I would like to start by offering my condolences to the family and friends of Bojan Spanja, former member of our European Working Group of People with Dementia, who has sadly passed away. Bojan was from Slovenia and was a member of the group from 2012 to 2015. He will be sorely missed by all of us.

We continue to follow the situation in Ukraine closely and have put together an online resources page with information and guidance to help support people with dementia and carers, during the ongoing war. Our national member associations, as well as colleagues at other national and international Alzheimer associations, are providing whatever support they can to people with dementia and their families caught up in this conflict.

Regarding our own activities this month, we hosted an online European Parliament Workshop on “Prioritising dementia in European policies on care, disabilities and equalities”, chaired by Sirpa Pietikäinen, MEP (Finland), Chairperson of the European Alzheimer’s Alliance. The event was attended by EU policymakers, representatives from national Alzheimer’s associations and national health ministries, as well as industry partners. During the event, our Chairperson Iva Holmerová launched our Dementia in Europe Yearbook 2021. This new report examines dementia-inclusive initiatives and communities, particularly in light of work done by the European Union, World Health Organization and World Dementia Council.

We also held a Company Round Table at which we gave sponsors and other delegates an update on our activities, our Clinical Trials Watch database and on recent policy developments. David Jefferys and Nicolas Creff from the European Federation of Pharmaceutical Industries and Associations (EFPIA) joined the meeting and gave attendees an update on the implementation of the Clinical Trials Regulation and on the newly launched Innovative Health Initiative (IHI).

Last week, we submitted a contribution to the European Commission’s call for evidence on the forthcoming European Care Strategy. The strategy aims to a.o. strengthen long-term care, as envisaged within the European Pillar of Social Rights. Our response to the call for evidence addresses key issues relevant for people with dementia and their carers, identifying additional areas of potential focus for the strategy, as well as further evidence and areas of work that we believe are key to improving long-term care services.

In closing, I have two exciting pieces of news to share. Firstly, our three open positions have now been filled and we are expecting our new colleagues at the start of June, expanding our small team from 11 to 14 people. Secondly, we have launched the call for abstracts for the 32nd Alzheimer Europe Conference, taking place in Bucharest from 17 to 19 October 2022. More information is available on our website, together with the abstract submissions form and online registration for in person and virtual participants.

Jean Georges
Executive Director
8 March: International Psychogeriatric Association and World Psychiatric Association make joint statement to support human rights of older persons during the war in Ukraine

On 8 March 2022, the following statement was made by the International Psychogeriatric Association (IPA) and World Psychiatric Association (WPA) concerning the war in Ukraine:

The unprecedented and escalating conflict in Ukraine has created a catastrophic and life-threatening situation for hundreds of thousands of people who have fled or are attempting to flee the country seeking safety. During such a turbulent time, leaders of IPA and WPA are very sensitive to and deeply concerned about the health and safety of older persons in Ukraine. The crisis created by this conflict is likely to disproportionately affect older persons, particularly those who live with physical and mental health conditions, and psychosocial disabilities. Ensuring continued access to essential care and medications for older persons will be critical as the violence continues and intensifies.

We are grateful to the following organizations, who are working to help alleviate the humanitarian crisis in Ukraine and to refugees in surrounding countries:

- **World Health Organization**
  WHO is working with both Ukraine and its neighbours to ensure essential medical supplies and equipment reach those in need.

- **Médecins Sans Frontières/Doctors Without Borders**
  MSF is shipping supplies to Ukraine and providing emergency response services to those affected by the conflict.

- **International Red Cross/Ukraine operations**
  The Switzerland-based international organisation is supporting the work of the Ukrainian Red Cross, including emergency assistance to families and health care facilities alike.

- **UN Refugee Agency**
  The international organisation is providing emergency assistance to families in Ukraine, including cash assistance and opportunities for resettlement.

Our greatest desire is for peace, and we stand in solidarity with so many around the world in calling for an immediate end to the violence.

https://www.ipa-online.org/news-and-issues/statement-on-ukraine

15 March: Alzheimer Europe has a new online resources page to help support people with dementia and carers, during the ongoing war in Ukraine

In order to support people with dementia and carers, during the ongoing war in Ukraine, Alzheimer Europe has put together a range of online resources with information and guidance. These currently cover national support and information in Ukraine, international support and information, as well as support in Ukraine’s neighbouring countries.

We will continue to closely monitor the situation and to update this page regularly. We invite our member associations (and others) to send us further information and resources via email, to info@alzheimer-europe.org

Relevant news developments for people with dementia and their carers in Ukraine will also be included in a new section in our online news and monthly newsletters, under the title “Ukraine updates and support”.

https://www.alzheimer-europe.org/resources/ukraine-resources
15 March: AGE Platform Europe highlights plight of older people during war in Ukraine and stresses importance of upholding their rights under International Law

On 15 March 2022, AGE Platform Europe published an update on its website, concerning the impact of the war in Ukraine, on older people.

Ukraine is among the fastest ageing countries in the world, with 7 million people aged 65 or older living in the country (2019 UN statistic). They represent 16.7% of the total population and their number was expected to reach 20% by 2030. These more than 7 million older people are currently at risk as a result of the Russian invasion. Whether they decide to stay in Ukraine or to leave the country, they deserve equal access to humanitarian aid, AGE Platform stresses.

The update highlights the plight of older people in conflicts and describes the current emergency response efforts being made. International law exists, it points out, to protect civilians in time of war and it should and must apply equally to older people. Specific protections and direct engagement with organisations of older people may be necessary to increase the visibility of and address the specific needs of this population, AGE Platform suggests.

The UN Special Rapporteur on the Rights of Persons with Disabilities and the UN Independent Expert on the Rights of Older Persons have emphasised the need to ensure accountability for any violations of the rights of older persons and those with disabilities in the conflict. They encourage civil society, the UN and other agencies, to actively monitor, record and report the situation on the ground. The full update of 15 March, on the situation of older people in the Ukraine, can be read, here:

https://www.age-platform.eu/special-briefing/ukraine-
%E2%80%98oldest%E2%80%99-humanitarian-crisis-world

22 March: Luxembourg National Research Fund provides temporary support for researchers who have fled the war in Ukraine

On 22 March, the Luxembourg National Research Fund (FNR) announced that it would provide temporary support for researchers who have fled the war in Ukraine. These persons should be employed at Luxembourg public research institutions in ongoing FNR projects for a maximum of 6 months based on requests for additional funding. The FNR earmarks EUR 1 million for these grants. Find out more:

https://www.fnr.lu/temporary-fnr-support-for-researchers-who-have-fled-the-war-in-ukraine/

22 March: Czech Alzheimer Society publishes leaflets in Czech, English and Ukrainian about medical help for people with dementia who have fled from Ukraine

The Czech Alzheimer Society has produced a number of leaflets in Czech, English and Ukrainian about medical help for people with dementia who have fled from Ukraine.

The leaflets can be viewed and downloaded as a PDF, here:


23 March: Alzheimer’s Disease International releases information cards on how to support people living with dementia and their carers during the war in Ukraine

On 23 March, Alzheimer’s Disease International (ADI) released a set of information cards on how to support people living with dementia and their carers during the Russian invasion of Ukraine.

This advice has been developed from ADI’s "Forgotten in a Crisis"
report and in accelerated response to the crisis in Ukraine. As such, they do not necessarily cover every consideration that needs addressing and will continue to be reviewed and updated on an ongoing basis.

These advice cards are intended for use by carers, humanitarian agencies, communities, local agencies and people living with dementia and may be adapted and applied to any emergency situation, crisis or natural disaster. ADI is currently in the process of translating this advice for more languages. The cards are available in English and Ukrainian via: https://www.alzint.org/resource/advice-for-carers-humanitarian-agencies-communities-and-people-living-with-dementia-during-times-of-crisis/

IN MEMORIAM

In Memoriam Bojan Spanja, 1955 - 2022

We were very sad to learn of the passing of our friend and former member of the European Working Group of People with Dementia, Bojan Spanja, on 7 March 2022. Bojan was born in June 1955 in Ljubljana, Slovenia. He trained as a systems engineer and worked for 20 years in the computer department of a big company. In 1996, he established his own company and successfully developed and sold computer software for 13 years. He was also an avid sportsman and angler, as well as a motorsports fan. Bojan was diagnosed with Alzheimer’s disease in 2010 and became a founding member of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) in 2012. He was nominated to the group by Spominčica - Alzheimer Slovenia and served on the EWGPWD from 2012 to 2015.

Everyone in the EWGPWD and at Alzheimer Europe who knew him remembers him fondly and he will be sorely missed by all of us. Our heartfelt condolences go out to his wife Mihela, family and friends.

ALZHEIMER EUROPE

22 March: Alzheimer Europe hosts online European Parliament Workshop

On 22 March, Alzheimer Europe hosted an online European Parliament Workshop, on “Prioritising dementia in European policies on care, disabilities and equalities”, chaired by Sirpa Pietikäinen, MEP (Finland), Chairperson of the European Alzheimer’s Alliance (EAA). The event was attended by EU policymakers, representatives from national Alzheimer’s associations and national health ministries and industry partners.

Ms Pietikäinen introduced a number of points to set the scene for the Workshop, noting the relevance of the place of dementia across policies on care, disabilities and equalities. She explained that currently, the EMPL and FEMM committees in the European Parliament were exploring the issues around the European Care Strategy, as well as noting the gendered nature of dementia and the caring responsibilities in the care sector (both formal and informal). Furthermore, she highlighted how dementia was a cognitive disability and as such, had the same entitlement to care and support, as well as the right to make decisions about their lives.

