This month, we have three new colleagues! Daphné and Soraya are both Project Officers and Cristina is a full-time Administrative Assistant. A very warm welcome to all three of them. We have got off to a good and busy start already, with the team attending our first series of face-to-face meetings in Brussels since February 2020!

The Board met on 13 June, and we held a roundtable meeting with sponsors on 14 June, as well as a lunch debate hosted by MEP Deirdre Clune and at which MEP Tilly Metz was a speaker. The topic was EU and WHO policies on neurological conditions. We appreciate the great collaboration we have with MEPs in the European Alzheimer’s Alliance and look forward to our next lunch debate, in September.

At this month’s lunch debate we launched our latest Dementia in Europe magazine as well as a special publication celebrating ten years of the EWGPWD. Both are available via our website. Members of the EWGPWD also met, to give their input on a set of guidelines on perceptions and the portrayal of dementia and to do Public Involvement work for the RADAR-AD project. Discussions also covered the group’s plans for its special symposium at this year’s Alzheimer Europe Conference. Members of the group were also able to finally say goodbye in person, to two people who left the group during COVID restrictions, Carol and Nina. Geert, who was a member of the current group, also stepped down. I want to thank all three of them for their hard work and dedication, and wish them well.

On the EU policy front, Alzheimer Europe has joined more than 300 civil society organisations to send a joint letter, calling on the European Commission to include the development of a European Civil Society Strategy in its 2023 work programme.

I am pleased to announce the launch of the “Alzheimer Europe Anti Stigma Award”, which will recognise an outstanding European initiative. Find out more in the Alzheimer Europe news section or via our website and apply before 1 September.

This month also saw the launch of a new project, PatternCog, in which Alzheimer Europe is co-leading a work package on public involvement and communication. Find out more in our EU Projects news section.

Last, but not least, thank you to everyone who submitted abstracts for our Annual Conference. The final selection has been made and the agenda is available on our website. Early Bird registrations are available until 15 July, so hurry and book your spot!

Our next newsletter will cover July and August and will be published in early September. In the meantime, I wish you an excellent summer!

Jean Georges
Executive Director
1 June: Alzheimer Europe welcomes three new colleagues

Alzheimer Europe is pleased to welcome three new colleagues, who joined the team on 1 June 2022.

Daphné Lamirel (pictured, left) is working as a Project Officer in the Public Involvement team. She holds an MSc in Clinical Mental Health Sciences from University College London and previously worked at the Global Alliance of Mental Illness Advocacy Network (GAMIAN-Europe) as the Projects and Communications Officer. Daphné’s role at Alzheimer Europe is primarily concerned with contributing to EU-research projects (EPND and eBrains) and supporting the development of the new European Carers Working Group (ECWP). She can be reached at Daphne.lamirel@alzheimer-europe.org

Soraya Moradi-Bachiller (pictured, centre) is working as a Project Officer. After finishing her masters in neuroscience at the INCYL (Spain) and in the biology of aging at the Paris-Saclay University (France), she started her Ph.D. at the Mario Negri Institute for Pharmacological Research (Italy). On 18 March 2021, Soraya was awarded the title of Doctor of Philosophy for her Ph.D. thesis entitled “Preclinical and clinical early Alzheimer's disease biomarker discovery using proteins and microRNAs carried by small extracellular vesicles”. She can be reached at Soraya.moradi-bachiller@alzheimer-europe.org

Cristina Pencea (pictured, right) is working as a full-time Administrative Assistant for the organisation. She has a Master in Business Administration in Tourism and Hospitality Industry from the Academy of Economic Studies in Bucharest, Romania and, prior to moving to Luxembourg, worked as Office Manager for an International High School and Sales Manager for Romanian hotels and tourism agencies. She speaks Romanian and English, as well as some French and Spanish. She can be reached at Cristina.pencea@alzheimer-europe.org

You can see a list of all our staff at: https://www.alzheimer-europe.org/about-us/who-we-are/staff

14 June: Alzheimer Europe hosts a face-to-face Company Round Table meeting in Brussels for the first time in two and a half years

On 14 June 2022, Alzheimer Europe hosted a Company Round Table meeting in Brussels. The meeting was a hybrid event, with many participants attending in person and some joining remotely. It was attended by a total of 43 delegates, including eight company representatives (from Alnylam, Biogen, Grifols, Lilly, Nutricia, Roche and TauRx), 11 members of the Alzheimer Europe staff, Alzheimer Europe Chairperson Iva Holmerová, who hosted the meeting, Chris Roberts, Chairperson of the European Working Group of People with Dementia and his wife and supporter Jayne Goodrick, members of the Alzheimer Europe Board and representatives from 19 member organisations of Alzheimer Europe.

The speakers at the event were: Cindy Birck, Project Officer, who discussed recent clinical trial developments and gave an update on our Clinical Trials Watch; Owen Miller, Policy Officer, who shared some recent Policy developments at World Health Organization and EU level; Dianne Gove, Director for Projects, who presented on Public Involvement in dementia research; and Jean Georges, Executive Director, who informed participants about Alzheimer Europe’s activities in 2022 and 2023, including 2023 Sponsorship Opportunities.

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 27 September 2022.

Sponsors of the month

Alzheimer Europe would like to express its gratitude to two new sponsors for its 2022 activities

Read more about sponsorship opportunities here: https://www.alzheimer-europe.org/about-us/governance/finances/2022-sponsorship-opportunities
Alzheimer Europe held a Lunch Debate on 14 June 2022, the first in-person event held since February 2020, focused on “Neurological conditions and mental health in EU and World Health Organization (WHO) Europe programmes”, attended by around 70 people, including national member organisations, civil society representatives, industry partners and policy makers.

Deidre Clune, MEP (Ireland), Vice-chairperson of the European Alzheimer’s Alliance (EAA) opened the session, welcoming people to the meeting, highlighting its timeliness in light of key programmes at an EU level, across the fields of health and research, as well as activities of the WHO and WHO Europe. Ms Clune noted that these developments have the potential to fundamentally change our understanding of, and approach to, neurological conditions.

EAA member Tilly Metz, MEP (Luxembourg), spoke about the work of the European Parliament’s Health Committee, including its call for a European Action Plan on Mental Health. In addition, she spoke of the importance of Brain Health across the life course, especially in the domain of prevention.

Ledia Lazeri, Regional Advisor, WHO Europe, provided an overview of the work underway on the European Framework for Action on Mental Health (EFAMH) 2021-2025, across its three areas: universal health coverage, protection against health emergencies, and mental health across the life course. She also introduced the pan-European Mental Health Coalition, which operationalises the EFAMH through six work packages, and involves a broad range of stakeholders, including NGOs, Member States, people with lived experience, etc. Specifically, work package three “Mental Health and Wellbeing of Older Adults”, will look at implementation of the WHO Global Action Plan on Dementia.

Marianne Takki, Team Leader, European Commission, introduced the EU’s forthcoming “Healthier Together” initiative, which will focus on five Non-Communicable Diseases (cardiovascular, diabetes, respiratory diseases, mental health and neurological conditions, and health determinants). The scope of action will cover areas including knowledge and data, promotion and prevention, screening and early detection, diagnosis and treatment, and quality of life.

Impressions from the lunch debate

Our lunch debate host Deirdre Clune, MEP
Pat McLoughlin, Deirdre Clune, Andy Heffernan and Cormac Cahill
Speaker Tilly Metz, MEP
Alzheimer Europe Chairperson Iva Holmerová thanking speakers and host
Speaker Joke Jaarsma, President, European Federation of Neurological Associations
Geert Van Laer, member of the EWGPWD
Speaker Catherine Berens, DG Research and Innovation, European Commission
Chairperson of EWGPWD Chris Roberts and his wife Jayne Goodrick
Members of the EWGPWD Stefan Eriksson (left) and Angela Pototschnigg (right), and supporter Johanna Pueringer (centre)
She noted that the Commission had run an open call to collect good practice examples and would be working with members states to implement these. Example of priority areas included ensuring high quality care, awareness raising and promoting mental wellbeing. The initiative will launch on 22 June 2022.

