ALZHEIMER EUROPE NEWSLETTER

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WELCOME

This month, Alzheimer Europe was delighted to meet with Dr Hans Kluge, Regional Director of the World Health Organization Regional Office for Europe. Our discussion focused on dementia policy, noting the positive developments at a global level, including the WHO Global action plan on the public heath response to dementia, and the Global Dementia Observatory, for which the Knowledge Exchange Platform has just been launched. The Platform contains key resources to support the implementation of the global action plan. The meeting with Dr Kluge also highlighted the excellent working relationship between the WHO, WHO Europe and Alzheimer Europe. I would like to thank him for taking the time to meet with us, for his interest in our work and for acknowledging the importance of dementia as a health priority.

Alzheimer Europe has issued a position statement, calling for people with dementia and their carers to be given priority in the ongoing COVID-19 vaccination campaigns across Europe. People with dementia have almost twice the risk for developing COVID-19 compared to their peers without dementia. They have also experienced a disproportionate impact of the pandemic, as have their carers, as a result of service cancellations, care home restrictions etc. Accordingly, we made three demands of European governments: Include dementia as a risk category for severe COVID-19; prioritise informal carers for the COVID-19 vaccine; and ensure that reasonable accommodations are made and support mechanisms are in place to allow ease of access to the vaccine, for these groups.

As well as this position paper, I am also pleased to announce that the journal Alzheimer’s and Dementia has published a paper by Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE), defining a European standard for the cognitive assessment of patients presenting to memory clinics and to which I was proud to be a contributing author.

This year, our Alzheimer’s Association Academy will continue in its online format and we were delighted, this month, to host the first of several sessions throughout 2021. The theme of this first instalment was sports and dementia and our expert speakers called in from France, Germany, Scotland and England. Two of the speakers at this event are also featured in our June 2021 Dementia in Europe magazine. Watch this space!

Finally, I would like to remind you to please submit your abstracts for the 31st Alzheimer Europe Conference, as the deadline for submissions is 30 June. We are looking forward to another exciting and engaging virtual conference. Our scientific committee will review all abstracts during July and applicants will hear back, shortly thereafter. Neuronet is also inviting Early Career Researchers (ECRs) from the Innovative Medicines Initiative’s neurodegeneration research projects to present their work. Neuronet ECRs whose abstracts are accepted will be granted a free registration to attend the three-day virtual conference. The deadline for submissions is also 30 June.

Jean Georges
Executive Director
COVID-19 SITUATION


On 10 May, the European Patients’ Forum (EPF) published the results of its survey on the impact of the COVID-19 pandemic on patients and patient organisations. The aim of this survey was to gather more information on the lived experience and impact of the COVID-19 pandemic on patients with chronic conditions, their communities and on patient organisations.

Conducted from 18 September to 18 October 2020, this survey received a total of 125 responses. 46% were patient organisations and 54% were individual patients or carers. Individual patients or their carers answered questions related to the challenges they faced, access to healthcare, their concerns and the quality of information provided by governments and healthcare professionals during the pandemic. The results of this survey show that there is significant room for improvement for both healthcare providers and national authorities on the clarity of information, communication and public health guidance, concludes the EPF.

Overall, 57 patient organisations responded to the survey with 43% representing European or national organisations. They were asked a variety of questions revolving around their operations during the pandemic, opinions on protection measures and their involvement in the management of the pandemic. These survey results indicate that the pandemic had a huge impact not only on the financial stability of patient organisations, but also on the way they work.

The EPF plans to complete a second edition of this survey, in the near future.

To find out more and to download the report, visit: https://www.eu-patient.eu/news/latest-epf-news/2021/impact-of-covid19-on-patients/

13 May: Eurocarers publishes report on the impact of COVID-19 on caregivers

Eurocarers has published a new report setting out the findings of research it undertook in collaboration with the Centre for Socio-Economic Research on Ageing at IRCCS-INRCA (National Institute of Health and Science on Ageing, Italy), examining the impact of COVID-19 on informal caregivers. Specifically, the work sought to:

- Document and analyse how the COVID-19 outbreak impacted on informal/family/unpaid carers’ health, caregiving situation, support networks, access to health and social services, working status, work-life balance and finances
- Collect the views and recommendations of carers on how to better support them in times of a pandemic.

The survey received 2,468 responses across, with the majority of responses coming from Czech Republic, Estonia, Finland, Germany, Italy, Portugal and Sweden.

The survey noted that there was an increase in the average number of hours provided by informal caregivers, with a significant majority reporting negative impact on their quality of life (77%) and their mental health/psychological state of mind (67%). A majority reported feeling overwhelmed as a result of the pandemic (62%), whilst only 18% of carers felt that their caregiving role was valued by society. For a number of the findings, the exacerbated gender imbalance was noted (e.g. the high number of women carers overall, a greater increase in hours of informal care provided by women etc).

The report concludes with a number of broad policy implications, including addressing gender imbalances, issues relating to work-life balance, improving social protections and pensions, and strengthening health and social care services.


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GRIFOLS

Sponsor of the month

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ALZHEIMER EUROPE

7 May: Alzheimer Europe calls for prioritisation of people with dementia and carers in COVID-19 vaccination programmes across Europe

On 7 May 2021, Alzheimer Europe issued a call for people with dementia and their carers to be given priority in the ongoing COVID-19 vaccination campaigns across Europe.

In its position statement, Alzheimer Europe notes that people with dementia have almost twice the risk for developing COVID-19 compared to their peers without dementia, with high rates of hospitalisation and a risk of mortality within six months of approximately 20% in certain populations. Those who become infected are also more prone to developing delirium, which can complicate the management of their current and future cognitive health.

Currently, countries vary significantly in their prioritisation of different groups for COVID-19 vaccination. The vast majority of European countries have prioritised frontline healthcare workers, long-term care facility residents and the oldest old in the first phases of vaccination, with a smaller number also prioritising social care personnel and professional carers. A small number of European countries, recognising dementia as a risk category for severe COVID-19, have prioritised people with dementia for COVID-19 vaccination. However, in the majority of countries, neither people with dementia, nor informal carers have been specifically identified as priority groups for the COVID-19 vaccination, despite their increased risk.

Alzheimer Europe notes the disproportionate impact of the pandemic already experienced by people with dementia and their carers, as a result of service cancellations, care home restrictions etc., and accordingly, makes the following three demands of European governments:

Include dementia as a risk category for severe COVID-19, prioritising people with dementia for the COVID-19 vaccine, independent of age, place of residence or other risk factors for severe COVID-19.

Prioritise informal carers for the COVID-19 vaccine, acknowledging their important contribution during the pandemic to the care, support and even survival of people with dementia, as well as the indirect protection vaccination can confer for the people for whom they care.

Ensure that reasonable accommodations are made and that support mechanisms are in place when organising and rolling out the vaccine to people with dementia, such as the possibility to be vaccinated at home and to have decision-making support, if required.

Commenting further, Alzheimer Europe’s Executive Director, Jean Georges, stated:

“People with dementia and their carers have often been overlooked and forgotten during this pandemic. Particularly during the early stages of the outbreak, public health measures designed to control the spread of the virus have had profound and often tragic consequences for people with dementia, their families and carers.

Governments must recognise that people with dementia, their families and carers have already been disproportionately affected by the pandemic and ensure that people with dementia and their carers will not be overlooked again in the development and implementation of vaccination strategies.

We urge governments across Europe to revise their approaches to vaccination campaigns and prioritise people with dementia and their carers, allowing a return to some semblance of normality for this vulnerable group.”

To download the position paper and the briefing document visit:

The position and briefing document received funding under an operating grant from the European Union’s Health Programme (2014-2020). The contents represent the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.

18 May: Alzheimer Europe hosts Alzheimer’s Association Academy session focusing on sports and dementia

On 18 May 2021, Alzheimer Europe held an online session of its popular Alzheimer’s Association Academy series. These Academy sessions have been running since December 2015, and have been online since the start of the COVID pandemic. The theme for the session of 18 May was “Sports and Dementia”.

There was a total of 41 participants at the Academy: 7 Alzheimer Europe staff members, including Executive Director, Jean Georges who chaired the meeting; 23 representatives of Alzheimer Europe’s national member associations from 14
different countries; 1 industry representative; 6 representatives of the European Working Group of People with Dementia (EWGPWD); and 7 expert speakers.

The first speaker was Renato Walkowiak, who presented Ping4Alzheimer, a joint initiative of the French Table Tennis Federation and France Alzheimer. According to some scientific studies, table tennis is one of the most suitable and recommended sports for older people, and may help to slow cognitive decline. With this in mind, Mr Walkowiak, whose grandmother passed away with Alzheimer’s dementia some years ago, began giving special sessions for people with dementia and carers at Levallois Sporting Table Tennis Club in the Hauts-de-Seine region of France, and the “Ping4Alzheimer” initiative was born. It was tested for two years (2018-2020) and the programme has been such a success that a partnership has now been created between the French Table Tennis Federation and France Alzheimer, with the aim of deploying the initiative nationally. Karine Teow of the International Table Tennis Federation and Lorène Gilly of France Alzheimer joined Mr Walkowiak for this presentation, each highlighting that their respective organisations were delighted to be involved in such a promising project.