The first presentation was delivered by Astrid Dentler, Member of Cabinet of Vice-President Dubravka Šuica, European Commission, who set out the priorities and objectives of the forthcoming European Care Strategy. She highlighted that the strategy would look at care throughout the life course, which will result in two recommendations to Council, one focused on the revision of the Barcelona Targets and one on long-term care. In particular, the strategy will seek to address long-standing systemic issues associated with care including accessibility, affordability and quality of care services. A consultation is currently for stakeholder contributions, with the strategy expected to launch in the third quarter of 2022.

Participants also heard from Inmaculada Placencia Porrero, Senior Expert - Social affairs, DG EMPL, European Commission, who outlined the EU’s European Strategy on the Rights of Persons with Disabilities 2021-2030 (ESRPD). She noted that in
Europe the majority of older adults have some form of disability and the majority of persons with disabilities are older people. It was further explained that the majority of people with disabilities need of some type of long-term care and support services. The ESRPD takes a broad approach looking to address challenges faced by people with disabilities in relation to rights, services, supports and socio-economic issues, amongst others. Specific areas for action identified within the 7 flagship initiatives and 8 priority areas of the ESRPD include deinstitutionalisation, accessibility (both physical and digital), access to services and support for people with disabilities to live independently.

Alejandro Moledo, Head of Policy, European Disability Forum (EDF), provided an overview of the current review of the EU’s compliance on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), including EDF’s contribution to the process. He explained that the process of the review of the EU’s implementation of the UNCRPD had commenced this month, with this being the second review of the EU (the first taking place in 2015). It was explained that EDF had produced and submitted an alternative report, highlighting a range of issues, including challenges in the legal harmonisation and enforcement of the UNCRPD and EU legislation, the lack of structured or documented process for engagement of people with disabilities, and the lack of a dedicated unit across all institutions with responsibility UNCRPD adherence. The process of review is ongoing and is expected to conclude in 2024.

Alzheimer Europe Chairperson, Iva Holmerová, launched the Dementia in Europe Yearbook 2021, which examines dementia inclusive initiative and communities. These activities which aim to create societies which support people with dementia, their families, carers and supporters to continue living as well as possible in their communities. She explained that the report revisited the issue in light of work by the EU, WHO and World Dementia Council, and examined examples of policies and resources developed across Europe.

Tilly Metz MEP (Luxembourg), member of the EAA, closed the session thanking speakers and attendees. She reflected on some of the key challenges raised during the meeting, as well as highlighting stigma, isolation and discrimination, as key challenges facing people with disabilities, which had been often exacerbated during the COVID-19 pandemic. She stressed that the EU’s work in these areas needed to focus on equal access to treatment and services, as well as greater support for people acting as informal caregivers. Presentations from the day can be viewed here: https://www.youtube.com/playlist?list=PLO-PgQHI1WQUgsuWZOdYEWLkKXIPsLYg

The next European Parliament Workshop will take place on 14 June 2022.

22 March: Alzheimer Europe report outlines dementia-inclusive activities across Europe

At an online European Parliament Workshop entitled “Prioritising dementia in European policies on care, disabilities and equalities”, on 22 March 2022, Alzheimer Europe launched its 2021 Dementia in Europe Yearbook dedicated to dementia-inclusive communities and initiatives. The Yearbook examines activities undertaken across Europe which aim to create societies which support people with dementia, their families, carers and supporters to continue living as well as possible in their communities.

The report notes that, since 2015, there have been a number of European and international policy developments, including the EU’s second Joint Action on Dementia, the World Health Organization’s Global Action Plan on the Public Health Response to Dementia 2017-2025, and World Dementia Council reports on the subject. These have helped prioritise dementia-inclusive initiatives and communities, as have the additional resources and materials which have been developed to support their implementation. Common themes across these areas of work include awareness-raising amongst the public, anti-stigma campaigns, inclusive communities and the involvement of people with dementia, their carers and supporters in decision-making.

Furthermore, Alzheimer Europe collated examples of good practice provided from its members, who shared examples which could potentially be replicated and spread across Europe. The report shows an extensive amount of work being undertaken across Europe, in the majority of cases, led by national Alzheimer associations. Governments (at different levels) appear to be taking on a greater role (whether through funding or participation) in areas including awareness raising and dementia-inclusive schemes.

However, there remain gaps across Europe, as well as a number of areas for improvement. For example, the involvement of people with dementia, their carers and supporters, remains highly variable, whilst the monitoring and evaluation of the impact of programmes is inconsistent. Taking these points into consideration, the 2021 Yearbook makes the following recommendations:
• People with dementia, carers and supporters should be involved in the development, implementation and monitoring of dementia-inclusive initiatives and societies.

• National, regional and local governments should provide sustainable and ongoing funding for projects and initiatives to create dementia-inclusive societies.

• National, regional and local governments should utilise the findings from existing work in the development and implementation of their own dementia-inclusive societies and initiatives, including that of the World Health Organization, the second Joint Action on Dementia and the World Dementia Council.

• Structured and continuous monitoring and evaluation of dementia-inclusive societies should be undertaken, particularly for cities and municipalities which self-describe as being dementia inclusive, etc. using a universal or at least European evaluation framework.

Commenting on the publication of the report, Alzheimer Europe’s Executive Director, Jean Georges, stated:

“We are delighted to see the progress that has been made in recent years on dementia-inclusive initiatives. Dementia-inclusive communities and initiatives are an essential component in ensuring that people with dementia, their families and carers are able to live well with the condition. It is encouraging to see such a wide variety of initiatives taking place at a local, regional and national level and the important role played by our members across Europe.”

“However, whilst this progress is welcome, there remain significant differences across Europe as to the development and uptake of these initiatives. People with dementia need to be involved to a greater degree in the decisions which affect them, whilst governments must commit to providing sustainable financing and resources to support dementia-inclusive initiatives across Europe.” The full report can be accessed on the website of Alzheimer Europe at: https://www.alzheimer-europe.org/reports-publication/dementia-inclusive-communities

23 March: Alzheimer Europe hosts online Company Round Table meeting

On 23 March, Alzheimer Europe hosted an online Company Round Table meeting, attended by representatives from Biogen, Eisai, EFPIA, GE Healthcare, GSK, Hoffmann-La Roche, Lilly, Novo Nordisk and TauRx. Also in attendance, were members of the Alzheimer Europe staff and representatives of member organisations.

David Jefferys from EISAI and chair of the EFPIA Alzheimer’s Dementia Special Interest Group addressed delegates with a presentation on the implementation of the clinical trials regulations and highlighted the new Clinical Trials Regulation that entered into application on 31 January 2022. Jean Georges updated sponsors and other delegates on Alzheimer Europe’s activities during the past year. It was also an opportunity to highlight Alzheimer Europe’s planned activities for 2022. Project Officer Cindy Birck gave then an overview of recent developments with regards to our Clinical Trials Watch database. Policy Officer Owen Miller shared some recent policy developments at the WHO and EU levels. Finally, Nicolas Creff from EFPIA gave an update on the Innovative Health Initiative (IHI). We would like to thank our sponsors and members for participating in this meeting and we look forward to welcoming them to the next Company Round Table meeting, on 14 June 2022.

29 March: Alzheimer Europe responds to European Care Strategy call for evidence

Alzheimer Europe has submitted a contribution to the European Commission’s call for evidence on the forthcoming European Care Strategy. The strategy aims to strengthen long-term care and early childhood education, as envisaged under the European Pillar of Social Rights.

Alzheimer Europe’s response to the call for evidence addresses key issues relevant for people with dementia and their carers, identifying additional areas of potential focus for the European Care Strategy, as well as further evidence and areas of work we believe the are key to improving long-term care services. In particular, Alzheimer Europe’s response highlights:

• The findings of the Dementia Monitor 2020 in relation to the accessibility and affordability of care services

• The good-practice work done in this area by the EU’s Second Joint Action on Dementia

• The need for the European Care Strategy to align with the World Health Organisation’s (WHO’s) recent framework on long-term care.

Alzheimer Europe’s contribution to the call for evidence can be accessed at: https://www.alzheimer-europe.org/policy/positions/european-commission-european-care-strategy/proposals

1 April: Alzheimer Europe opens call for abstracts for its 32nd Annual Conference

We are delighted to invite you to the 32nd Alzheimer Europe Conference (#32AEC), organised in collaboration with Societatea Română Alzheimer. The in-person conference itself in Bucharest, Romania will take place from 17 to 19 October 2022. This will be a hybrid event, with some carefully selected
sessions broadcast for our online audience. The event will be held under the banner “Building bridges”. As in previous years, we hope that #32AEC will be a great networking opportunity, bringing together people with dementia, their carers and supporters, volunteers and staff of Alzheimer associations, policymakers, health and social care professionals, researchers, academics and industry representatives from across Europe and beyond.

We have identified a number of key topics for which we would like presenters to submit abstracts. We are confident that we will be able to continue and build on the success of previous years where we received over 300 abstracts for oral and poster presentations. The call for abstracts covers a broad range of topics, as we want to promote a multi-disciplinary and multi-professional approach to dementia. Alzheimer Europe is calling for abstracts for oral and poster presentations on the following subjects:

(Inter)National dementia strategies; Arts and culture; Brain health and dementia prevention; Carer training and support; COVID-19 and dementia; Cross border dementia initiatives; Dementia-friendly initiatives; Gender, sex and sexuality in dementia; Home care and support; Intellectual disability and dementia; Minority ethnic groups; Needs and experiences of people with dementia; Non-Alzheimer’s dementias; Psychosocial interventions; Residential care; Technology; Timely diagnosis; and Young onset dementia. To find out more and to submit your abstract, please visit: https://www.alzheimer-europe.org/conferences/2022-bucharest/abstract-submission

As organisers, we are deeply grateful to our sponsors who support our activities and our Annual Conference in particular. This support makes it possible for us to provide highly competitive registration rates.

Registrations will open very soon and Early Bird reduced prices apply until 15 July 2022. We look forward to welcoming you to Bucharest in October!

