March saw two new publications for Alzheimer Europe: Our latest ethics report, identifying key recommendations on legal capacity and decision making of people with dementia; and the “Dementia Monitor 2020”, outlining the state-of-play of dementia policy in Europe. We were also involved in two new research papers, published in the Journal of Health Expectations, both based on the work of the PARADIGM project. Dianne Gove and Ana Diaz were among the co-authors of the first article, on “Understanding multi-stakeholder needs, preferences and expectations to define effective practices and processes of patient engagement in medicine development: A mixed-methods study”, and Ana is a co-author of the second article, “Evaluation of patient engagement in medicine development: a multi-stakeholder framework with metrics”.

We are delighted to be increasingly involved in EU-funded dementia research projects and one such project which recently came to an end was European Prevention of Alzheimer’s Dementia (EPAD). EPAD announced this month that its latest and final dataset, which went into open access in late 2020, has now been incorporated into the Alzheimer's Disease Data Initiative (ADDI) Alzheimer’s Disease Workbench.

Finally, on the EU project front, the new H2020-funded project, AI-Mind, which is focusing on artificial intelligence for dementia prevention, held its official kick-off meeting, attended by almost 50 project contributors from 15 partners, including Alzheimer Europe.

Taking a look at the EU landscape, there have been some exciting developments in the past weeks, including the European Union’s EU4Health programme being published in the Official Journal of the European Union, which marks the new programme’s official start. The EUR 5.1 billion programme will undertake a range of actions in relation to health across the EU, with around 20% earmarked for prevention.

The European Commission launched two important documents, this month: a new disability rights strategy, outlining how the Commission aims to support the rights of people with disabilities across the EU; and an Action Plan on the European Pillar of Social Rights, which was proclaimed by the European Parliament, the Council and the Commission in 2017, at the Gothenburg Summit. The Pillar sets out 20 key principles and rights essential for fair and well-functioning labour markets and welfare systems, and the new Action Plan sets out how the EU intends to achieve these.

Also, at the EU level, we have joined other health-focused civil society organisations in supporting a manifesto, coordinated by European Health Forum Gastein, focused on shaping the future of the EU’s European Health Union. The manifesto sets out a series of goals, policies and principles and calls upon European leaders, within the European Council and as part of the Conference on the Future of Europe, to embed these in the European Health Union.

I hope you enjoy our newsletter!

Jean Georges
Executive Director
COVID-19 SITUATION

11 March: WW-FINGERS researchers describe how study protocols and processes have been adapted during the COVID-19 pandemic

The Finnish FINGER trial was among the first to show the cognitive benefit of multi-domain interventions including exercise, improved diet, social stimulation and management of lifestyle factors in older people at risk of developing dementia. World-Wide FINGERS (WW-FINGERS) is an interdisciplinary network that brings together several clinical studies and research groups evaluating preventive interventions targeting modifiable risk factors based on the FINGER model, including the US-POINTER, J-MINT and AgeWell.de studies, three clinical trials in the US, Japan and Germany.

In a perspective article, published in the journal Alzheimer’s & Dementia: Translational Research and Clinical Interventions, Dr Susanne Rohr, Prof. Mark Espeland and colleagues in the WW-FINGERS study shared experiences on the design and management of clinical research during the COVID-19 pandemic. The article describes COVID-19-related experiences from US-POINTER, J-MINT and AgeWell.de and alterations and adaptations made necessary by the pandemic in these clinical trials involving people at risk for cognitive decline and dementia.

For example, the Japanese 18-month multidomain intervention for dementia prevention trial called J-MINT has been affected by the pandemic mainly in the recruitment process. Compared to the schedule originally planned, the progress of the study has been delayed more than half a year. J-MINT investigators describe how face shields and/or masks and social distancing are used during exercise classes, while in Germany, AgeWell.de participants are offered assessments in their homes as well as at study sites. While recruitment and baseline assessments were completed before the pandemic for the AgeWell.de study, infection control measures and post-intervention follow-up assessments have been impacted. In addition, authors provided recommendations for future behavioural intervention trials and emphasised the importance of ensuring that study designs are sufficiently flexible to enable lifestyle interventions to be delivered in a physically distanced environment, with remote follow-up assessments as required. The authors identify some statistical considerations, indicating that study designs may need to be adapted to preserve statistical power and facilitate statistical analyses.


18 March: Care Quality Commission review finds that more than 500 people in the UK were put on "do-not-resuscitate" orders during the pandemic, without their consent

According to a report by England’s Care Quality Commission (CQC), more than 500 people in the United Kingdom were put on "do-not-resuscitate" orders without their consent or their carers’ consent during the coronavirus pandemic. The report was published on 18 March.

“From the beginning of the COVID-19 pandemic, there were concerns that ‘do not attempt cardiopulmonary resuscitation’ (DNACPR) decisions were being made without involving people, or their families and/or carers if so wished, and were being applied to groups of people, rather than taking into account each person’s individual circumstances,” said the CQC in its report.

Out of 2,048 adult social care providers who responded to the CQC's information request, 5.2% (508 out of 9,679) of DNACPR decisions put in place since 17 March 2020 "had not been agreed in discussion with the person, their relative or carer". In one care home, everyone over 80 with dementia had a DNACPR order applied.

The report comes after the UK’s Department of Health and Social Care requested a rapid review into the do-not-resuscitate decisions following "concerns that they were being inappropriately applied to groups of people without their knowledge."

"Across the review process, whilst inspectors did find some examples of good practice, they also found a worrying picture of poor involvement of people using services, poor record keeping, and a lack of oversight and scrutiny of the decisions being made," the study found.

The CQC has called for government action to address a "worrying variation" in people’s experiences of do-not-resuscitate decisions and “to take responsibility for delivering improvements in this vital and sensitive area.” The CQC report can be read here:


ALZHEIMER EUROPE

9 March: New Alzheimer Europe report identifies key recommendations on legal capacity and decision making of people with dementia

On 9 March 2021, Alzheimer Europe launched a new report, “Legal capacity and decision making: The ethical implications of lack of legal capacity on the lives of people with dementia”, which looks at the intersection between legal rights and...
ethical considerations in relation to legal capacity and decision making.

The working group responsible for the report was set up by Alzheimer Europe in 2020 and was composed of experts in dementia, law, ethics, policy, research, psychology and the experience of having dementia and supporting people with dementia. This report contains a detailed discussion and extensive recommendations on guardianship measures, treatment, care and support, communication of the diagnosis, advanced care planning, participation in research, coercive measures, restrictions of freedom during the COVID-19 pandemic, and civil and political life. The following are some of the key recommendations developed by the working group:

- Guardianship legislation should be reframed as decision-making support. Substitute decision making, which would be the most extensive guardianship measure, should only be applied when all other options have been considered or tested, and have not proven sufficient to protect the rights of people with dementia.
- Support should be organised in a systematic and structured manner such as in the combined supported decision-making model.
- There should be greater monitoring of how legislation to involuntarily detain people with dementia is used and how this could be amended to reflect a supported decision-making approach.
- Procedural safeguards should be developed to protect the rights and wellbeing of people with dementia in residential respite care and day care, and in other places where they are not free to leave but have not been lawfully detained.
- Restraint should only be tolerated in extreme situations where the physical and mental integrity of the person with dementia is in serious and imminent danger and as a last resort, unless there is no time or it would be too risky to attempt another approach.

Governments should set up independent inquires into the management of dementia care during the COVID-19 pandemic and develop guidelines to help ensure that future pandemics or similar crises are managed in a way that is both ethical and legal.

People should be allowed to confirm their desire for their advance directive to remain valid should they at some point lack the capacity to renew it or to transfer decision-making responsibility to a named person of their choice.

Every person should have access to an independent supporter to make a will and to include members of their entourage in this process if they wish.

A diagnosis of dementia or guardianship measure should never result in the automatic loss of the right to vote, marry, divorce or make a will or advance directive.

Dianne Gove, Director for Projects at Alzheimer Europe and co-author of the report, stated: “Any loss of the right to make decisions, including both formal and informal restrictions, can have a considerable psychological, emotional and practical impact on people’s lives and wellbeing. It is important to reflect on ethical issues related to legal capacity and decision making, such as the need to respect human rights, protect the dignity of all human beings, and ensure that everyone with dementia can enjoy and fully participate in civil, political, economic, social and cultural life.”

Jean Georges, Executive Director of Alzheimer Europe, added: “It is important that lawmakers, policy makers, health and social care professionals, administrative bodies, notaries and the general public all work together to remove obstacles and provide appropriate and timely support to maximise the potential for people with dementia to exercise their legal capacity. We need to create flexible and humane systems and move away from mentalities, traditions and taken-for-granted assumptions that prevent people from making decisions and from living their lives in accordance with their own wishes and values. Appropriate support, reasonable adjustments and safeguards must be in place to maximise freedom of choice and equal opportunities for people with dementia across the whole of society.”


The report “Legal capacity and decision making: The ethical implications of lack of legal capacity on the lives of people with dementia” received funding under an operating grant from the European Union’s Health Programme (2014–2020).

**15 March: Alzheimer Europe adds a new trial to its Clinical Trials Watch**

Alzheimer Europe continues to develop and improve its Clinical Trials Watch (CTW), an innovative online resource providing up-to-date accessible information on clinical trials currently recruiting participants in at least one European country.

The service currently provides information on nine phase II and seven III clinical trials that are investigating drugs for the prevention and treatment of dementia and/or Alzheimer’s disease (AD).

