18 projects of the Innovative Medicines Initiative (IMI) neurodegeneration (ND) portfolio.

This comprehensive resource is an integral part of Neuronet’s endeavour to boost collaboration across the research portfolio by assisting in identifying gaps, multiplying the portfolio’s impact, and enhancing its visibility with related initiatives in Europe and worldwide.

“The Neuronet Knowledge Base tool intends to bring the “better together” team concept to life and overcome the inherent fragmentation often found in a project-based research landscape,” said Carlos Díaz, CEO SYNAPSE and Neuronet Coordinator.

Programme overview

As well as providing a summary overview of the IMI neurodegeneration research programme through its interactive dashboard, the Neuronet Knowledge Base includes links to over 380 publications and more than 350 publishable deliverable reports, acting as a one-stop shop to explore the diverse projects and outputs of the programme.

Knowledge Base tools

An “Asset Map” gives a comprehensive view of the different assets resulting from the projects, such as genetic datasets, clinical cohorts, and data platforms. The interactive map allows users to obtain more detailed information about the specific assets of each project. Furthermore, the Knowledge Base offers access to a regulatory, health technology
assessment & payer engagement Decision Tool to help researchers identify the key processes and procedures for engagement with these stakeholders at key points in the development of an asset.

**Staying up to date on scientific progress and activities**

In addition to project and programme-related information, users can also access an agenda listing key upcoming scientific conferences and view a feed with the latest project-related activities.

“This newly developed platform is key in Neuronet’s effort to centralize and integrate the vast amount of knowledge generated within the ND IMI portfolio,” said Lennert Steukers, Associate Director, Clinical Scientist, Janssen Pharmaceutica NV, and Neuronet Leader. “The Knowledge Base sets the stage for future research tools to inform and shape the next generation of research and advancements in the neurodegeneration field.”

The Knowledge Base can be accessed here:

https://kb.imi-neuronet.org/

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**EU project acknowledgements**

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

- **AMYPAD** – grant agreement 115952
- **EU-FINGERS** – INTER/JPND/19/BM/14012609
- **LETHE** – grant agreement 101017405
- **NEURONET** – grant agreement 821513
- **PRIME** - grant agreement 847879
- **PRODEMON** - grant agreement 779238
- **RADAR-AD** – grant agreement 806999
- **VIRTUALBRAINCLOUD** – grant agreement 826421

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**Members of the European Alzheimer’s Alliance**

Currently, the total number of MEPs in the Alliance stands at 95, representing 26 Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer’s Alliance (EAA):

Austria: Monika Vana (Greens/EFA). Belgium: Petra de Sutter (Greens/EFA); Frédérique Ries ( Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans ( Renew Europe). Bulgaria: Radan Kanev ( EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk ( Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D). Croatia: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). Cyprus: Costas Mavrides (EPP). Czech Republic: Tomáš Zdechovský (EPP). Denmark: Margrethe Auken (Greens/EFA); Christel Schaldemose (S&D). Estonia: Urmas Paet ( Renew Europe). Finland: Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Mia Petra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). France: François-Xavier Bellamy (EPP); Dominique Bilde (S&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet ( Renew Europe); Anne Sander (EPP); Chrysovala Zacharopoulou ( Renew). Germany: Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). Greece: Manolis Kefalogiannis (EPP); Stelios Kouloglu (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraki (EPP); Elissavet Vozember-Vronidi (EPP). Hungary: Tamás Deutsch (EPP); Ádám Kós (EPP). Ireland: Barry Andrews (ALDE); Deirdre Clune (NI); Ciárán Cuffe (Greens/EFA), Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke ’Ming’ Flanagan (GUE/NGL); Billy Kelleher ( Renew Europe); Seán Kelly (EPP); Mairead McGuinness (EPP); Grace O’Sullivan (Greens/EFA). Italy: Isabella Adinolfi (NI); Brando Benifei (S&D); Pierfrancesco Majorino (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). Lithuania: Vilija Blinkevičiute (S&D). Luxembourg: Marc Angel (S&D); Charles Goerens ( Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Isabel Wiseler-Lima (EPP). Malta: Roberta Metsoła (EPP); Alfred Sant (S&D). Netherlands: Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). Poland: Elżbieta Lukacijewska (EPP); Jan Olbrycht (EPP). Portugal: Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D). Romania: Cristian-Silviu Busoi (EPP); Marian-Jean Marinescu (EPP). Slovakia: Ivan Stefáneck (EPP). Slovenia: Franc Bogovič (EPP); Milan Brglez (S&D); Tanja Fajon (S&D); Klemen Groselj ( Renew Europe); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP). Spain: Iñasun 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).
Members of the European Alzheimer’s Alliance (EAA) have shown their support for the prioritisation of dementia at an EU level, following the publication of the Alzheimer Europe’s report, “Dementia as a European Priority – A Policy Overview”. EAA Vice Chairs, Christophe Hansen MEP (EPP, Luxembourg) and Hilde Vautmans (Renew, Belgium), as well as EAA members Martin Brglez MEP (S&D, Slovenia) and Chrysoula Zacharopoulou MEP (Renew, France), have outlined why they believe that dementia must be prioritised across the health, social and research policies of the EU, including EU4Health and the Horizon Europe research programme.

To highlight their support of the recommendations and aims of the report, Alzheimer Europe conducted a mini-campaign on social media, including images and quotes from these MEPs. You can see the Twitter Cards for each MEP here:

- Martin Brglez
- Christophe Hansen
- Hilde Vautmans
- Chrysoula Zacharopoulou

The Policy overview can be downloaded from:

1 January: EU DEVELOPMENTS

Portugal has taken over the rotating Presidency of the Council of the EU for the first half of 2021, under the motto ‘Time to deliver: a fair, green and digital recovery’. In addition, the country has set out its three overarching priorities during its mandate, including:

- To promote a recovery leveraged by the climate and digital transitions
- To implement the European Pillar of Social Rights of the European Union as a distinctive element for ensuring a fair and inclusive climate and digital transition
- To strengthen Europe’s autonomy whilst remaining open to the world, taking a leading role in climate action and promoting a digital transformation in the service of people.