Some important dates:
1 April 2022: Call for abstracts open
15 May 2022: End of abstract submissions
15 June 2022: Results of abstract evaluation
15 July 2022: End of early bird registrations
10 October 2022: Virtual Platform opens
17-19 October 2022: Conference in Bucharest
31 January 2023: Closing of access to virtual conference platform with recordings of videos and posters. Please click here for registration information: https://www.alzheimer-europe.org/conferences/2022-bucharest/registration-fees

Alzheimer Europe networking

On 1 March, Ange attended a Neuronet working group meeting on data sharing.
On 1 March Ana and Cindy attended the meetings of the EU-FINGERS Advisory Board.
On 2 March, Jean had a call with the European Federation of Neurological Associations (EFNA) and GAMIAN-Europe.
On 2-3 March, Ange participated in the quarterly EMA PCWP-HCPWP meeting.
On 8, 15, 25 and 30 March, Jean and Owen met with representatives of EFNA and GAMIAN-Europe on patient involvement in brain research.
On 9 March, Owen attended an online session of the EFPIA Patient Think Tank on the Innovative Health Initiative.
On 10 March, Ange participated in a DataSavesLives webinar.
On 10-11 March, Dianne and Ana participated in the RADAR-AD annual meeting.
On 14 March, Jean had talks with Roche and the EFPIA Alzheimer’s Platform.
On 14 March, Ana attended an ADAIR virtual seminar.
On 14-15 March (Brussels, Belgium), Gwladys attended the BIAForum.
On 15 March, Owen attended the online launch of the WHO framework on long-term care.
On 15 March, Ange joined a meeting on dissemination for the PRIME project.
From 16 to 18 March (Barcelona, Spain), Jean attended the AD/PD Conference.
On 17 March (Barcelona, Spain), Jean met with representatives from Biogen, Lilly, Novo Nordisk, Prothena and Roche.
On 18 March, Ange participated in an EMA Raw Data Advisory Group meeting.
On 18 March (Barcelona, Spain), Jean moderated a symposium “Where does our hope come from in Alzheimer’s disease” at the AD/PD Conference.
On 21 March, Jean met with Paola Barbarino and Chris Smith from Alzheimer’s Disease International.
On 22 March, Cindy attended the PRODEMOS WP leads meeting.
On 22 March, Ange, Cindy and Chris participated in the Neuronet Communication Expert meeting.
On 22 March, Alzheimer Europe organised its European Parliament workshop “Prioritising dementia in European policies on care, disabilities and equalities”.
On 23 March, Alzheimer Europe organised a company round table meeting.
On 23 March, Ange participated in an EPND sustainability workshop.
On 24 March, Ange, Dianne and Jean attended a Neuronet working group meeting on ethics and patient privacy.
On 28 March, Jean attended an online information session for networks supported by the CERV programme.
On 28 March, Jean attended an Astellas symposium on multimorbidities.
On 29 March, Ana, Dianne and Ange organised a call with Eodyne for the VirtualBrainCloud project.
On 30 March, Cindy, Chris, Jean and Ange attended the Neuronet Scientific Coordination Board meeting.
On 30 March, Dianne and Ana participated in an INTERDEM Task Force meeting about the use of technology during COVID.
On 30 March, Owen attended a Biogen briefing session on Development and implementation of dementia plans and strategies.
On 31 March, Jean attended the MIRIADE Supervisory Board.

EU PROJECTS

28 February: PRODEMOS project publishes new paper investigating attitudes and views on healthy lifestyle interventions for prevention of dementia and cardiovascular disease

The Prevention of Dementia using Mobile phone Applications (PRODEMOS) project has published a new paper in the journal BMJ Open, entitled “Attitudes and views on healthy lifestyle interventions for the prevention of dementia and cardiovascular disease among older people with low socioeconomic status: a qualitative study in the Netherlands”.

In this study, authors explored the attitudes, experiences and views of Dutch low socioeconomic status older adults on healthy lifestyles for the prevention of cardiovascular disease and dementia. Authors also aimed to study the potential role for coach-supported mHealth use, facilitating development and further adaptation of the PRODEMOS mHealth intervention. In total, 19 semi-structured interviews were performed in the Netherlands. Participants were 55 years or over, had a low socioeconomic background, no dementia diagnosis but had dementia risk factors, and possessed a smartphone. Findings suggested that participants had low levels of self-efficacy to change their lifestyle behaviour, and may benefit from lifestyle interventions with human support. Such lifestyle support should ideally take into account the individual’s own autonomy and should emphasize the direct, short-term gains of lifestyle changes for daily life. Moreover, given that the social network is important to start and maintain lifestyle behaviour change, involving peers may be a valuable approach when developing lifestyle interventions for low socioeconomic status older adults. You can read the paper, here: https://pubmed.ncbi.nlm.nih.gov/35228289/
Further information on the PRODEMOS project can be found here: https://www.prodemos-project.eu

1 March: The EU-FINGERS Advisory Board participates in its fourth consultation

The EU-FINGERS project will advance the understanding of, and the interventions for, the prevention of cognitive decline and Alzheimer’s dementia. The project aims to develop tools and methods for researchers working in the field of prevention of Alzheimer’s disease and dementia.
EU-FINGERS has set up an Advisory Board in January 2021. The Advisory Board is composed of people with an interest on the topic of brain health and prevention of dementia from seven
countries in Europe (Finland, Hungary, Luxembourg, Netherlands, Spain, Sweden, United Kingdom). Alzheimer Europe, in close coordination with the other partners in the project, is responsible for the coordination of the EU-FINGERS Advisory Board and the contribution of its members.

Members of the Advisory Board were split in three smaller groups and met online on 1 March. The focus of the meeting was on online registries for study participants. During the meeting, members discussed on the content and access to the registry and the motivations to join and to stay in the long term. All meetings were very interactive and lively and the feedback received was very valuable for the project. Project Officers Cindy Birck and Ana Diaz participated in the different meetings.

**1 March: New partnership between AMYPAD and ADDI powers global open access to project’s data**

The Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) consortium has recently announced a collaboration with the Alzheimer’s Disease Data Initiative (ADDI), a medical research organisation dedicated to fundamentally transforming Alzheimer’s disease (AD) research, accelerating progress towards new treatments and cures for AD and related dementias. This five-year partnership aims to share the data generated by the AMYPAD Prognostic and Natural History Study (PNHS) beyond the project duration in the ADDI platform. The AD Workbench is an open, global and free cloud-based platform for scientists to accelerate discoveries and innovations for AD and related dementias.

The first internal data-release of the AMYPAD PNHS study has been made in November 2021. Data from the multiple data sources have been integrated using the Aridhia Workspaces infrastructure, which has now been set-up within ADDI. The first data, together with the metadata describing the dataset, are now accessible through the AD Workbench for all members of the AMYPAD consortium. Further releases will be made periodically over 2022. Data access for researchers outside AMYPAD will be granted in the future through the AD Workbench FAIR metadata catalogue.

ADDI represents an excellent opportunity for AMYPAD to collaboratively mine its treasures in the AD Workbench. This collaboration will be extremely fruitful for AMYPAD in terms of its long-term sustainability plans.

**1 March: NEURONET hosts meetings of its Patient Privacy & Ethics and Data Sharing working groups**

Neuronet is an Innovative Medicines Initiative (IMI)-funded coordination and support action, designed to support and enhance collaboration between the diverse projects in the IMI neurodegeneration portfolio. In 2019, Neuronet launched four Working Groups, cross-project spaces for experts to discuss common issues, priorities and opportunities for synergy and collaboration. Each Neuronet Working Group is focused on a particular area of concern for IMI Neurodegeneration projects: data sharing, ethics & patient privacy, sustainability and regulatory/HTA interactions.

This month, Neuronet convened online meetings of its Working Groups (WGs) on data sharing and ethics & patient privacy. On 1 March, Lennert Steukers and Jessie van Houcke (Janssen) co-moderated a meeting of the data sharing WG, attended by data experts from EMIF, EPAD, Mobilise-D, IDEAS-FAST and RADAR-AD along other IMI projects. The data sharing WG has recently finalised a deliverable report on the barriers to data sharing in the public-private partnership setting, outlining recommendations to overcome some of these obstacles. During the WG meeting, discussions focused on issues with data harmonisation and challenges posed by the varied use of common data models in different data initiatives.

On 24 March, Jean Georges (Executive Director of Alzheimer Europe) moderated a meeting of the ethics & patient privacy WG, which was attended by ethics and data protection experts working on IMI neurodegenerative disease projects. Discussions were focused on an upcoming deliverable for the Working Group, which will analyse clauses relevant to patient privacy in informed consent forms and data management plans created by projects, aiming to identify commonalities and areas of good practice.

**10 March: The EPAD genomic data is now available on the Alzheimer’s Disease Workbench**

The European Prevention of Alzheimer’s Dementia (EPAD) consortium, in their partnership with Aridhia and Alzheimer’s Disease Data Initiative (ADDI), have announced that the EPAD genomic data has been incorporated into the Alzheimer’s Disease (AD) Workbench to provide even greater value to the global neuroscience research community.

https://www.imi-neuronet.org/
A key achievement of the 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 the 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 AD Workbench, which is an open, global and free cloud-based platform for scientists to accelerate discoveries and innovations for AD and related dementias.

This incredibly rich data source has now been enriched with the EPAD genomic data. It is an important step in continuing to share the EPAD LCS data in the long-term and ensuring that this valuable resource is used by the research community to generate as much knowledge as possible.

https://ep-ad.org/the-epad-genomic-data-is-now-available-on-the-alzheimers-disease-workbench/

10-11 March: Third annual consortium meeting gathers over 50 RADAR-AD project members online to discuss the progress of their work and future plans

Once a year, RADAR-AD project members from different work streams, patient representatives and scientific advisors gather to present the status of their work, discuss challenges and share ideas for future collaboration and output. The 2022 RADAR-AD annual meeting took place on 10 and 11 March, online, due to the COVID-19 pandemic. Around 50 consortium members took part in the discussions during this meeting.