In March 2021, the INFROnt-3 trial has been added to the service. The purpose of this Phase II study is to evaluate the safety and efficacy of AL001 in participants at risk for or with frontotemporal dementia due to heterozygous mutations in
the progranulin gene. The study is recruiting participants in nine European countries. Further information about the CTW is available on: http://www.alzheimer-europe.org/Research/Clinical-Trials-Watch

15 March: Alzheimer Europe publishes videos from online European Parliament workshop

Following its successful European Parliament Workshop hosted online, on 23 February, Alzheimer Europe has shared the recordings of the presentations made at the event. Each presentation is publicly available on the Alzheimer Europe YouTube channel: https://youtube.com/playlist?list=PLQH1WQPx6S44tR25C19b9xOIrVv37

23 March: Alzheimer Europe continues to comply with EMA’s strict eligibility criteria

On 23 March 2021, the European Medicines Agency (EMA) confirmed that Alzheimer Europe continues to comply with its strict eligibility criteria, as defined by its Management Board, and can continue to be involved in its activities. The list of all the patients’ and consumers’ organisations that are involved in EMA activities can be viewed here: http://bit.ly/38l1g9o

30 March: Alzheimer Europe outlines state-of-play of dementia policy in Europe

Luxembourg, 30 March 2021 – Alzheimer Europe has launched a new report, “Dementia Monitor 2020”, providing a high-level overview of how countries across Europe have responded to the challenges posed by dementia. Alzheimer Europe’s Dementia Monitor 2020, provides a high-level overview of countries across Europe, outlining their responses to dementia, across 10 areas, including care and support services, participation in European research, policy drivers and legal protections. The report was developed by Alzheimer Europe, working together with its national member associations.

Alzheimer Europe published a similar report in 2017 which established a benchmark for countries and has made it possible to identify changes in the dementia landscape over the past three years.

Some key highlights from the Dementia Monitor 2020 include:

- Care and support services continue to be largely insufficiently available, despite some minor improvements since 2017
- A majority of care and support services continue to receive some level of financial support from the state (either fully funded or co-funded)
- An increasing number of countries are engaging in policy processes designed to prioritise dementia, for example, through the development of dementia strategies
- Countries in central and eastern Europe continue to be less well represented in clinical trials related to dementia
- A majority of countries continue to have a poor level of legal protections in place to guarantee the rights of people with dementia or carers, particularly in relation to employment matters
- There continues to be significant differences between Western and Northern European countries and those in Central and Eastern Europe in terms of how governments are responding to dementia.

Commenting on the launch of the report, Alzheimer Europe’s Executive Director, Jean Georges, stated: “There is a mixed picture emerging from the Dementia Monitor 2020. Whilst we have seen some minor improvements in the availability and affordability of care since the 2017 Dementia Monitor, it remains the case that overall, too many services remain insufficiently available. Whilst progress in the areas of policy and international commitments are certainly welcome, it is evident that there is still much work to do in order to translate commitments on paper into everyday reality for people living with dementia. The number of people with dementia in Europe is likely to double by 2050, increasing from 9.78 million to 18.8 million. People with dementia and their carers must be supported throughout the duration of the illness, from the point of diagnosis through until the end of life. If this is to be achieved, particularly in light of an inevitable increase in demand for supports and services, we must see significant investment in health and social care systems to fix the shortcomings in the availability and financial support, as well as securing their long-term sustainability. Alzheimer Europe strongly calls upon the EU to use its Cohesion Funds, including the EU4Health programme, to support Member States to address the identified gaps in care and support services for people living with dementia.”

Alzheimer Europe gratefully acknowledges the support of the gold and silver sponsors of its public affairs activities which made this report possible.

---

**Alzheimer Europe networking (online)**

On 1 March, Gwladys had a meeting with our Zoom account contact.

On 2 March, Jean had a meeting with the Global Brain Health Institute.

On 2 March, Owen attended an online briefing session by Biogen, focusing on educational needs for healthcare professionals.

On 2 and 3 March, Ange attended a joint meeting of the EMA Patient’s and Consumer’s Working Party (PCWP) and Healthcare Professional’s WP (HCPWP).

On 3 March, Jean met with the EFPIA Alzheimer’s disease platform.

On 3 March, Cindy and Ana attended the EU-FINGERS Advisory Board meeting.

On 4 March, Ana and Dianne participated in the RADAR-AD Patient Advisory Board informative meeting.

On 4 March, Ana participated in a webinar organised by the EHDEN project.

On 4 March, Jean had a meeting with Roche.

On 5 March, Ange and Jean attended a Neuronet meeting on the Neurocohort.

On 5 March, Cindy and Ange attended the Neuronet Working Group on Data Sharing meeting.

On 5 March, Gwladys had a meeting with LiveOnlineEvent.

On 8 March, Ana participated in a meeting of the EU FINGERS Advisory Board.

On 8 March, Jean attended the meeting of the PAVE (Project Alzheimer’s Value Europe) initiative.

On 9 March, Jean met with the Global Council on Ageing.

On 9 March, Ange attended a PRIME project meeting on dissemination and involvement of patient organisations.

On 9 March, Gwladys and Stefanie had a meeting with EventsForce.

On 10 March, Jean had a meeting with AbbVie.

On 11 March, Dianne and Ana participated in various consultations with members of the RADAR-AD Patient Advisory Board.

On 11 March, Cindy, Jean, Chris and Ange attended the kick-off meeting of the AI-Mind project.

On 11 March, Owen attended a webinar organised by European Health Forum Gastein on a future European Health Union.

On 12 March, Ange and Owen attended an online meeting with the WHO, to discuss their development of a blueprint for dementia research.

On 12 March, Dianne, Ana and Ange attended a meeting with Eodyne on TVB_Cloud project activities.

On 18 March, Ana participated in a RADAR-CNS webinar.

On 22 March, Cindy, Jean, Chris and Ange attended the Neuronet Scientific Coordination Board meeting.

On 22 March, Gwladys attended a workshop on Legal matters for associations and event planners: Negotiations, Contracts, and events cancellations, by Association World.

On 22 and 23 March, Jean participated in the Roche AD Patient Advisory Group.

On 23 March, Owen and Jean met with Biogen representatives.

On 23 March, Cindy and Jean attended a meeting of the PRODEMOS project.

On 24 March, Jean met with Roche.

On 24 March, Dianne attended a DAI webinar on LGBTI people, kindness and dementia.
On 24 March, Gwladys attended “Virtual Helsinki for Meetings and Events”.

On 24 March, Owen attended a workshop by the European Commission, focused on the forthcoming EU4Health programme.

On 24 March, Dianne and Cindy attended the first AI-Mind WP leaders meeting.

On 25 March, Ana participated in a PARADIGM webinar on monitoring and evaluating patient engagement activities.

On 26 March, Cindy and Jean met with Alector.

On 26 March, Dianne attended the MinD network meeting.

On 30 March, Jean met with Janssen.

On 30 March, Kate attended the Council meeting of Alzheimer’s Disease International.

On 30 March, Owen attended an online meeting hosted by the WHO about their forthcoming global action plan on epilepsy & other neurological disorders.

On 30 March, Ange attended a PRIME webinar on neurodevelopmental disorders.

On 30 and 31 March, Jean, Dianne and Ana participated in the RADAR-AD Annual Meeting.

---

**EU PROJECTS**

3 February: ADAIR project holds its second General Assembly

On 3 February, the “From air pollution to brain pollution – novel biomarkers to unravel the link of air pollution and Alzheimer’s disease” (ADAIR) consortium held its second General Assembly (GA), virtually. ADAIR applies a precision medicine approach to stratify individuals to subgroups for risk estimation and future AD prevention, ultimately aiming to target air pollution induced effects in those individuals that can most benefit from them. The project investigates the novel, ambitious hypothesis that the pollutant exposure environment of an individual alters cellular mechanisms and functions, resulting in the expression of measurable biomarkers associated with AD.

The Project Coordinator, Associate Professor Katja Kanninen, opened the GA, which was attended by 21 delegates representing 7 institutions and organisations in the consortium. During the GA, the Coordinator and work package leaders reported scientific progress, to date, as well as planned work for the coming months. At present, the team led by Professor Jan Topinka, from the Institute of Experimental Medicine at the Czech Academy of Sciences, has commenced multi-omic analysis for biomarkers of air pollutant exposure effect and AD risk factors. Due to COVID-19, planned research mobility between partnering institutions in 2021 is currently on hold.

Jean Georges, Executive Director of Alzheimer Europe attended the ADAIR GA. Alzheimer Europe is an external collaborator in the ADAIR project and is involved in managing and promoting successful exploitation of research results from the ADAIR project. This includes generating a strong interest within the relevant stakeholder communities such as policymakers, health and safety sector, and patient advocacy groups. Most recently, the consortium was introduced to the public at the 30th Virtual Alzheimer Europe Conference. The consortium is also planning to hold a parallel session at the 31st Alzheimer Europe Conference in November 2021, where partners will present research results. The next ADAIR General Assembly will be held on 8 June 2021, and is tentatively proposed as a hybrid event.

Further information on the project and consortium can be found here: https://adair-jpnd.eu/

15 February: Neuronet Working Group on HTA and regulatory interactions holds an online meeting, identifying key challenges relating to the use and development of digital endpoints

On 15 February, Neuronet hosted an online meeting of its Working Group on Health Technology Assessment (HTA) and Regulatory interactions, moderated by Diana O’Rourke from the National Institute for Health and Care Excellence (NICE). The main focus of this meeting was on the considerations and issues for the use of digital endpoints in HTA submissions for new health technologies and in other guidance. To support these discussions, 3 external HTA experts (Anja Schiel (NoMA), Niklas Hedberg (TLV/EUnetHTA) and Sheela Upadhyaya (NICE)) were invited to the meeting to provide their perspectives in relation to a number of questions.
Diana kicked off the meeting with a brief introduction to Neuronet and an overview of the role and objectives of the Working Group. Next, David Nobbs (IDEA-FAST), Lynn Rochester (Mobilise-D) and Gul Erdemli (RADAR-AD) each delivered short presentations describing the development of digital endpoints within their respective projects. Following the presentations, Anja, Niklas and Sheela answered questions relating to HTA bodies’ experiences of the use of digital endpoints as evidence in HTA submissions, and the requirements and expectations of HTA bodies in relation to using digital endpoints. The Working Group also discussed the potential opportunities for informal engagement with HTA bodies within the context of IMI projects where discussions can take place much earlier in the process and are not related to a specific health technology.

The discussions from the Working Group meeting will inform the development of a white paper on the challenges faced by technology developers in engagement with regulatory and HTA agencies.


18-21 February: RADAR-AD represented at 12th Panhellenic Conference of Alzheimer’s Disease and the 4th Mediterranean Conference on Neurodegenerative Diseases

The RADAR-AD project was represented at the 12th Panhellenic Conference of Alzheimer’s Disease (PICAD) and the 4th Mediterranean Conference on Neurodegenerative Diseases (MeCOND), between 18 and 21 February 2021.