Mr Georges asked the three speakers whether they would be willing to share their knowledge and expertise with other countries and organisations, should they wish to set up similar initiatives. All three were happy to help, but pointed out that Mr Walkowiak would be the best first port of call, given his experience in setting the project up.

The second presentation was delivered by Alzheimer Europe Board member Sabine Jansen, from the Deutsche Alzheimer Gesellschaft (DAIzG), Germany. She described the partnership that has developed between her organisation and the Deutsche Olympische Sportbund (German Olympic Sports Confederation), aiming to involve as many people with dementia as possible in sports clubs throughout Germany. The programme, called "Sport bewegt Menschen mit Demenz" (sport moves people with dementia) emerged from Germany’s National Dementia Strategy, which was launched in 2019. The first of the four fields of action in the strategy is "Developing and establishing dementia-inclusive communities to enable people with dementia to participate in society", which includes sports and sports clubs. A box of materials was developed in 2020, which is available to sports clubs and Alzheimer associations, in order to motivate and support their participation in this initiative.

Mr Georges asked whether Ms Jansen could give any indication of how many local chapters/regional organisations were interested in joining this project. She responded that nearly all of the DAIzG’s regional chapters are interested and willing to participate, as they find this to be a new and interesting concept.

In response to a comment about how best to involve people in rural areas, from carer Nélida Aguiar in Madeira, Portugal, Ms Jansen also stressed that it is almost easier to involve people in rural areas in Germany, because so many small villages have sports clubs and these are such an integral part of community life already.

The next presentation was given by Chris Kelly from Alzheimer Scotland and Richard McBrearty from the Scottish Football Museum. They described a joint project called Football Memories, which has been running for over ten years, starting initially as a one-year pilot project in 2009. It was established by the Scottish Football Museum and by members of the Scottish Football Heritage Network. The project also involved Alzheimer Scotland and Glasgow Caledonian University and such was its success that Alzheimer Scotland took over the running of the reminiscence project, with the Scottish Football Museum providing support as a senior partner.

Chris Kelly presented an off-shoot of the project, which he created in 2019: a dementia-friendly walking football league, developed to help give people living with dementia the opportunity to remain involved with football. It offers slow-paced five-a-side games, played at Hampden stadium, Scotland’s national stadium. The project, called “Hampden Heroes”, also gives participants the chance to compete and win the Alzheimer Scotland Walking Football League and Glasgow Cup. This league was dreamt Richard McBrearty introduced delegates to Scotland’s Football Archive, which represents thousands of images from the history of the game in Scotland. The website enables groups throughout Scotland to access the digital collections of the Scottish Football Museum for “reminiscence activities”.

Over the past 5-10 years, other similar initiatives have started across the globe and indeed Football Memories partners with the Netherlands and Brazil. Delegate Donal Murphy, representing The Alzheimer Society of Ireland, commented that they are about to launch a similar project, taking the learnings from Scotland. EWGPWD member Kevin Quaid, also from Ireland, mentioned his love of hurling and the Irish project is looking to also involve the Gaelic Athletic Association (GAA).

The final talk was on "Sport and dementia risk", given by Michael Hornberger, who is the Professor of Applied Dementia Research at the Norwich Medical School, University of East Anglia, United Kingdom. His talk was mainly focused on the link between traumatic head injury and dementia. He began by emphasising the importance and benefits of sports, both for general wellbeing and for dementia risk-reduction, which he said can be reduced by up to 30% through regular exercise. There is, however, a risk of dementia associated with heavy contact sports-related head injuries.

The clinical evidence of a link between traumatic head injury and dementia has been known since the 1920s. The initial evidence was based mostly on boxers, who often develop dementia-like symptoms later in life. The boxers' post mortem brains showed that they have similar protein changes in their brains to people with Alzheimer’s disease. These changes, named Chronic Traumatic Encephalopathy (CTE) and have also...
been demonstrated in professional players of sports such as rugby, American football and ice hockey.

The key injury to avoid, he noted, is concussion and in particular repeated concussions. Now, many sports have concussion protocols in place, as it is increasingly recognised that concussion can have a significant impact on brain health and future dementia risk, but it is not only concussion that can cause neuroinflammation, but also “sub-concussive” events. These may be caused, for example, by heading the ball in football. For this reason, heading the ball has been banned in children’s football, since the young brain is more prone to injury.

In closing, Prof. Hornberger again highlighted that physical activity and sports in general are extremely beneficial for brain health and that people should be encouraged to be physically active, but should be aware of the risk posed by repeated impact to the head.

Jean Georges complimented all the speakers on their informative and engaging presentations and on the positive impact their work is having on people with dementia and carers. He also thanked them all for their willingness to support other associations wishing to set up similar initiatives in their own countries.

The Alzheimer’s Association Academy received funding under an operating grant from the European Union’s Health Programme (2014-2020). Alzheimer Europe gratefully acknowledges the support of its gold and silver sponsors and of the corporate sponsors of the Alzheimer’s Association Academy.

27 May: AE adds two new Phase II trials to its Clinical Trials Watch

In May 2021, Alzheimer Europe has added two new Phase II trials to its Clinical Trials Watch (CTW) - an innovative online resource providing up-to-date accessible information on clinical trials currently recruiting participants in Europe. The service provides information on twelve Phase II and six Phase III clinical trials that are investigating drugs for the prevention and treatment of dementia and/or Alzheimer’s disease (AD).

The two new trials from the company Alector are recruiting research participants in several European countries:

- **INFRONT-2**: The purpose of this study is to evaluate the safety and efficacy of AL001 in people at risk or with frontotemporal dementia. All participants will receive an intravenous infusion of AL001 every four weeks.
- **INVOKE-2**: The purpose of this study is to evaluate the safety and efficacy of AL002 in people with early AD. Research participants will receive either an intravenous injection of AL002 or placebo every four weeks.

Further information about the CTW is available on:

http://www.alzheimer-europe.org/Research/Clinical-Trials-Watch

31 May: One month left to submit your abstracts for the virtual 31st Alzheimer Europe Conference

We are delighted to invite you to submit abstracts and register for the upcoming 31st Alzheimer Europe Conference #31AEC, which will be a virtual conference, under the banner “Resilience in dementia: Moving beyond the COVID-19 pandemic”, from 29 November to 1 December 2021.

The call for abstracts will close on 30 June 2021. Find out more and submit your abstracts, here:

Call for abstracts - 2021 Online - Conferences - Alzheimer Europe (alzheimer-europe.org)

You can also take advantage of the early bird registration fees until 15 September 2021. Register now and benefit from the reduced registration fee of EUR 75 instead of EUR 125. Special rates are available for people with dementia, students and member association of Alzheimer Europe.

https://www.alzheimer-europe.org/Conferences/2021-Online/Conference-registration-fees

Alzheimer Europe networking (online)

On 4 May, Dianne attended the INTERDEM AT taskforce meeting.

On 4 May, Ana and Dianne took part in a mentoring event between MIRIADE ESRs and EWGPWD members.

On 5 May, Jean attended the Supervisory Board meeting of the MIRIADE project.

On 5 May, Jean attended the launch of the WHO Global Dementia Observatory Knowledge Exchange Platform.

On 6 May, Ange attended a meeting of the Neuronet NEURO cohort taskforce.

On 6 May, Dianne and Ana attended a meeting with Roche.

On 7 May, Ana and Dianne organised a consultation with the EWGPWD as part of the VirtualBrainCloud project, Ange attended.

On 7 May, Chris and Cindy organised a meeting of the Neuronet Communication Experts’ Community.

On 11 May, Owen attended a meeting of the Patient Think Tank hosted by the European Federation of Pharmaceutical Industries and Associations.

On 11 May, Ange attended a PRIME meeting on dissemination to patient organisation.

On 11 May, Ange co-moderated a plenary session at an I+HD workshop on health data use.

On 11 and 18 May, Chris joined a lecture on the development of virtual leisure activities for people living in retirement homes at the University of Vechta (Germany).

On 11 May, Ana attended the Biogen ICARE AD Steering Committee.

On 11 May, Cindy, Kate and Dianne attended the colloque « Si ce n’est pas Alzheimer, c’est quoi? » organised by France Alzheimer.

On 12 May, Owen attended an operating grant task force meeting of the European Patients’ Forum meeting of the EU4Health Civil Society Alliance.

On 12 May, the Alzheimer Europe Board had an information meeting with Biogen on the US and European regulatory process.

On 12 May, Dianne and Ana attended the Alzheimer Academy session Working online with Working Groups of people with dementia.

On 16 May, Gwladys attended the Familiarization Session of ICCA Benefits and Tools.

On 17 May, Jean and Owen attended an operating grant task force meeting of the European Patients’ Forum.

On 17 May, Jean met with Grifols.

On 17 May, Ana and Dianne attended the DISTINCT hackathon.

On 17 May, Ange attended a collaborative webinar between PRIME and RECOGNISED.

On 18 May, Owen attended an operating grant task force meeting of the European Patients’ Forum meeting of the EU4Health Civil Society Alliance.