The country has outlined that as part of its efforts to strengthen the European social model, a two-day Social Summit will be held on 7-8 May, in an effort to give momentum to realising the European Pillar of Social Rights across all Member States.

In addition, the Presidency has stated its intention to support the creation of a European Health Union, to strengthen the capacity to respond to public health crises, as well as building capacity to produce and distribute safe vaccines, in Europe and beyond. More information on the programme and events of the Presidency can be found at:
www.2021Portugal.eu

1 January: European Commission launches call for best practice examples for non-communicable diseases

The EU’s Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases recently identified their priorities in public health, with the prevention of non-communicable diseases identified as a key issue.

As a result, the European Commission is now calling for the identification and submission of best practices that can be shown to contribute to the prevention of non-communicable diseases, with a particular focus on the reduction of the use of tobacco products, improving the environmental determinants of health, reducing overweight and obesity, and reducing alcohol-related harm.

The Commission will invite the submitters/owners of the top ranked best practices to present them to Member States’ representatives in a Marketplace event, where countries may select their favourites for joint implementation across the EU. The implementation of those best practices may subsequently be supported by EU funding programmes.

EU DEVELOPMENTS
1 January: UK to participate in Horizon Europe research programme

On 24 December, the United Kingdom Government and the European Union announced the finalisation of the “EU-UK Trade and Cooperation Agreement” setting out the future relationship between the two, in relation to trade and a number of EU programmes.

As part of this agreement, the UK will retain access to the Horizon Europe research programme (2021-2027), however, its access will be less favourable compared with the UK’s access to Horizon 2020 when it was a Member State of the EU.

Under the Agreement, the UK will retain its ability to contribute and participate in the programme, as an Associate Member of the programme, and will be able to apply for top-tier membership, which would allow it to continue coordinate research within Horizon Europe. However, the agreement does not finalise all details of the UK’s association with the Horizon Europe programme and further negotiations will be required to formally “associate” with the programme.

The UK’s annual pay-in to EU programmes will be calculated based on the country’s gross domestic product as a share of EU GDP. A further sum, the participation fee, will be levied at 4% of the country’s operational sum. This contribution may be adjusted upwards or downwards “retrospectively”, depending on the level of funding received by the UK, compared to its contribution. The UK will also receive money in return should its researchers be excluded from any aspects of the Horizon Europe programme.

You can read further detail in the text of the Agreement which can be accessed at: https://ec.europa.eu/commission/presscorner/detail/en/ip_20_2531

12 January: EU Joint Programme on Neurodegenerative Disease Research (JPND) opens its 2021 call

The EU Joint Programme - Neurodegenerative Disease Research (JPND) has announced a new joint transnational call inviting multi-national research teams to submit proposals for ambitious, innovative and multi-disciplinary collaborative projects aimed at identifying and measuring pre-diagnostic physiological effects and related biomarkers that can be linked to the development of neurodegenerative diseases.

Proposals submitted under this call must focus on one or several of the following neurodegenerative diseases: Alzheimer’s disease and other dementias, Parkinson’s disease and PD-related disorders, prion diseases, motor-neuron diseases, Huntington’s disease, spinocerebellar ataxia and spinal muscular atrophy.

The JPND is committed to Patient and Public Involvement, and proposals are expected to engage patients, carers and the public.

In addition, proposals must focus on one or several of the following research areas:

- Demonstrating the relationship between early neurodegenerative processes and physiological disturbances,
- Applying cutting-edge methods or technologies to improve the detection of early symptoms,
- Human or animal studies to decipher the neurodegeneration-derived processes causing early disease-specific signatures,
- Using digital technologies to link recognisable symptoms to physiological changes associated to neurodegeneration,
- Relating prognostic signs of disease with real-life measurement of physiological disturbances using home-monitoring and/or wearable devices, including wireless sensors for patient monitoring.

Pre-proposals must be submitted no later than 15.00 C.E.T. on 2 March 2021. For more information about the call, see: http://bit.ly/2MNuzuL

28 January: European Commissioner publishes Green Paper on Ageing

The European Commission has launched its Green Paper on Ageing, beginning a policy debate on the challenges and opportunities of Europe’s ageing society.
The Green Paper outlines the impact of demographic changes in the EU, examining its effect on both the economy and society. Furthermore, the Commission is inviting stakeholders to contribute to a public consultation, which will run for 12 weeks.

The Green Paper identifies the need to introduce measures across a range of policy areas, including promoting healthy lifestyles, lifelong learning and strengthening health and care systems to provide care and support for a growing older population.

There are two specific references to dementia within the Green Paper, including in relation to the EU4Health programme, as well as the potential of lifelong learning to prevent cognitive decline and dementia.

Following the consultation, the Commission will consider possible policy responses to reinforce efforts in Member States and regions to address the issues around ageing.

You can access the Green Paper here: https://ec.europa.eu/info/sites/info/files/1_en_act_part1_v8_0.pdf

You can access the consultation here: https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12722-Green-Paper-on-Ageing/public-consultation

MEMBERS’ NEWS

1 January: Alzheimer Croatio conference achieves record attendance

In mid-December last year, Alzheimer Croatio held the 6th educational conference on Alzheimer’s disease - EDUKAL 2020, which surpassed all previous ones in the number of participants. The topic "COVID and dementia" virtually brought together 350 participants, which is 50% more than in previous years.