Thanos Stavropoulos, Postdoctoral Research Associate at the Centre for Research and Technology Hellas (CERTH), who works on RADAR-AD’s device selection and analytics, together with his fellow research associates from CERTH represented the project, at PICAD and MeCoND. He introduced the audience to the RADAR-AD project by focusing on the study setup, data collection methods and platform integration and talked specifically about the Banking App that the RADAR-AD consortium developed for the main study. He explained that the RADAR-AD study is already taking place in several European countries, and aims at leveraging different combinations of wearables, smart home devices and applications, in three different settings: during a lab assessment visit, independent living at home and a fully equipped digital smart home. To achieve this goal, the RADAR-AD consortium has selected wearable devices and built applications that can collect digital biomarkers for critical functional domains. One example is the Banking App, which is used in the first or main RADAR AD study to assess the ability of people living with Alzheimer’s disease to manage finances by using an ATM simulation.

Read the full news story here.

1 March: DISTINCT project researchers find that low-cost robots may have potential to improve the psychosocial health of people with dementia

Robotic pets are a seen as a viable substitute to animal-assisted therapy, and have been used to provide companionship and psychosocial benefits for people with dementia. However, the affordability of such technology has remained an issue. For instance, the price of a pet robot can range from EUR 1,500 to EUR 6,000. This can affect the accessibility of this technology for people with dementia. In an article that was recently published in the journal JMIR Rehabilitation and Assistive technology, researchers working on the DISTINCT project explored the potential of lower-cost alternatives.

In comparison to pet robots that were shared among people in group settings, lower-cost pet robots were more often used individually. This could be attributed to the more affordable cost, making individual ownership of the technology more accessible. In view of the ongoing COVID-19 pandemic, this is especially relevant, given that shared use of devices is discouraged, in order to reduce the transmission of infections. The researchers also found that the lower-cost robot pets had similar positive impacts to those seen in studies using other costlier robotic pets, such as reduced agitation and improved mood.

This research suggests that, despite the differences in technological capabilities between lower and higher cost robots, the lower-cost options also hold the potential to address some of the psychosocial needs of people with dementia. However, higher quality of evidence is needed to confirm these findings. The researchers also recommend that future studies should compare the use of low-cost robotic pets with other pet robots.

The full text of the research article can be found here: https://rehab.jmir.org/2021/1/e25340

5 March: Neuronet convenes meeting of Working Group on data sharing, addressing FAIR data, technical challenges and digital technologies

On 5 March, Neuronet convened an online meeting of its data sharing Working Group (WG), co-moderated by Lennert Steukers (Janssen; Project Leader for Neuronet) and Manuela Rinaldi (Janssen; Neuronet consortium member). The Neuronet Working Groups are cross-project spaces for experts in Innovative Medicines Initiative (IMI) neurodegeneration
projects, providing them with a forum to address common issues and priorities and identify opportunities for synergy and collaboration. The Working Groups are organised around four key areas of interest for IMI projects, one of which is data sharing; the others are HTA/regulatory interactions, patient privacy & ethics, and sustainability.

Kicking off the data sharing WG meeting, Herman van Vijmen (Janssen), Leader of the FAIRplus IMI project, provided an introduction to FAIRplus, which is developing guidelines and tools to make data Findable, Accessible, Interoperable and Reusable (FAIR). The overarching aim of the project is to enhance knowledge sharing, accelerating innovation and paving the way to insights that could benefit society. To do this, FAIRplus has recently developed a FAIR cookbook as well as legal templates, to support IMI projects in making their data FAIR. Herman van Vijmen described the sections of the FAIR cookbook and discussed the importance of making data FAIR to meet the sustainability objectives of IMI projects.

Next, Carlos Diaz (Synapse; Neuronet Project Coordinator) outlined some of the technical challenges associated with data sharing, highlighting the complexity of sharing datasets that use different data dictionaries, involve multiple data sources and formats, and usually contain sensitive, personal information. Digital data sharing and remote monitoring technologies were next on the agenda, with discussions on how best to support projects that generate and use digital biomarker datasets collected using wearable technologies, for example. Closing the session, Angela Bradshaw (Alzheimer Europe; Neuronet consortium member) provided an overview of the recent Alzheimer Europe report on data sharing in dementia research, summarising the background to this report and its key findings and recommendations.

https://www.imi-neuronet.org/working-groups/

8 March: EU-FINGERS Advisory Board meets in February and March

The JPND-funded project, EU-FINGERS, kicked off in 2020 with the aim of advancing preventive strategies for risk reduction and prevention of cognitive decline and Alzheimer’s dementia. An important outcome of this project will be the “Multimodal Precision Prevention Toolbox”. This Toolbox will include different tools enabling the next generation of clinical trials, to identify precision prevention strategies for Alzheimer’s dementia. Precision Medicine takes into account individual characteristics, in terms of biology, lifestyle and environment, to optimise disease treatment and prevention.

EU-FINGERS set up an Advisory Board in January 2021 composed of people affected by or with an interest in Alzheimer’s disease and brain health. The Advisory Board has been very active during the months of February and March. Members of the Advisory Board were split in three smaller groups and met online on 25 February and 3 March. In the meetings, members discussed about the terminology which is often used to refer to prevention, the relevance of this type of research and interventions for people affected by the condition, and the main barriers and facilitators for participating in prevention initiatives. The discussions were co-facilitated by Ana Diaz (Alzheimer Europe) and Francesca Mangialasche (Karolinska Institute). In addition, on 8 March, five members of the Advisory Board participated in a meeting in which they provided feedback on a survey which is currently being developed in the project to explore and describe the perspectives of memory clinic clinicians on (communicating about) early diagnosis of Alzheimer’s disease, dementia risk and prevention. This work was facilitated by Heleen Hendriksen (VU University Medical Center). All meetings were very interactive and lively and the feedback received was very valuable for the project. Project officers Cindy Bick and Ana Diaz participated in the different meetings.

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

10 March: EPAD releases its first data and sample access report

A key achievement of the European Prevention of Alzheimer’s Dementia (EPAD) project was the establishment of a Longitudinal Cohort Study (LCS) that has screened over 2,000
participants and collected a wide range of cognitive, clinical, neuroimaging and biomarker data to help further our understanding of the early stages of Alzheimer’s disease. EPAD has made this database open access and publicly available to the research community through the EPAD LCS Research Access Process (ERAP).

On 10 March 2021, EPAD has released a report presenting an analysis of applications made to access the EPAD data and samples. This first bulletin covers applications made between May 2019 and January 2021.

A total of 125 applications was processed between the reporting period. 93% of applications was approved, while 5% was withdrawn and 2% was denied. Reasons for an application being denied include the identity of an applicant cannot be established or the applicant is named as a co-applicant on an already approved application.

There are three types of requests. “Data only” accounts for about 56% of the total applications received. About 31% of the researchers requested for the “MRI scans” whereas 13% of the researchers were interested in “biological samples”.

It is also interesting to note that about 65% of applications received came from researchers within EPAD partner organisations while 35% of the applications were from researchers outside of the EPAD partner organisations.


11 March: AI-MIND convenes its kick-off meeting online

On 11 March, the new H2020-funded project AI-Mind kicked off in an online meeting. AI-Mind aims to facilitating a paradigm shift in clinical practice. AI-Mind will create intelligent digital tools for screening of brain connectivity and dementia risk estimation in people affected by mild cognitive impairment.

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

Ira Haraldsen (Oslo University Hospital, OUS, Norway) coordinator of the AI-Mind project, kicked off the meeting by welcoming almost 50 project contributors to the meeting. Following on from the introductory session, each work package lead had the opportunity to introduce its objectives and involvement in the project. All 15 partners of the consortium actively participated in the online meeting.

Alzheimer Europe will be involved in the ethics, Patient and Public Involvement (PPI) and communication activities of the project. Jean, Angela, Cindy and Chris took part in the meeting.

Visit the project’s website for more information:
https://www.ai-mind.eu/

12 March: The World-Wide FINGERS Network organises an online meeting

World-Wide FINGERS (WW-FINGERS) is an interdisciplinary network to share experiences, harmonise data and plan joint international initiatives to reduce risk of cognitive impairment or dementia.

On 12 March, Miia Kivipelto and Maria Carrillo welcomed almost 100 WW-FINGERS Network members to an online meeting. They provided insights into the network both internally as well as in the context of the global pandemic. They also highlighted that it is great to see how the WW-FINGERS Network has been growing reaching more than 30 countries, with the recent inclusion of two countries Luxembourg and Turkey.

The goal of the meeting was to continue the conversation on the SARS-CoV-2 survey within the WW-FINGERS network. Six members shared the progress surveying study participants in South-Korea, Singapore, Japan, Netherlands, Argentina and Cuba. They also shared their experiences on the survey including challenges, lessons learned, barriers and facilitators. These updates could be useful for countries, which have not yet launched the survey to address potential challenges and determine strategies.
Next, opportunities for dissemination such as presentations or special sessions at the Alzheimer’s Association International Conference (AAIC) and the Clinical Trials on Alzheimer’s Disease (CTAD) conference were mentioned. Jean Georges, Executive Director, and Cindy Birck, Project Officer, of Alzheimer Europe attended the meeting.

18 March: The final EPAD dataset is now available on the Alzheimer’s Disease Workbench

The European Prevention of Alzheimer’s Dementia (EPAD) consortium, in their partnership with Aridhia, are proud to announce that the EPAD V.IMI dataset has been incorporated into the Alzheimer’s Disease Workbench to provide even greater value to the global neuroscience research community.

The latest and final EPAD dataset went into open access to all researchers from over the world in November 2020 through the EPAD Research Access Process website. The final dataset is called Version.IMI (V.IMI) as it represents all the data collected and processed during the Innovative Medicines Initiative (IMI) funding period of EPAD. This contains the final longitudinal data including cognitive, clinical, biomarker and neuroimaging data sets from over 2,000 participants of the EPAD Longitudinal Cohort Study (LCS). Screening for the first participant in the LCS occurred in May 2016 and finished in early 2020. All 2,096 participants who consented and were included into the dataset are entered in this final V.IMI release.