On 18 May, Dianne and Ana attended Alzheimer Academy session Working online with Working Groups of people with dementia.

On 20 May, Dianne and Owen attended Alzheimer Europe’s working group meeting to prepare the EC survey on cross-border protection.

On 21 May, Owen attended a webinar on the European Health Data Space consultation hosted by the European Patients’ and the European Commission.

On 25 May, Iva, Jim, Jean and Owen met with Hans Kluge, Regional Director of WHO Europe.

From 25 to 27 May, Jean and Ana attended Dementia Forum X at which Chris Roberts made a contribution of public involvement in JPND research.

On 25 May, Cindy and Jean attended the PRODEMOS Work Package Leaders meeting.

On 25 May, Dianne attended Biogen’s meeting Understanding Alzheimer’s Disease: The Gender Gap & How to Address it.

On 28 May, Jean attended a meeting of the GSK Health Advisory Board.

On 31 May, the Alzheimer Europe Board met.

On 31 May, Ange attended the PRIME steering group meeting.

EU PROJECTS

30 April: Al-Mind communication team publishes its first video interview

On 30 April, the communication team of the Al-Mind project released their first video interview. In this short video, Al-Mind Project Coordinator Dr Ira Haraldsen (Oslo University Hospital) introduces the main goals of the project. On behalf of the Norwegian Health Association, Anne Rita Øksengård highlights the need for research initiatives enhancing early prediction methods. This new initiative is based on state-of-the-art technology and the international collaboration of 15 partners. The Al-Mind project will develop a digital platform that aims to shorten the time of dementia diagnosis from years to one week by using artificial intelligence to screen brain connectivity.
Alzheimer Europe, partner of the AI-Mind project, has provided support to produce this video. AI-Mind work-package leaders will share more insights on the planned activities in the upcoming videos.

This article reflects only the author’s view and the Commission is not responsible for any use that may be made of the information it contains. Take a look at the video on the AI-Mind YouTube channel: https://www.youtube.com/watch?v=bLC0-gKgGKo

5 May: The AMYPAD project has been extended for an additional year

Originally scheduled to be a 60-month project in total, beginning October 2016 and ending September 2021, the Amyloid Imaging to prevent Alzheimer’s disease (AMYPAD) project has been extended by 12 months to now come to an end in September 2022. The Innovative Medicines Initiative (IMI) has officially approved the request for an extension to the project in order to ensure the full delivery of the project objectives, within the original financial resources. This extension will allow to complete delivery of the work plan, by specifically finalising tasks and activities which are essential to address key project objectives. Due to the global COVID-related events, some of these have suffered considerable delays, which would not be recoverable within the initial duration of the project.

COVID-19 brought the recruitment to a complete halt in mid-March 2020 and also impacted the data analysis. Within the Diagnostic and Patient Management Study, the extension of twelve months will allow the team to achieve both data quality and full delivery of key objectives, such as health economic outcome analyses, crucial elements of the AMYPAD project. With recruitment starting to resume and additional Parent Cohorts being added to the AMYPAD Prognostic and Natural History Study, the extension of twelve months will allow the study to deliver on study objectives, and it will also facilitate the data integration across all cohorts to its further data analysis in the study.

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

7 May: Communication representatives of neurodegeneration research projects exchange on best practices

On 7 May, representatives of 12 Innovative Medicines Initiative neurodegeneration research projects met virtually to exchange on best practices in communication and common challenges in their day-to-day work.

The community consists of communication representatives from the Innovative Medicines Initiative’s neurodegeneration research portfolio and is moderated by Alzheimer Europe. The meetings are organised on a quarterly basis and aim to provide a platform for cross-project exchange regarding challenges faced and best practices adopted in overcoming them. Furthermore, they serve as a basis to plan for collaborative activities in the endeavour to represent the portfolio as a whole and support visibility of the 386 million EUR research programme.

The meeting was attended by representatives of the AMYPAD, EPAD, IDEA–FAST, IMPRIND, Mobilise-D, MOPEAD, PD-MIND, PHAGO, RADAR-AD, RADAR-CNS and ROADMAP projects along with members of the Neuronet consortium.

The meeting kicked off with general updates on Neuronet activities since the previous meeting that was held in December 2020. This included an update on the success of the latest communication campaign with short clips introducing the various projects as part of Brain Awareness Week.

Next, each of the representatives provided a short presentation with updates (or introductions for newly onboarded projects) on communication/dissemination plans/strategies (also including needs & challenges faced) as well as envisaged activities until March 2022.

Each presentation was followed by a question and answers round. Due to the high number of represented projects and engaged discussions, the initially planned 2-hour meeting did not suffice to include all presentations. Therefore, a follow-up call is already in the planning for June.

http://www.imi-neuronet.org

7 May: Alzheimer Europe organises consultations with the EWGPWD as part of the VirtualBrainCloud project

The Horizon 2020-funded VirtualBrainCloud project is developing a decision support system for clinicians, aiming to enhance the early diagnosis and personalised treatment of neurodegenerative diseases such as Alzheimer’s (AD) and Parkinson’s disease. As part of the VirtualBrainCloud project, Eodyne is adapting its RGS interactive platform for neurorehabilitation, aiming to tailor this platform to meet the needs of people with neurodegenerative disease.

On 29 April and 7 May, Alzheimer Europe organised consultations with the European Working Group of People with Dementia (EWGPWD), to provide Eodyne with feedback from the perspectives of people with dementia. Following on from a December consultation, which assessed the preferences for
different platform formats (e.g. smartphone or computer), these consultations were designed to test the Eodyne RGSApp, a smartphone-based app which includes several "brain training" games. The consultations were facilitated by Ana Diaz and Dianne Gove from Alzheimer Europe, as well as Santiago Brandi and Marc Domenech from Eodyne.

Over the course of a week, participants learned how to use the RGSApp and then trialled each of the games, providing valuable feedback on the acceptability and usability of the platform and each of the games hosted in RGSApp. This feedback will now be used to further adapt and modify RGSApp, with further consultations anticipated over the coming months.


17 May: PRIME hosts a webinar to present its sister project, RECOGNISED to the consortium

The Horizon 2020-funded PRIME project ("Prevention and Remediation of Insulin Multimorbidity in Europe") aims to unravel how brain disorders throughout life can be traced to alterations in insulin signalling and how this relates to type 2 diabetes and obesity. Its sister project, RECOGNISED ("Retinal and cognitive dysfunction in type 2 diabetes: unravelling the common pathways and identification of patients at risk of dementia") is studying whether eye tests can identify people with diabetes at risk of dementia, also investigating the biological mechanisms that may link retinal dysfunction to cognitive decline.

On 17 May, PRIME organised a webinar for the project consortium, during which Prof. Noemi Lois (Queen’s University, Belfast) gave an overview of the RECOGNISED project. During the webinar, Prof. Lois explained how RECOGNISED is undertaking two clinical studies, in which people with type 2 diabetes will undergo retinal scans, cognitive assessments and other clinical tests. Participants in the longitudinal study will be followed for 30 months, with regular tests to see how the scans and assessments change over time and during the course of cognitive decline. Alongside, RECOGNISED researchers will perform detailed mechanistic studies in cells and animal models of type 2 diabetes and Alzheimer’s disease. In doing so, they hope to understand which genes and pathways might be involved in the retinal dysfunction that can accompany cognitive decline. The RECOGNISED presentation was followed by a question-and-answer session, identifying several areas for potential collaboration between PRIME and RECOGNISED.

17 May: RADAR-AD project publishes two new papers in scientific journals

The RADAR-AD project has published two new papers this month. The first is an article published in the journal “Alzheimer’s Research and Therapy”, explaining the design of the RADAR-AD clinical study. The aim of the RADAR-AD study is to assess how well Remote Monitoring Technologies (RMTs) can measure impairment in activities of daily living in all stages of Alzheimer’s disease (AD).

Impairment in activities of daily living in AD is typically measured using standard clinical questionnaires. However, these questionnaires are only performed once in a while, and depend on someone’s memory. RMTs, such as smartphone applications, wearables and home-based sensors, can change these periodic assessments to more frequent or even continuous monitoring. Moreover, these RMTs do not rely on recall or do not need any action on the part of patients or caregivers at all, and therefore measure more objectively.

First complete results from the RADAR-AD study are expected to be published in 2022. Read the article, called “Remote monitoring technologies in Alzheimer’s disease: design of the RADAR-AD study”, here:

Remote monitoring technologies in Alzheimer’s disease: design of the RADAR-AD study | Alzheimer’s Research & Therapy | Full Text (biomedcentral.com)

The second new article from the RADAR-AD consortium was published in the journal “Frontiers in Aging Neuroscience”. The article shows how people affected by AD can be involved in the design and implementation of dementia research studies, in particular in the selection of devices (wearables) to assess and monitor function in AD in a trial.

It includes members of the Patient Advisory Board (PAB) appointed for the RADAR-AD project, who have been involved in the project right from the start. The article can help other researchers involved in similar trials with the selection of devices and to understand some of the preferences, expectations and concerns of people affected by AD about remote assessment of their condition with wearables and devices.