The conference was divided into four thematic units that discussed the impact of epidemiological measures on life with dementia, the ways in which COVID-19 affects people with dementia, general problems of mental health care and people with dementia and the impact of dementia friendly communities and organisations in Croatia.

Evaluating EDUKAL 2020, the participants said that this conference was one of the best so far. In the conclusions of the conference, they pointed out that the Parliamentary Health Committee should be encouraged to speed up Alzheimer Croatio’s proposal for a draft national strategy to combat dementia. They also stated that the City of Zagreb, as a dementia friendly community, should continue to work on developing a local strategy to improve the quality of life of people with dementia, as well as continuing the public service dementia education programme. Furthermore, they recommended that at least one drug that slows the development of dementia be re-requested to be placed on the list of free drugs.

The initiative to ask the competent ministries for support for the implementation of the establishment of dementia-friendly information points, with accompanying education and the development of appropriate information material, was also supported. Finally, the participants were in agreement that it is necessary to extend the MiniCog research, launched by Alzheimer Croatia in the Croatian capital, on cognitive impairment in older people and MoCa testing in nursing homes across the whole country.

1 January: Alzheimer’s Disease Association of Heraklion “ALLILENGII” reports on 7th Pan-Cretan Interdisciplinary Conference on Alzheimer’s Disease and Related Disorders

The proceedings of the 7th Pan-Cretan Interdisciplinary Conference on Alzheimer’s Disease and Related Disorders and the 3rd Pan-Hellenic Conference on Active and Healthy Aging was organised by the Alzheimer’s Disease Association of Heraklion “ALLILENGII” (5-7 November 2020). This year, all sessions were held online, due to the extraordinary circumstances we face, in the aftermath of World Alzheimer’s Month as well as the 15th anniversary of the founding of ALLILENGII, under the banner "Let's talk about dementia - No one should feel alone". This message underlines the importance of social solidarity despite the presence of COVID-19, which has changed our lives, our habits and our social contacts.

Delegates learned about the problems and difficulties that the pandemic presented in primary healthcare and the experience of GPs. They were informed about new technologies, services and synergies of public and private sector bodies all aiming at promoting healthy and active ageing in the Region of Crete. They learned about the latest news concerning the diagnosis of dementia such as measuring phosphotau 181 protein in patients' serum, and new future treatments such as the anti-β-amyloid antibody, aducanumab.
Interesting data were presented on sleep and its relationship with dementia, as were results from the THALIS programme and the older population of Crete, and the results from the Program for the Promotion of Active and Healthy Aging in Heraklion. Practical knowledge and exercises for the prevention of falls in the older population, and the new idea of "medical tourism" for older people were also presented.

Important information was shared about internet services in the time of pandemic, as well as the potential threats posed by the phenomena of telemedicine and e-government. European epidemiological data on the pandemic were presented; as were the principles of Geriatrics, the specialty that deals with the elderly in terms of maintaining their health; and functionality and quality of life were also addressed. There were 4,381 projections of these conferences.

12 January: France Alzheimer launches national survey on citizens’ knowledge of cognitive impairment

France Alzheimer, in collaboration with Professor Bertrand Fougère (CHU Tours) and the “Fédération des Centres Mémoire” (Federation of Memory Centres), have launched a major national survey, to establish the French people’s knowledge of cognitive disorders related to Alzheimer’s disease and dementia. It was launched on 12 January, via the France Alzheimer website.

This quick, anonymous online national survey will collect data with the aim of improving prevention campaigns.

Link to the survey:
https://troublescognitifs.evalandgo.com/s/index.php?a=JTk1bSU5N28lOUY=&id=JTk3bSU5NGklOTYlQUU

20 January: The Alzheimer Society of Ireland hosts online workshop examining use of social robots in dementia care

The Alzheimer Society of Ireland (ASI), in collaboration with NUI Galway and IT Sligo, hosted a successful free online workshop that sought to describe how social robots are being used in dementia care, and explore how they may be used in future care models in Ireland.

As part of the Erasmus+ funded Prospero project, the online workshop, “Using Social Robots in Dementia Care - Current Challenges and Future Possibilities”, took place on 20 January 2021. Over 110 delegates, from countries across Europe including the United Kingdom, Denmark, Germany, Italy, Malta, Greece and Belgium, attended the event.

Delegates at the workshop came from a variety of backgrounds, including social care practitioners, dementia experts, family carers, academics, roboticians, nursing students and occupational therapists. They had the opportunity to listen to a range of presentations describing current practice.

For example, The ASI is currently using Paro, the most widely researched care robot on the market. Paro is a therapeutic baby seal who responds to conversation and touch, which can bring comfort and support to residents. Having a robot like Paro can provide the same comfort and engagement levels can be really therapeutic for people with dementia.”

Delegates also participated in an interactive workshop to express their views on the future of social robots in dementia care. Many agreed that social robots can provide complementary care, but that more thought needs to go into robot design and functionality. Many other issues were raised, including those of cost versus benefit of using a robot and the importance of tailored and flexible design for the specific needs of people with dementia.

This workshop was funded by Erasmus+ Strategic Partnerships for Higher Education, and is part of the Prospero project which aims to examine and devise new ways of teaching future care professionals about how social robots can be used.

Pictured: Orchard Day Care Centre Manager Mary Hickey with Paro

21 January: Alzheimer Slovenia creates online workshop content for multiple European projects

Spominčica (Alzheimer Slovenia) has recently developed several contents for workshops in Erasmus+ projects such as AD-GAMING (adgaming.ibv.org), AD-AUTONOMY (adautonomy.eu), and DS-AGEING (dsageing.eu). During these workshops, the association has also created art together with older people (over 65) and people with dementia, as part of the Erasmus+ project AD-ARTS (adarts.eu), where they are developing a training programme on the use of creative art therapies to complement other therapies focused on minimising cognitive and behavioural decline. At Spominčica workshops, the participants prove to be able to create interesting things that involve different cognitive skills.

http://www.spominicica.si/
In 2021, Alzheimer Bulgaria launches an Erasmus+ project “3D4elderly”. The project aims to create innovative learning pathways that increase the quality of the work of caregivers and staff members working with people with Alzheimer’s and older people with dementia, as well as to raise the quality of life of people with dementia, using 3D technology.