EPAD is proud to partner with the Alzheimer’s Disease Data Initiative (ADDI) to help further the understanding of the early stages of Alzheimer’s disease (AD) and accelerate scientific progress. The V.IMI dataset has been incorporated into the Alzheimer’s Disease Workbench and is now available to ADDI researchers. This cloud-based platform has recently been launched to accelerate discoveries and innovations for AD and related dementias. The AD Workbench is guided by three main principles: increasing data sharing, easing data access, and developing new tools and analytics for researchers to use and share. It is open, inclusive, global and easy to use.

http://ep-ad.org/2021/03/18/the-final-epad-dataset-is-now-available-on-the-alzheimers-disease-workbench/

22 March: New PARADIGM articles published

In the last few months, two new articles have been published in peer-reviewed journals based on the work carried out by the Innovative Medicines Initiative (IMI) funded PARADIGM project.

The first article, entitled “Understanding multi-stakeholder needs, preferences and expectations to define effective practices and processes of patient engagement in medicine development: A mixed-methods study”, focuses on the needs of different stakeholders when participating in Public Involvement activities in medicines development (i.e. in research priority setting, clinical trial design and early dialogues with Health Technology Assessment bodies).

The second article, entitled “Evaluation of patient engagement in medicine development: a multi-stakeholder framework with metrics”, describes how the PARADIGM monitoring and evaluation framework was developed and refined, and provides a few examples of how organisations in the project used the framework. Both articles were published in the Journal of Health Expectations and are available online (open access). Dianne Gove is a co-author of the first article, and Ana Diaz of both.

22 March: Neuronet convenes 6th meeting of its Scientific Coordination Board

On 22 March, the Innovative Medicines Initiative (IMI) funded Neuronet Coordination and Support Action convened the sixth Scientific Coordination Board meeting (SCB). The Board plays a central role in determining how Neuronet should direct its efforts. As leaders of IMI neurodegeneration projects, the SCB members bring wide-ranging scientific, clinical, R&D and computational expertise to the table, helping us to identify key challenges and priorities to address.

The meeting was attended by representatives of the AETIONOMY, ADAPTED, AMYPAD, EPAD, EMIF, IDEA-FAST, IMPRIND, Mobilise-D, MOPEAD, PHAGO, PD-MitoQUANT, PRISME2 and RADAR-AD projects along with members of the Neuronet consortium. Carlos Diaz, Coordinator of Neuronet, kicked off the SCB meeting by providing some general updates on Neuronet activities since the previous SCB meeting, which was held on 1 October 2020.

These activities include new updates and the public launch of the Knowledge Base & Asset Map, as well as our landscaping exercise of initiatives and gap analysis, collaborations between EPAD and PHAGO as well as IDEA-FAST and MOBILISE-D, among others.

Next, Pieter Jelle Visser introduced the European Platform for Neurodegenerative Diseases (EPND) consortium which is planned to be launched in the course of 2021.
This was followed by an introduction to a survey that Neuronet developed to better understand the impact of IMI projects on their company. The survey has already been piloted at Janssen and Sanofi.

As a last point on the agenda, the project leads Lennert Steukers (Janssen) and Carlos Diaz (SYNAPSE) discussed the evaluation and sustainability of Neuronet with the SCB. This focussed on the asset-based view Neuronet aims to shine on the outputs of the programme, rather than only highlighting the projects and their ongoing work. This topic was followed by a short presentation in preparation for a follow-up survey for formal evaluation of Neuronet’s work. Jean, Ange, Cindy and Chris took part in the meeting.

https://www.imi-neuronet.org/6-neuronet-scientific-coordination-board-meeting/

**23 March: RADAR-AD project publishes its second newsletter**

With its e-newsletters, the RADAR-AD project (Remote Assessment of Disease and Relapse – Alzheimer’s Disease) provides readers with the latest project updates. It is sent out every six months and in March 2021, the second edition was launched.

You can read the newsletter, here.

**31 March: Members of RADAR-AD Patient Advisory Board participate in several activities in March**

During the month of March, the RADAR-AD Patient Advisory Board (PAB) has been very active. The core members of the

PAB met on 4 March. The meeting was informative and members were updated about the progress and plans for the RADAR AD studies.

On 11 March, all members of the PAB, including members of the European Working Group of People with Dementia, took part in a consultation about the technology and sensors planned for the two project sub-studies which will be launched in coming months.

In addition, two members, Chris Roberts (pictured, top left) and Nelida Aguiar actively participated in the Annual Meeting of the project which was held on 30 and 31 March. They referred, in their speeches, to the relevance of involving people affected by Alzheimer’s disease in research projects and to their positive experiences as members of the core PAB. Director for Projects Dianne Gove and Project Officer Ana Diaz participated in all the meetings and activities.

**EU project acknowledgements**

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

- **AI-MIND** – grant agreement 964220
- **EPAD** – grant agreement 115736
- **EU-FINGERS** – INTER/JPND/19/BI/14012609
- **Neuronet** - grant agreement 821513
- **PARADIGM** - grant agreement 777450
- **RADAR-AD** - grant agreement 806999

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

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

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

Provide security for all Europeans, protecting them from the major threats to health and from the vulnerability that is created by living a precarious existence.

Enable everyone’s voice to be heard, so that policies that affect their health are created with them and not for them.

The full text of the Manifesto can be found here: https://europeanhealthunion.eu/#manifest

2-3 March: EMA hosts a joint meeting of its patients & consumers and healthcare professional Working Parties, addressing COVID-19, Big Data and personalised medicine

On 2 and 3 March, the European Medicines Agency (EMA) hosted a joint meeting of its Patients and Consumers (PCWP) and Healthcare Professional’s (HCPWP) Working Parties. Held over two days, and attended by over 70 representatives of patient and HCP organisations, the meeting included updates on COVID-19 vaccines and therapeutics, advanced therapy medicinal products (ATMPs), personalised medicine and Big Data.

In November 2020, Emer Cooke began her mandate as the Executive Director of the EMA. Dr Cooke kicked off day 1 of the PCWP/HCPWP meeting by welcoming all attendees and introducing herself to the assembled audience, emphasising that the EMA places great value on its interactions with PCWP.
and HCPWP members. Marco Cavalieri and colleagues then provided a detailed update on COVID-19 vaccines and therapeutics, noting that vaccine hesitancy has proved a particular challenge in recent months. In response, the EMA are prioritising public engagement and transparency for vaccine information, providing updates through their website, social media feeds and via public-facing webinars, including one to be held on 26 March. Dr Cavalieri reported encouraging data on the immunogenicity of ChAdOx1, the AstraZeneca/University of Oxford vaccine that was approved by the EMA in January, and identified three key classes of COVID-19 therapeutics currently being discussed: SARS-CoV-2 antibody combinations, immunomodulators and anticoagulants.

Next, an update was provided on medicines development and authorisations, focusing on the European Reference Networks (which bring together patients, specialists and other stakeholders in specific rare or low-prevalence disease areas) and ATMPs such as gene and cell therapies. Martin Dorazil, deputy Head of DG SANTE at the European Commission, identified the key assets and achievements of the ERNs portfolio, including greater coordination between dispersed stakeholders and the development of new clinical practice guidelines. In particular, discussions on ERNs and ATMPs emphasised the importance of real-world data, obtained through routine clinical practice, in supporting health policymaking and post-authorisation follow-up.

Day 2 of the PCWP/HCPWP meeting was primarily focused on personalised medicines and Big Data. Personalised medicine uses information about a person's genes or proteins to prevent, diagnose or treat disease. Anthony Humphries of the EMA and Ejner Moltzen of ICPerMed (the International Consortium for Personalised Medicine) outlined how discoveries from frontier research on the genetics and molecular basis of disease are slowly progressing towards implementation in healthcare, supported by the growing adoption of electronic healthcare records by EU Member States. Looking ahead, ICPerMed see greater patient involvement in personalised medicine as crucial to progress, and are working towards the launch of a European Partnership in personalised medicine (EP PerMed).

On the Big Data front, Peter Arlett (EMA) and Nikolai Brun (Heads of Medicines Agencies/HMA), co-Chairs of the Joint Steering Group on Big Data, reported on the activities of the group in 2020, which included the launch of a collaboration roadmap for real-world evidence, data protection workshops and the development of education programmes for Big Data upskilling. Looking ahead to 2021, much of the focus will remain on real-world evidence, with deliverables on data quality, workshops on Artificial Intelligence and meta-data, and continuing pilot activities of the European Health Data Space. In particular, the Steering Group will continue to develop DARWIN EU (Data Analysis and Real-World Interrogation Network), a network of data, expertise and services designed to support better decision-making by EMA and other regulatory committees. Drawing the two-day meeting to a close, Fergus Sweeney provided an overview of an updated guideline for Good Clinical Practice (GCP), a process that ensures ethical and scientific quality standards for clinical research are met. The updated guideline will provide enhanced guidance on GCP for trials that use innovative designs and/or use novel data sources. A key principle for the guideline is respecting the rights, safety and wellbeing of trial participants, and ensuring that risks borne by participants are proportionate to the expected benefits and importance of the trial objectives.

4 March: European Commission launches Action Plan on the European Pillar of Social Rights

On 4 March 2021, the European Commission launched its Action Plan on the European Pillar of Social Rights, setting out actions and initiatives the EU intends to take to implement and realise the aims of the Pillar.

The European Parliament, the Council and the Commission proclaimed the European Pillar of Social Rights in 2017 at the Gothenburg Summit, setting out 20 key principles and rights essential for fair and well-functioning labour markets and welfare systems. The Pillar is structured around three chapters:

- Equal opportunities and access to the labour market
- Fair working conditions
- Social protection and inclusion.

To realise the principles within the Pillar, the Action Plan introduces three headline targets for EU Member States to achieve by 2030:

- At least 78% of people aged 20 to 64 should be in employment
- At least 60% of all adults should participate in training every year
- The number of people at risk of poverty or social exclusion should be reduced by at least 15 million.

The 2030 headline targets align with the UN Sustainable Development Goals and, together with a revised Social Scoreboard, will allow the Commission to monitor Member States' progress under the European Semester.