Catherine Berens, Deputy Head of Unit, Europe Commission, focused on the place of brain research at a European level and the actions of the European Commission in supporting this work. She explained that within the Horizon Europe programme, Pillar One would address the need for more basic research and improved research infrastructures, whilst Pillar 2 has a dedicated health cluster, which will support improved collaboration. Pillar 3 will boost innovation, improving technologies and systems, such as data infrastructures. Finally, a potential future Brain Health partnership was explored, which aims to bring together brain research initiatives under a single umbrella – this is expected to launch in 2025.

Joke Jaarsma, President of the European Federation of Neurology (EFNA), introduced the patient perspective on brain health, highlighting the importance of involving patients in brain health policy. She highlighted challenges and existing barriers, noting that patient participation or engagement often limits the ability of patients to set the agenda for brain health. As such, a Call to Action drafted by Alzheimer Europe, EFNA and GAMIAN-Europe has been issued, demanding that national and EU governing bodies develop and implement policies to ensure early and meaningful engagement to support involvement of patients across all sectors. Specifically, this should include well-defined, transparent processes that are systematically embedded and ingrained in workstreams.

Alzheimer Europe Chairperson Iva Holmerová closed the session by thanking attendees and speakers for their contributions to the Lunch Debate.

The next European Parliament Workshop will take place on 27 September 2022. The videos of the presentations from the Lunch Debate can be found at:

https://www.youtube.com/playlist?list=PLO-PgQHl1WQW8Y1Siogzhto_AJYTXGWWM9
the new Dementia Plan 2021-2025 which builds on the excellent work undertaken in Flanders, Belgium, in recent years. Turning to policy and advocacy matters at a national level, Lorène Gilly of France Alzheimer outlines the “Alzheimer’s has disappeared” campaign taking place during the presidential and legislative elections. We continue at the national level, as Clodagh Whelan of The Alzheimer Society of Ireland (ASI) talks about the briefing session for politicians led by ASI during Brain Health Week in March. Staying with the theme of brain health, the following article examines a patient organisation-led Call to Action, in which Alzheimer Europe has been heavily involved, demanding greater patient involvement in brain health policy at an EU level.

Moving to international policy, Marine Uldry of the European Disability Forum (EDF) outlines the current review of the EU compliance with the United Nations Convention on the Rights of Person with Disabilities and explains how EDF contributed to the process. Finally, Laura Garcia Diaz of the World Health Organization shares how they have been involving people with dementia in the review of resources for the Global Dementia Observatory Knowledge Exchange Platform.

In our final section, Dementia in Society, we open with an article looking at what the governments and Alzheimer associations in my country (Czech Republic) and in Poland are doing to support people affected and displaced by the ongoing invasion of Ukraine, particularly those affected by dementia. In the next article, Pat McLoughlin, former CEO of The Alzheimer Society of Ireland reflects on his time at the organisation, from which he recently retired – we wish him a happy and well-deserved retirement! Staying in Ireland, we look at the appearance of Helen Rochford-Brennan on The Tommy Tiernan Show. Helen, a member of the EWGPWD, highlighted issues around diagnosis, advocacy, funding and homecare. In our final article, we hear from Professor Jean-Charles Lambert and Dr Céline Bellenguez about their fascinating research identifying novel risk loci for Alzheimer’s disease, and about their development of a new genetic risk score for Alzheimer’s disease.

Our magazine also has a special supplement, in which we celebrate 10 years of the inspirational work of the EWGPWD. You can find out more about this in a separate news item about the launch of this special publication.

Alzheimer Europe is grateful for the support of its corporate sponsors, without whom the Dementia in Europe magazine would not be possible.


It is also possible to order paper copies via: https://www.alzheimer-europe.org/product/dementia-europe-magazine-issue-39

**14 June: Special publication celebrates 10 years of the European Working Group of People with Dementia**

Alzheimer Europe is proud to launch a special publication, to celebrate 10 years of the inspirational work of the European Working Group of People with Dementia (EWGPWD). Congratulations to the group on its 10th anniversary! The publication was launched by MEP Deirdre Clune at our European Parliament lunch debate in Brussels on 14 June 2022, together with the latest Dementia in Europe magazine (issue 39).

The EWGPWD was launched by Alzheimer Europe and its member associations in 2012 and is composed entirely of people with dementia, who are nominated by their national Alzheimer associations. Each term of office lasts two years, with the current term ending in October 2022. The group operates independently and members elect their own Chairperson and Vice-Chairs. The Chairperson is an ex-officio member on the Board of Alzheimer Europe, with full voting rights. Group members work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people living with dementia. They also consult on EU-funded research projects and participate actively in Alzheimer Europe’s annual conferences and contribute towards Alzheimer Europe’s work on ethical issues. They attend international dementia-related events, including at the European Parliament, as representatives of the EWGPWD.

Until the end of 2021, the important work of the group was funded by an operating grant under the European Union’s Health Programme. It is now funded by a new operating grant from the European Union, under the Citizens, Equality, Rights and Values (CERV) programme.

The Alzheimer Europe team and Board look forward to continuing their collaboration with the EWGPWD and would like to express their gratitude to the Executive and members of the group, past and present, for their hard work and support.

A big thank you to the Alzheimer Europe Foundation, which sponsored this publication.

You can download the celebratory publication, here: https://www.alzheimer-europe.org/sites/default/files/2022-06/celebrating_10_years_of_the_ewgpwd_june_2022.pdf

It is also possible to order paper copies, via: https://www.alzheimer-europe.org/product/celebrating-10-years-european-working-group-people-dementia
14-15 June: Members of the European Working Group of People with Dementia meet in Brussels

On 14 and 15 June, the European Working Group of People with Dementia (EWGPWD) and their supporters met in Brussels. This was the second face-to-face meeting since the beginning of the pandemic.

The meeting started with a farewell to two members of the previous working group (Carol Hargreaves and Nina Baláčková) and a member of the current working group (Geert Van Laer). Chris Roberts (Chair of the EWGPWD) and Iva Holmerová (Chair of Alzheimer Europe) thanked them for their very valuable contributions to the EWGPWD and Alzheimer Europe’s work. They were presented with their awards by Iva Holmerová.

The first session focused on gathering input on a set of guidelines on perceptions and the portrayal of dementia and people with dementia that were developed in 2013 by Alzheimer Europe’s ethics working group. The discussions were facilitated by Dianne Gove (Director for Projects), Ana Diaz (Project Officer), Soraya Moradi-Bachiller (Project Officer) and Daphné Lamirel (Project Officer). All members and supporters provided a range of valuable ideas, perspectives and comments to help revise the guidelines.

The second day of the EWGPWD meeting revolved around the Remote Assessment of Disease and Relapse – Alzheimer’s Disease (RADAR-AD) project. Members of the EWGPWD are part of the RADAR-AD Patient Advisory Board (PAB). Larry Gardiner and his wife, Ildikó Pósta, who are also members of the PAB joined the discussions. Four researchers from RADAR-AD delivered a series of presentations on different aspects of the research project, including a recap of the project, work on functional domains, plans for the analysis of the data, and ethical and regulatory issues. Each presentation was followed by lively interaction with the members of the RADAR-AD PAB, who provided feedback and raised questions about the various points that had been presented. Finally, Chris Roberts (Chair of the EWGPWD) moderated a discussion about the EWGPWD special symposium, which will be held in Bucharest during the annual conference. There was plenty of enthusiasm from the members of the EWGPWD and those present discussed what they would like to present.

16 June: Alzheimer Europe adds two new trials to its Clinical Trials Watch

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

- **ROMEMA Phase II trial** validating whether chronic intake of roflumilast can improve cognition in people with (amnestic) mild cognitive impairment and in people with mild dementia (Maastricht University Medical Center)
- **SKYLINE Phase III trial** evaluating gantenerumab in cognitively unimpaired people with the earliest biological signs of AD (Roche).