The project introduces an innovative approach to tackle one of the first symptoms of a person with Alzheimer’s dementia: short-term memory loss. Some research states that it is possible, in the early stages of Alzheimer’s, to recover lost memories by stimulating specific hippocampal neurons, the area of the brain responsible for recording short-term memories.

For this reason, people with Alzheimer’s need cognitive stimulation exercises that activate memories, language, perceptions, reasoning, creativity, sociability and above all well-being. The use of 3D printing will help these people by offering them a multisensory experience thanks to the tools created.

The project team is composed of four partners from four different European countries (Italy, Spain, Bulgaria and Lithuania) and with various profiles: 3D printing experts (CEIPES and CETEM) close to the academic and business sector, and non-governmental voluntary organisations working in the interest of the community; BETI, a Research Institute, working in the field of ICT and education technologies with target groups composed of adults; and Alzheimer Bulgaria, the partner who works with people with Alzheimer’s and dementia, responsible for introducing and implementing the innovative 3D printing methods to them and their carers.

25 January: Polish Alzheimer’s Association has a new logo

As of January 2021, the Polish Alzheimer’s Association has adopted a new logo.

You can find out more about the association and its work, via its website www.alzheimer-waw.pl

25 January: Turkish Alzheimer Association presents “Tell Me a Story”

“Tell Me a Story” is a project designed to improve the quality of life of people with dementia, by reducing the depressing effects of the COVID-19 pandemic due to the difficult and isolated conditions they have to cope with. It is an endeavour that includes innovative methods of presenting fairy tales or stories, that are important building blocks of a person’s cultural values. Within the scope of the project, easy-to-access digital tools are used for storytelling, where the person with dementia watches the stories, which are recorded on five-minute-videos by volunteers, with acting and impersonating - to make the experience livelier. With the active participation of volunteers, the project also helps support public awareness of Alzheimer’s disease and the needs of people with dementia.

The first audio-visual stories were recorded by the staff of the Alzheimer Derneği (Turkish Alzheimer Association), reading and recording carefully chosen stories that are enjoyable, entertaining and joyful. These short videos were uploaded on the association’s YouTube channel and a group of caregivers was invited to test the videos with their loved ones. Upon the positive and enthusiastic feedback of this group, it was decided to develop the project, aiming to reach a wider audience.

Recently, volunteers are being accepted to the project, through digital forms published on the Turkish Alzheimer Association’s website. Volunteers are asked to record themselves reading a 5-to-6-page story, slowly and clearly, so that viewers with dementia can easily hear and understand. Once the videos are ready, volunteers share them with the editorial board formed for this project.

In the selection phase for the stories used, the volunteers are advised to avoid sad, frightening or worrying themes that include negative events such as death, sickness, separation, pain, abandonment, etc. They are also told to avoid offensive and abusive language and not to select juvenile stories aimed at children. It is important to pick stories that are appropriate for the age of the adult as well as ones that will cheer them up and preferably prompt them to laugh and feel energised. In addition, the stories are especially requested to be recorded using animation and voice-over techniques rather than prose reading, so that the viewer will be more engaged.
The story videos that meet these expectations will be announced on social media channels and will be a source of entertainment for all Turkish-speaking people, whether in Turkey or abroad.

This project aims to make older people - who constitute 8.6% of Turkey's population, i.e. more than 7 million citizens - feel more valued, dignified and socially connected, hence maintain their quality of life.

**25 January: Alzheimer Society of Ireland presents Year in Reflection Video - 2020**

The Alzheimer Society of Ireland (ASI) has produced a video thanking its staff who all worked so hard to adapt our services and supports in 2020. The ASI recognises that everyone made such a huge effort to support people living with dementia and their carers through the COVID-19 health crisis in 2020.

The ASI would like to thank all its staff, advocates, ambassadors, volunteers and everyone for their support during 2020 and wishes everyone the very best for 2021.

The charity has continued to support people with dementia and their families during COVID-19, as its Home Care, Dementia Advisers, National Helpline and Online Family Carer Training have remained open, and it has also implemented new ways of providing ASI supports remotely to its clients.

You can watch The ASI’s year in reflection video here: [https://www.youtube.com/watch?v=NLGseOm2bVA&t=4s](https://www.youtube.com/watch?v=NLGseOm2bVA&t=4s)

**31 January: Tipperary County Council partners with Ireland’s "Dementia: Understand Together" campaign and aims to better support people with dementia during COVID-19**

2020 has been a particularly difficult year for people living with dementia and their carers, family and friends. Many have been staying at home and some services had to be changed to help protect people with dementia from COVID-19. Important social connections, activities and therapeutic interventions so crucial for wellbeing have been missed. This group of people will need support from the community to stay well and stay connected.

There have been many innovations in recent months to help support people living with dementia, including online dementia cafes, Zoom sing-alongs by dementia-inclusive choirs, and resources including an At Home Activities Booklet and Weekly Planner for people living with dementia to help add structure and meaningful activities to their day. But research findings show that many have been struggling with loneliness, isolation, carer fatigue and a deterioration of the disease.

Tipperary County Council is aiming to have a community response to support people with dementia during COVID-19 and into the future, and is embarking on the journey of making its towns and villages dementia aware. Partnering with the Dementia: Understand Together campaign. The project aims to increase understanding of dementia, and to inspire people in communities who are affected by the condition to take practical steps.