As part of the Action Plan, a number of concrete actions are outlined, including the implementation of the Strategy on the Rights of Persons with Disabilities 2021-2030. You can read more about the launch of the Action Plan here:

5 March: Joint Declaration on the Conference on the Future of Europe

A Joint Declaration from the European Council, Parliament and Commission has been published, outlining the objectives, structure, scope and timing of the Conference on the Future of Europe.

The Conference is the forum for debating the future actions and direction of the European Union as a whole, with citizens of the EU, as well as Member States and EU institutions, contributing to the process.

The Conference will be placed under the authority of the three institutions, represented by the President of the European Parliament, the President of the Council and the President of the European Commission, acting as its joint presidency.

The work of the presidency will be supported by an executive board, composed of three representatives and four observers from each institution. National Parliaments will be closely involved, as well as other bodies or groups, notably the Committee of Regions and the European Economic and Social Committee.

The joint declaration will be signed by the Presidents of the European Parliament, the Council and the European Commission, acting as joint chairs. The Conference will then start its work, and a formal event is envisaged for 9 May, Europe Day, in Strasbourg.

The Conference is expected to reach conclusions to provide guidance on the future of Europe by Spring 2022.

The full text of the Joint Declaration can be found here: https://bit.ly/3ucl3lz

5 March: European Commission launches disability rights strategy

On 5 March 2021, the European Commission launched the “Union of Equality: Strategy for the rights of persons with disabilities 2021-2030” report, setting out how the Commission aims to support the upholding the rights of people with disabilities across the EU.

The Strategy builds on the previous European Disability Strategy 2010-2020, seeking to ensure that all persons with disabilities in Europe, regardless of their sex, racial or ethnic origin, religion or belief, age or sexual orientation are able to:

- exercise their human rights
- have equal opportunities, equal access to participate in society and economy
- decide where, how and with whom they live
- move freely in the EU regardless of their support needs
- live free from discrimination.

Furthermore, the Strategy takes account of the diversity of disability comprising long-term physical, mental, intellectual or sensory impairments (in line with Article 1 of the United Nations Convention on the Rights of Persons with Disabilities).

The new strategy contains a number of actions and flagship initiatives in various domains including around the areas of:

- Accessibility – being able to move and reside freely but also to participate in the democratic process
- Quality of life – to live independently, including de-institutionalisation, social protections and non-discrimination at work
- Equal participation – eliminating discrimination and violence, ensuring equal opportunities in relation to justice, education, culture, sport and tourism, as well as equal access to all health services.

You can read the full strategy here: https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8376&furtherPubs=yes

An easy read version of the strategy is available at: https://ec.europa.eu/social/main.jsp?catId=1535&langId=en

9 March: European Parliament formally adopts EU4Health programme

On 9 March, the European Parliament voted to approve the EU4Health programme for 2021-2027, with 631 votes in favour, 32 against and 34 abstentions.

The new EU4Health programme will contribute in areas where the EU can add value and complement Member States’ policies, with objectives including strengthening health systems by supporting countries to coordinate with each other and share data, as well as making medicines and medical devices more available, accessible and affordable.

The programme will also support actions linked to e-health and the creation of the European “health data space”. Promoting access to quality healthcare, improving mental health and accelerating the fight against cancer will also be supported.

During the plenary debate, MEPs highlighted the key role that the new programme will play in fighting health inequalities, both between member states and between different social groups. They also welcomed the establishment at EU level of a stockpile of essential medical supplies and equipment, which
complements the work being done under rescEU, and a reserve of medical and support staff to be mobilised in the event a health crisis.

Once the European Council has also formally approved the regulation, it will enter into force on the day following its publication in the Official Journal of the European Union. The regulation will apply retroactively from 1 January 2021.

You can read more on the regulation here:

https://bit.ly/3m3vMvy

29 March: EU4Health programme enters into force

On 29 March, the European Union’s EU4Health programme was published in the Official Journal of the European Union, marking the new programme’s official entry into force.

The EUR 5.1 billion programme will undertake a range of actions relation to health across the EU, with around 20% earmarked for prevention. The programme has four overarching objectives:

1. Improve and foster health in the Union by:
   - Supporting actions for disease prevention, health promotion and addressing health determinants
   - Supporting global commitments and health initiatives.

2. Protect people in the Union from serious cross-border threats to health by:
   - Strengthening the capability of the Union for prevention, preparedness and response to cross-border health threats, including through a new bio-preparedness authority, the European Health Emergency Preparedness and Response Authority (HERA)
   - Supporting actions complementing national stockpiling on essential crisis relevant products
   - Establishing a structure and training resources for a reserve of medical, healthcare and support staff.

3. Enhance the availability, accessibility and affordability of medicinal products, medical devices and crisis-relevant products by:
   - Encouraging sustainable production and supply chains and innovation in the Union, while supporting efficient use of medicinal products.

4. Strengthening health systems resilience and resource efficiency though:
   - Strengthening health data, the uptake of digital tools and services and the digital transformation of healthcare systems, including by supporting the creation of a European Health Data Space
   - Promoting the implementation of best practices and promoting data sharing
   - Enhancing access to quality, patient-centred, outcome-based healthcare and related care services
   - Supporting integrated work among Member States, and in particular their health systems.

You can read the full regulation for the EU4Health programme here:

https://bit.ly/3wh4UwM

MEMBERS’ NEWS

18-21 February: Greek Alzheimer association organises 12th Panhellenic Conference on Alzheimer’s Disease and Related Disorders (PICAD) and 4th Mediterranean Conference Neurodegenerative Diseases (MeCoND)

Alzheimer Hellas, in cooperation with the Panhellenic Institute of Neurodegenerative Diseases, successfully organised the 12th Panhellenic Conference on Alzheimer’s disease and Related Disorders and the 4th Mediterranean Conference on Neurodegenerative Diseases, which were conducted for the first time virtually from 18-21 February 2021, from Thessaloniki.

The combination of these two conferences hosted many renowned scientists in the field (over 340 speakers from Greece, USA, France, UK, Germany, Austria, Italy, Russia, Spain, Bulgaria, Turkey, Iran, Egypt, Sweden, Belgium, Switzerland etc.), who presented and shared results of the latest scientific research, pharmaceutical and non-pharmaceutical trials and the application of new technologies. The events also provided an opportunity for various healthcare professionals to present their contribution to patients and carers.

Over 3,200 clinicians (neurologists, psychiatrists, geriatricians, neuroscientists, molecular genetics, neuropathologists, neurobiologists, neuropsychologists, pharmacists, psychologists, social workers, physiotherapists) and representatives from biomedical and pharmaceutical
1 March: Jersey Alzheimer’s Association changes its name to Dementia Jersey

Our member association in Jersey has adopted a new name, Dementia Jersey (formerly the Jersey Alzheimer’s Association), as of March 2021, as well as a new logo.

The offices remain at the same address, but there is a new email address, website and Facebook address:

Email: info@dementia.je
Website: www.dementia.je
Facebook: www.facebook.com/pg/Dementiajersey/

16 March: Cyprus Alzheimer Association releases new video showcasing Memory Walks and support received in 2020

The Cyprus Alzheimer Association has released a new video, which showcases some of its work during 2020, with particular focus on Memory Walks. The video shows some of the people involved in supporting the association, and acknowledges all the volunteers who worked so hard and the benefactors who gave generously, to ensure people living with dementia in Cyprus had the support they needed, despite difficult circumstances during the pandemic. You can watch the video (with English subtitles) here: https://1drv.ms/v/s!AiYqV5uyOEvDjQH5swYByqdmRU7N?e=mGwUz5

18 March: Deutsche Alzheimer Gesellschaft launches online information service in Arabic

Deutsche Alzheimer Gesellschaft (DAlzG) has launched a new online information service in Arabic. Migrants and people with a migration background in Germany often search for information in their own languages when they are affected by dementia. A service which is available in a person’s mother tongue makes it easier to understand and helps to plan the next steps. The DAlzG website offers information about the disease, diagnosis, and caring for someone with dementia, in Polish,
Russian, Turkish and English, and now in Arabic. The site contains explanatory films and a network map with advice and support services. An additional part of the information provided is aimed at those involved in counselling and care for the elderly. Here, they can find information and materials about dementia, migration and cultural sensitivity. It is estimated that there are around 100,000 people with a migration background in Germany who have dementia. They and their families need advice, help and support. It is therefore urgently necessary that all areas of care for the elderly also adapt to the needs and wishes of this target group. The implementation was financially supported by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth. See the website, here:

www.demenz-und-migration.de

21 March: Alzheimer’s Disease Association North Macedonia organises series of events marking Brain Awareness Week 2021

On the occasion of International Brain Awareness Week March 15-21, 2021, the Alzheimer’s Disease Association North Macedonia and MMSA (Macedonian Medical Students Association) organised some events and lectures. Dr Dragan Ilievski (pictured, centre), President of Alzheimer’s Disease Association North Macedonia, appeared on MRT Television (Macedonian radio television) for a discussion about etiopathogenesis (risk factors) genetics, and prevention of Alzheimer’s disease (AD). Dr Dragan also held a lecture for medical students in Skopje, organised by MMSA Local Officer Simona Ristovska and National Officer Bojan Janevski. The organisation also held an online lecture with neurologist Arben Taravari, talking about neurodegenerative diseases. A particular highlight among these events was a lecture on "Impact of the corona virus on the lives of people with dementia".

22 March: NVO Futura Montenegro involved in research project DEMONSTRATE

The Faculty of Medicine in Podgorica conducts research on Alzheimer’s disease (AD), within a project funded by Ministry of Science of Montenegro. The project is called “New methods for risk stratification for the progression of cancer and AD in patients in Montenegro – DEMONSTRATE”. Alzheimer Europe’s national member association in Montenegro, NVO Futura, provides the following report on the research being conducted in this project:

It has been shown that the incidences of AD and cancer are inversely correlated. Probably, in these two diseases, signal pathways are deregulated in the opposite direction, but these mechanisms have still not been elucidated. The proposed research will be focused on the study of the specific circulatory miRNA levels, which are involved in the pathogenesis of both diseases. Based on this research approach, one of the project’s aims is to find circulatory biomarkers for AD, with the potential for clinical application.