Further information about the CTW is available on: https://www.alzheimer-europe.org/research/clinical-trials

17 June: 32nd Alzheimer Europe Conference agenda available online. Register now to get Early Bird registration rates!

Alzheimer Europe would like to thank everyone who submitted abstracts for its 32nd Annual Conference (#32AEC). The final selection has been made and notifications have been sent to all applicants. Our committee reviewed all 268 submitted abstracts and selected:

- 45 Quick Oral Presentations
- 56 in-person poster presentations and 14 virtual poster presentations
- 110 in-person oral presentations and 58 virtual oral presentations.

Alzheimer Europe and the EWGPWD would like to thank Nina, Carol and Geert for their great work, enthusiasm and dedication. They will be sadly missed but always remembered. We wish them all the best and hope to keep in touch!
We are really excited about our first hybrid conference which is being held in person in Bucharest, with some carefully selected sessions broadcast for our online audience. View the agenda, here: https://www.alzheimer-europe.org/conferences/2022-bucharest/detailed-programme

Early Bird registration fees are available until 15 July, so register now, to avoid missing out! https://www.alzheimer-europe.org/conferences/2022-bucharest/online-conference-registration

Keep an eye on https://www.alzheimer-europe.org/Conferences and on our social media accounts (Twitter, Facebook, LinkedIn) for more information about registrations, the virtual conference platform, and all other aspects of the conference.

#32AEC is organised under the banner “Building Bridges” and will take place from 17 to 19 October 2022.

22 June: Alzheimer Europe invites applications for its new Anti-Stigma Award

On 22 June 2022, Alzheimer Europe announced a new award, recognising an outstanding initiative aimed at combatting stigma and promoting a positive image of dementia and people living with dementia. The Alzheimer Europe Anti-Stigma Award will be presented at the closing of the upcoming Alzheimer Europe Conference in Bucharest.

The award is open to individuals and organisations established in a member country of Alzheimer Europe and which has been developed and/or implemented in the past three years (2019-2022), in Europe. It can be for projects, campaigns, films, videos, publications or books which aim to address the stigma attached to dementia.

Interested organisations and individuals should send information on their initiative via the special application form provided, by the deadline of 1 September 2022. Applicants may be short listed and may be asked to present their initiative to the members of the Award Committee at a virtual meeting on 15 September 2022.

The winner will be announced on the final day of the Alzheimer Europe Conference, 19 October 2022. The award will consist of a cash prize of EUR 5,000 and a trophy. The travel and accommodation costs for the conference will also be covered by Alzheimer Europe.

More information can be found at: https://www.alzheimer-europe.org/our-work/anti-stigma-award

The application form can be downloaded via: https://www.alzheimer-europe.org/sites/default/files/2022-06/ae_anti-stigma_award_-_application_form.pdf

Alzheimer Europe gratefully acknowledges the support of the sponsors of the Alzheimer Europe anti-stigma award: Alzheimer Europe Foundation, Biogen, Lilly and Roche.

Alzheimer Europe networking

On 1 June, Jean attended the policy squad of the Finding Alzheimer’s Solution Together (FAST) Council.

On 1 June, Owen attended an online meeting of the EU4Health Civil Society Alliance.

On 1 and 2 June, Ange participated in the quarterly EMA Patient’s and Consumer’s Working Party meeting.

On 3 June, Owen attended an online meeting hosted by DG SANTE on the Healthier Together NCD initiative.

On 7 June (London, UK), Cindy attended the AMYPAD sustainability workshop.

On 8 June, Cindy, Ana, Dianne and Soraya attended the online Pattern-Cog kick-off meeting.

On 8 June (London, UK), Jean attended the Council Meeting of Alzheimer’s Disease International.

On 9 June, Owen attended an online meeting of European Disability Forum’s European Non-Governmental Organisations group.

On 9 June (London, UK), Jean met with representatives of the Women’s Brain Project.

On 9 and 10 June (London, UK), Jean attended the Annual Conference of Alzheimer’s Disease International and presented on Alzheimer Europe’s “Public involvement activities in dementia research”.

On 9 June, Chris gave a presentation about the Neuronet project at the IDEA-FAST project’s monthly forum.

On 9 and 10 June (London, UK), Jean met with representatives of Lilly, Prothena and TauRx.

On 10 June, Ange joined a webinar on the rules and procedures of the Innovative Health Initiative (IHI).

On 13 June (Brussels, Belgium), the Alzheimer Europe Board met.

On 14 June (Brussels, Belgium), Alzheimer Europe organised a company round table meeting.

On 14 June (Brussels, Belgium), Alzheimer Europe organised a European Parliament lunch debate on “Neurological conditions and mental health in EU and WHO Europe programmes.”
On 14 June (Brussels, Belgium), Ange participated in an IHI networking and brokerage event.

On 14 and 15 June (Brussels, Belgium), Dianne, Ana, Daphné and Soraya participated in the meeting of the European Working Group of People with Dementia (EWGPWD).

On 15 June, Cindy attended a meeting of the European Group of Governmental Experts on Dementia.

On 17 June, Alzheimer Europe convened a meeting of the European Group of Governmental Experts on Dementia.

On 17 June, Owen attended an online launch of the WHO’s World Mental Health Report.

On 22 June, Owen attended an online launch of the DG SANTE’s Healthier Together NCD initiative.

On 23 June, Ange joined a webinar on the IHI neurodegenerative diseases call topic.

From 23 to 25 June (Bordeaux, France), Gwladys attended the ICCA Destination Marketing European Business Workshop.

On 24 June (Brussels, Belgium), Ange moderated a DataSavesLives session at the European Patients’ Forum Congress.

On 25 June (Vienna, Austria), Jean attended the Dementia and Cognitive Disorders Panel of the European Academy of Neurology.

On 25-26 June (Athens, Greece), Dianne attended the 25th EDF General Assembly.

From 26 to 28 June (Vienna, Austria), Jean attended the Congress of the European Academy of Neurology.

On 27 June, Dianne and Ana attended the Interdem taskforce meeting on the use of technology by people with dementia during the pandemic.

On 27 June, Ange participated in a meeting of the European Medicines Agency Advisory Group on Raw Data.

On 28 June, Dianne attended the MinD project network meeting.

On 28 June, Dianne attended a meeting of the Dementia Toolkit Initiative.

On 28 June, Owen attended an online meeting of the MEP Interest Group on Accessible Healthcare, focused on the forthcoming Pharmaceutical Strategy.

**EU PROJECTS**

**30 May: VirtualBrainCloud project convenes a virtual General Assembly meeting**

On 30 May, the H2020-funded VirtualBrainCloud project held its General Assembly (GA) meeting online, summarising recent project developments and discussing upcoming plans. Chaired by Prof. Petra Ritter of Charité University Hospital Berlin, the meeting was attended by over 20 project participants, including representatives from the 17 institutions that make up the VirtualBrainCloud consortium. Angela Bradshaw (Project Officer) represented Alzheimer Europe at the meeting.

The main goal of VirtualBrainCloud is to facilitate the personalised prevention and treatment of dementia, by creating a decision support system for clinicians. Based around a cloud platform for personalised brain simulations, this system will integrate data from multiple sources (e.g. brain scans, genetic screens and neuropsychological tests) in a secure online environment.

Discussions at the GA meeting centred around the recent project review carried out by the European Commission and expert reviewers. Reviewers highlighted the many achievements of the project, as well as its strong publication record. Work in the final year of VirtualBrainCloud will be focused on identifying pathways for non-commercial exploitation, and involving healthcare professionals and patients in the further development of the VirtualBrainCloud platform and tools.