The programme for the event included presentations about the progress of the clinical study, the functional domains and modelling work, the RADAR-base data platform and the remote measurement devices used in the project, as well as the ethics and regulatory work done in RADAR-AD. In addition, members from Alzheimer Europe discussed the work on patient engagement in RADAR-AD and the activities of the Patient Advisory Board (PAB) appointed for the project. The PAB involves people with mild cognitive impairment, dementia (predominantly Alzheimer’s dementia) and their carers (e.g. family members and friends). The RADAR-AD PAB has been actively involved in several activities since the start of project in January 2019. You can find out more about the PAB members and their work here. Read the full story here.

24 March: IDoService project hosts second series of co-design workshops on developing skills exchange service

The second series of co-design workshops for the IDoService project took place in February and March 2022. Like the workshops at the end of last year, people living with mild to moderate dementia and their support persons met with researchers face-to-face during a Dementia Café run by Age UK Salford. Workshops with staff from charities and organisations related to dementia and social or volunteer activities were organised online.

Insights from these exchanges allowed the research team to have a better overview of the user service journey right before and after a dementia diagnosis in Greater Manchester. Discussions were about where, and in which format IDoService might be able to support participation in activities and volunteering opportunities for people living with mild to moderate dementia.

The importance of a strength-based approach has been highlighted again and the workshops participants and research team elaborated together on which tools might be supportive to people. In particular, exchanges have been around a Skills and Preferences Inventory that could help to define opportunities for people for active participation in activities as well as volunteering by providing contact with relevant organisations, charities, or services through a “skills fair”, or similar.

The next project step will be to prototype this skills exchange service through tailored regular one-to-one sessions with three to four people living with mild dementia interested in being among the first people to benefit from and try this service. For more information see www.idoservice.org

For any questions or suggestions contact Dr Isabelle Tournier by email idoservice@mmu.ac.uk or on Twitter @idoservice4dem1.

25 March: AD Detect & Prevent project announces positive results from first of four clinical studies to evaluate “Starry Night” cognitive test for early detection of AD

The AD Detect & Prevent project has sent the following report, with results from the first of four clinical studies to evaluate the “Starry Night” cognitive test for early detection of Alzheimer’s disease (AD):

A study led by Professor Masud Husain, at the University of Oxford, has evaluated the feasibility and performance of a cognitive test that is intended for early detection of Alzheimer’s disease (AD), called Starry Night. Brain+ developed the test as a gamified version of a lab-based test by Professor Husain’s team, which has been proven to be sufficiently sensitive to detect pre-symptomatic AD.
The test works on the well-described clinical findings that individuals at high risk of developing Alzheimer’s dementia but who exhibit no overt clinical symptoms show a particular cognitive deficit pattern related to memory and attention. The test is designed to run on smartphones and tablets so that people can use it from home, thus allowing for scalable and remote testing.

AD can begin with pathological changes in the brain up to 20 years before symptoms appear, at which point the disease has already caused significant cognitive impairment. If AD can be detected at an earlier stage, it would allow more effective action to be taken with lifestyle interventions, traditional pharmaceuticals, digital therapeutics, or a combination of all of these. Thus, early detection is key.

The Oxford study of the Starry Night test examined a total of 131 healthy participants of all adult ages, including people over the age of 50. The objective of the study was to evaluate the test against the original lab test by comparing key outcomes. The results showed that the critical test outcomes were comparable between the two versions of the test, thus validating the feasibility of the test. As a secondary result, the study showed that individuals without regular access to neurology clinics could successfully use the test. This is important because it demonstrates that the test is suitable for scalable remote testing in people’s homes.

The study is the first of four clinical studies; all evaluating the Starry Night test and expected to read out in 2022. Considering the findings from this study, Brain+ will now begin the planning of a large-scale trial to gather normative data on the test. This will provide a population performance baseline, against which to compare individuals at risk of developing AD for more effective future disease detection and treatment. For more information, see the project website:

https://www.addp.eu/

30 March: Neuronet convenes 8th meeting of its Scientific Coordination Board

On 30 March, the Innovative Medicines Initiative (IMI) funded Neuronet Coordination and Support Action convened the seventh 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 AMYPAD, EMIF, EPND, IDEA-FAST, IM2PACT, IMPRiND, PD-MitoQUANT, PHAGO, PRISM2 projects along with members of the Neuronet consortium. Carlos Díaz (Synapse), 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 22 October 2021. Matthias Gossel, Alliance Manager at Sanofi, introduced himself as the representative for IM2PACT, as Dominique Lesuisse was unavailable.

These activities include new updates of the Asset Map by Lewis Killin (Synapse) and the HTA/Regulatory Decision tool by Fatima Salih (NICE).

Next, Angela Bradshaw (Alzheimer Europe) provided an update on work underway to support a new special issue of Frontiers in Neurology, entitled “Impact of public-private collaborative research on AD: the case of the IMI”. The editors of the special issue are Elisabetta Vaudano (IMI), Jean Georges (AE), Martin Hofmann-Apitius (Fraunhofer SCAI), Donald Lo (NIH) and Monica Ensini (European Commission), and the abstract deadline is 18 May, with a deadline for full manuscripts of 18 July.

This was followed by a look at current activities of Neuronet with regards to the NEUROCohort, by Lewis Killin. Lewis explained that NEUROCohort stems from the EPAD LCS study, which brought together over 30 sites and included 1600 participants. The goal of NEUROCohort is to support new studies wanting to engage sites in Europe, acting as an honest broker towards funders and external researchers and easing challenges with recruitment, contracting and other administrative processes. This European “parent cohort” would an agile structure on top of which new research studies could be developed. There is no baseline funding for NEUROCohort so it is very much a coalition of the willing; it aims for breadth (small number of variables; minimal common data model) rather than depth, and is supported by the Medical Informatics Platform.

Followed by that, Nina Coll (Synapse), provided an update on future meetings that are planned as part of Neuronet’s activities, including a final Consortium meeting, to which the SCB members are cordially invited. As a last point on the agenda, the project leads Lennert Steukers (Janssen) and Carlos Díaz led a roundtable discussion around the last six months of Neuronet’s IMI funding period with a focus on priorities and sustainability. The meeting ended with a wrap-up and concluding remarks by Carlos Díaz who thanked the SCB for their continued support and contribution, and for making Neuronet a success.

https://www.imi-neuronet.org/neuronet-convenes-8th-meeting-of-its-scientific-coordination-board/
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:

AD Detect & Prevent – grant agreement 820636
AMYPAD – grant agreement 115952
EPAD – grant agreement 115736
NEURONET – grant agreement 821513
PRODEMOS – grant agreement 779238
RADAR-AD – grant agreement 806999

EU-FINGERS is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project. The project is supported through the following funding organisations under the aegis of JPND www.jpnd.eu: Finland, Academy of Finland; Germany, Federal Ministry of Education and Research; Spain, National Institute of Health Carlos III; Luxemburg, National Research Fund; Hungary, National Research, Development and Innovation Office; The Netherlands, Netherlands Organisation for Health Research and Development; Sweden, Swedish Research Council. Grant agreement: INTER/JPND/19/BM/14012609.

Members of the European Alzheimer’s Alliance

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

Austria: Claudia Gamon (Renew Europe); Monika Vana (Greens/EFA). Belgium: Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). Bulgaria: Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk ( Renew Europe); Tsvetelina Penkova (S&D); Sergei Tomashik (ECR). Cyprus: Costas Mavrides (S&D). Czech Republic: Tomáš Zdechovský (EPP). Denmark: Margrethe Auken (Greens/EFA); Christel Schaldemose (S&D). Estonia: Urmas Paet (Renew Europe). Finland: Alvina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Mikaela Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). France: François-Xavier Bellamy (EPP); Dominique Bide (S&D); Nathalie Colin-Oesterlé (EPP); Anoufajan (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP); Chrystolou Zarachoupolou (Renew). Germany: Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). Greece: Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyriki (EPP); Elisavet Vozemberg-Vrionidi (EPP). Hungary: Tamás Deutsch (EPP); Ádám Kósá (EPP). Ireland: Barry Andrews (ALDE); Deirdre Clune (NI); Ciarán Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke ‘Ming’ Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Grace O’Sullivan (Greens/EFA). Italy: Isabella Adinolfi (NI); Brando Benifei (S&D); Pierfrancesco Majorino (S&D); Patrizia Toia (S&D). Luxembourg: Filipa Esterlé (EPP); Anne Sander (EPP); Mia Hessel (S&D); Chrysoula Zacharopoulou (Renew). Malta: Roberta Metsola (EPP); Alfred Sant (S&D). Netherlands: Jeroen Lenaers (EPP); Annie Schreier-Pierik (EPP). Poland: Elżbieta Łukacijewska (EPP); Jan Olbrycht (EPP). Portugal: Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D). Romania: Cristian-Silviu Bușoi (EPP); Marian-Jean Marinescu (EPP). Slovenia: Franc Bogovič (EPP); Milan Brglez (S&D); Tanja Fajon (S&D); Klemen Grosček (Renew Europe); Irene Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP). Spain: Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilari (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtasun (Greens/EFA). Sweden: Jytte Guteland (S&D); Peter Lundgren (ECR).
EU DEVELOPMENTS

1 March: Mental Health Europe publishes UNCRPD alternative report

Mental Health Europe (MHE) has published its alternative report on the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) by the European Union (EU).

The second review process for the EU's compliance and implementation of the UNCRPD commenced in March 2022. As part of the review process, organisations such as including NGOs are able to provide their own report on UNCRPD implementation, allowing them to raise relevant matters which may otherwise be overlooked.