As the conclusions reveal, the PAB highlighted some features expected by the researchers such as the importance of comfort and convenience but also others that might have otherwise been overlooked, such as feedback indications. Read the article, called “Wearable Devices for Assessing Function in Alzheimer’s Disease: A European Public Involvement Activity About the Features and Preferences of Patients and Caregivers”, here:

Frontiers | Wearable Devices for Assessing Function in Alzheimer’s Disease: A European Public Involvement Activity About the Features and Preferences of Patients and Caregivers | Frontiers in Aging Neuroscience
17-23 May: IDoService webinar raises awareness about dementia

The IDoService project organised a webinar on “Designing support and social participation to foster wellbeing during the dementia journey” as part of Dementia Action Week, to raise awareness about dementia, and how to make societies more dementia-friendly and inclusive for all. Dementia Action Week is a national, annual event in the United Kingdom, organised by Alzheimer’s Society. This year’s edition took place from 17-23 May.

This webinar offered the opportunity to think about how design can support people living with dementia and their loved ones. The programme brought together researchers, people with lived experience of dementia or caring, and a public and patient involvement manager. Discussions between panellists and attendees pointed out the need to stay fully involved in the community, in “everyday places”, and to actively participate in meaningful activities. Societies need to offer more inclusive opportunities - not necessarily dementia-labelled - to support and empower people living with dementia to participate meaningfully in and contribute to their families, social networks, neighbourhoods, and communities. Specific concerns arose during the Questions & Answer session on awareness in ethnic minority communities, regarding diagnosis and access to services and support.

The question “how to make our societies more dementia-friendly and inclusive for all?”, which guided the webinar, was raised regularly by the 11 key stakeholders during the first 3 focus groups and follow-on interviews that were conducted by the IDoService project team in March and April. The next step will be to discuss the availability and accessibility of meaningful activities with people with dementia and their care partners, and the project expects the issue of awareness to surface, there, as well.

Alongside the project’s Twitter account (@idoservice4dem1) and the website, the webinar opened another interactive way to engage in discussions related to the project. The detailed programme, as well as the webinar recording, are available on: www.idoservice.org

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

For any questions or suggestions about The IDoService project and its activities, please do not hesitate to contact the research team at: idoservice@mmu.ac.uk

21 May: Neuronet ECR submission for the virtual Alzheimer Europe Conference is open!

Neuronet invites Early Career Researchers from the Innovative Medicines Initiative’s neurodegeneration research projects to present their work at the upcoming Alzheimer Europe Conference. Applicants whose abstracts are accepted for a Quick Oral or Poster presentation will be granted a free registration to attend the three-day virtual conference. The deadline for submissions is 30 June. Submit your abstract here:

https://www.alzheimer-europe.org/Conferences/2021-Online

27 May: Al-Mind has been successful in the EBRAINS Research Infrastructure Voucher Call

The Al-Mind project has been granted access to EBRAIN’s implementation support among thirteen other innovative projects from Europe, United States and Canada.

EBRAINS is a new digital research infrastructure, created by the EU-funded Human Brain Project (HBP), to foster brain-related research and to help translate the latest scientific discoveries into innovation in medicine and industry, for the benefit of patients and society.

Together with a dedicated expert from the Human Brain Project, Al-Mind will develop and implement tailored infrastructure features to enhance brain modelling and simulation platform. Al-Mind develops a new biomarker in dementia and a new medical device to effectively screen and predict the risk of dementia in the European population with mild cognitive impairment. With the merge of the Al-Mind data into the HBP infrastructure provided by EBRAIN, the Al-Mind project will be able to better model the algorithm, test and finally apply artificial intelligence-based diagnostics in clinical settings. As an HBP Partnering Project, the Al-Mind consortium will have the opportunity to develop further collaborations and make a huge impact on health and technological progress.

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https://www.ai-mind.eu/
EU project acknowledgements

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Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 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):

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EU DEVELOPMENTS

6 May: European Commission publishes COVID-19 therapeutics strategy

The European Commission has published strategy on COVID-19 therapeutics to support the development and availability of medicines to treat the effects of the virus, covering the lifecycle of medicines from research, development and manufacturing, through to procurement and deployment.

The strategy includes clear actions and targets, including authorising three new therapeutics to treat COVID-19 by October 2021 and possibly two more by end of the year. These actions and targets and grouped under the following headings:

- Research, development and innovation
- Access to, and swift approval of, clinical trials
- Scanning for candidate therapeutics
- Supply chains and delivery of medicines
- Regulatory flexibility
- Joint procurement and financing
- International cooperation to make medicines available to all.
The Commission will draw up a portfolio of 10 potential COVID-19 therapeutics and by June 2021, identify the five most promising ones. In addition, it will organise events for industrial actors involved in therapeutics to ensure enough production capacity and swift manufacturing. You can read more at: https://ec.europa.eu/commission/presscorner/detail/en/IP_21_2201

8 May: European Council publishes “Porto Declaration” during EU Social Summit

At the EU Social Summit (7-8 May), held as part of the Portuguese Presidency of the Council of the European Union, the European Council published the “Porto Declaration” committing to prioritising actions to implement the European Pillar of Social Rights.

The declaration contains 13 points across a broad range of themes, including the recovery from the COVID-19 pandemic, including:

- Committing to reducing inequalities, defending fair wages, fighting social exclusion and tackling poverty, taking on the objective of fighting child poverty and addressing the risks of exclusion for particularly vulnerable social groups such as the long-term unemployed, the elderly, persons with disabilities and the homeless.
- Committing to increasing efforts to fight discrimination and work actively to close gender gaps in employment, pay and pensions, as well as promoting equality and fairness for every individual in society.
- Stressing the importance of closely monitoring, including at the highest level, the progress achieved towards the implementation of the European Pillar of Social Rights and the EU headline targets for 2030.

The full text of the declaration can be read at: https://www.consilium.europa.eu/en/press/press-releases/2021/05/08/the-porto-declaration/

11 May: Proposing a common basis for data access across Europe: I^HD host a plenary with the Digital Health Society

The European Institute for Innovation through Health Data (I^HD) and the Digital Health Society (DHS) recently announced the launch of two programmes for 2021, following on from their 2020 roundtables on health data systems. As part of the first programme, "Proposing a common basis for data access across Europe", I^HD and DHS hosted a virtual plenary session on 11 May, aimed at exploring and developing a draft basis for health data access across Europe.

The plenary was kicked off by Markus Kalliola of TEHDAS (Towards a European Health Data Space), who provided an overview of the TEHDAS joint action, which is aiming to develop joint European principles for the secondary use of health data. The objective of the second part of the session, which was co-moderated by Bledlyn Rees and Carina Dantas of DHS and Angela Bradshaw of Alzheimer Europe, was to identify the key questions to consider in developing a social compact for health data use and sharing, including the return of value from health data use. Plenary participants included representatives of patient organisations, healthcare providers, researchers, data protection experts and industry associations.

This introductory plenary will be followed by small Working Group meetings, culminating in a final plenary session in late June.

17-21 May: European Public Health Week addressing the need to work together, counts 212 events across 40 countries and in 19 different languages

The third edition of the European Public Health Week (EUPHW) was organised from 17-21 May 2021. Institutions and individuals across 40 countries organised a total of 212 events in 19 different languages. The European Public Health Week is an initiative from European Public Health Association (EUPHA), co-funded by the European Commission and with the support of the World Health Organization (WHO) – Regional Office for Europe.

The event called for governments and health systems to "join forces for healthier populations". Each day of the week was dedicated to a specific topic and the number of the events per day ranged from 38 to 47. Around half of the events were organised by at least two partner institutions, and every day was kicked-off by a webinar of one of the official partners or collaborators of the EUPHW.

The specific topics covered, were:

1. The first day addressed the need for clear communication from science to policy, health literacy for all and community involvement.
2. The second day addressed new challenges in mental health.
3. The third day addressed "Your Local Community" and had the highest number of events organised during the EUPHW.
4. The fourth day was dedicated to "All for one health".
5. The fifth and final day addressed "Leaving No One Behind".

Read more about this event, here:
https://eupha.org/repository/advocacy/European%20Public%20Health%20Week%202021_EUPHA%20Statement.pdf

26 May: Alzheimer Europe meets with WHO Europe Regional Director

On May 26, Alzheimer Europe had a meeting with Dr Hans Kluge, Regional Director, World Health Organization Regional Office for Europe.

In attendance, from Alzheimer Europe, were:
• Iva Holmerová, Chairperson
• Jim Pearson, Honorary Secretary
• Jean Georges, Executive Director
• Owen Miller, Policy Officer.

During the meeting, Alzheimer Europe and Dr Kluge discussed the position of dementia policy, noting the positive developments at a global level (including the global action plan on dementia, the Global Dementia Observatory etc.), as well as the excellent working relationship between the WHO, WHO Europe and Alzheimer Europe.

Alzheimer Europe expressed its hope that dementia could receive a similar level of focus at the WHO Europe level, noting the high mortality rate from dementia in the WHO Europe region, whilst also suggesting the value of a dedicated person to address dementia across different WHO Europe workstreams.