Despite the pandemic, that has slowed research activities, the DEMONSTRATE team, with the help of the non-governmental organisation Futura, has made significant progress on data and sample collection and is currently working on isolation of circulating micro-RNAs. The next important phase of the study aims to use the RT-qPCR approach to determine differences in expression patterns of selected micro-RNA species between the group of participants with colon cancer and normal cognitive function, and the group with AD, but no history of cancer.

Based on the part of the clinical data that has been analysed so far, DEMONSTRATE team members presented their research at the 14th World Congress on Controversies in Neurology – CONy, in late 2020. The poster titled “Improving the Diagnosis of Cognitive Impairment in Montenegro on the Path of Learning” by Isidora Rovčanin Dragović, Ljiljana Radulović, Jevto Eraković, Miodrag Radunović, Goran Popivoda, Tijana Vuković and Nataša Popović was presented at the conference.

Since the estimated prevalence of dementia in Montenegro was lower compared to most of the European countries in 2019 (1.06%), this research tried to answer why dementia in Montenegro is underdiagnosed. The results suggest that there is a need for continuous education at the primary health care level and the use of adequate screening tools by physicians. Results also identified a negative behavioural model in patients and delays in medical consultation, related to stigma. The DEMONSTRATE team is now also working on designing research to identify the level of stigma among the general public, in order to raise awareness about AD and dementia in Montenegro.
POLICY WATCH

23 March: All Wales Dementia Care Pathway of Standards is published

Over the past two years, Improvement Cymru has worked with over 1,800 people to finalise the “All Wales Dementia Care Pathway of Standards”, which was published on 23 March 2021. The aim is to improve dementia care for individuals and their carers, by providing a clear pathway towards implementing effective standards within dementia care, in the next two years.

This work has been led by Improvement Cymru as part of the Dementia Care Programme and directed by the requirements of the Dementia Action Plan for Wales, overseen by the Welsh Government Dementia Oversight Implementation and Impact Group (DOIIG).

The 20 standards have been designed to be dynamic and to respond to evaluation and supporting evidence. They sit within four themes: Accessible, Responsive, Journey, Partnerships & Relationships, underpinned by Kindness & Understanding. The standards have been developed using the Improvement Cymru Delivery Framework and it is anticipated that work will focus on developing a two-year Delivery Framework Guide for the regions across Wales. The Delivery Framework will offer the regions the time, support and assistance to undertake engagement, coproduction, scoping, readiness and self-assessment that will provide the information needed for putting them into practice.

The All Wales Dementia Care Pathway of Standards document can be accessed and downloaded here:


SCIENCE WATCH

25 February: Researchers identify two new genes linked to Alzheimer’s disease

A Chinese research team of Tianjin Medical University has discovered two new genes potentially involved in Alzheimer’s disease (AD). Findings have been published in the journal PLOS Genetics.

In the published study, scientists explored the genes expressed at higher and lower levels in the hippocampus, part of the brain involved in the memory, of 111 people with AD compared to those with healthy brains. In addition to several genes that were already known to contribute to the disease, they identified two new genes called PTPN9 and PCDHA4. They reported that the presence of the two genes is related to the size of the hippocampus and a diagnosis of AD. It is unclear what role the two newly identified genes could play in the disease, but the functional annotation revealed that PTPN9 participated in neurogenesis and dephosphorylation and both PTPN9 and PCDHA4 were involved in nervous system development.

https://journals.plos.org/plosgenetics/article?id=10.1371/journal.pgen.1009363

25 February: Researchers study the association between sex and cognitive decline

On 25 February, US researchers from the University of Michigan published an article on sex differences in cognitive decline disorders in the journal JAMA Network Open.

In the published study, scientists used data from 26,288 participants, including 11,775 men and 14,913 women. All participants had no history of dementia or stroke at baseline and no incidence of dementia or stroke before the first cognitive assessment.

The primary outcome was change in global cognition. Secondary outcomes were change in memory and executive function. Looking at the results from the analyses, the team found that women had significantly higher baseline performance than men in global cognition, executive function and memory. Compared with men, women had significantly faster declines in global cognition, executive function but not in memory.

The scientists therefore suggested that women may have greater cognitive reserve but faster cognitive decline than men, which could contribute to sex differences in late-life dementia.

https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2776902?resultClick=3
1 March: Preclinical study shows improvement in cognitive function after cannabidiol treatment in a model of Alzheimer’s disease

A team of researchers led by Prof. Babak Babak of Augusta University have recently published an article in the Journal of Alzheimer’s disease, in which they show that administering cannabidiol improves cognitive function in a mouse model of Alzheimer’s disease (AD).

Cannabidiol, a chemical compound found in the cannabis plant, can act to reduce inflammation, by suppressing the production of pro-inflammatory factors and preventing the activation of inflammatory cells. Recent studies indicate that inflammation may contribute to the development of AD, promoting the deposition of amyloid plaques in the brain. In their new publication, Prof. Babak and colleagues sought to examine the effect of regular cannabidiol administration on inflammation in AD, using the 5xFAD mouse model of early-onset familial AD.

Tracking the expression of IL-33 and TREM2, two inflammatory proteins that are thought to promote clearance of amyloid beta, they observed that cannabidiol administration increased the expression of these proteins in the brain. Alongside, the researchers observed a reduction in amyloid plaques in the brains of mice treated with cannabidiol, and an improvement in cognitive function. Further studies are ongoing, looking at whether cannabidiol can help prevent the onset of AD symptoms in this animal model, and evaluating different methods of cannabidiol administration.

https://www.nature.com/articles/s41598-021-83851-4

1 March: Analyses in AD mouse models identify links between the gut microbiome, epigenetics and cognitive performance

A team of researchers led by Prof. Jacob Raber recently published an article in Scientific Reports, identifying links between the gut microbiome, altered DNA methylation in the hippocampus, and cognitive performance in mouse models of Alzheimer’s disease (AD).

Several lines of preclinical research point to the existence of a gut-brain axis, connections that link the enteric (or intestinal) nervous system with the central nervous system and brain. How our gut microbiome - the collection of bacteria and other microorganisms that live in our intestines - influences the gut-brain axis is a hot topic for investigation, with recent research indicating that there may be a connection between reduced microbial diversity and AD.

In their article, Prof. Raber and colleagues sought to identify whether the gut microbiome influences behavioural and cognitive performance in animal models of AD. Using two different mouse models of AD, they observed that the biodiversity and composition of the gut microbiome appeared to be linked to different behavioural and cognitive traits (e.g. nest building), which in turn were influenced by the AD genotype of the mice. Looking more closely at epigenetic marks in DNA from brain cells of these mice, the researchers observed altered methylation - a chemical modification that can determine whether a gene is expressed or repressed - in regions within the Tomm40 and ApoE genes. Altered methylation of these genes, both of which are linked with AD, appeared to correlate with changes in the gut microbiome. Moving forwards, future work will focus on identifying whether modifying the diet of these mice can influence the genetic changes and cognitive traits linked to AD.

https://content.iospress.com/articles/journal-of-alzheimers-disease/jad210025

1 March: Preclinical researchers uncover mechanism that may explain loss of smell in Alzheimer’s disease

Recently, a team of researchers led by Prof. Cheil Moon (Daegu Gyeongbuk Institute of Science and Technology, Korea) published an article in Alzheimer’s Research and Therapy, identifying a potential mechanism that may explain why many people with Alzheimer’s disease experience abnormal olfaction. Olfactory dysfunction, or difficulty with smelling, is thought to affect almost 90% of people with Alzheimer’s disease (AD), with individuals reporting either loss of smell (anosmia) and/or difficulty identifying particular smells. Smell processing involves several areas of the central nervous system, with olfactory sensory neurons (OSNs) playing a particularly prominent role in propagating 'smell' signals to the olfactory bulb in the brain.

In their article, Prof. Cheil Moon and colleagues report on the results of studies performed in the 5xFAD mouse model of AD, revealing that the OSNs of these mice show reduced responses to odorants. In particular, they observed reduced activation in the glomerulus of the olfactory bulb, a specialised region of the brain that deals with smell. Looking more closely at the
distribution of amyloid-beta proteins, a key driver of AD, the researchers saw that the regions with higher levels of amyloid-beta coincided with the regions that showed reduced activation after exposure to smells. Together, these results suggest that olfactory dysfunction in AD may be linked to amyloid-beta accumulation in regions of the brain that are responsible for detecting and identifying smells.


1 March: Researchers develop a new molecule that may reduce the amyloid plaques in mouse models

Indian scientists from the Jawaharlal Nehru Centre in Karnataka have developed a new molecule that may reduce the toxicity of amyloid beta, the main component of the amyloid plaques found in the brains of people with Alzheimer’s disease (AD). This work has recently been published in the journal Advanced Therapeutics.

The study established the molecule called TGR63 as the lead candidate to rescue neuronal cells from amyloid toxicity. Scientists found that TGR63 treatment showed a significant reduction of amyloid burden in the cortex and hippocampus region of the brain of mouse models and reversed cognitive decline. In addition, mouse models treated with TGR63 showed an amelioration of learning deficiency, memory impairment and cognitive decline.


3 March: Laboratory study shows how ApoE4 disrupts the lipid composition of brain cells in AD

The E4 allele of the apolipoprotein E gene (termed ApoE4) is the most prominent genetic risk factor for Alzheimer’s disease (AD). As a protein that shuttles cholesterol and other lipids between and into cells, ApoE plays an important role in determining lipid balance. In their 3 March study, published in Science Translational Medicine, Dr Gregor Sienzki, Prof. Li-Huei Tsai and colleagues probed the role of ApoE4 in human brain cells, showing that ApoE4 alters the expression of multiple genes involved in lipid metabolism, increasing the uptake of unsaturated lipids into these cells.

Brain cells called astrocytes are thought to be the main source of ApoE4 in the brain. Generating human astrocytes from induced pluripotent stem cells (iPSC), the researchers noted that ApoE4 astrocytes were laden with unsaturated lipids, containing far more lipid droplets than ApoE3 astrocytes. Mining gene expression data from people with different ApoE genotypes, they discovered that the expression of genes involved in the processing of lipids and cholesterol were upregulated in ApoE4 carriers, whereas genes involved in the breakdown of lipids were repressed.