The MHE alternative report was produced in cooperation with its members with expertise in mental health and human rights. It highlights a number of issues including continued inappropriate use of language in policy, the lack of progress on an anti-discrimination directive and the need for greater involvement of people with disabilities in the EU’s policy making processes. The full alternative report can be read at: https://www.mhe-sme.org/wp-content/uploads/2022/02/MHEs-alternative-report_2022-EU-review_final-vFINAL.pdf

2-3 March: EMA convenes a virtual meeting of its Patients and Consumers’ and Healthcare Professionals Working Parties

On 2-3 March, the European Medicines Agency (EMA) hosted an online meeting of its Patient and Consumer’s (PCWP) and Healthcare Professionals Working Parties (HCPWP). The meeting was attended by all eligible patient organisations and professional bodies, and was chaired by Juan Garcia Burgos (EMA), Kaisa Immonen (European Patient’s Forum; PCWP) and Ulrich Jaeger (HCPWP). Angela Bradshaw (Project Officer) represented AE at the meeting.

The first half of the meeting was kicked off by Marco Cavalieri and Priya Bihari of EMA, who provided updates on COVID-19 vaccines, therapeutics and their safety surveillance. Marco outlined the results of new research on the efficacy of vaccination and boosters against the omicron variant of COVID-19, and explained how recently-approved treatments like nirmatrelvir/ritonavir work to reduce the severity of disease. Priya focused on the safety surveillance that EMA carries out for COVID-19 vaccinations and treatments, highlighting a new section of the EMA website dedicated to accessible information on safety that can help combat misinformation.

Next, representatives outlined recent activities and progress on different EMA initiatives and projects, including the ACT-EU (Accelerating Clinical Trials in the EU), DARWIN (Data Analysis and Real-World Interrogation Network) and BDSG (Big Data Steering Group). ACT-EU was launched in January this year and aims to transform the EU clinical research environment, building on the new Clinical Trials Regulation in support of medical innovation and better patient outcomes. DARWIN is a federated network of data, expertise and services that is working on supporting the use of real-world evidence in clinical trials and for regulatory decision-making.

Meanwhile, the BDSG progress report highlighted ongoing work on promoting stakeholder involvement in EMA initiatives on real-world data, and plans to enable data transformation of the EU regulatory network – a key deliverable for the EMA Network Strategy. Inga Abed (EMA) drew day 1 of the meeting drew to a close by explaining how EMA plans to engage stakeholders and communicate about its extended mandate, which reinforces EMA’s role in crisis preparedness and management for medicinal products and medical devices.

The second day of the EMA PCWP/HCPWP meeting was mainly focused on awareness-raising and the perspectives of member organisations of the PCWP and HCPWP.

First on the agenda was Ana Hidalgo of EMA, who delivered a presentation explaining how advanced therapy medicinal products (ATMPs) such as gene and cell therapies are developed and evaluated at the European level.

On the agenda was Ana Hidalgo of EMA, who delivered a presentation explaining how advanced therapy medicinal products (ATMPs) such as gene and cell therapies are developed and evaluated at the European level.

Next, representatives of member organisations spoke about topics of particular relevance to medicines development; among others, Natacha Bolanos of the European Haematology Association explained their recommendations for reducing bureaucracy in clinical trials, while Marilena Vrana of the European Heart Network spoke about issues with the implementation of the EU Medical Device Regulation and the availability of cardiac devices for patients with heart diseases.

The meeting was drawn to a close by the two co-Chairs, Kaisa Immonen and Ulrich Jaeger, who were thanked for their hard work over the past two years. New co-Chairs will be elected.
later this year, and will lead the PCWP and HCPWP during the upcoming EMA mandate between 2022-2025. 

7 March: European Investment Bank provides EUR 7.5 million loan for research and development of blood test for Alzheimer’s disease

The European Investment Bank (EIB) has granted a EUR 7.5 million loan to Diadem, a company developing the first blood-based prognostic test for the early prediction of Alzheimer’s disease (AD). The loan granted under the Pan-European Guarantee Fund’s venture debt programme, an integral part of the EUR 540 billion EU aid package agreed in 2020 to counter the economic crisis caused by the coronavirus pandemic, is intended to support the development and commercialisation of Diadem’s prognostic blood test for the early detection of AD.

Headquartered near Milan, Italy, Diadem was founded in 2012 as a spin-off of the University of Brescia, with the support of the Italian Ministry of Education, Universities and Research. The test is a non-invasive biomarker blood test that can identify with a high level of accuracy whether individuals over the age of 50 with signs of cognitive impairment will or will not progress to AD up to six years before definitive symptoms are apparent.

EIB Vice-President Gelsomina Vigliotti said: “Diagnostics for neurodegenerative conditions such as Alzheimer’s disease have not been able to identify patients early enough in the disease process to allow interventions to slow or stop disease progression. With this investment, the EIB is confirming its commitment to research and to companies such as Diadem that are at the forefront of biotechnology innovation. We expect this EIB funding to contribute to a revolution in Alzheimer’s disease diagnostics.”

The EIB is the long-term lending institution of the European Union owned by the Member States. It provides long-term funding for sound investments to contribute to the EU’s strategic objectives. The Bank finances projects in four priority areas: infrastructure, innovation, climate and environment, and small and medium-sized enterprises (SMEs). Between 2019 and 2021, the EIB Group provided more than EUR 36 billion in financing for projects in Italy.

The European Guarantee Fund (EGF) was created by the EIB Group with contributions from Italy and other EU Member States to protect businesses that are struggling amid the crisis caused by COVID-19.

14 March: European Commission issues joint call for best practice examples

The European Commission has issued a call inviting governmental and non-governmental actors to submit proposals for best practices on non-communicable diseases (NCDs), as part of the ‘Healthier together’ – EU Non-Communicable Diseases Initiative. NCDs represented 80% of the EU’s disease burden before the COVID-19 pandemic, therefore the Commission is calling for best practices focusing on prevention and management of the following NCDs:

- Cardiovascular diseases
- Diabetes
- Chronic respiratory diseases
- Mental health and neurological disorders
- Health determinants.

The European Commission will invite the owners of the top-ranked best practices to present them to representatives from EU countries, which may lead to joint/wider implementation across the EU under the EU funding programmes. The deadline for submissions is 15 May 2022. Further information can be found on the Commissions’ Best Practice Portal:


23 March: Council of Europe publishes social rights reports

The European Committee of Social Rights (ECSR), part of the Council of Europe, has published reports on 33 states, in relation to their compliance on the articles of the Charter of Social Rights relating to the thematic group “Health, social security and social protection”.

The ESCR adopted 401 conclusions, including 165 conclusions of non-conformity and 110 conclusions of conformity with the Charter. In 126 cases, the Committee was unable to assess the situation due to insufficient information (“deferrals”). Of particular note:

- Information on life expectancy provided by States and other sources reveals that wide differences exist between men and women, regions, urban and rural areas, income and level of education.
- The Committee again found little or no progress in many states in relation to social security. Inadequate minimum level of income-replacement benefits is still the main ground of non-conformity. The minimum levels of unemployment benefit, sickness benefit and disability
benefit in many countries fall below 40% of median equivalent income.

- In many states the level of social assistance paid to a single person without resources remains below the poverty threshold.
- With regard to the rights of older persons, the Committee found that in many states, older persons lack adequate resources enabling them to lead a decent life and play an active role in the community. Legislation prohibiting discrimination outside employment is still lacking in certain States.

Further information and the individual country conclusions can be accessed at:


**POLICY WATCH**

**14 March: Council of States in Switzerland rejects motion for national research programme on Alzheimer’s disease**

After the National Council of Switzerland had come out strongly in favour of a national research programme on Alzheimer’s disease, the Council of States has now rejected the motion (motion 18.3835). The Council of States is the upper house of the Federal Assembly of Switzerland, with the National Council being the lower house.

Alzheimer Switzerland, Swiss Memory Clinics and the Synapsis Foundation - Alzheimer Research Switzerland have expressed their regret at this decision, in a press release dated 14 March 2022. "In view of the increasing number of people with a diagnosis of dementia, the impact on those affected, and the societal challenges, measures in the areas of research, prevention and support are urgently needed", they stress.

Currently, some 146,500 people in Switzerland have dementia, with approximately 60% of these cases being caused by Alzheimer’s disease. The risk increases with age and, with a rapidly aging population, it is estimated that 315,400 people in Switzerland will be affected by Alzheimer’s disease or another form of dementia by 2050.

In view of the impact on those affected, the costs to the health system and the shortage of qualified personnel, the three organisations believe that there is an urgent need for long-term national research into Alzheimer’s disease, as called for in motion 18.3835 by former National Councillor Eymann. While the National Council clearly supported the motion, the Council of States rejecting it is "a missed opportunity to advance research and send a strong signal to the many people with dementia and their families".

In the release, they jointly call for rapid, sustainable and effective research and point out that only one project of the National Research Programme "Health Systems" focuses on dementia, but it concentrates on diagnosis. Neither the National Dementia Strategy nor the National Dementia Platform have the financial resources to conduct research on Alzheimer’s disease.

In view of the current and future societal challenges, there is also an urgent need for preventive action, they note, while early detection programmes could reduce the progression to severe forms. Furthermore, people with dementia and their families are often left to fend for themselves after diagnosis, whereas they ought to benefit from dementia-specific counselling and support services, recognised by law and therefore financially covered.

**22 March: World Health Organization launches framework for long-term care**

The World Health Organization (WHO) has launched a “Framework for countries to achieve an integrated continuum of long-term care". The framework was developed in consistency with the existing strategy, action plan and frameworks on healthy ageing, and was based on the latest evidence and consultations with a range of stakeholders including WHO’s expert advisory group.

Through the framework, WHO aims to provide guidance by highlighting key components of long-term care systems to support countries in their journey to establish sustainable and equitable long-term care provision.