Dr Kluge acknowledged the importance of dementia as a health priority, identifying areas where dementia will be a key area of focus (including through a roadmap on healthy ageing, the coalition of stakeholders on mental health etc.), whilst also suggesting there would be opportunities for Alzheimer Europe to play a greater contributing role in this work. Alzheimer Europe and WHO Europe agreed to continue to share relevant information and developments and identify future areas for collaboration.

MEMBERS’ NEWS

26 April: Alzheimer Bulgaria holds second “Meet the Expert” webinar for 2021 with Professor Liana Apostolova

On 26 April, Alzheimer Bulgaria held its second “Meet the Expert” webinar for 2021, with Professor Liana Apostolova. The target groups were dementia carers and non-medical professionals involved in care (social workers, psychologists and other therapists). During the first quarter of 2021, two webinars were held: One for medical specialists in dementia field, in January; and one for carers and non-medical professionals, in April. With the exceptional collaboration and grant from Prof. Liana Apostolova and moderated by Petya Nikolova, Alzheimer Bulgaria organises webinars supporting the dementia community in Bulgaria.

Liana Apostolova is a professor of Neurology, Radiology and Genetics at Indiana University Medical School, Indianapolis, US. Her research focuses on the early symptomatic and pre-symptomatic stages of Alzheimer’s disease.

The main topics covered at the webinar for carers, in April, were: medical and non-medical therapeutic treatment, vaccine development, quality-of-life issues, non-government programmes, and there was a Q&A session with carers. During the webinar for HCPs, in January, the topics covered were: the latest clinical studies and relevant data comparison, guidelines, screening and diagnostic methods and genetics as a factor in Alzheimer disease.

Recordings of the webinars can be viewed here:
https://www.youtube.com/playlist?app=desktop&list=PLy7d9wXmiilP_1G5WjSU3RiWA7t44hb75F

The next webinar in the “Meet the Expert” series with Prof. Apostolova will be organised in autumn 2021.
11 May: France Alzheimer hosts a virtual conference dedicated to Alzheimer’s related diseases

On May 11, France Alzheimer hosted its 100% digital conference under the banner “If it’s not Alzheimer’s, what is it? Diagnostic wandering for related diseases”. The event was hosted by medical and social expert Hélène Delmott (pictured, left) and was attended by more than 700 people. The agenda included round tables, debates, testimonials and question-and-answer sessions with the panel of specialists.

The idea behind the theme of the conference was to explore some of the issues involved in diagnosis of Alzheimer’s and other less well-known/understood types of dementia and neurocognitive disorders. There was a particular focus, in the afternoon, on major neurocognitive disorders of vascular origin.

You can download the brochure “Better understanding vascular neurocognitive disorders” (in French) that France Alzheimer has just published on this subject:

Brochure_1erReperes_DemancesVasculaire_2021_Web.pdf

The morning session kicked off with a welcome speech from Joël Jaouen, President of France Alzheimer. Other highlights of the morning included a testimonial from Michèle Muchenstrum whose long-awaited diagnosis of Lewy body dementia took ten years to reach. Ms Muchenstrum was followed by Prof. Paul Frappe, President of the College of General Medicine in France, who completed the testimonial section of the morning. There was also a Zoom meeting on the topic of “diagnostic wandering”, chaired by Guillaume Fernandez, Lecturer in sociology at the University of Western Brittany, and a roundtable on “related diseases”, involving three experts, Prof. Mathieu Ceccaldi who spoke about clinical aspects, Prof. Pierre Krolak-Salmon who extolled the virtues of a precise diagnosis, and Prof. Claire Paquet who focused on examining the most useful approaches to diagnosis. Joël Ankri, Professor Emeritus and Scientific Reference of the Neurodegenerative Diseases Roadmap rounded off the morning session.

The afternoon began with a testimonial from Dr Martial Fraysse, a member of the National Academy of Pharmacy. A Zoom discussion followed, focusing on vascular dementia and involving neurologists Dr Marie-Anne Mackowiak and Prof. Olivier Godefroy. Dr Denise Strubel and Judith Mollard then took the floor to share with delegates what types of support are offered by France Alzheimer.

The final session of the conference featured Prof. Audrey Gabelle, President of the Federation of Memory Centres, University Professor and Hospital Practitioner of Neurology at the CHU and the University of Montpellier, in conversation with conference host Hélène Delmotte.

Alzheimer Europe was represented at the France Alzheimer conference by Director for Projects Dianne Gove, Project Officer Cindy Birck and Communications Officer Kate Boor Ellis.

To view videos of the conference sessions (in French), see: Colloque Maladies apparentées 2021 - 1 - Introduction - YouTube

11 May: Alzheimer’s Society campaign film highlights challenges faced by carers

Alzheimer’s Society (UK) has brought out a short and impactful campaign ad, emphasising some of the challenges facing carers of people with dementia.

The two-minute film is an intimate and sensitive portrayal of a woman’s daily life as she cares for husband with dementia and battles, fruitlessly, for much-needed support. It is released at a time when the UK’s social care system is once again under scrutiny, with campaigners calling for a clear, budgeted plan to ensure reform.

Alzheimer’s Society’s aim is to raise awareness and also encourage people to sign its "Cure the Care System" petition, which can be found here:

Cure The Care System | Alzheimer’s Society (alzheimers.org.uk)

Watch the short film, here:

Cure the Care System - YouTube

13 May: Irish Dementia Working Group hosts transport symposium "How Was Your Journey Today?"

On 13 May, the Irish Dementia Working Group (IDWG), supported by The Alzheimer Society of Ireland and Dementia: Understand Together in Communities, hosted a Transport Symposium – “How Was Your Journey Today?”

IDWG members know that being able to travel can be a key factor in helping people with dementia retain their independence and stay connected and engaged in their communities. As COVID-19 restrictions lift and people living with dementia return to travel, there is heightened anxiety within a changed travel landscape. This timely event fostered
understanding among providers of the unique challenges faced by people living with dementia and offered solutions support them to take meaningful action.

Speakers included: people living with dementia Kevin Quaid (who also chaired the event - pictured), Sean Mackell and Marguerite Keating; dementia travel expert Andy Hyde of Go Upstream; and representatives of the National Transport Authority and Irish Rail. The symposium also heard from researcher Cathal Blake, whom the IDWG had commissioned to undertake research on the lived experience of people living with dementia using public transport.

Fiona Foley, National Co-ordinator of Dementia Understand Together in Communities, outlined the collaboration and work that the IDWG, Understand Together team and transport providers have undertaken to increase awareness and understanding of dementia, including training and workshops. Commenting on this, Kevin Quaid, who is also a member of the European Working Group of People with Dementia (EWGPWD), said "disabilities can be invisible, and knowing a staff member understands that when I travel makes all the difference!"

The group was delighted that representatives from all public transport providers in Ireland attended the event.

20 May: Hungarian Interprofessional Dementia Approach (INDA) programme holds two press conferences

The Hungarian Interprofessional Dementia Approach (INDA) programme held two press conferences on 20 May 2021, in Győr and in Székesfehérvár. The occasion was an important milestone of the Hungarian dementia programmes. Agnes Egervari (pictured), President of the Social Custer Association summarised the results of the successful period:

- More than 100 informal caregivers accomplished their year-long training in 6 different cities.
- Representatives of different professions worked together and found new ways of collaborating for people with dementia. The essence of the interprofessional approach is that the representatives of different professions work together for a common goal and share their existing knowledge. However, "interprofessionalism" is not only about sharing information but also about developing a joint action plan or protocols, collaborating, and making decisions on a particular issue.
- A marketing strategy for dementia communication has been developed, which is adaptable in different communities. The INDA2 programme has produced spots, short movies, and documentaries, shared free of charge on online interfaces. The movie made within INDA2 presented the main messages of the programme, the consortium partners, and gave an insight into the everyday moments of the project work.

Impact assessment programmes were also carried out and evidenced the INDA programme’s efficiency. See: www.demencia.hu

27 May: Dementia Carers’ Campaign Network (Ireland) collaborates with visual and dance artists to share stories of caring for someone with dementia

The Dementia Carers Campaign Network (DCCN), supported by The Alzheimer Society of Ireland, is an advocacy group for those who have experience caring for a loved one with dementia. The DCCN aims to be a voice of, and for, dementia carers in Ireland and to raise awareness of issues affecting families living with dementia.

Most recently, members of the DCCN, and other family carers supported by The Alzheimer Society of Ireland, collaborated with visual artist Marie Brett and dance artist Philip Connaughton (pictured), to share their stories of caring for someone with dementia.

The resulting artwork is a cross-disciplinary installation which re-imagines the hidden, and often challenging, aspects of caring, while exploring the possible implications of new capacity legislation for family carers.
Acclaimed artist Marie Brett is regarded by many as a leading exponent of trans-disciplinary social arts practice, and she brings her unique vision to this contemporary artwork. The piece, which combines live dance and spoken word with floor drawing and sculptural and video elements, is creatively and sensitively brought to life by award-winning dance artist and choreographer Philip Connaughton.