**8 June: The ERA-PerMed-funded Pattern-Cog project hosts its kick-off meeting**

On 8 June, the Pattern-Cog project hosted its kick-off meeting online. Funded by ERA PerMed, Pattern-Cog stands for “Personalised aging pattern for early risk detection and prevention of cognitive impairment and dementia in cognitively healthy individuals”. The 3-year project aims to improve dementia prevention strategies by developing and validating a machine learning-based personalized medicine framework for detecting the earliest signs of impending cognitive decline, enabling early and personalised multi-domain interventions. Findings from multi-domain lifestyle trials have emphasized that intervention effectiveness may be dependent on a methodology that does not yet exist, i.e., the accurate identification of at-risk individuals who are most likely to benefit. Pattern-Cog will address this methodological gap by:

- developing methods for predicting future cognitive decline based on clinical data and distinguishing between healthy individuals at higher risk for mild cognitive impairment and dementia and those who remain healthy and
- testing the methodology in ongoing dementia prevention trials. Instead of a standard machine learning approach, we propose an innovative concept of personalised aging pattern rooted in data from healthy individuals.
Pattern-Cog brings together six partners and is led by Jussi Tohka (University of Eastern Finland). Alzheimer Europe is co-leading a workpackage on public involvement and communication. Joining the kick-off meeting were representatives from the six partner organisations. Jussi Tohka opened the meeting by outlining the aim and structure of the project. Next, the workpackage (WP) leaders gave brief presentations identifying key objectives, tasks and interdependencies with other WPs. After a short break, the consortium members discussed practicalities and project’s management. Drawing the meeting to a close, Jussi Tohka thanked all partners and wishing them lots of success over the next three years of Pattern-Cog.

9 June: Digital twins for disease modelling: eBRAIN-Health project awarded funding by Horizon Europe

On 9 June, the Berlin Institute of Health at Charité University Hospital (BIH; Germany) announced that the eBRAIN-Health project has been awarded funding through the Horizon Europe research and innovation framework programme. eBRAIN-Health will be coordinated by Prof. Petra Ritter, BIH Johann Quandt Professor of Brain Simulation and Head of the Brain Simulation research group at BIH, and Head of Charité’s Department of Neurology and Experimental Neurology.

eBRAIN-Health aims to develop a decentralised, privacy-compliant research platform that simulates complex neurobiological phenomena of the brain, including the processes that drive the development of diseases such as Alzheimer’s disease. The project involves 20 partners, including Alzheimer Europe, and EBRAINS AISBL, the coordinating body of the EU flagship Human Brain Project. The project is due to be launched in July and will run for four years, with a total budget of almost 13 million EUR.

A variety of information will be brought together for the research platform. This information includes brain imaging studies, behavioural studies and lifestyle surveys, as well as clinical data from thousands of patients and healthy controls. The data is combined with biological information from knowledge databases and made available for research purposes. The resulting "digital twins" of the brain will allow a large number of researchers to conduct innovative research within a powerful digital platform. In addition, the complex, individualised brain simulations have the potential to improve our understanding of brain function and disease; improve diagnosis and risk prediction, and optimise potential therapies. Project coordinator Professor Petra Ritter welcomed the funding by the Infrastructure Program of the European Commission: "We are pleased that our consortium has been trusted by the European Commission to develop a European infrastructure for health data [...], the approval of this new major project recognises our contribution in the EU Flagship Human Brain Project for the development of cloud services for sensitive health data. These developments will contribute to the establishment of the European Health Data Space - an important pillar of future health research in Europe."

10 June: RADAR-AD project granted one-year extension due to delays caused by COVID-19

The Remote Assessment of Disease and Relapse – Alzheimer’s Disease (RADAR-AD) project has announced that it was granted a one-year extension, to make up for delay caused by the COVID-19 pandemic.

RADAR-AD aims to find new digital biomarkers for cognition and function in people living with Alzheimer’s disease (AD). Due to the restrictions surrounding the COVID-19 pandemic, enrolment of research participants in the RADAR-AD clinical studies was severely hampered. The need for a project extension was therefore clear to all consortium members, and after making some adjustments in the project timeline as well as in the budgets, a new RADAR-AD end date was agreed upon: the new project end date is 30 June 2023.

This extension will, among other things, allow for more time to achieve RADAR-AD’s goals. These include the enrolment of the envisioned 220 participants in the main RADAR-AD study, the analysis of the collected data and performance of modelling work, the engagement with the European Medicines Agency, and development of a sustainability plan for the envisioned results of the project.

https://www.radar-ad.org/newsroom/one-year-extension-radar-ad

17 June: The baseline paper of the AMYPAD Diagnostic Study has been published

The Amyloid Imaging to Prevent Alzheimer’s Disease (AMYPAD) consortium recently published a paper which presents the participants’ baseline features of the AMYPAD Diagnostic and Patient Management Study (DPMS). This study aims to investigate the clinical utility and cost-effectiveness of amyloid-PET in Europe. A total of 840 participants with subjective cognitive decline plus (SCD+), mild cognitive impairment, or dementia were recruited in eight European memory clinics.

The aim of this article is to discuss the implemented enrolment strategies and describe the baseline features of the AMYPAD DPMS participants in order to assess whether the sample is representative of a wider memory clinic population and to ensure that the future study results will be reliable and generalisable.
The paper entitled “Description of a European memory clinic cohort undergoing amyloid-PET: The AMYPAD Diagnostic and Patient Management Study” has been published in the journal Alzheimer’s & Dementia, the journal of the Alzheimer’s Association and can be read here:

https://doi.org/10.1002/alz.12696

20 June: RADAR-AD study finds subjective cognitive decline may indicate transitional preclinical stage of AD with network changes and brain connectome interruptions

Novel research by the Remote Assessment of Disease and Relapse – Alzheimer’s Disease (RADAR-AD) researchers focusing on brain connectivity abnormalities and network metrics provides pieces of evidence that subjective cognitive decline (SCD) may indicate a transitional preclinical stage of Alzheimer’s disease (AD) with network changes and brain connectome interruptions. It is the first ever reported study which investigates brain connectivity by using High Density Electroencephalography to explore network changes in SCD with regards to people in the healthy control group, people with mild cognitive impairment, and people with AD, while performing a short-term memory task and a visual attention task.

The full article was published in the Journal of Alzheimer’s Disease, here: https://content.iospress.com/articles/journal-of-alzheimers-disease/jad215421

24 June: IDoService project designs “I Can Do Pathway” booklet to support wellbeing through activities

The IDoService project now enters its last four months, which will be devoted to testing and improving the service prototype created. Based on stakeholders’ inputs, the research team developed the “I Can Do Pathway” framework, comprising a set of coaching sessions to deliver the service. The aim is to help support people living with mild dementia to better identify opportunities for participation in meaningful activities. The objective is to explore people’s strengths and preferences to offer concrete guidance about how to access these activities. A special focus is put on volunteering as it can offer an especially rewarding experience and satisfaction to help others.

The service prototype comprises three coaching sessions delivered by a dementia advisor or someone with a similar position who has been trained to deliver the “I Can Do Pathway”. They take the role of “wellbeing mentor” and support people to explore 1) their strengths and interests, 2) what they want to do and what’s on offer around them, and 3) what to do and what support they need. A visual and interactive booklet has been developed to guide people with dementia as well as mentors through this pathway.

The project is now in the process of testing the service prototype with people living with mild dementia with support from a local charity, Age UK Salford. The testing will be essential for trying out and refining the prototype so that it works for people with dementia as well as for the charities’ needs, providing a standardised tool to use and deliver the service in their daily practices.

For more information see www.idoservice.org and for any questions or suggestions contact Dr Isabelle Tournier by email idoservice@mmu.ac.uk or Twitter @idoservice4dem1

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, Innovative Medicines Initiative 2, and the Innovative Health Initiative Joint Undertakings. The Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA. The projects in this newsletter are:

AMYPAD – grant agreement 115952

eBRAIN-Health

PatternCog

RADAR-AD – grant agreement 806999

VirtualBrainCloud – grant agreement 826421
Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 91, 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 Stanichev (S&D).

**Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR).

**Cyprus:** Costas Mavrides (S&D).

**Czech Republic:** Tomáš Zdechovský (EPP).

**Denmark:** Margrethe Auken (Greens/EFA); Christel Schaldemose (S&D).

**Estonia:** Urmas Paet (Renew Europe).

**Finland:** Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP).

**France:** François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP).

**Germany:** Alexandra Geese (Greens/EFA); Erik Markwardt (Greens/EFA); Angelika Niederer (EPP); Terry Rentke (Greens/EFA).

**Greece:** Manolis Kefalogiannis (EPP); Stelios Koulloglou (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyra (EPP); Elissavet Vozemberg-Vronidi (EPP).

**Hungary:** Tamás Deutsch (EPP); Ádám Kós (EPP).

**Ireland:** Barry Andrews (ALDE); Deirdre Clune (NI); Ciarán Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke ’Ming’ Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Grace O’Sullivan (Greens/EFA).

**Italy:** Isabella Adinolfi (NI); Brando Benifei (S&D); Pierfrancesco Majorino (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D).

**Lithuania:** Vilija Blinkevičiute (S&D).

**Luxembourg:** Marc Angel (S&D); Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Isabel Wiseler-Lima (EPP).

**Malta:** Roberta Metsola (EPP); Alfred Sant (S&D).

**Netherlands:** Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP).

**Poland:** Elżbieta Łukacijewska (EPP); Katarzyna Skwarczynska (EPP); Anna Zalewska (EPP). Alonso Becerra (SP); António Jorge (EPP); Carlos Pinto de Miranda (EPP); Carolina Miranda (S&D); Mohammad Ammar (ECC); Miriam Staudte (SP).

**Romania:** Cristian Silviu Busoi (EPP); Marian-Jean Marinescu (EPP).

**Slovakia:** Ivan Stefanec (EPP).

**Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (S&D).

**Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtasun (Greens/EFA).

**Sweden:** Jytte Gulden (S&D); Peter Lundgren (ECR).

In the opinion, the EESC outlines that it considers engaging in dialogue with civil society and social partners as constituting an effective way for policy-makers to understand the varying needs of people belonging to different social groups.

Furthermore, the opinion states that there should be no repression of social dialogue and civil society dialogue in the EU, whilst consultation processes should be easy to find and to access. The EESC points at the potential for civil society to assist policy-makers in essential tasks such as monitoring, but that this should be accompanied with funding and technical support to enable CSOs to build capacity. The full opinion can be read at: [https://www.eesc.europa.eu/en/our-work/opinions-information-reports/opinions/role-civil-society-organisations-guardians-common-good-post-pandemic-recovery-and-reconstruction-eu-societies-and](https://www.eesc.europa.eu/en/our-work/opinions-information-reports/opinions/role-civil-society-organisations-guardians-common-good-post-pandemic-recovery-and-reconstruction-eu-societies-and)
Alzheimer Europe’s renewed registration will be valid for the period from 1 July 2022 to 30 June 2026. More information on the collective complaints process is available at:


21 June: Alzheimer Europe joins 300+ civil society organisations across Europe calling for an EU Civil Society Strategy in the European Commission work programme 2023

Following a European Parliament report by MEP Anna Júlia Donáth (Hungary) and several recommendations of the Conference on the Future of Europe, 300+ civil society organisations (CSOs) across Europe including, Alzheimer Europe wrote a joint letter, calling on Ursula von der Leyen, President of the European Commission, Věra Jourová, Vice-President for Values and Transparency in the European Commission and Didier Reynders, EU Commissioner for Justice, to include the development of a European Civil Society Strategy in the European Commission work programme 2023. Read the letter, here:


21 June: European Parliament committees pass motion on the future of care

Two of the European Parliaments committees, the Employment and Social Affairs Committee (EMPL) and the Women’s Rights and Gender Equality Committee (FEMM), have passed a report on the future of care in the European Union. The rapporteurs were Sirpa Pietikäinen, MEP (Finland) and Milan Brglez, MEP (Slovenia), who are also Chair and a member of the European Alzheimer’s Alliance (EAA), respectively.

The report called for the forthcoming European care strategy to support reform of care and social security systems in Member States, to better meet the needs and the rights of citizens, including those set out in the European Pillar of Social Rights, and to build resilience for future crises. The report highlights the shortage of accessible and affordable long-term care services, as well as chronic underinvestment in the care economy, resulting in significant challenges for the 44 million informal carers across the EU. It calls on the EU to provide funding opportunities for recovery after the pandemic, guaranteeing timely and equal access to quality care services to people of all generations in line with a rights-based and life-course approach. Specifically, it identifies the needs for care for older persons, prevention and rehabilitation services, long-term care and other forms of support for persons with disabilities, to ensure that support is provided in a comprehensive and integrated manner and responds to individuals’ physical and psychological needs.

In addition, the report notes the effect of demographic changes in Europe, highlighting that as the population ages, further demands for care and support services will be placed on care systems. In particular, there is a specific reference to figures from the Alzheimer Europe Yearbook 2019, noting that the number of people living with dementia is set to double by 2050. The motion will now be voted on in a Plenary session of the European Parliament. The full report passed by the committees is available at:


22 June: European Economic and Social Committee publishes opinion on role of civil society

The European Commission has launched the “Healthier Together: EU Non-Communicable Diseases (NCDs) Initiative”, to support EU Member States to reduce the burden of NCDs across Europe. The initiative identifies effective actions and the available legal and financial supporting tools across five main areas: cardiovascular diseases; diabetes; chronic respiratory diseases; mental health and neurological disorders; and, addressing underlying risk factors. The Initiative will have a budget of EUR 156 million under the 2022 work programme of the EU4Health programme.

The strand on mental health and neurological disorders contains priority areas which have direct or broad relevance for Alzheimer’s disease (AD) and dementia, including:

- Priority Area 1: Supporting favourable conditions for mental health and increasing resilience; implementing mental-health-in-all policies
- Priority Area 2: Promoting mental wellbeing and preventing mental disorders
- Priority Area 3: Improving timely and equitable access to high quality services
- Priority Area 4: Protecting rights, enhancing social inclusion, and tackling stigma associated with mental health problems
- Priority Areas 5-6-7: Supporting EU countries to develop and implement national plans for stroke encompassing the
entire chain of care (5); Improve screening and monitoring of stroke within primary care (6); increasing awareness of stroke among the general population and vulnerable populations in particular (7)

- Priority Area 8: Changing attitudes towards dementia, and tackling stigma associated with dementia
- Priority Area 9: Prevention and early detection of neurological diseases, in particular AD and dementia
- Priority Area 10: Implementing person-centred integrated care models, to better manage neurological disorders and support the quality of life of patients and their families.

The full NCD Initiative paper is available at: https://ec.europa.eu/health/system/files/2022-06/eu-ncd-initiative_publication_en_0.pdf

23-24 June: European Patients’ Forum Congress held in Brussels

The European Patients’ Forum (EPF) held its in-person European Congress during on 23 and 24 June. The event took place in Brussels, at DoubleTree by Hilton Hotel, but was also partially live streamed, for those who opted for joining online. Keeping in mind the experience and lessons learned from the 2021 online Congress, this year’s event included a wide audience of patient representatives (including Alzheimer Europe), policymakers, health systems experts, healthcare profession representatives, academics, and industry representatives.

The 2022 EPF Congress was dedicated to exchanging ideas and good practices in patient empowerment and involvement, gaining a greater and genuine understanding of the wealth of experiential knowledge and expertise that patients bring to health system design and strengthening, and much more.

EFP expressed its heartfelt thanks to Stella Kyriakides, European Commissioner for Health and Food Safety, for delivering the opening keynote speech, which addressed the context for and introduced the principles of the European Health Data Space. Summarising the two Congress days, EPF commented that the DataSavesLives toolkit was co-developed by a group of patient organisation representatives and advocates, including Alzheimer Europe, and is designed to equip these organisations and individuals with the information and materials they need to have constructive dialogues about health data use.