The framework is primarily intended to be used by governments and policymakers and provides a checklist which helps to assess existing long-term care systems, identify potential gaps, and support planning for implementation.

As outlined in the new framework, long-term care systems and services should:

- Be person centred and aligned with the person’s values and preferences
• Optimise functional ability over time and compensate for loss of intrinsic capacity
• Be provided in the community
• Provide integrated services in a continuum
• Include services that empower the older person
• Emphasise support for carers and care workers.

The framework can be downloaded at: https://www.who.int/publications/i/item/9789240038844

SCIENCE WATCH

28 February: Vivoryon Therapeutics receives approval of Chinese clinical trial application for varoglutamstat in Alzheimer’s disease

On 28 February, Vivoryon Therapeutics N.V., a clinical stage company focused on developing innovative small molecule-based medicines, announced the China’s Center for Drug Evaluation (CDE) approval of its Clinical Trial Application of varoglutamstat for Alzheimer’s disease (AD) in China.

Varoglutamstat, also named PQ912, is an investigational oral small molecule medicine for the treatment of early AD. Varoglutamstat is currently being investigated in two Phase II clinical trials with early and mild AD: the European VIVIAD study and the US VIVA-MIND study. Vivoryon Therapeutics has received Fast Track designation for varoglutamstat in early AD by the US Food and Drug Administration (FDA) in December 2021. The designation enables Vivoryon to have more frequent interactions with the FDA during the development process. The main goal of the fast-track program is to accelerate the review of therapies that potentially improve care for serious diseases.


1 March: New study reveals a new genetic risk factor for cognitive decline in people with dominantly inherited Alzheimer’s disease

Dominated inherited Alzheimer’s disease (DIAD) is a rare familial form of AD that is caused by inherited mutations in three genes: presenilin 1, presenilin 2 or amyloid precursor protein. People who have DIAD often start having symptoms of dementia before the age of 50, caused by the accelerated accumulation of damaging amyloid and tau proteins in their brain. In their new study of DIAD, a team of researchers from Australia, the US and Germany have identified how a mutation in the BDNF gene accelerates cognitive decline in people with DIAD.

Brain-derived neurotrophic factor (BDNF) plays an important role in the survival and growth of neurons in the brain. Previous work by the Lim group at Monash University found that people carrying a mutation in the BDNF gene (called BDNF Val66Met) showed faster cognitive decline than peers without BDNF mutations. To find out how BDNF Val66Met affects the phosphorylation and accumulation of Tau proteins in the brains of people with DIAD, the researchers studied longitudinal data from the Dominantly Inherited Alzheimer’s Disease Network (DIAN) and the Alzheimer’s Disease Neuroimaging Initiative (ADNI). In total, they analysed cerebrospinal fluid (CSF) samples and clinical data from 374 study participants with DIAD, 230 of whom carried the BDNF Val66Met mutation. 125 participants without DIAD were drawn from the ADNI group.

By carrying out mass spectrometry analyses of proteins in CSF samples, the researchers were able to construct proteomic profiles of all the participants analysed, cross-referencing data on different types of phosphorylated tau to data from brain imaging scans and clinical test scores. Presymptomatic individuals with DIAD and the BDNF Val66Met mutation had poorer episodic memory, smaller hippocampal volume and higher levels of pTau217, pTau181 and total Tau protein compared to those without the BDNF Val66Met mutation. Similarly, symptomatic individuals with DIAD and the BDNF Val66Met mutation showed significantly poorer cognition and higher Tau levels. This suggests that strategies that boost BDNF in pre-symptomatic stages of AD, for example, physical exercise, may have beneficial effects on Tau accumulation and cognition.

https://jamanetwork.com/journals/jamaneurology/fullarticle/278827

3 March: Roche starts a new Phase III AD prevention trial with gantenerumab

On 3 March, the biotechnology company Roche has announced the launch of a new Phase III Alzheimer’s disease (AD) prevention trial with gantenerumab, an investigational anti-amyloid antibody.

Roche, the Banner Alzheimer’s Institute’s Alzheimer’s Prevention Initiative, the Massachusetts General Hospital, and the University of Southern California Alzheimer’s Therapeutic Research Institute have jointly leveraged their scientific expertise to design the new study. This SKYLINE trial will evaluate gantenerumab in cognitively unimpaired people with the earliest biological signs of AD. The double-blind and
placebo-controlled trial will enrol 1,200 participants, in US and Europe, aged 60 – 80 years who are amyloid positive confirmed by assessing cerebrospinal fluid (CSF) or positron emission tomography (PET), and who show no signs of cognitive impairment. The primary endpoint is change from baseline to Year 4 in the Preclinical Alzheimer’s Cognitive Composite-5 score – an endpoint designed to measure subtle changes in cognitive function.


4 March: Eisai initiates the submission of application data of lecanemab in Japan

On 4 March, Eisai announced the initiation of a submission to the Pharmaceuticals and Medical Devices Agency (PMDA) of application data under the prior assessment consultation system in Japan for lecanemab (BAN2401), an investigational antibody targeting amyloid beta, for the treatment of Alzheimer’s disease (AD).

Based on discussions with the Ministry of Health, Labour and Welfare and PMDA, Eisai applied to PMDA with the aim of shortening the review period of lecanemab. This process is conducted at the development stage before the new drug application submission, which is based on available quality, non-clinical and clinical data.

The agency approved Eisai’s request and Eisai has submitted the non-clinical lecanemab data to PMDA. The additional data of the application package will be submitted hereafter. The lecanemab Clarity AD Phase III clinical study for mild cognitive impairment due to AD and mild AD is ongoing. Eisai plans to obtain the primary endpoint data from Clarity AD study (BAN2401), an investigational antibody targeting amyloid beta, for the treatment of Alzheimer’s disease (AD).

The study included three cohorts of participants with FTD: asymptomatic FTD-GRN mutation carriers, symptomatic FTD-GRN participants, and symptomatic FTD-C9orf72 participants. Data presented focused on the FTD-C9orf72 cohort and included 12-month data for up to 10 participants with at least one post-baseline clinical outcomes assessment, who received 60 mg/kg of AL001 every four weeks. As of the data cut, six FTD-C9orf72 participants had completed 12 months of treatment and all biomarker and clinical outcomes assessments.

Preliminary results demonstrated that AL001 is generally well tolerated. The treatment with AL001 demonstrated target engagement and resulted in increases in progranulin levels in participants. Clinical outcome assessments found participants treated with AL001 demonstrated a trend toward a delay in disease progression.

In addition, Alector is currently enrolling participants in the US, Europe and Asia for its INFRONT-3 Phase III pivotal clinical study of AL001. Participants will receive either AL001 or placebo intravenously every four weeks for the duration of the 96-week study and will be given the option to continue receiving treatment in an optional open-label extension study after the 96-week treatment period.


18 March: Researchers publish data from Phase III aducanumab trials

On 18 March, data from the pivotal Phase III EMERGE and ENGAGE trials for aducanumab were published in the Journal of Prevention of Alzheimer’s Disease (JPAD). The peer-reviewed manuscript includes results from the primary, secondary and tertiary endpoints in the trials, as well as safety data and biomarker sub-studies.

Aducanumab is a monoclonal antibody treatment that targets amyloid beta proteins in the brain, leading to clearance of these damaging proteins by the immune system. The randomised,
double-blind and placebo-controlled ENGAGE and EMERGE Phase III clinical trials investigated the efficacy and safety of aducanumab in participants with mild cognitive impairment and mild dementia due to Alzheimer’s disease (AD), delivering aducanumab or a placebo to participants via intravenous infusion once every 4 weeks over 76 weeks. These studies involved 348 sites in 20 countries.

Both trials were halted early based on results from a futility analysis of interim data, pooled from the first approximately 50% of enrolled participants. The primary endpoint was met in EMERGE but not ENGAGE (CDR-SB, an integrated scale that assesses both function and cognition). In EMERGE, high-dose aducanumab demonstrated a difference of -0.39 vs placebo in the mean change from baseline in CDR-SB score at week 78, a 22% reduction in decline. Data from EMERGE demonstrated a statistically significant change across all four primary and secondary clinical endpoints. ENGAGE did not meet its primary or secondary endpoints.

A dose-and time-dependent reduction in pathophysiological markers of AD was observed in both trials. These sub studies showed a dose- and time-dependent reduction in amyloid PET SUVR. Reductions in plasma p-tau181 levels were positively correlated with reductions in amyloid PET SUVR at week 78. The most common adverse event was amyloid-related imaging abnormalities-edema.

https://doi.org/10.14283/jpad.2022.30

**20 March: touchNEUROLOGY discusses new therapeutics for neurodegeneration, as well as sargramostim for mild-to-moderate Alzheimer’s disease during AD/PD 2022 conference**

During this year’s Alzheimer’s & Parkinson’s Diseases Conference, AD/PD 2022, touchNEUROLOGY caught up with Dr Tim Bartels (UK Dementia Research Institute, University College London) to discuss some of the highlights in the field of new therapeutics for neurodegeneration, and also the presentation of functioning MRI agents for α-Synuclein. Watch the video, here.

TouchNEUROLOGY also spoke to Prof. Huntington Potter (University of Colorado, Denver, USA) to discuss sargramostim, an innate immune system modulator which has been investigated in a phase 2 study to determine if it can safely halt or reduce cognitive decline and brain pathology in participants with mild-to-moderate Alzheimer’s disease (AD). The phase 2 results (NCT01409915) to investigate whether inflammation and the innate immune system in AD may provide therapeutic benefit, and what will be the next steps in the development of sargramostim in AD. Watch the video, here.