The aim of this artwork is to build new audiences, to offer topical thinking and reflection space, and to encourage philosophical consideration of how human rights can be promoted and protected in Ireland. Family carers who contributed to this project were moved by the experience. “I was sceptical at first, but I found the process incredibly cathartic, and it released a lot of inner feelings,” said Ray Cregan, Vice-Chair of the DCCN.

The artwork was intended as a live performance in 2020, but due to COVID-19 restrictions, the piece was re-imagined as a socially distanced live event without audience, and documented by film, created entirely during a Level 5 Lockdown. The Irish Museum of Modern Art kindly agreed to stream it for two weeks in April 2021, and a bespoke website www.yesbutdoyoucare.ie now houses the artwork and supporting contextual materials such as contributor's interviews, written texts, plus responses to the artwork.

For more information on the DCCN please visit www.alzheimer.ie or email advocacy@alzheimer.ie

Policy Watch

19-20 May: WHO organises a virtual workshop and consultation meeting for the development of their Dementia Research Blueprint

Following on from the successful development of their Research & Development Blueprint for COVID-19, the World Health Organisation are now working on the creation of a Dementia Research Blueprint. The aim of this Blueprint is to accelerate global dementia research and innovation and to make research more productive and efficient, with a focus on equity, diversity, and inclusiveness in all stages from generation to implementation.

On 19 & 20 May, the WHO organised a virtual workshop and consultation meeting for the development of the Dementia Research Blueprint. Jean Georges and Angela Bradshaw represented Alzheimer Europe at the meetings. Involving a variety of stakeholders from research, industry, NGOs and patient organisations, the first day kicked off with welcome remarks from Ren Minghui (Assistant Director-General, Communicable and Non-Communicable Diseases, WHO), Soumya Swaminathan (Chief Scientist, WHO), Devora Kestel (Director, Mental Health & Substance Abuse unit, WHO) and Berrie Holtzhausen (Director of Alzheimer Dementia Namibia, living with dementia). Representatives from the Science division and Brain Health Unit of the WHO then provided an overview of how their Research Blueprint development process works, summarising recent progress on developing the Dementia Research Blueprint.

Highlighting recent findings from the WHO Global Dementia Observatory, Neerja Chowdhary and Rodrigo Cataldi (WHO) noted that dementia research investment and output currently lags far behind other non-communicable diseases. He presented the results of a recent WHO survey for the Blueprint, which collated responses from a diverse range of stakeholders and identified four areas of dementia research: 1) disease mechanisms, origins and models; 2) diagnosis, drug development and clinical trials; 3) brain health and risk reduction; 4) health and social care research. This was followed by a panel discussion where experts from a range of backgrounds identified their priorities for the Dementia Research Blueprint, which included expanding access to low- and medium-income countries (LMICs), greater global collaboration and training for health practitioners, and ensuring the involvement of people with dementia in research. The panel discussion included presentations from Henry Brodaty (University of New South Wales, Australia), George Vradenburg (Global CEO Initiative on Alzheimer’s Disease) and Roger Marple (dementia advocate, Canada) among others.

The four areas of dementia research identified by Neerja Chowdhary and Rodrigo Cataldi formed the basis of the consultation meeting on 20 May. Experts and representatives from industry, academia, NGOs and patient organisations participated in four working group consultations (one on each area) identifying gaps that need to be addressed and key enablers, also identifying future perspectives for each topic. The input from these working groups will help shape the final Dementia Research Blueprint, which will be launched in 2022.
23 April: TouchNEUROLOGY Editorial Board member Jeffrey Cummings discusses use of BAN2401 in early stage Alzheimer’s disease

TouchNEUROLOGY recently spoke with Jeffrey Cummings (Department of Brain Health, University of Nevada, Las Vegas, US), one of its Editorial Board members, to discuss the use of BAN2401 in early stage Alzheimer’s disease, and Amyloid Related Imaging Abnormalities (ARIA)-E alterations and their utility in amyloid-modifying trials.

The interview was filmed at the American Academy of Neurology Virtual Annual Meeting 2021, held online between 17 and 22 April 2021, and was published online on 23 April 2021. You can watch it, here:


23 April: Researchers develop a new mouse model to study late-onset AD

On 23 April, US researchers from the University of California published an article reporting the development of a new mouse model demonstrating aspects of Alzheimer’s disease (AD)-like pathology. The study appeared in the journal Nature Communications.

Over 170 AD mouse models have been generated, however these models mimic early-onset AD, also known as familial autosomal-dominant forms of the disease, which accounts for less than 5% of total AD cases. These existing AD mouse models contain disease-causing mutations found in familial risk human genes such as the amyloid precursor protein and presenilin 1.

In the published paper, scientists used a new approach by changing three amino acids in the mouse amyloid precursor protein. This leads to age-dependent impairments in cognition, inflammation, synaptic plasticity, brain volume and others consistent with human changes. This mouse model is what the researchers are calling a “platform model” for late-onset AD, which encompasses 95% of AD cases.

“This mouse is a foundational step toward modelling late-onset AD with its hallmark features of plaques and tangles,” said Grant MacGregor, professor of developmental and cell biology and study co-author.


1 May: Study analysing AT(N) biomarker profiles reveals that individuals with high AD biomarker levels can remain dementia-free

The AT(N) Framework is an Alzheimer’s disease classification scheme that groups fluid and brain imaging biomarkers based around the underlying disease processes they detect. For example, brain scans and cerebrospinal fluid measurements of amyloid are grouped under ‘A’, while biomarkers that measure tau are grouped under ‘T’. Together, AT(N) profiles are designed to help clinicians and researchers better understand and categorise the disease processes that may lead to dementia.

To check the accuracy and diagnostic capability of AT(N) profiles, a group of researchers led by Prof. Paul Crane (University of Washington, Seattle, US) calculated the AT(N) profiles for a large community-based cohort of individuals, basing their calculations on autopsy correlates of AT(N). In their study, published recently in Alzheimer’s and Dementia, Prof. Crane and colleagues found that out of 603 individuals with complete AT(N) profiles and known dementia status, over 30% were biomarker-positive for amyloid, tau and neurodegeneration (A+T+(N)+). However, almost a third of individuals with this high-risk biomarker status remained dementia-free before death. This suggests that a substantial proportion of older individuals may be resilient to cognitive decline, despite having high levels of amyloid, tau and neurodegeneration.

10 May: Gregory Branigan discusses impact of oestrogen therapies on Alzheimer’s disease pathways

TouchNEUROLOGY recently spoke with Gregory Branigan (University of Arizona, US), about the impact of oestrogen therapies on Alzheimer’s disease (AD) pathways.

The interview was filmed at the American Academy of Neurology Virtual Annual Meeting 2021, held online between 17 and 22 April 2021, and was published online on 10 May 2021. You can watch it, here:

10 May: Cortexyme provides update on its GAIN Phase II/III trial for AD

On 10 May, Cortexyme, a clinical-stage pharmaceutical company developing novel treatments for altering the course of Alzheimer’s disease (AD) and other neurodegenerative disorders, provided an update on expected clinical data readouts and reported first quarter 2021 financial results.

The GAIN Trial is a Phase II/III randomised, double-blind and placebo-controlled study that is evaluating the efficacy, safety and tolerability of two dose levels of COR388 oral capsules in people with mild to moderate AD. The trial has enrolled 643 participants in the US, France, Spain, Poland, Netherlands and UK and approximately one-third of participants are pending completion in the study. 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 company plans to present baseline data from the GAIN trial at upcoming conferences.


10 May: Cassava Sciences announces the initiation of a cognition maintenance study in Alzheimer’s disease

On 10 May, the biopharmaceutical company Cassava Sciences announced the initiation of a Cognition Maintenance Study (CMS) to evaluate simufilam in people with 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.

Cassava Sciences is currently evaluating the long-term safety and tolerability of simufilam in a one-year and open-label study in people with mild-to-moderate AD. The new CMS study is a double-blind, multi-centre, randomised and placebo-controlled study with people with mild-to-moderate AD who have completed at least one year of open-label treatment with simufilam. A group of participants will continue to receive simufilam and the other group will receive placebo. This study is aiming to evaluate the changes in cognition over six months in participants who continue treatment with simufilam versus those who stop treatment. The company plans to recruit 100 participants in the US and Canada. In addition, Cassava Sciences plans to initiate a Phase III clinical program with simufilam in AD in 2021.


13 May: AI-designed antipsychotic drug to enter Phase 1 clinical trials for AD psychosis in the US

Exscientia has announced that DSP-0038, a novel small molecule inhibitor developed in collaboration with Sumitomo Dainippon Pharma, is shortly to enter Phase 1 clinical trials for treatment of Alzheimer’s disease (AD) psychosis.

DSP-0038 is a small molecule drug designed to block a serotonin receptor called 5-HT2A, whilst activating a similar serotonin receptor called 5-HT1A. DSP-0038 was designed using Exscientia’s AI technology, which is able to quickly model drug interactions by processing and analysing large quantities of data. DSP-0038 was chosen to enter a Phase 1 clinical trial based on its potency and selectivity, targeting the desired receptors whilst avoiding similar receptors and unwanted targets. It is hoped that by selectively targeting these two serotonin receptors, DSP-0038 will work as an effective antipsychotic in AD, also improving symptoms such as aggression, anxiety and agitation.