In December 2020, representatives of community groups, businesses and other organisations participated in dementia awareness sessions provided by The Alzheimer Society of Ireland, as well as action planning. All local councillors were invited to a dementia training in January 2021. Inclusive design training for town planners and a walkability audit are also a part of the programme.

**28 January: Italy finally gets funding for its National Dementia Plan**

Precisely in the last days of 2020, a disastrous year for all of us we know, Italy has seen a little light at the end of the tunnel, on a matter that Federazione Alzheimer Italia has been campaigning on for years. The Parliament has approved an amendment to the 2021 budget law which provides for funding EUR of 15 million over 3 years, for the National Dementia Plan.

The Plan was created with the aim of providing strategic indications for the promotion of appropriate and adequate interventions to combat social stigma, protection and guarantee of rights, updated knowledge, coordination of activities, all aimed at the correct integrated management of dementia. Approved in 2014, it placed Italy among the first countries to have a national dementia plan; with the also demonstrated, however, that a plan without funding is not enough.

Finally, the approval of this funding lays the foundations to begin transforming the objectives of the Plan into concrete actions, thus allowing the planning of new interventions to support people with dementia. The Italian Ministry of Health has 60 days to indicate the criteria and methods for allocating
the funds. Although small, the amount allocated is a symbol of hope for people with dementia and their families. It represents a first step towards being able to provide concrete help in protecting the rights of people with dementia and their families, and in improving their quality of life.

The amendment included in the budget law was inspired by the bill of Senator Barbara Guidolin, and was written with the collaboration of Federazione Alzheimer Italia. Federazione Alzheimer Italia hailed this news as a great achievement, shared with all people with dementia, family members, healthcare professionals and all those who share the association’s goals:

"Now more than ever it is essential that our institutions demonstrate unity and give a concrete signal, by listening to the voice of people with dementia", concluded Gabriella Salvini, President of Federazione Alzheimer Italia.

SCIENCE WATCH

31 December: Axsome Therapeutics launches a Phase III trial of AXS-05 in AD agitation

On 31 December, the company Axsome Therapeutics, which develops therapies for the management of central nervous system disorders, announced that it has started a Phase III clinical trial with its drug candidate AXS-05 for the treatment of Alzheimer’s disease (AD) agitation.

The ACCORD Phase III trial is a randomised, double-blind and placebo-controlled trial to evaluate the efficacy and safety of AXS-05 in the treatment of AD agitation. Topline results from the ACCORD trial are expected in mid-2022.

AXS-05 received the Breakthrough Therapy designation from the US Food and Drug Administration (FDA) in August 2020. A Breakthrough therapy designation is a process to expedite the development and review of drugs for serious or life-threatening conditions. The Breakthrough therapy designation for AXS-05 in AD agitation was supported by positive results from the pivotal ADVANCE-1 Phase II/III study, which enrolled 366 US participants with agitation associated with AD. This trial met its primary endpoint by demonstrating a statistically significant improvement in AD agitation.


5 January: BioXcel Therapeutics announces positive results from its TRANQUILITY study for the treatment of agitation in dementia

On 5 January, BioXcel Therapeutics, a clinical-stage biopharmaceutical focused on drug development that utilises artificial intelligence to identify improved therapies in neuroscience and immuno-oncology, announced positive topline results for its Phase Ib/II trial evaluating BXCL501 for the treatment of agitation in dementia.

The TRANQUILITY Phase Ib/II trial was a randomised, double-blind, placebo-controlled and ascending dose study evaluating the efficacy, pharmacokinetics, safety and tolerability of BXCL501 in people of 60 years and older who have acute agitation associated with all forms of dementia. A total of 54 participants were enrolled in the trial; they received BXCL501 at either 30 µg (n=16), 60 µg (n=20), 90 µg (n=4) or placebo (n=14). 87% of these participants had Alzheimer’s disease (AD).

Top-line results showed that BXCL501 was generally well tolerated, with no severe or serious adverse events reported, with the most common side effect being somnolence. The trial met its secondary efficacy endpoints in the higher evaluable dose (60 µg) compared to placebo as BXCL501 was found to statistically reduce the agitation in people with different forms of dementia, including AD, as measured by several agitation scales. These reductions were both rapid and durable.


11 January: Biogen launches new virtual research study with Apple, aiming to develop digital biomarkers to monitor cognitive performance and decline

On 11 January, Biogen announced the launch of a new virtual research study in collaboration with Apple. Using the Apple Watch and iPhone as platforms, Biogen will examine whether technologies such as these can be used to monitor cognitive performance and screen for cognitive decline over time. The study will be launched later this year, aiming to enrol participants of all ages to determine which digital biomarkers most effectively monitor cognitive performance across the lifespan, and whether they can identify early signs of mild cognitive impairment, which can foreshadow the development of dementia. The study has been designed to comply with data protection regulations and will ensure that data is
11 January: Eli Lilly announces positive top results from Phase II study of donanemab in Alzheimer’s disease

On 11 January, the pharmaceutical company Eli Lilly announced that its Phase II clinical trial evaluating donanemab in Alzheimer’s disease (AD) met its primary endpoint. Donanemab is an investigational antiamyloid therapy, targeting a modified form of beta amyloid called N3pG.

The Phase 2 TRAILBLAZER-ALZ trial was a randomised, placebo-controlled, double-blind and multi-centre study evaluating the safety, tolerability and efficacy of donanemab in people with early symptomatic AD. The study enrolled 272 participants from Canada and US based on cognitive assessments, amyloid plaque imaging, and tau imaging.

The study reported that donanemab showed a significantly slower decline in cognition and daily function compared to placebo. Donanemab met the primary endpoint of change from baseline to 76 weeks in the Integrated AD Rating Scale (iADRS), slowing decline by 32% relative to placebo. The iADRS is a clinical composite tool combining the cognitive measure ADAS-Cog13 and functional measure ADCS-iADL, two measures used in AD.