The 2022 European Patients’ Forum (EPF) Congress was held in Brussels between 23-24 June, under the banner “Continuing the conversation on digital transformation”. It brought together representatives of the EPF member organisations, patient advocates, industry, regulators and researchers, for discussions around real-world data use, data sharing, digital health and health literacy, among others.

The DataSavesLives interactive session at the 2022 EPF Congress in Brussels addressed three specific areas: engaging with digital health tools (moderated by Estefania Cordero of EPF); communicating effectively about health data (moderated by Lars Münter, of the Danish Committee for Health Education) and risks and benefits of engaging with health data initiatives (moderated by Angela Bradshaw of Alzheimer Europe). During these interactive breakout sessions, audience members tested and trialled tools from the DataSavesLives toolkit, and exchanged ideas for an upcoming training Bootcamp to take place in October 2022. Feedback from session participants emphasised the importance of transparency, trustworthiness and meaningful involvement of patients and caregivers in health data initiatives and developments. To access the DataSavesLives toolkit:

https://datasaveslives.eu/toolkit
28 June: Innovative Health Initiative launches calls for research proposals

The Innovative Health Initiative (IHI), the public private research partnership between the EU and industry, has launched its first calls for research proposals. In total, six topics have been included across two calls, including:

- Better support for patients with neurodegenerative diseases plus other diseases
- Next generation imaging and image therapy for cancer
- Towards more personalised, multi-modal cancer treatments
- Unlocking the potential of health data to improve care and advance research
- Improved prediction, prevention, diagnosis and monitoring of cardiovascular diseases
- A methodology to advance the early stage development of health technologies in the EU.

The first four topics (on cancer, neurodegenerative diseases and health data) are launched under IHI call 1. The topics on cardiovascular disease and early feasibility studies fall under IHI call 2. The deadline for proposals for both calls is **20 September 2022**.

IHI will contribute up to EUR 135 million to projects funded under IHI call 1. Applicants to this call must ensure that at least 45% of the total project costs are met via contributions from IHI private partners and/or IHI contributing partners. For IHI call 2, the IHI contribution is around EUR 22 million, a figure that will be matched by the contributions committed by private and contributing partners. Further information on the calls can be found at: https://www.ihi.europa.eu/news-events/newsroom/innovative-health-initiative-launches-first-calls-proposals

**POLICY WATCH**

11 June: Council of Europe pauses progress of Oviedo Convention Additional Protocol

At the **1434**th meeting of the Council of Europe’s Committee of Ministers, further consideration of the Additional Protocol to the Oviedo Convention on Bioethics was temporarily paused. The draft Protocol would advocated for a framework which would permit governments to maintain or pursue practices in the area of mental health, including involuntary treatment and placement. This approach had been criticised by a number of disability civil society organisations, including the European Disability Forum (EDF).

In its decision, the Committee directed the Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO) to revise the framework to promote the use of voluntary measures in mental healthcare services. Additionally, it called on the CDBIO to issue a report on relevant case law of the European Court of Human Rights related to mental health. Finally, it was also specified that key civil society organizations, such as EDF, should be included in these tasks. Only once these tasks have been completed, will consideration of the draft Additional Protocol resume. The text of the decisions can be found at: https://search.coe.int/cm/Pages/result_details.aspx?ObjectID=0900001680a675e6

17 June: World Health Organization launches mental health report

The World Health Organization (WHO) has published “World mental health report: Transforming mental health for all”, a review of the global approach to mental health, which provides a blueprint for governments, academics, health professionals, civil society and others to transform services and supports.

The report notes that in 2019, nearly a billion people were living with a mental disorder. The disabling effect of mental health conditions was highlighted, noting that people with severe mental health conditions die on average 10 to 20 years earlier than the general population, mostly due to preventable physical diseases. Furthermore, social and economic inequalities, public health emergencies, war, and climate change are highlighted as structural threats to mental health.

The report notes that even before the advent of the COVID-19 pandemic, only a small proportion of people had access to effective, affordable and quality mental health care. In particular, the gap between high and, low- and middle-income countries in treating conditions such as depression is stark.

Drawing on the latest evidence available, showcasing examples of good practice, and voicing people’s lived experience, WHO’s report highlights where change is most needed and how it can best be achieved.

All 194 WHO Member States have signed up to the Comprehensive mental health action plan 2013–2030, which commits them to global targets for transforming mental health. Whilst, some progress has been achieved over the past decade, countries are urged to speed up their implementation through three ‘paths to transformation’:

- Deepen the value and commitment we give to mental health.
17 June: France Alzheimer denounces decree to revoke drivers’ licenses even prior to a dementia diagnosis

France Alzheimer denounced a recent decree banning people with neuro-evolutionary pathologies such as Alzheimer’s disease (AD) from driving as soon as they are diagnosed, and even as soon as any signs of cognitive problems appear. The decree in question updates a list of medical conditions that it states are incompatible with driving a vehicle, with new conditions including cognitive disorders such as AD and related disorders. To put it plainly: the diagnosis of the disease goes hand in hand with the withdrawal of the keys. The decree states: "Incompatibility is definitive if the diagnosis has been made".

"People with cognitive disorders linked to these pathologies must no longer drive as soon as cognitive decline appears", the Road Safety Authority said in a press release. The decision of incompatibility can even be taken before the diagnosis. "As long as there is doubt about the nature of the disorder," the Official Journal also states. A specialist opinion is requested without delay from a multi-professional team that includes one or more specialist doctors. This order came as a surprise to France Alzheimer and raises many questions such as: Who takes the decision? What measures will be taken to support people with disabilities and their carers? What solutions can be proposed to them in the face of mobility problems?

The association also felt incomprehension and anger, because it is involved with the Fondation Médéric Alzheimer, as well as the Prévention Routière, and therefore the State, in a study on mobility, driving and Alzheimer’s disease. The conclusions should be unveiled in a few months. Taking car keys away from a sick person is ultimately inevitable, notes France Alzheimer, but people with dementia are all different. Moreover, we need to support the person with dementia and their carer during this stage of their life, and offer them solutions in terms of mobility, notes France Alzheimer.

France Alzheimer and related diseases was not the only organisation to express indignation. This was also the case for the French Society of Geriatrics and Gerontology (SFGG), the Federation of Memory Centres (FCM), the Old’Up association and the Fondation Médéric Alzheimer. Faced with this incomprehension and outcry, the Road Safety Authority seemed to take a step backwards quite quickly. “It is not a question of banning people who have just been diagnosed with Alzheimer’s from driving,” the organisation, which depends on the Ministry of the Interior, told Le Parisien, thus contradicting the order and the press release. “This decree in fact contains several scales: firstly, the treating doctor provides their analysis but they can ask for the opinion of an approved doctor who can themselves ask for cognitive tests.”

In a joint press release, the SFGG, the FCM, France Alzheimer and Old’Up called for a collective reflection with the Road Safety Authority, which has already expressed its agreement to change the decree and resume work together. France Alzheimer will now refer the matter to the Ombudsman’s office, asking them to take a position on this order.

31 May: TauRx shares initial data from its Phase III trial for AD

On 31 May, the company TauRx Therapeutics Ltd announced initial data from its Lucidity Phase III trial for the treatment of Alzheimer’s disease (AD). The Lucidity trial is a randomised, double-blind and placebo-controlled study evaluating the safety and efficacy of hydromethylthionine mesylate in people with AD encompassing mild cognitive impairment due to AD. Hydromethylthionine mesylate (which TauRx refer to under the chemical abbreviation, HMTM) acts by blocking abnormal accumulation of Tau protein in the brain.

The study enrolled 598 people with AD who were randomly assigned to one of two doses of HMTM (8 or 16 mg/day), or a placebo, twice daily for one year. Participants have now move forward to an additional one-year open label phase. Initial data suggested that those receiving the experimental tau-targeting drug experienced a decline in cognitive and functional measures than would be expected based on published research. The data analysis is ongoing and will be reported at a later date. In addition, the safety profile was favourable and consistent with prior studies of the experimental therapy. The company is planning to present an update at the 35th Global Conference of Alzheimer’s Disease International (ADI) in June 2022.