To probe the potential mechanisms causing the disruption in lipid composition, the researchers studied a model yeast system, using in-depth genetic screens to identify key proteins that might mediate the disruptive effects of ApoE4. One such protein, OP1, pointed to a potential role for choline deficiency in altering the lipid balance of ApoE4 brain cells. Choline is an essential nutrient, and one that is used to make lipid membranes for cells. By supplementing ApoE4 astrocytes with choline, researchers were able to correct the lipid disruption observed in these cells. Studies are now ongoing in ApoE4 animal models to evaluate choline supplementation as a potential remedy for ApoE4-induced lipid defects in AD.


8 March: Acadia Pharmaceuticals provides regulatory update on its drug application for pimavanserin

On 8 March, Acadia Pharmaceuticals Inc, announced a regulatory update on its supplemental new drug application for pimavanserin for the treatment of hallucinations and delusions associated with dementia-related psychosis.

Pimavanserin is an antipsychotic drug, approved by the US Food and Drug Administration (FDA) for the treatment of Parkinson’s disease psychosis. The FDA has accepted the filing of the supplemental new drug application for pimavanserin in July 2020 for the treatment of hallucinations and delusions associated with dementia-related psychosis. This application is supported by findings from the HARMONY Phase III trial, which evaluated the safety and efficacy of pimavanserin for the treatment of hallucinations and delusions associated with Lewy Bodies, vascular dementia and frontotemporal dementia. The drug met its primary endpoint of delaying relapse of psychosis in people with dementia-related psychosis compared to placebo.

The company announced that it received a notification from FDA stating the identification of deficiencies that preclude discussion of labelling and further steps in the approval process of pimavanserin as a possible treatment of dementia-
related psychosis. The FDA stated that this notification does not reflect a final decision on the information under review, but likely reflects a need for more information. The company plans to work with the FDA to learn the nature of the deficiencies and seek to resolve them.


9 March: Cognito Therapeutics announces positive results from Phase II study in Alzheimer’s disease

On 9 March, Cognito Therapeutics, a clinical-stage company developing digital therapeutics for neurodegenerative diseases announced results from its Phase II trial investigating neuromodulation therapy for Alzheimer’s disease (AD). This device uses gamma frequency technology as a way to stimulate the brain in a non-invasive way.

The Overture Phase II study is a multi-centre, randomised and controlled trial aiming to study the safety, adherence rates and efficacy of an audio-visual stimulation treatment in people with mild to moderate cognitive impairment. 76 participants aged 50 and older received the therapy or the placebo for one hour each day in their home. Results showed that after six months, participants who received the treatment had a significant 84% slowdown in functional decline compared to the placebo group. In addition, there was a significant 61% reduction in whole brain atrophy as well as in volumetric loss among the group receiving the stimulation treatment.

The company is planning to move onto a large-scale pivotal clinical trial of its neuromodulation therapy, which received a Breakthrough Device Designation by the US Food and Drug Administration (FDA) in January 2021.


13 March: Phase II trial results show a reduction in clinical decline for participants receiving donanemab

On 13 March, Dr Mark Mintun, Dr Daniel Skovronsky and co-investigators published topline results of the TRAILBLAZER-ALZ clinical trial, which was designed to evaluate the efficacy of the anti-amyloid antibody, donanemab. These results were presented at the 2021 AD/PD conference, and published simultaneously in the New England Journal of Medicine (NEJM).

TRAILBLAZER-ALZ was a Phase II, multi-centre, randomised and placebo-controlled clinical trial of donanemab in people with early, symptomatic Alzheimer’s disease (AD). TRAILBLAZER-ALZ, which was sponsored by Eli Lilly, enrolled 257 participants aged between 60 and 85, 131 of whom were assigned to receive donanemab. Donanemab is an antibody that specifically targets a form of modified amyloid protein that is present in established amyloid plaques in the brains of people with AD. Over the course of 72 weeks, participants received a monthly intravenous infusion of donanemab or placebo, undergoing regular clinical evaluations that included MRI and PET scans, neuropsychological tests, biomarker measurements and other assessments.

Encouragingly, analysis of the TRAILBLAZER-ALZ results revealed that participants receiving donanemab showed slower cognitive and functional decline, as measured using the iADRS scale (an average difference of 3.2 points compared to placebo). In objective terms, authors of the study suggested that this was equivalent to 25% slower disease progression in the donanemab group. However, no significant differences in secondary outcome (e.g. CDR-SB and MMSE scales) were observed. Similar to clinical trials of other anti-amyloid antibodies, TRAILBLAZER-ALZ revealed a substantial reduction in brain amyloid load over 76 weeks, as measured using amyloid-PET scans. Over 26% of participants receiving donanemab also showed signs of ARIA-E, a measure of fluid accumulation in the brain observed via magnetic resonance imaging (MRI). A follow-on trial, TRAILBLAZER-ALZ2, is currently enrolling participants to study the safety and efficacy of donanemab over a longer period of time, with an estimated completion date in March 2023.


24 March: New study shows improvement in cognition after sargramostim treatment

On 24 March, US researchers from the University of Colorado Anschutz Medical Campus published an article evaluating the effect of sargramostim in improving cognition and reducing pathology in people with mild-to-moderate Alzheimer’s disease (AD). Sargramostim is a medication often used to boost white blood cells after cancer treatments. Findings were published by Alzheimer’s & Dementia: Translational Research and Clinical Interventions, an open access journal of the Alzheimer’s Association.

Researchers conducted a randomised, double-blind and placebo-controlled phase II trial to evaluate the safety and
Efficacy of sargramostim treatment in people with mild to moderate AD. 40 US participants received injections of either sargramostim or placebo for five days a week for three weeks. Results showed that short-term sargramostim treatment was well tolerated and increased immune cells. In addition, the treatment increased cognitive measures and measures of blood biomarkers of AD (i.e. amyloid and tau). Scientists are planning to start a larger trial of sargramostim in AD.


24 March: Alzheimer’s Research UK announces three-year partnership with Boston University Alzheimer’s Disease Center

On 24 March, the UK charity Alzheimer’s Research UK announced a new partnership with Boston University Alzheimer’s Disease Center (BU ADRC). Alzheimer’s Research UK is leading the Early Detection of Neurodegenerative diseases (EDoN) project to develop an innovative approach to detect conditions like Alzheimer’s disease (AD) years before the symptoms of dementia start. The project is funded by Alzheimer’s research UK, Bill Gates and Iceland Foods Charitable Foundation, bringing together 11 project partners with a track record in data science, clinical and neurodegenerative research.

EDoN will leverage on smartphone apps as well as the more and more used wearables (including smart watches & headbands) to collect data from up to 50,000 people. The collection focusses on measures such as sleep, neural activity, cognition, speech and language, gait, heart rate, fine motor skills but also physical activity. In addition, the project will also leverage on already collected data. After the collection and transfer of the data, project partners aim to validate the information using clinical data (such as brain scans).

As part of the new partnership, BU ADRC will support data collection and engage up to 200 participants (with and without dementia) who will use wearables (as well as two smartphone apps) the data will then be shared with researchers from the EDoN project.

By doing so, the team hopes to be able to develop robust machine learning models that recognise patterns which indicate potential early stages of conditions like AD. If they are to succeed, the partners aim to develop a toolkit that will enable doctors to apply the most promising measures in their daily practice to identify the people with the highest risk of developing symptoms in future. Ultimately, the consortium plans to test its final digital device in up to 1 million people through health checks, beforehand.

https://www.eurekalert.org/pub_releases/2021-03/aru-cys032421.php

DEMENTIA IN SOCIETY

23 February: Report on “Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers” is published in the US

To live well with dementia, people need care, services, and supports that reflect their values and preferences, build on their strengths and abilities, promote well-being, and address needs that evolve as cognitive impairment deepens.

People living with dementia co-manage their care with or rely on the support of a wide range of carers, including spouses, other family members and friends, and direct care workers in homes or residential care settings. While dementia care has improved in the past few decades, many people still lack access to high-quality care and are not living as well as they might. Disadvantaged groups, especially racial and ethnic minorities, still face challenges in access to care, services, and supports, due to deep and persistent inequities.

A report published in February 2021 by The National Academies of Sciences Engineering Medicine (US), on “Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward” examines the complex body of evidence on dementia care and informs decision making about which interventions are ready to be broadly disseminated and implemented. It also offers a blueprint to guide future research using methods that are inclusive, equitable, and yield critical information for real-world implementation, toward the ultimate goal of better supporting people living with dementia and their carers in living as well as possible.

Read the report:

https://bit.ly/3m84K6z

NEW PUBLICATIONS & RESOURCES

26 February: WHO and ITU launch new guide on introduction of dementia risk reduction and carer support using mobile technology

The World Health Organization (WHO)’s new mDementia handbook, launched on 26 February 2021, aims to help countries to introduce and scale up dementia mHealth programmes (delivered through mobile devices, such as phones and tablets). The handbook and accompanying mHealth programme content include a module on reducing the risk of dementia and another on support for carers of people with dementia. The handbook was developed by the
WHO Mental Health and Substance Use Department and BeHe@lthy BeMobile (BHBM), a joint initiative between the WHO and the International Telecommunications Union (ITU).

The first of the modules, mDementionPrevention, aims to encourage people who are middle-aged or older to manage modifiable risk factors, such as physical inactivity, tobacco use, unhealthy diets and harmful use of alcohol, to delay the onset or slow the progression of dementia. The second module, DementiaSupport, is based on the WHO’s skills and knowledge training programme for carers of people with dementia, iSupport. It provides tailored support to address the physical and mental health impacts associated with caring for people with dementia.

The mDementia Handbook outlines how an mHealth programme can be used to strengthen existing dementia prevention and carer support programmes. It sets out the steps and considerations for successfully implementing mDementia at scale. The content can be adapted to support countries’ own national guidelines and existing health system interventions and to the local context and culture.

3 March: Music for Dementia publishes Musical Dementia Care Pathway to illustrate how music can accompany and support people on their journey with dementia

Music for Dementia (UK) has published a Musical Dementia Care Pathway (pictured), inspired by the NHS Dementia Well Pathway. The Musical Dementia Care Pathway is intended to show how music fits into people’s lives and how it can be used to support people through their journey with dementia. The idea is to bring to life the ways music can accompany people on their journey with dementia from living well to end-of-life care. Personalising the music to the individual is key, as everyone will follow their own pathway according to their personal life experiences and preferences.