Donanemab also showed consistent improvements in secondary endpoints measuring cognition and function as compared to placebo, but not all of these secondary endpoints reached statistical significance. Key secondary endpoints include changes between baseline and 76 weeks in the Alzheimer’s Disease Assessment Scale-Cognitive Subscale (ADAS-Cog13), ADCS-iADL, MMSE, and Clinical Dementia Rating Scale Sum of Boxes (CDR-SB) scores. Biomarkers such as amyloid and tau deposition in the brain were also assessed as secondary outcomes at week 76. In TRAILBLAZER-ALZ, donanemab showed a reduction of amyloid plaques with an average of 78%, or an 84 centiloid reduction at 76 weeks compared to a baseline of 108 centiloids. The company added that the safety of donanemab was acceptable and consistent with observations from Phase I data. In the donanemab treatment group, amyloid-related imaging abnormalities – edema (ARIA-E) occurred in 27% of treated participants, with an overall incidence of 6% experiencing symptomatic ARIA-E.

Patients assessed in TRAILBLAZER-ALZ are still participating in the ongoing follow-up trial TRAILBLAZER-EXT. The company plans to present the full results of TRAILBLAZER-ALZ at an upcoming conference. In addition, a second Phase II trial TRAILBLAZER-ALZ 2 is evaluating the safety, tolerability and efficacy of donanemab in people with early AD. The TRAILBLAZER-ALZ 2 was initiated in June 2020.

12 January: LSP and Philip Scheltens launch new, unique fund to fight dementia

On 12 January, European life sciences investor LSP (Life Sciences Partners) announced the launch of the LSP Dementia Fund, dedicated to fighting neurodegenerative diseases. The fund is being managed by world-renowned Dutch dementia researcher Professor Philip Scheltens (pictured).

The LSP Dementia Fund will focus on all stages of development of dementia drugs and medtech (medical technology) and as such is the first of its kind in the world. The focus will be on finding novel treatments for different neurodegenerative diseases that cause dementia, as well as generating a financial return for investors.

Prof. Scheltens said: "I am excited to make this move in my career to realise treatment options for patients, building on and combining it with the work I was able to do at the Alzheimer Center Amsterdam. I am very honoured to be a part of the LSP team, the largest and most experienced life sciences investor in Europe."

18 January: Biohaven’s experimental AD drug fails to meet its co-primary endpoints in Phase II/III study

On 18 January, Biohaven Pharmaceutical, a clinical-stage biopharmaceutical company with a portfolio of innovative candidates targeting neurological diseases, announced that its Phase II/III clinical trial of troriluzole in Alzheimer’s disease (AD) has missed its co-primary endpoints. This experimental drug modulates glutamate, the dysfunction of which is known to be implicated in AD.

In this randomised, double-blind and placebo-controlled study evaluating the efficacy and safety of troriluzole, 350 US research participants with mild to moderate AD received oral
capsules (280 mg of troriluzole or placebo) once daily for 48 weeks. A focused analysis showed that participants taking the drug, troriluzole, showed no statistically significant cognitive improvement compared to a placebo after 48 weeks on the study’s prespecified co-primary endpoints on the Alzheimer’s Disease Assessment Scale-Cognitive Subscale 11 (ADAS-cog) and the Clinical Dementia Rating Scale Sum of Boxes (CDR-SB). Troriluzole also did not differentiate from placebo on the key secondary measure of hippocampal volume assessed by magnetic resonance imaging (MRI). Top-line results showed that troriluzole was relatively well tolerated and demonstrated a safety profile consistent with previous studies of troriluzole.

The company is continuing to analyse the data, including additional secondary and exploratory efficacy analyses and biomarker data. These results are expected in the coming months and will be presented at an upcoming scientific meeting.

http://prn.to/36urE18

20 January: Trials@Home consortium invites patients and patient organisations to complete a survey on Remote Decentralised Clinical Trials

The Trials@Home consortium, a public-private-partnership funded by the European Commission and The European Federation of Pharmaceutical Industries and Associations (EFPIA), will explore the opportunities of moving clinical trials from the traditional clinic setting to the participant’s immediate surroundings. These so-called Remote Decentralised Clinical Trials (RDCTs) make use of new digital innovations and enable participants to visit a clinical trial centre less frequently, if at all.

In order to create these outcomes and develop training and educational materials, the consortium has launched a survey, aimed at patient organisations and the patients they represent, to explore opinions on RDCTs and find out how to help people to understand the matter better, by developing tailored training and education materials.

At the end of the survey, respondents are given the option to leave their contact details, if they wish to be kept informed about the outcomes of the survey, the resulting training materials or the possibility to potentially join panel discussions in the future. You can take the survey, here:

https://www.surveymonkey.com/r/S55Fj9P

21 January: Recent Think Brain Health conference focused on personalised plans, blood biomarkers and early conversations

The delay and prevention of neurodegenerative brain diseases through lifestyle changes and the anticipated benefits of ongoing research were the topics of a two-day virtual conference, Think Brain Health – a policy, clinical and research challenge, held in November 2020. The conference covered key aspects of the Think Brain Health initiative, highlighting the need to act early to:

- promote public understanding that preventing brain disease is possible and that "what is good for the heart is good for the brain"
- prepare healthcare professionals to manage people with or at risk of neurodegenerative brain disease
- prioritise research and build infrastructure to enable prevention, early detection and management of neurodegenerative brain disease.

A key discussion topic was delivery of interventions by primary care services, aimed at alleviating modifiable risk factors for dementia, and the distinct savings this provides to healthcare systems. Patients also highly value information about dementia risk estimation and shared decision-making; therefore, effective communication is key.