TauRx will now pursue regulatory submission and coverage for HMTM. On 18 May, prior to the LUCIDITY initial data being

- Reshape environments that influence mental health, including homes, communities, schools, workplaces, health care services, natural environments.
- Strengthen mental health care by changing where, how, and by whom mental health care is delivered and received.

The full report can be accessed at: https://www.who.int/publications/i/item/9789240049338

SCIENCE WATCH

15
released, the UK Medicines and Healthcare products Regulatory Agency (MHRA) granted the company an Innovation Passport, which is the first stage of the Innovative Licensing and Access Pathway (ILAP). It is intended to speed up development and approval times.


2 June: Project Alzheimer’s Value Europe study could help prepare healthcare systems for 416 million people at risk of developing Alzheimer’s disease

PAVE

On 2 June 2022, Project Alzheimer’s Value Europe (PAVE) published new findings in the peer-reviewed journal, Alzheimer’s & Dementia, on the prevalence of Alzheimer’s disease (AD). The study findings are significant and could help prepare healthcare systems going forward, particularly with innovative therapies under development.

The study group, made up of a steering committee of European clinical experts, supported by health research experts and a representative of Alzheimer Europe, conducted a review of published evidence focusing on large meta-analyses with multiple cohorts and including data on both clinical diagnosis and biomarkers. The research includes a literature search of published epidemiological evidence across the AD continuum, including people at risk of developing AD, and those with Prodromal AD and Alzheimer’s dementia.

Some of the group’s main findings are:

- 22% of the global population aged 50 and over (and women more than men) could benefit from future prevention strategies, including interventions and treatments with the potential to stop or slow the progression of AD.
- There is a potential window of opportunity for proactive and preventive measures, including efforts to encourage brain health activities.
- Proactive and preventive measures present the best opportunity for extending cognitive function and the ability to live independently without significant care support.
- It is vital to accurately define AD and its different stages, as well as quantifying and stratifying the affected populations, with a specific focus on who could benefit from future new treatments.

Jean Georges, Executive Director at Alzheimer Europe, was one of the authors of this study. He commented:

“Research to understand and further define the stages of Alzheimer’s disease will help identify populations and individuals at risk of developing dementia and most likely to benefit from brain health promotion programmes and interventions. It is our hope that policy makers and healthcare systems can use this research to inform new policies and programmes for the fight against Alzheimer’s disease.”

PAVE is a collaborative, multi-stakeholder forum committed to AD research, value assessment and funding, with particular focus on emerging therapies and diagnostics. PAVE was established to increase collaboration and understanding between key stakeholders in the AD ecosystem within Europe, including regulators, bodies responsible for health technology assessment, payers, clinicians, patient advocates, and industry members. PAVE’s membership defines the projects and research of PAVE, aimed at developing solutions to the challenges related to value assessment of and funding for emerging AD therapies and diagnostics in Europe. The effort is funded by Hoffmann-La Roche (Roche), Biogen and Eli Lilly. This study was funded by Roche and Biogen.


2 June: Research study reveals the link between early-appearing lysosome pH deficits and extracellular amyloid deposits in AD mouse models

Autophagosomes are microscopic bodies that help balance the inner environment within the cell. They do this by engulfing defective cellular components, which are then degraded when the autophagosomes fuse with cell structures called lysosomes.

Alterations in this degradation pathway have been implicated in the development of Alzheimer’s disease (AD). However, the link between these alterations and the formation of amyloid plaques in the brain is not yet understood. In a new published study in Nature Neuroscience journal, a team of researchers led by Ralph A. Nixon and Ju-Hyun Lee of the New York University Langone Health (New York, US) identified the relationship between the extracellular accumulation of amyloid and the neuronal lysosomal dysfunction in five different mouse models for AD.

In order to study the autophagy-lysosomal pathway in the brain, the researchers used different mouse models where they tracked and measured the acidity, also known as pH, inside the lysosomes of brain cells during the development of AD. By tracking pH using confocal microscopy, the researchers were able to show that lysosomes were less acidic in animal models of AD. This change of pH was linked to the accumulation of cellular debris and proteins, such as the amyloid precursor protein (APP) metabolites, long before the AD mouse models develop amyloid plaques in the brain.

The researchers also demonstrated that the enlarged and faulty lysosomes containing the APP metabolites (amyloid (Aβ) and APP-ßCTF) accumulate around nuclei of neurons, distort their plasma membrane and end up shaping them in a structure with a unique pattern called PANTHOS (poisonous flower) which was also identified within the neurons of human AD brain tissue. The accumulation of Aβ within the faulty lysosomes causes them to
break down. The researchers suggested that this could lead to the accumulation of Aβ in brain cells, which then become extracellular amyloid deposits when the cells die. This study points towards lysosome dysfunction as an early cause of extracellular amyloid deposition. Furthermore, strategies targeting lysosome pH deficits may be a beneficial pharmacological target to help prevent the downstream AD-related pathologies.

https://www.nature.com/articles/s41593-022-01084-8

8 June: Biogen withdraws application for aducanumab from Swiss licensing and supervisory authority

Biogen has withdrawn its application for aducanumab to be approved as a treatment for early Alzheimer’s disease (AD) by Swissmedic, the Swiss licensing and supervisory authority. In a recent announcement, Biogen also notified the European Medicines Agency (EMA) about the withdrawal of its marketing authorisation application for aducanumab for the treatment of early AD, on 22 April 2022. The drug was previously approved in the US by the Food and Drug Administration (FDA), in June 2021. The FDA approval, which was granted via its “accelerated approval pathway”, came with specific conditions.

Several centres in Switzerland will participate in another study, to further explore the efficacy and safety of aducanumab. Alzheimer Switzerland and Swiss Memory Clinics welcomed this decision which they said “puts patient safety first”.

13 June: Financial altruism shows possible link to cognitive profile of early Alzheimer’s disease

Elderly populations are more be inclined to use their money for charitable purposes and more likely to encounter financial abuse. Yet little is known about the link between charity donation behaviours and cognitive decline in older adults. 

In this context, researchers have sought to investigate the link between one’s willingness to give away money and signs of early Alzheimer’s disease (AD), in a study published on 13 June 2022, in the Journal of Alzheimer’s disease.

67 older adults who did not have dementia or cognitive impairment, with an average age of 69, were put into pairs with an anonymous person. They were given the sum of 10 dollars which they were asked to allocated as they wished (in incremental sums of 1 dollar), between the anonymous person and themselves. The researchers also proceeded to assess individuals’ cognitive status. The participants underwent neuropsychological tests that are commonly used to detect the presence of early AD.

The study findings revealed that individuals who were willing to bestow more money to the anonymous person exhibited significantly lower scores on the early Alzheimer’s-sensitive cognitive measures. According to the authors, these results could indicate that changes in altruistic behaviour could be a sign of early AD. They also note that more research is needed to understand the link between altruism and cognition, and that advances in this field could help with earlier detection of AD and recognising unhealthy patterns of altruistic behaviours. Furthermore, they say this could also forge a better understanding of how to best protect older adults and people with cognitive decline from financial exploitation, such as online scams.

https://content.iospress.com/articles/journal-of-alzheimers-disease/jad220187

14 June: Semorinemab does not slow clinical progression of AD, according to Tauriel study results published in JAMA Neurology

Tauriel was a Phase 2, randomised and placebo-controlled clinical trial that was conducted between October 2017 and July 2020 in North America, Europe and Australia, designed to test the safety and efficacy of semorinemab. On 14 June, the Tauriel investigators published topline results in JAMA Neurology, showing that treatment with semorinemab did not slow clinical progression of Alzheimer’s disease (AD) compared to placebo.