**20 March: Athira Pharma presents an overview from its ACT-AD Phase II Trial in mild to moderate AD**

On 20 March, Athira Pharma, a clinical-stage biopharmaceutical company aiming to restore neuronal health in neurodegenerative diseases presented the study overview and baseline data from its ACT-AD Phase II clinical trial at the International Conference on Alzheimer’s and Parkinson’s Disease and Related Neurological Diseases (AD/PD 2022).

This 26-week study is a randomised, double-blind and placebo-controlled trial evaluating fosgonimeton (ATH-1017) for the treatment of mild-to-moderate Alzheimer’s disease (AD). Fosgonimeton is an investigational drug designed to enhance the activity of hepatocyte growth factor (HGF) and its receptor, MET, to impact neurodegeneration and regenerate brain tissue. 77 participants have been enrolled in the US and Australia. The mean age is 71.4 years, with 50.6% female and 49.4% male. This includes 31 participants with mild AD and 46 with moderate AD. They were randomly assigned to receive a daily subcutaneous injection of either ATH-1017 at low-dose (40 mg/day), ATH-1017 at high-dose (70 mg/day), or a placebo. At a preliminary data cut, 57 participants completed the study and approximately 14% discontinued prior to study completion. Top-line data are expected in the second half of 2022.


**MEMBERS NEWS**

**8 March: All Party Oireachtas Group on Dementia Chair Senator Fiona O’Loughlin hosts Alzheimer Society of Ireland special briefing on brain health and dementia**

The Alzheimer Society of Ireland (ASI) led a special briefing in the AV Room in Leinster House at the Irish Government Buildings in Dublin, on the topic of Brain Health for people living with dementia. The event was hosted by the All Party
Oireachtas Group on Dementia Chair Senator Fiona O’Loughlin, on 8 March 2022, in advance of Brain Awareness Week (14-20 March). The ASI, clinicians, academics, and the Global Brain Health Institute (GBHI) showcased opportunities to increase prevention, and shared significant developments in medical treatments.

The briefing, which was attended by 40 politician representatives, including Members of Parliament (TDs) and Senators, and 14 parliamentary staff, heard that up to 40% of dementias are preventable, highlighting the need to resource early intervention, awareness and new treatments. The briefing highlighted the need for sufficient resources to fund these opportunities as there are 64,000 people living with dementia in Ireland and the number is forecast to more than double in the next 25 years.

The ASI Interim CEO Siobhan O’Connor said: “This briefing to our elected representatives is one of hope. We can all look after our brain health, and we should talk to our doctor as early as possible if any changes in memory become apparent. Many steps can be taken which will make a real difference. If we address early risk factors such as hearing loss, high blood pressure, diabetes, smoking and depression then – according to the Lancet Commission – 40% of dementias are preventable.”

Briefing Speakers:
• Mr Kevin Quaid, living with Lewy Body Dementia, Chair Irish Dementia Working Group, Author
• Professor Iracema Leroi, Professor Geriatric Psychiatry, Faculty member Global Brain Health Institute
• Professor Sean Kennelly, Consultant Physician Geriatric and Stroke Medicine, Faculty Member Global Brain Health Institute
• Professor Mary McCarron, Professor Intellectual Disability and Ageing, Dean Health Faculty TCD
• Ms Samantha Taylor, Head of Risk, Compliance and Dementia Advisory Services, The ASI.

16 March: Larissa Alzheimer’s association organises “I Care for the Caregiver” event

On 16 March 2022, the President of the Larissa Alzheimer’s association (EENAL), Eleni Nifli gave an interview on the municipal radio of Larissa highlighting the important work of family caregivers, the impact this can have on them, and highlighting their needs, in order to try to mobilise the Ministry of Health for their support. Moreover, she encouraged caregivers to take care of themselves.

Afterwards, caregivers were welcomed into the offices of the EENAL for a festive, honorary event that was organised under the banner: “I Care for the Caregiver”. Participants were informed, by healthcare professionals, about their rights. They also heard advice about improving their quality of life, managing stress and adopting humour in communicating with the person they are caring for or supporting.

A discussion with the caregivers followed, which was accompanied by refreshments given out by EENAL volunteers. The caregivers highlighted some of the problems caused by COVID-19, such as gaps in medical coverage, isolation etc., and requested from the President that a guest house be put in place to provide temporary accommodation for people with dementia, allowing carer burden to be somewhat alleviated. Then, they thanked the President, the members of the Board of Directors, the Scientific Officer and the volunteers for their selfless and continuous support.

The event closed with traditional music and a musical kinetic exercise accompanied by the melody, “The Kites” by Mikis Theodorakis.

23 March: Alzheimer Hellas announces launch of Erasmus+ programme “Game4CoSkills”

Alzheimer Europe’s national member association in Greece, Alzheimer Hellas, has announced the launch of a new Erasmus+ programme called “Game4CoSkills”. Here is their report:

Adults with intellectual disabilities often exhibit traits that may affect their personal lives. Characteristics such as difficulties in speech, memory, attention, thinking, and ‘challenging behaviour’. This can result in low self-esteem and reduced social interaction. New technologies, including the use of mobile phones for games, have the potential to enhance cognitive abilities.

Based on the perceived needs of adults with intellectual disabilities, the European Erasmus+ programme “Game4CoSkills” was launched to enhance cognitive abilities, as well as learning strategies through an innovative mobile game. The programme will last 24 months and 6 countries are participating: Austria (Austrian Association of Inclusive Society-AIS), Cyprus (Synthesis Center for Research and Education), France (Interactive 4D), Greece (Alzheimer Hellas), Italy (Euro-Net), and Turkey (Avrasya Yenilikçi Toplum Derneği). A total of 180 people will participate, 120 adults with intellectual disabilities (20 people from each country) and 60 adult carers (10 from each country).

The purpose of this programme is to create a mobile game, through which to promote the development of cognitive abilities such as memory, calculation, perception, speech, dexterity, versatility and attention to detail, as well as learning strategies.
29 March: There are half a million Dementia Friends in the Netherlands

There are now half a million Dementia Friends in the Netherlands, ensuring together that people with dementia are able to continue participating, reports Alzheimer Nederland.

There are currently around 290,000 people with dementia in the Netherlands, and that number will grow to half a million by 2040. In day-to-day life, therefore, citizens will increasingly interact with people living with dementia. Most people with dementia live at home (70%). They do the daily shopping, go to the hairdresser, the dentist, and to sports clubs and gyms. In order to slow down the progression of the disease slightly, to increase well-being and offer relief to carers and supporters, it is essential that we all "do our bit", says Alzheimer Nederland, as it allows people with dementia to continue to participate in society for as long as possible. Alzheimer Nederland and the Ministry of Public Health launched the programme "Samen dementievriendelijk" ("Dementia-friendly Together"), in 2016. In March 2022, a milestone has been reached: half a million people are part of this dementia-friendly programme. These 500,000 Dementia Friends in the Netherlands have registered on the website https://www.samendementievriendelijk.nl/

On this website, it is possible to follow free online courses so that people know how to deal with dementia, which is important, as 1 in 5 people will get dementia, meaning there is a good chance that we all will be affected, either getting dementia ourselves, or as a carer, or simply outside on the street, at work or at the gym. The objective is that all those with dementia, and their carers, feel better supported in their environment and by society.

"And with these 500,000 dementia friends, we’re well on our way." explains Gerjoke Wilmink, Executive Director, Alzheimer Nederland. "In the coming years we will train even more Dutch people and make them aware of the impact of dementia. Everyone deserves to be able to continue participating."

At Griffensteyn tennis club in Zeist, for example, people with dementia are very welcome. There, trained volunteers organise a weekly tennis hour, followed by a cup of tea, for around ten participants with dementia. The aim is for them to remain part of society and to become physically stronger, which will benefit their health and well-being. Jan (79) has Alzheimer’s dementia and has been part of the group since its launch in November 2021. “It doesn’t matter whether you play well or not. The exercise, the contact and being part of a club does me good.”

The aim of the programme is that people with dementia and their carers feel better supported, not only through professional support but also by society. The objective of Samen dementievriendelijk is to make Dutch society dementia friendly by offering year-round campaigns aimed at behavioural change through national TV, social media and an extensive training programme (14 free online courses and trainings, on location). This approach is focused on a learning strategy; learning how to recognise the signs of dementia will help people to act in an appropriate and supportive manner. Step-by-step, participants of the training courses learn skills that are important when coming into contact with people with dementia. After all, people want to help people with dementia when they are better informed about how to do so.

https://www.samendementievriendelijk.nl/

Alzheimer’s Society Annual Conference 17 May 2022
Registration open
Sponsored by Rothesay

DEMENTIA IN SOCIETY

17 March: Take part in Ireland’s first ever National Nursing Home Experience Survey

Ireland’s first ever National Nursing Home Experience Survey is underway, with a selection of nursing homes across the country taking part. The survey is being run by the National Care Experience Programme, a joint initiative from the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health. They ask people about their experiences of care in order to improve the quality of health and social care services in Ireland. Find out more at http://yourexperience.ie

NEW PUBLICATIONS AND RESOURCES

1 March: Chris Roberts and Jayne Goodrick feature in "The Ageing Scientist" podcast on young-onset dementia

What is young-onset dementia? What is it like living with dementia at a younger age and caring for a loved one? In a podcast by "The Ageing Scientist", aired at the start of March 2022, Chris Roberts and his wife Jayne Goodrick spoke to dementia researcher Dr Clarissa Giebel, sharing their personal story about living with dementia and caring, and changing mind-
set about how to live with dementia. Dr Monica Cations also joined the panel and discussed her insights into how the Australian care sector supports people with young-onset dementia. Chris Roberts is the Chairperson of the European Working Group of People with Dementia.

The Ageing Scientist is a podcast series on all things ageing, discussing topics with experts in the field including academics, care providers, carers and people with dementia. It is run by Dr Clarissa Giebel.