Furthermore, determining individual risk scores for all neurodegenerative brain disorders will aid healthcare professionals in managing populations – of those at risk and those already diagnosed. Identifying and managing at-risk populations will also require programmes that encompass risk profiling, early detection and personalised prevention plans.

An additional consideration is that rates of adherence to separate treatment programme interventions have been shown to vary. Therefore, public health strategies need to be personalised and consumer-focused to ensure engagement.

Finally, next steps encompassing encouragement, enhanced communication and education will help guide the development and implementation of suitable risk-reduction interventions – by embracing population-level factors and areas of importance to the individual that will encourage adherence to interventions.

If you were unable to attend the conference or want to revisit any of the presentations, you can find them all on the Think Brain Health website.

LIVING WITH DEMENTIA

25 January: Kevin Quaid, Vice-Chairperson of the EWGPWD, writes about his book “Lewy Body Dementia Survival and Me”

It’s a very broad statement “Living with dementia”; it can refer to so many people, the person who has dementia, the carer and indeed the entire family and close friends of the person diagnosed with dementia. So, what is it like to live with
dementia? Well, the short answer is that it’s not nice, because dementia, in all its forms, is both progressive and incurable and that should be enough to discourage anybody and to make you feel that it is the end; but this is not necessarily so. For a lot of people, it can be a new beginning and a completely new path in life, maybe you have had to give up your job or give up driving or give up something that you loved doing, which is often the case.

There are a few things that can be done, however, to make sure you get the very best out of a bad situation and the most important is to get the correct diagnosis of the type of dementia that you have, I think there are around 400 different types, and many times I have heard people say that their doctor has told them that they have “a touch of dementia” or “a sort of dementia”; that, to me, is totally inexcusable. Imagine going to a doctor and being told that you had “a touch of cancer” or that you had “a sort of cancer”! The first question would be: what type of cancer? and all the scans would be done in order to find out the type, so as the right form of treatment could be given for the type of cancer that has been diagnose. The exact same thing should be done with dementia, because the treatment that will work for one type of dementia might not work for another. Just to give you an example: I have Lewy body dementia and I have very little memory problems but my main problems actually occur at night, with nightmares and hallucinations, whereas a person with Alzheimer’s may have memory problems and will need totally different treatment and totally different medication, and that is just comparing two types of dementia, both are called dementia yet their symptoms are miles apart.

Another thing that I can tell you about dementia is that it can be harder on the carer than the person with dementia, because they are the ones that can see the lives of their loved ones change before their very eyes.

When I was diagnosed with Lewy body dementia, I wanted to find a new path in life, because I had to give up work and driving, and to my surprise I found that I have a love of writing. I became one of the first people in the world to write a book about Lewy Body Dementia from the patient’s point of view, and I now write a weekly column for a local newspaper. I have also started writing my second book, on how to live life after a horrible diagnosis. I want to show that there is still a life to be lived, and my one piece of advice about living with dementia is: never give up! Keep your brain active and keep on living.

If anyone wants a copy of my book it is available on Amazon and Kindle.

DEMENTIA IN SOCIETY

22 January: French comedian Elie Semoun releases documentary about his father’s final years, with Alzheimer’s dementia

French comedian, actor, director, writer and singer Elie Semoun lost his father, Paul Semoun, to Alzheimer’s dementia, in September 2020. Paul Semoun died in a nursing home and had not been able to see his family during the weeks leading up to his death, due to COVID restrictions.

Elie Semoun filmed many moments during the last four years of his father’s life, and has released a documentary called “Mon Vieux”, which looks at this period and reflects the pain felt by him and his family, but also the love, warmth and moments of real humour.

Elie Semoun said that he made this documentary, not only to remember and honour his father, but also to remind people of the importance of listening to, and respecting, one’s elders. He has also expressed his anger at the restrictions which prevented him and his father, and many other families, from sharing the last weeks or months of life, together.

“Mon Vieux” was aired in December 2020, on French television.

29 January: British drama film “Supernova” goes on US release

Supernova is a British drama film written and directed by Harry Macqueen. While it had its world premiere at the San Sebastián International Film Festival in 2020, it was released in the United States on 29 January 2021 and is scheduled to be released in the United Kingdom on 5 March 2021.

Sam and Tusker, played by Colin Firth and Stanley Tucci respectively, have been partners for 20 years. The couple are as passionately in love as they have ever been, but in the two years since Tusker was diagnosed with young-onset dementia, their lives have had to change. They decide to take a road trip together, while Tusker is still able to travel, reconnecting with friends and family and visiting the places of their past. As their journey unfolds, their individual ideas for the future begin to collide, secrets are aired, plans go awry, and their love is tested to its limits.
JOBS OPPORTUNITIES

20 January: Two job opportunities available to work with PriDem project, at University College London

There are currently two available opportunities to work with the PriDem (Primary care led support in dementia: Developing best practice) programme grant, which aims to evaluate acceptable, feasible and sustainable models of primary care and coordinated post-diagnostic dementia care, to maintain and improve quality-of-life for people with dementia and their families. The project is looking for two people to join its team, both based at University College London. The project is working with Newcastle University and also has international links. The two positions are:

Senior Research Fellow / UCL Programme Manager - This post is based in the UCL Centre for Ageing Population Studies (CAPS) - a multi-disciplinary group with expertise in intervention development, qualitative research, epidemiology and clinical trials. The post is available immediately and funded until 30 September 2022, in the first instance. The main role of the appointee will be to manage and implement new models of dementia care in the feasibility and implementation study in the final two years of the PriDem programme. Find out more: https://bit.ly/3aobkAb

Research Assistant - the main role of this post will be responsibility for the process evaluation as part of the wider feasibility and implementation study. The post holder will produce data collection and recruitment materials, recruit participants, undertake longitudinal semi-structured qualitative interviews and the analysis of data, which will draw on Normalisation Process Theory. This post is funded until 31 March 2022, in the first instance. Find out more: https://bit.ly/2NXsPQn

If you are interested please email g.rait@ucl.ac.uk or Jane Wilcock j.wilcock@ucl.ac.uk. The closing date for applications is 3 February 2021.