The clinical trial will take place in the US and will be led by Sumitomo Dainippon Pharma.

17 May: AC Immune updates on the progress of its pTau vaccine trial for AD, paving the way for expansion to Phase 2b/3

Together with its strategic partner, Janssen Pharmaceuticals Inc., AC Immune SA has recently announced the expansion of its Phase 1b/2a clinical trial evaluating ACI-35.030, a vaccine targeted at phosphorylated Tau proteins (pTau).

AC Immune SA launched its clinical trial of ACI-35.030 in July 2019, aiming to recruit 32 participants with early Alzheimer’s disease (AD) to evaluate the safety, tolerability and immunogenicity of the vaccine. As a vaccine candidate, ACI-35.030 has been designed to stimulate the generation of antibodies to pTau, which should bind to pathological Tau proteins in the brain and target them for clearance by the immune system. Recent results indicate that the treatment is
well-tolerated, with no clinically-relevant safety concerns and eliciting a potent antibody response against pTau.

AC Immune now plans to recruit additional participants to the second highest dose group, supporting continued development of ACI-35.030 into Phase 2b/3.

17 May: Alzheimer Europe contributes to DZNE paper on “Harmonizing Neuropsychological Assessment for Mild Neurocognitive Disorders in Europe”

The journal Alzheimer’s and Dementia has published a paper defining a European standard for the cognitive assessment of patients presenting to memory clinics. The tests covered in the paper include advanced tests sensitive to the typical memory deficits of Alzheimer’s disease, new tests sensitive to different neurodegenerative conditions (e.g., frontotemporal dementia), and the most effective traditionally-used tests.

The consensus was led by Dr Marina Boccardi at DZNE-Rostock and the list of contributing authors includes Alzheimer Europe’s Executive Director Jean Georges, alongside other European experts on Alzheimer’s disease and on cognitive assessment; methodologists; clinical neuropsychologists; and neurologists from academic and non-academic memory clinics. Co-led by the University of Geneva and hosted by the European Alzheimer’s Disease Consortium (EADC), the consensus also involved experts from United States and Australia.

Some of the benefits of developing a standard assessment across European memory clinics are:

- Results from cognitive assessments would be immediately comparable across centres, while a standard assessment would allow comparisons with results from any clinic, as is the case for blood tests.
- This in turn would make for greater reliability and efficiency, and would lower costs.
- Standard assessment would also benefit research, allowing researchers to select homogeneous participants and to pool data from different centres (with the patients’ consent).
- All this would align clinical activities with the most recent scientific advancements on new biomarkers or treatment options, further closing the gap between dementia care and the standard of care of other diseases already benefitting from modern and standardised clinical procedures.
- As well as reducing costs and increasing reliability of diagnosis, this standard will help early detection of Alzheimer’s and related disorders, allowing greater access to improved and personalised treatment.

https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.12365

19 May: Grifols and Fundació Acé announce the launch of an AMBAR Center in Barcelona

Grifols’ AMBAR Phase 3 clinical trial was designed to assess the effect of plasma replacement therapy in Alzheimer’s disease (AD), delivered via intravenous infusions. The results of this trial, which were published in Alzheimer’s and Dementia in 2020, showed that the AMBAR procedure could slow cognitive decline in people with mild or moderate AD.

Following on from the completion of the AMBAR clinical trial, which recruited almost 500 participants via 41 different treatment centres in Spain and the US, Grifols has announced the opening of an AMBAR centre in Barcelona, in collaboration with Fundació Acé. The new AMBAR centre will be managed by Fundació Acé, and is located at its medical centre in Barcelona. It is hoped that the Barcelona AMBAR centre, alongside others in the EU, US and China, will generate further medical data to help optimise the development of the AMBAR procedure.

LIVING WITH DEMENTIA

17 April: EWGPWD member Angela Pototschnigg is interviewed by Austria’s biggest newspaper

An interview with Angela Pototschnigg, a member of the European Working Group of People with Dementia (EWGPWD), appeared on 17 April 2021, in the Health supplement of the KRONE - Austria’s highest-circulation daily newspaper. Many thanks to Angela’s supporter Johanna Pueringer for her help in translating the interview to English, to share with Alzheimer Europe’s readers:

"MANY THINGS ARE STILL POSSIBLE IN MY LIFE, but with support I can do even more!"

A person affected by dementia talks about her life and her volunteer work for Alzheimer Austria.

Angela POTOTSCHNIGG in an interview with Ingrid Korosec, Member of the Federal Parliament of Vienna and President of the Austrian Seniors’ Association (Österreichischer Seniorenbund):

Two years ago, you were diagnosed with dementia. What symptoms did you have at the beginning?
My memory and concentration problems started in 2011, I was diagnosed with burnout and soon after I received my first dementia medication. But it was still a long journey to a valid diagnosis - I didn’t get it until 2019.

You did not react to your illness by withdrawing, but you are active in Alzheimer Austria. Why and what exactly do you do?

Alzheimer Austria supported me through counselling and many talks. They didn’t see only my limitations but also those things I was really good at, so that I was able to build on that and find new strategies for my life.

Today, I offer peer counselling at Alzheimer Austria, for people who are going through similar experiences to me. In 2018, I was nominated by Alzheimer Austria to join Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD).

How do you organise your everyday life?

I try very hard to keep order and I write a lot of things down. At the end of each day, I meticulously prepare for the next one and my daughters are supportive when it comes to big decisions. In my activities as a self-advocate, I get assistance from Alzheimer Austria.

Dementia is a very upsetting diagnosis. What advice would you give to relatives?

Of course, the diagnosis can come as a shock and can be frightening! I decided to talk about my limitations, but also about what else is still possible in my life - and these are not the sad images that society is often shown. For me, this disease is another way of experiencing old age.

My advice to relatives is: inform yourself about the disease, attend self-help groups, and please be respectful and patient with us!

What particularly bothers you about the public discussion around dementia? People with dementia themselves rarely seem to get a word in, and most of the time the discussion is only about them.

Yes, that's how it is! So-called 'experts' often decide on services for us, or decide what would be best for us, but only we know how it feels to live with this disease and what our real worries and needs are. In my mind, the word dementia is stigmatizing in itself, and I know that it scares many people - who wants to be called "out of one's mind" or "away from one's spirit"?

Dementia is a big topic, in the context of the Taskforce on Care, particularly because populations are ageing. Do you have any specific requests and wishes to express to the politicians involved?

We need support immediately after diagnosis - The type of support where people actively approach us with information and assistance, and accompany us for a while! Post-diagnostic support exists in Scotland, for example. Personal assistance is also an important issue, so that we can be active and involved in society for longer.

See the original KRONE article:

https://www.alzheimer-europe.org/var/plain_site/storage/original/application/805f27bb3140bcb165dbe5b781c57b1.pdf

27 April: EWGPWD member Margaret McCallion shares her thoughts on Alzheimer Scotland’s Fair Dementia Care campaign

Margaret McCallion (pictured), who is a member of both the European Working Group of People with Dementia (EWGPWD) and the Scottish Dementia Working Group (SDWG), has shared her thoughts on the Fair Dementia Care campaign being run by Alzheimer Scotland, as part of a blog piece posted by the SDWG, on 27 April 2021.

The blog piece:

Right now, in Scotland, people living with advanced dementia in care homes don’t have equality of access to free health and nursing care that someone diagnosed with another progressive, life limiting condition would have. They have to pay for this care because it is not recognised as health care. This inequality was highlighted in the ‘Delivering Fair Dementia Care for People with Advanced Dementia Report’ which was published in 2019. Following the report, the Fair Dementia Care Campaign was launched and started to raise awareness of the lack of equality of access to healthcare for people with advanced dementia, and set out to achieve fair care by working with the Scottish Government. Alzheimer Scotland asked members, supporters and the general public to sign up and support the campaign, and to date have over 18,000 signatures.

There is estimated to be 90,000 people living with dementia in Scotland today, and with an ageing population this figure is only set to increase. This is an issue that can impact anyone, and it’s often never thought about until people find themselves at a point of crisis.
When the COVID-19 pandemic hit in early 2020, it shone a spotlight on this inequity. May people in care homes tragically lost their lives and others were unable to have visitors due to restrictions, and still, people with advanced dementia continue to face care home charges for what are clearly health and nursing care needs. On 6 May 2021, the Scottish General Election will be held. Alzheimer Scotland are calling on candidates to pledge their support for the campaign, specifically around the assessment process and the charging policies. Ahead of the election, Alzheimer Scotland are asking members and supporters to contact their candidates to sign a pledge to deliver Fair Dementia Care. Find out how you can support the campaign here.

Margaret McCallion's comment: "I think the report and campaign are really well done. Yes, it’s clear that the campaign only focuses on people further along their dementia journey, but I think it’s really good that dementia care issues are being put forward to the government. To all candidates, no matter what party, I’d like to say that dementia affects everyone. No matter your affiliation, all candidates should sign the pledge. I think there should be no question that candidates should want to sign this pledge."