8 March: Liverpool Dementia & Ageing Research Forum website launched

The Liverpool Dementia & Ageing Research Forum has launched its new website. The Forum, in existence since 2019, aims to bring together professionals and people with lived experience, to discuss and advance understanding of improving care for dementia and ageing. It hosts a number of events, focusing on different topics in the field of dementia. The new website includes links to past and upcoming events, pulling together the numerous activities happening across the Forum.

https://liverpooldementiaageingresearchforum.co.uk/

10 March: TouchNEUROLOGY introduces its new learning activity focused on recognising and treating Alzheimer's disease

TouchNEUROLOGY has new learning activity in the form of a video interview with two experts, focusing on "Recognizing and treating Alzheimer’s disease: The importance of a multidisciplinary approach for early diagnosis and continuum of care".

The two experts in Alzheimer’s disease describe the impact of early diagnosis on therapy and care, from the physician’s and patient’s points of view:


14 March: Brain Health Scotland launches My Brain Health Plan online quiz app

Brain Health Scotland started this year’s Brain Awareness Week with the launch of its new My Brain Health Plan online quiz app. The quiz asks users a few quick questions about their life and routine and uses these answers to generate personalised tips and advice on areas to take action for maintaining brain health. Users are then encouraged to apply this advice to setting a series of "Brain Health Pledges" - commitments to take positive steps for better brain health. The quiz can be found at:

www.brainhealth.scot/brainhealthplan

EDUCATION

17 March: Alzheimer Society of Ireland currently recruiting for online Family Carer Training course

The Alzheimer Society of Ireland (ASI) is currently recruiting for its award-winning Home Based Care - Home Based Education online course for family carers of people with dementia.

The ASI offers training to family carers looking after a loved one with dementia. Family carers can either be the primary carers for the person with dementia or those indirectly involved in caring. This Family Carer Training programme aims to develop family carers’ knowledge of Alzheimer’s and other dementias, and their caring skills, to enable them to respond more confidently to their family members’ needs. It also provides opportunities for carers to meet other carers and share their experiences.
Delivered by experienced ASI staff members, the course provides new information on dementia and gives participants time and space to reflect on their own caring experiences, whilst listening to and learning from others’ experiences. The course is delivered in a warm, safe environment where confidentiality of all is valued and respected. Find out more and register, via:

https://alzheimer.ie/about-dementia/family-carer-training/

17 March: University College Dublin researchers seek trial participants for their non-verbal communication app

Dr Aviva Cohen and her team at University College Dublin, Ireland, have developed an innovative new app called Empathic, aiming to help people who are no longer able to communicate verbally to independently communicate their emotions. It uses artificial intelligence (AI) to interpret short recordings of non-verbal vocalisations. Dr Cohen and her team are now looking for people who fall into this category, as well as their formal and informal care providers, to trial the app. For further information visit www.seamlesscare.ie or email Aviva@seamlesscare.ie

25 March: Registrations are open for KU Leuven 2022 Summer Course on Ethics in Dementia Care

The Centre for Biomedical Ethics and Law of the KU Leuven is organizing the 8th edition of its Summer Course on Ethics in Dementia Care, taking place in Leuven, Belgium, from 5-8 July 2022. The language of instruction will be English.

The objective of the course is to foster exchanges on foundational, clinical-ethical and organisational-ethical approaches to dementia care practices. During the course, national and international experts will give presentations on various ethical topics in the domain of dementia care. There will be time for intensive discussions. This course will be of interest to participants from diverse professional backgrounds, such as medicine, nursing, psychology, social work, gerontology, health care administration, philosophy and theology, and to PhD students undertaking courses of study in these areas. Detailed information on programme, funding opportunities, registration and payment can be found at:


18 March: WHO’s Brain Health Unit seeks qualified consultants

The Brain Health Unit (BRH) within the World Health Organization’s Department of Mental Health and Substance Use (MSD) is building a roster of qualified consultants to conduct a variety of technical tasks with all levels of experience to actively contribute to specific elements of the Unit’s work.

The BRH aims to promote optimal brain development, cognitive health and wellbeing and prevention and care for neurological disorders across the life course through leadership and policy dialogue, development of technical and normative products and country capacity building in the following areas:

- Child and adolescent brain health and neurodevelopment
- Maternal mental health
- Treatment and care for neurological disorders (e.g. epilepsy, dementia,) and neurodevelopmental disabilities
- Promotion of brain health and prevention of neurological disorders

For a detailed job description and information on how to apply to the roster please see here:

https://careers.who.int/careersection/ex/jobdetail.ftl?job=2201958&tz=GMT%2B01%3A00&tzname=Europe%2FZurich

Applications close on 4 April 2022.
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<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>1 April</td>
<td>AMYPAD symposium “Perspectives on biomarker testing for AD in people without dementia”</td>
<td>Cindy, Jean, Dianne</td>
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<tr>
<td>4 April</td>
<td>Alzheimer Europe Board</td>
<td>AE Board and staff</td>
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<td>4 April</td>
<td>Neuronet meeting on common data models</td>
<td>Ange</td>
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<tr>
<td>4 April</td>
<td>WHO Europe briefing on activities in Ukraine for Non-State Actors</td>
<td>Kate</td>
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<td>6 April</td>
<td>Award ceremony for the winners of the World JAIN challenge</td>
<td>Chris</td>
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<tr>
<td>6 April</td>
<td>EU-FINGERS and LETHE join educational event</td>
<td>Cindy and Ana</td>
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<tr>
<td>6 April</td>
<td>EWGPWD meeting</td>
<td>Ana and Dianne</td>
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<td>6 April</td>
<td>EU Commission - High-Level Group on the future of social protection and of the welfare state in the EU</td>
<td>Owen</td>
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<tr>
<td>7 April</td>
<td>European Parliament communications offer for Civil Society Organisations</td>
<td>Kate and Chris</td>
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<td>7 April</td>
<td>RADAR-AD PAB meeting</td>
<td>Ana and Dianne</td>
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<td>7 April</td>
<td>BBMRI-ERIC stakeholder forum</td>
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<td>8 April</td>
<td>Expert interview on continence care for Essity</td>
<td>Dianne</td>
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<td>12 April</td>
<td>Al-MIND consultation with people with MCI</td>
<td>Ana and Dianne</td>
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<tr>
<td>20 April</td>
<td>Pattern-Cog Executive Management Board</td>
<td>Jean</td>
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<tr>
<td>23 April</td>
<td>European Patients’ Forum Annual General Meeting</td>
<td>Jean</td>
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<td>25 April</td>
<td>EFPIA Alzheimer’s Platform</td>
<td>Jean</td>
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<td>26 April</td>
<td>Alzheimer’s Association Academy on “National Alzheimer’s associations giving a voice to people with dementia and carers”</td>
<td>AE staff</td>
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<tr>
<td>26 April</td>
<td>Al-MIND consultation with person with MCI</td>
<td>Dianne and Ana</td>
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<td>26 April</td>
<td>MinD network meeting</td>
<td>Dianne</td>
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<tr>
<td>28 April</td>
<td>EPND Management Board</td>
<td>Ange</td>
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<td>28 April</td>
<td>JPND Midterm Symposium for Supported Projects</td>
<td>Ana</td>
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<tr>
<td>28-29 April</td>
<td>European Alzheimer’s Disease Consortium (Athens, Greece)</td>
<td>Jean</td>
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## CONFERENCES 2022

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<th>Date</th>
<th>Meeting</th>
<th>Format/ Place</th>
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<tr>
<td>28 April</td>
<td>Diagnostik und Früherkennung von Demenzerkrankungen, <a href="https://demenz-konferenz.ch/">https://demenz-konferenz.ch/</a></td>
<td>Bern (Switzerland) and online</td>
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<tr>
<td>1-3 June</td>
<td>XII Biennial Conference – Barcelona Pittsburgh, <a href="https://www.fundacioace.com/bcnpit/">https://www.fundacioace.com/bcnpit/</a></td>
<td>Barcelona &amp; online</td>
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<tr>
<td>7-9 June</td>
<td>7th World Conference on Adult Capacity, <a href="https://wcac2022.org/">https://wcac2022.org/</a></td>
<td>Edinburgh, Scotland</td>
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<td>8-10 June</td>
<td>30th European Social Services Conference, <a href="https://essc-eu.org/">https://essc-eu.org/</a></td>
<td>Hamburg, Germany</td>
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<td>9-11 June</td>
<td>35th Global Conference of Alzheimer’s Disease International, <a href="https://adiconference.org/">https://adiconference.org/</a></td>
<td>London &amp; online</td>
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<td>25-28 June</td>
<td>8th EAN Congress, <a href="https://www.ean.org/congress2022">https://www.ean.org/congress2022</a></td>
<td>Vienna, Austria</td>
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<tr>
<td>20-22 September</td>
<td>Dementia Lab Conference - The residue of design, <a href="https://www.dementialabconference.com/">https://www.dementialabconference.com/</a></td>
<td>Leuven, Belgium</td>
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<td>17-19 October</td>
<td>32nd Alzheimer Europe Conference, <a href="https://www.alzheimer-europe.org/Conferences">https://www.alzheimer-europe.org/Conferences</a></td>
<td>Bucharest, Romania</td>
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<td>21-24 October</td>
<td>2022 IPA International Congress, <a href="https://www.ipa-online.org/events/events-calendar/2022-lisbon">https://www.ipa-online.org/events/events-calendar/2022-lisbon</a></td>
<td>Lisbon, Portugal</td>
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<td>29 November-2 December</td>
<td>Clinical Trials on Alzheimer’s Disease (CTAD 2022), <a href="www.ctad-alzheimer.com">www.ctad-alzheimer.com</a></td>
<td>San Francisco, USA</td>
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32nd Alzheimer Europe Conference
Building bridges
Bucharest, Romania
17 to 19 October 2022

www.alzheimer-europe.org/conferences  #32AEC