NEW PUBLICATIONS & RESOURCES

25 January: IDoService project gets going

As previously announced, the IDoService project titled “Facilitating Inclusion and Empowerment of People Living with Dementia through Access to Cultural and Creative Activities” was launched in October 2020. The IDoService, which is based at Manchester Metropolitan University, will conduct research and a pilot study in the area of Greater Manchester to develop the service. Offering a high level of dementia-friendliness is a priority for the region, as evidenced by the GBP 2.29m programme Dementia United launched in 2017, making Greater Manchester an exciting place for this project.

The IDoService takes a service design approach to co-develop, implement and evaluate a service that could help people living with mild dementia to connect with relevant groups, charities or other activity groups to realise themselves. Service design can be defined as the use of creative design tools and methods (e.g., co-design workshop) to develop or improve services. The IDoService objective is to support people to plan, connect with, and take part in activities they enjoy and in which they can have an active contribution.

The project’s first three months have allowed the research team to settle and get going with the project. Amongst others, activities included learning more about the various dementia-related charities and opportunities in Greater Manchester regarding meaningful activity participation and making contacts.

The next step is to speak to people with dementia and people from dementia organisations, through focus groups and individual interviews, which is planned in early February 2021. The project will speak to people living with mild to moderate dementia, as well as their family and friends, and other stakeholders in the field of dementia support, activities and advocacy. Their lived experience is essential to a better understanding of the availability, accessibility, needs, and wishes regarding leisure opportunities, and as a basis for developing the IDoService.

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

EDUCATION

1 January: European Federation of Neurological Associations (EFNA) launches online learning modules

The European Federation of Neurological Associations (EFNA) has developed a series of e-learning modules linked to advocacy activities. The modules have been developed with the aim of upskilling participants in relation to how they can effectively advocate, particularly in at a time where advocacy work is taking place online. The modules focus on different...
aspects of advocacy, including identifying and engaging key stakeholders, developing partnerships, hosting successful online events and developing and disseminating key advocacy messages.

The courses are video-based and divided into sections that can be watched independently at times that suit the viewer. Each module includes supporting notes and worksheets, as well as an option to take a quiz on the content and receive a personalised certificate of completion. You access the resources at: https://www.efna.net/elearning/

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>
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<tr>
<td>1 February</td>
<td>Meeting with EFPIA AD Platform</td>
<td>Jean</td>
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<tr>
<td>1 February</td>
<td>Brussels European Association Forum</td>
<td>Gwladys</td>
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<td>3 February</td>
<td>ADAIR General Assembly Meeting</td>
<td>Ana and Jean</td>
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<td>4 February</td>
<td>Management Group of Dementia Panel of European Academy of Neurology</td>
<td>Jean</td>
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<tr>
<td>5 February</td>
<td>High Impact Virtual Engagements webinar series</td>
<td>Gwladys</td>
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<tr>
<td>10 February</td>
<td>EFPIA Patient Think Tank</td>
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<tr>
<td>16 February</td>
<td>Meeting with Janssen</td>
<td>Cindy</td>
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<tr>
<td>16 February</td>
<td>PAVE Steering Committee Meeting</td>
<td>Jean</td>
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<tr>
<td>16 February</td>
<td>National Institute for Health Research (NIHR) webinar “Do we need to adapt study design and protocols“</td>
<td>Jean and Cindy</td>
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<tr>
<td>17 February</td>
<td>EPAD Scottish Sites Meeting</td>
<td>Cindy</td>
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<td>22 February</td>
<td>AE Board meeting, Alzheimer Europe Foundation meeting,</td>
<td>AE Board and staff</td>
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<tr>
<td>23 February</td>
<td>Alzheimer Europe Company Round Table, European Parliament workshop</td>
<td>AE members and staff</td>
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<tr>
<td>23 February</td>
<td>Carers Interest Group Meeting</td>
<td>Owen</td>
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<tr>
<td>24 February</td>
<td>Alzheimer Europe Public affairs meeting</td>
<td>AE members and staff</td>
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<td>24 February</td>
<td>Meeting with Roche</td>
<td>Jean</td>
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<tr>
<td>25 February</td>
<td>Virtual meeting of the INTERDEM social health task force</td>
<td>Dianne and Ana</td>
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### CONFERENCES 2021

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>18-21 Feb</td>
<td>12th Panhellenic Conference of Alzheimer’s Disease (PICAD) and the 4th Mediterranean Conference on Neurodegenerative Diseases (MeCoND), <a href="http://www.alzheimer-conference.gr">www.alzheimer-conference.gr</a></td>
<td>Thessaloniki, Greece</td>
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<tr>
<td>10 March</td>
<td>Liverpool Dementia &amp; Ageing Research Forum webinar: 'What really matters to people living with dementia?'</td>
<td>Webinar</td>
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<tr>
<td>23-26 September</td>
<td>15th World Congress on Controversies in Neurology (CONy)</td>
<td>Dubai, United Arab Emirates</td>
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<tr>
<td>26-29 October</td>
<td>Digital transformation of healthcare: the added value of patient partnerships (EPF)</td>
<td>Virtual event</td>
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<tr>
<td>29 Nov-1 Dec</td>
<td>31st Alzheimer Europe Conference</td>
<td>Bucharest, Romania</td>
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31st Alzheimer Europe Conference
Building bridges
Bucharest, Romania
29 November to 1 December 2021
www.alzheimer-europe.org/conferences #31AEC