This video explains more about the Pathway:
https://www.youtube.com/watch?v=DhrFBDxUX2A

24 March: New book on "Bridging the Family Care Gap" explores expected future shortages of family caregivers of older persons and identifies potential solutions

A new book, "Bridging the Family Care Gap", published by Elsevier, explores expected future shortages of family caregivers of older persons and identifies potential solutions. The book examines the sustainability and availability of care management models and whether they can be effectively scaled up to meet community needs. It identifies newly emerging policy initiatives at local, state, and federal levels (in the US). The book addresses the state of family caregiving science, dissemination and implementation of promising programmes and supports, technological innovations, and other strategies to offset the family care gap. This edited volume also explores lay healthcare workers as guides, interpreters, and advocates in healthcare systems that provide continuity of contact for family caregivers. Chapter 13 deals with “Leveraging volunteers to support dementia family caregivers.”

Find out more, here:
https://www.elsevier.com/books/bridging-the-family-care-gap/gaugler/978-0-12-813898-4

24 March: New book "Perspectives on the Person with Dementia and Family Caregiving in Ireland" by Suzanne Cahill features foreword by EWGPWD member Helen Rochford-Brennan

A new book, "Perspectives on the Person with Dementia and Family Caregiving in Ireland", by Professor Suzanne Cahill, examines the dementia landscape since late 2014, following the launch of Ireland’s first National Dementia Strategy and addresses a gap in the evidence base on dementia care in Ireland. Although the topics explored in the book - such as obtaining a diagnosis, accessing home care services and moving into a nursing home - relate to Ireland, they are discussed against the backdrop of policy, practice and research developments in dementia in other parts of the world. In this way the book provides the reader with a wealth of information including research evidence, best practice guidelines and international expertise.

The book, which has a foreword written by Helen Rochford-Brennan, member and former Chairperson of the European Working Group of People with Dementia (EWGPWD), is dedicated to Mnánah Éireann (women of Ireland), in
recognition of the hard physical and emotional work that caregivers (mostly women) do, behind closed doors. Throughout the book, an appeal is made for more state support to be given to these formal and informal caregivers. Find out more, here: https://www.peterlang.com/view/title/72144

JOB OPPORTUNITIES

22 March: Université de Paris offers funded PhD position in Clinical Neuropsychology and social cognition

A PhD position in Clinical Neuropsychology and social cognition is being offered at the MC2Lab, Université de Paris.

The MC2Lab, Université de Paris invites applications for a funded PhD position in the field of clinical neuropsychology starting from October 2021 (duration of 36 months). The successful applicant will get the opportunity to carry out a research project about neuropsychology of social cognition in neurological diseases with an original cross-cultural perspective. From a theoretical point of view, the project aims at studying the role of social and cultural context on the individual’s social cognitive functioning. From a clinical point of view, the successful applicant will collaborate to validate new neuropsychological tools reliable for people with a low level of education and/or of multicultural origin, to detect patients with social behavioural disorders. The proposed studies will be conducted in France and in the Netherlands (with an in-doc of at least two months). The plan to compare different European countries is guided by the objective of adopting a new cross-cultural approach in neuropsychology. The successful applicant will work under the supervision of Pauline Narme (Assistant professor in neuropsychology) at the MC2Lab, Institute of Psychology, Université de Paris, France. They will also work under the supervision of Janne Papma and Sanne Franzen from the department of Neurology of the Erasmus Medical Center in Rotterdam, Netherlands.

Requirements:
- Less than 12 months living in France during the last 3 years
- Master’s degree in Psychology (obtained less than 4 years before the beginning of the present PhD position)
- Clinical experience in Neuropsychology
- Good English language skills.

Candidates with previous experience in neuropsychology of ageing and with proficiency in Arabic language are particularly encouraged to apply. Interest in and/or basic skills in virtual reality technology will be considered a plus.

Deadline for submission: 9 April 2021.
Apply here: https://4impact.u-paris.emundus.io/

24 March: Alzheimer Disease Data Initiative seeks Director of Government Relations

The Alzheimer’s Disease Data Initiative (ADDI) is a non-profit medical research organisation supported by Gates Ventures and a coalition of partners. Its mission is to accelerate the accessibility and utility of data to advance scientific breakthroughs within Alzheimer’s disease (AD) and dementia research. ADDI’s focus is to increase interoperability of existing data platforms globally, increase sharing of dementia-related data from academic and industry sources, and empower scientists to find, search, combine, and analyse data that could lead to new discoveries in dementia research. Foundational to achieving these aims is the ADDI Alzheimer’s Disease Workbench (AD Workbench), a cloud-based data sharing and analytics platform that empowers researchers around the world to share data, resources, and tools to achieve the ADDI vision of eliminating AD. The AD Workbench is intended to remove the barriers of siloed, non-interoperable data, establish an environment to enable digital innovation at scale for AD and to deliver on ADDI programme objectives more effectively and collaboratively.

As ADDI’s work expands, the initiative is seeking an individual to lead day-to-day implementation of several key work streams around its AD programmes. Specifically, this position will include a mix of planning, strategy development, execution, evaluation, and external engagement. It will also require the ability to manage deadlines for multiple programmes and projects, work collaboratively both within the small team at ADDI and with external partners, help expand the reach, scope and impact of advocacy efforts, and coordinate closely with the Gates Ventures teams.

Location: Greater Seattle Area, US. Find out more, and apply, here: https://boards.greenhouse.io/addi/jobs/4366337003?gh_src=d718c2c43us

EDUCATION

19 March: Brain Health Scotland offers free course on "Understanding Brain Health: Preventing Dementia" - developed in partnership with The University of Edinburgh

Brain Health Scotland has launched a free online course on "Understanding Brain Health: Preventing Dementia", developed in partnership with The University of Edinburgh. The course is entirely free and is open to anyone interested in learning more about brain health and the diseases which can lead to dementia. No specific prior knowledge required.
Over four weeks, learners explore:
1) the biology of brain diseases
2) risk factors for brain disease
3) clinical research programmes
4) healthcare services and brain health around the world.
It is open for registration now, via:
https://edin.ac/3kfQI1G

29 March: Apply now for the Alzheimer’s Association Interdisciplinary Summer Institute!

The Alzheimer’s Association Interdisciplinary Summer Research Institute (AA-ISRI) is an immersive, no-cost opportunity for early career researchers in psychosocial care and public health to launch a career in dementia science and accelerate breakthroughs in the field.

During the five-day programme, experts will offer diverse perspectives on ground-breaking research through group sessions and individual mentoring. Twenty-four applicants will be selected for this exclusive experience and applications are due by 8 April 2021.

https://www.alz.org/summer-research-institute/overview.asp

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

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

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

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 April</td>
<td>Familiarization Session of ICCA Benefits and Tools</td>
<td>Gwladys</td>
</tr>
<tr>
<td>6 April</td>
<td>Journée scientifique: les essais cliniques de la maladie d’Alzheimer à l’épreuve de leur fiabilité</td>
<td>Dianne</td>
</tr>
<tr>
<td>7 April</td>
<td>Alzheimer Europe Board</td>
<td>AE Board and staff</td>
</tr>
<tr>
<td>8 April</td>
<td>Meeting of the European Working Group of People with Dementia</td>
<td>Dianne and Ana</td>
</tr>
<tr>
<td>12 April</td>
<td>NeuroCOHORT taskforce meeting</td>
<td>Ange</td>
</tr>
<tr>
<td>14 April</td>
<td>Management Board of EAN Dementia Panel</td>
<td>Jean</td>
</tr>
<tr>
<td>14 April</td>
<td>IMI hearing for EP ND project</td>
<td>Jean and Ange</td>
</tr>
<tr>
<td>15 April</td>
<td>EU4Health Civil Society Alliance</td>
<td>Owen</td>
</tr>
<tr>
<td>19-20 April</td>
<td>Joint HMA/EMA workshop on AI in medicines regulation</td>
<td>Ange</td>
</tr>
<tr>
<td>20 April</td>
<td>Alzheimer’s Association Academy: “Sports and dementia”</td>
<td>AE members, sponsors and staff</td>
</tr>
<tr>
<td>22 April</td>
<td>RADAR-AD Extension meeting</td>
<td>Jean, Dianne and Ana</td>
</tr>
<tr>
<td>22 April</td>
<td>VirtualBrainCloud General Assembly</td>
<td>Ange and Jean</td>
</tr>
<tr>
<td>23 April</td>
<td>Meeting with Roche</td>
<td>Jean</td>
</tr>
<tr>
<td>29 April</td>
<td>Meeting of the European Working Group of People with Dementia</td>
<td>Dianne and Ana</td>
</tr>
<tr>
<td>30 April</td>
<td>Meeting with EFPIA AD Platform</td>
<td>Jean</td>
</tr>
</tbody>
</table>

# CONFERENCES 2021

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Format/ Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 April</td>
<td>Ageing Better with ICTs – Hackathon, co-organised by The World Summit on the Information Society (WSIS) and the Global Coalition on Aging (GCOA) [<a href="https://www.hackerearth.com/challenges/hackathon/ageing-better-with-icts/">https://www.hackerearth.com/challenges/hackathon/ageing-better-with-icts/</a>]</td>
<td>Virtual</td>
</tr>
<tr>
<td>23-26 September</td>
<td>15th World Congress on Controversies in Neurology (CONy), <a href="https://cony.comtomed.com/">https://cony.comtomed.com/</a></td>
<td>Dubai, United Arab Emirates</td>
</tr>
<tr>
<td>26-29 October</td>
<td>Digital transformation of healthcare: the added value of patient partnerships (EPF), <a href="https://epfcongress.eu/">https://epfcongress.eu/</a></td>
<td>Virtual</td>
</tr>
<tr>
<td>29 Nov-1 Dec</td>
<td>31st Alzheimer Europe Conference, <a href="https://www.alzheimer-europe.org/Conferences/Bucharest-2021">https://www.alzheimer-europe.org/Conferences/Bucharest-2021</a></td>
<td>Bucharest, Romania</td>
</tr>
</tbody>
</table>