DEMENTIA IN SOCIETY

15 May: Call for registration of participants in the World JAIN Challenge

In close collaboration with INTERDEM, Alzheimer Nederland and Alzheimer Europe, JAIN will organize the World JAIN Challenge on 23 and 24 March 2022. The announcement of the winners will be on 6 April 2022.

The World JAIN Challenge (WJC 2022) is a public competition for developed or prototyped technical products and services based on Artificial Intelligence that support the quality of life and self-reliance of people with memory problems or dementia and their informal carers and that will support professionals and informal carers in providing optimal care for their loved ones. The event is organized for people with memory problems or dementia, informal carers, healthcare professionals, and others interested in these topics. The WJC 2022 is a competition in which an independent jury determines which is the best technical prototype or fully-fledged product of the World.

Developers, companies, universities, healthcare institutions, healthcare professionals who want to participate in the WJC can make themselves known and register with the secretary of the event.

Registration of prototype and product descriptions is possible from 15 May 2021 to 28 January 2022. The closing date for registration of participants in the WJC 2022 is Friday 28 January 2022 – 12:00 PM (GMT).

Upon submission, entrants will receive guidelines that the submissions of a prototype and product description must adhere to, as well as the terms and conditions applicable to the WJC. See: World JAIN Challenge Guidelines & Terms and Conditions

Register (Registration form will be automatically presented on the website).

People who want to participate in the Challenge must submit their product prototype or a full-fledged product description in accordance with undermentioned guidelines to registration.wjc@jainprojects.com

The evaluation procedure of received product descriptions is carried out under the coordination of JAIN and INTERDEM.

https://www.jainprojects.com/world-jain-challenge-guidelines-terms-and-conditions-for-participants/

17 May: Participate in a 30-minute phone audio-recorded interview to share your thoughts on the See Pain More Clearly initiative

See Pain More Clearly is looking for participants for a study to evaluate the effectiveness of its social media initiative to mobilise knowledge about pain in dementia. If you are a health professional working with individuals with dementia; a family member or informal caregiver of a person with dementia or a policymaker, you can participate, here: https://www.seepainmoreclearly.org/participate-in-our-study
NEW PUBLICATIONS & RESOURCES

5 May: WHO launches Global Dementia Observatory Knowledge Exchange Platform

On 5 May 2021, the World Health Organization (WHO) launched its Global Dementia Observatory Knowledge Exchange Platform (GDO KE Platform) during a one-hour webinar.

The GDO KE Platform contains key resources to support the implementation of the Global action plan on the public health response to dementia 2017-2025 and its seven action areas. It provides a space for stakeholders to share resources (e.g. policies, guidelines, case studies and examples of good practice) to facilitate mutual learning and promote the exchange of knowledge in the area of dementia.

All resources are submitted by users of the GDO KE Platform or any member of the general public. Resources are mapped to at least one of the strategic action areas of the global dementia action plan. Automated filters allow users to search for country, region or language-specific resources, narrow down their searches by types of resources (e.g., policies, trainings, tools, practice examples) and other filters.

A comprehensive review process consisting of a panel of peer reviewers who are experts in the field of dementia, a focus group of people with lived experience of dementia and the WHO Secretariat ensure that selected resources meet quality and good practice criteria. Users of the platform are also invited to leave comments and rate the resources to further enhance the discussion about ways to promote and strengthen dementia practice.

An online launch event was held which Jean Georges, Executive Director, and Owen Miller, Policy Officer were in attendance for Alzheimer Europe, whilst Helen Rochford-Brennan, a member of the European Working Group of People with Dementia (EWGPWD), participated on a panel during the event.

The Knowledge Exchange platform can be accessed at: https://globaldementia.org/en

10 May: New book on "The Problem of Alzheimer’s: How Science, Culture, and Politics Turned a Rare Disease Into a Crisis and What We Can Do About It" published by Jason Karlawish

Dr Jason Karlawish, co-director of the Penn Memory Center at the University of Pennsylvania in Philadelphia, US, has published a new book, called "The Problem of Alzheimer’s: How Science, Culture, and Politics Turned a Rare Disease Into a Crisis and What We Can Do About It". The book takes us inside laboratories, the homes of people living with dementia, carers’ support groups, progressive care communities, and Dr Karlawish’s own practice at the Penn Memory Center.

Part case studies, part meditations on the past, present and future of the disease, the book looks at Alzheimer’s disease (AD) from its beginnings to its recognition as a crisis. It gives an account of decades of missed opportunities and of health care system failures, all the while listing the biomedical breakthroughs that may allow AD to finally be prevented and treated. The author also discusses how to live with dementia and how people with dementia can reclaim their autonomy and redefine their sense of self, how families can support their loved ones, and the innovative reforms we can make as a society that would give carers and people with dementia a better quality of life. The book is available for purchase as of early 2021.
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.

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<tr>
<th>Date</th>
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<tr>
<td>1-2 June</td>
<td>Patients and Consumer’s Working Party of the European Medicines Agency</td>
<td>Jean</td>
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<tr>
<td>3 June</td>
<td>EWGPWD meeting</td>
<td>Dianne, Ana and Jean</td>
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<tr>
<td>4 June</td>
<td>Neuronet Communications Experts’ Community</td>
<td>Ange, Cindy and Chris</td>
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<td>7 June</td>
<td>Dementia Panel of the European Academy of Neurology</td>
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<td>9 June</td>
<td>World Dementia Council webinar on data sharing for dementia research</td>
<td>Ange and Jean</td>
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<tr>
<td>9 June</td>
<td>ADAIR General Assembly</td>
<td>Ana and Jean</td>
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<td>9 June</td>
<td>PACT Partners' Assembly</td>
<td>Owen</td>
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<td>10 June</td>
<td>EDF ENGO meeting</td>
<td>Owen</td>
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<td>11 June</td>
<td>Symposium of University of Eastern Finland</td>
<td>Jean</td>
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<tr>
<td>11 June</td>
<td>Neuronet Ethics and Patient Privacy Working Group</td>
<td>Jean, Dianne, Ange</td>
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<tr>
<td>14 June</td>
<td>Alzheimer Europe Annual General Meeting</td>
<td>AE members, Board and staff</td>
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<tr>
<td>15 June</td>
<td>European Parliament Workshop &quot;The Alzheimer’s spectrum: Changing our understanding of Alzheimer’s disease and dementia&quot;</td>
<td>AE members, Board and staff</td>
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<td>15 June</td>
<td>IMI Impact event</td>
<td>Ana and Dianne</td>
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<td>15 June</td>
<td>I**HD plenary 2: proposing a common basis for health data use</td>
<td>Ange</td>
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<td>16 June</td>
<td>Eisai Global Alzheimer’s Disease Advocacy Advisory Board</td>
<td>Ange</td>
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<td>16 June</td>
<td>European Group of Governmental Experts on Dementia</td>
<td>Owen and Jean</td>
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<tr>
<td>17 June</td>
<td>Alzheimer Europe Company round table meeting</td>
<td>AE sponsors, members and staff</td>
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<td>17 June</td>
<td>RADAR AD Webinar on regulatory issues</td>
<td>Ana and Dianne</td>
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<td>17 June</td>
<td>TVB_Cloud virtual GA meeting</td>
<td>Jean and Ange</td>
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<td>17 June</td>
<td>Information meeting with Biogen</td>
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<td>18 June</td>
<td>DataSavesLives Core Group meeting</td>
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<td>19 June</td>
<td>Scientific Panel of European Academy of Neurology</td>
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<td>21 June</td>
<td>Recognised Annual Meeting</td>
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<td>22 June</td>
<td>Neuronet Working Group on Data Sharing</td>
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<td>25 June</td>
<td>GSK Health Advisory Board</td>
<td>Jean</td>
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<td>25 June</td>
<td>RADAR-AD PAB meeting</td>
<td>Dianne and Ana</td>
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<tr>
<td>29 June</td>
<td>EU-Atlas: Dementia and Migration</td>
<td>Dianne</td>
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<tr>
<td>29 June</td>
<td>EWGPWD meeting</td>
<td>Dianne and Ana</td>
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## CONFERENCES 2021

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<tr>
<th>Date</th>
<th>Meeting</th>
<th>Format/ Place</th>
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<tbody>
<tr>
<td>26 -30 July</td>
<td>Alzheimer's Association International Conference (AAIC),</td>
<td>Amsterdam, Netherlands &amp; Virtual</td>
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<td><a href="https://www.alz.org/aaic/overview.asp">https://www.alz.org/aaic/overview.asp</a></td>
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<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>
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<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>
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<tr>
<td>29 Nov-1 Dec</td>
<td>31st Alzheimer Europe Conference, <a href="https://www.alzheimer-europe.org/Conferences/2021-Online">https://www.alzheimer-europe.org/Conferences/2021-Online</a></td>
<td>Virtual</td>
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31st Alzheimer Europe Conference
Resilience in dementia: Moving beyond the COVID-19 pandemic
Virtual Conference
29 November - 1 December 2021
www.alzheimer-europe.org/conferences  #31AEC