Semorinemab is an antibody that targets the human tau protein, which accumulates in tangles within the brain during the development of AD. Early stage studies showed that Semorinemab was effective in animal models of AD and had a favourable clinical safety profile. The Tauriel study recruited over 400 participants from 97 sites across North America, Europe and Australia, randomising participants to receive a placebo or one of three increasing doses of semorinemab. Participants, who had mild cognitive impairment or dementia due to AD, received a monthly dose of semorinemab via intravenous infusion, for a period of 73 weeks. Primary outcomes were changes from baseline on the CDR-SB scale of cognition and function (CDR-SB: Clinical Dementia Rating – Sum of Boxes), adverse events and magnetic resonance imaging assessment of brain structure.

The Tauriel study data revealed that participants who received semorinemab experienced similar increases in CDR-SB score as those receiving a placebo. This indicates that semorinemab
treatment under the conditions of the trial was not able to slow disease progression. However, the trial confirmed that the drug has an acceptable and well-tolerated safety profile, similar to the results of the Phase 1 trial of semorinemab.

https://jamanetwork.com/journals/jamaneurolology/article-abstract/2793069

14 June: Actinogen Medical has announced an upcoming Phase II study for AD

Actinogen Medical is a biotechnology company developing innovative treatments for neurological diseases associated with dysregulated brain cortisol. The company is currently developing its lead compound, Xanamem, as a new therapy for Alzheimer’s disease (AD), major depressive disorder, fragile X syndrome, and other neurological diseases where reducing cortisol inside brain cells could have a positive impact.

Positive results for its Phase I/II XanaMIA Part A trial were recently announced. The double-blind, placebo-controlled, dose-ranging study evaluated Xanamem in 107 healthy elderly people aged 50-80 years. Findings showed the drug’s ability to rapidly enhance attention and working memory. In addition, Xanamem was safe and well-tolerated.

On 14 June, Actinogen Medical announced that it has finalised the designs for its planned Phase II trials in AD and major depressive disorder. The AD XanaMIA Part B Phase II trial will be a six-month dose-ranging, placebo-controlled trial in approximately 300 people with early stages of AD, including people with mild cognitive impairment as well as people with mild AD. Outcomes will be measured by the Cogstate Cognitive Test Battery used in the recent XanaMIA Part A trial, supplemented by a variety of other tests of memory, attention and executive function. Results are expected in 2024.


16 June: Roche provides update on Alzheimer’s Prevention Initiative study evaluating crenezumab in autosomal dominant AD

On 16 June, Roche together with Banner Alzheimer’s Institute, announced top-line results from the Alzheimer’s Prevention Initiative (API) Autosomal Dominant Alzheimer’s Disease (ADAD) Colombia Trial.

The Phase II API-ADAD study, which has been running for more than a decade, evaluated crenezumab, an investigational medicine, to slow or prevent Alzheimer’s disease (AD) in a population of cognitively unimpaired people who carry a specific genetic mutation which causes early-onset AD. The trial enrolled 252 people who are members of the world’s largest extended family with ADAD in Colombia, with 94% of participants completing the study. Participants were randomised to receive crenezumab or placebo over five to eight years.

Results showed that the trial did not meet its co-primary endpoints. Crenzumab did not slow or prevent cognitive decline in people with an inherited form of the disease. In addition, the drug did not show a statistically significant clinical benefit in episodic memory function. No new safety issues were identified. Further analyses of data are ongoing. Initial data will be presented at the upcoming Alzheimer’s Association International Conference (AAIC) on August, 2.

Roche discontinued two phase III trials of crenezumab in people with early AD in 2019 based on the results from a pre-planned interim analysis. Within its AD pipeline, Roche is also evaluating gantenerumab in autosomal dominant AD, as well as for preventing sporadic AD and treating early AD in late-stage clinical trials. Results from the phase III GRADUATE studies of gantenerumab in early AD are expected in Q4 2022.

https://www.roche.com/media/releases/med-cor-2022-06-16

17 June: Study uncovers novel findings about the healthcare costs associated with dementia

In light of ageing population trends, global healthcare costs associated with dementia are predicted to reach USD 2 trillion per year by 2030, according to a study published in BMJ Global Health in April 2022. This has prompted many researchers to look into the different factors that are contributing to these rising costs. Yet, few have looked at costs over long periods of time, or by comparing costs associated with dementia versus a general population group.

In the present study, researchers at the Global Brain Health Institute (GBHI) at Trinity College, collaborated with the Health Economics Unit of Lund University, Sweden, to analyse healthcare costs for 21,184 people, over 17 years. A novel finding uncovered by the researchers is that healthcare costs for people with dementia were 10 to 15% higher than the general population, as early as 10 years before they received their formal dementia diagnosis. This might indicate that healthcare needs for people with dementia arise a long time before people are formally diagnosed with the condition.

When people receive their official diagnosis, the associated healthcare costs are twice as high as those for the general population. Yet, these healthcare costs start decreasing after the year of formal diagnosis and four years after receiving a
diagnosis, the healthcare costs are equivalent to those of the comparison group of the study (composed of the general population).

The authors of the study posit that this might be because care services are covered by municipalities and are considered social costs, and therefore do not belong to the healthcare sector. According to the authors, it is also possible that dementia contributes to a decrease in one’s expression of needs, thereby reducing contact with the healthcare sector. The researchers also suggest that after several years, people with dementia might not be sufficiently prioritised in the healthcare system and therefore do not receive adequate care during this time.


20 June: A single brain scan may improve the diagnostic accuracy of Alzheimer's disease

Alzheimer’s disease (AD) is a multifactorial disease and therefore, several tests are usually performed to evaluate and measure all the critical factors that contribute to its progression. The three most known features that characterise AD are the accumulation of amyloid and tau proteins, and the structural brain changes related to neurodegeneration or brain atrophy. These are related to the brain’s structure and function and can be identified by using brain scans. However, the diagnostic accuracy of brain scans increases when combined with other tests, such as blood, memory or cognitive tests.

In a new study published in the Nature Portfolio Journal, Communications Medicine, a team of researchers led by Eric O. Aboagye of the Imperial College London (London, UK) presents a new approach based on a single brain scan able to predict whether a person has AD.

This new approach uses magnetic resonance imaging (MRI) brain scans in combination with an artificial intelligence algorithm. To develop this novel approach, the researchers proceeded to use brain scans and segment the brain images into 115 regions. Subsequently, they extracted more than 650 structural features for each region related to size, shape, intensity and texture, among others. To identify the changes to these features and determine whether these changes could predict AD, the researchers first trained the algorithm on brain scans obtained from the Alzheimer’s Disease Neuroimaging Initiative (ADNI). They then tested the algorithm on brain scans from four different cohorts which were divided into two groups. The first one was the control group and included brain scans from people with diseases unrelated to AD (Frontotemporal Dementia and Parkinson’s disease), and healthy controls. The second group, named the disease group, consisted of people with AD-related mild cognitive impairment and AD.

Overall, this unsupervised and MRI-based algorithm accurately predicted an AD-related pathology in 98% of the cases and distinguished between early and late stages of AD in 79% of them. Furthermore, the researchers identified changes in areas of the brain not previously associated with AD. This new approach suggests that the MRI-based algorithms may improve the information that clinicians usually obtain from brain scans, by identifying individuals at the early stages of the disease and brain areas possibly involved in or affected by the progression of the AD.

https://www.nature.com/articles/s43856-022-00133-4

21 June: Biogen terminates phase IV ICARE-AD trial of aducanumab in AD

The global biotechnology company Biogen has recently indicated it has terminated an observational study of its approved Alzheimer’s disease (AD) drug aducanumab, following its post on ClinicalTrials.gov.

The company noted in the details that the termination of the phase IV ICARE-AD trial was “a result of the national policy for coverage, it is expected there will be limited aducanumab-awa prescription and usage in routine clinical practice, making the study not feasible for enrolment.”

The trial was to be a prospective, single-arm, multicentre, non-interventional study of aducanumab as prescribed in the post-marketing setting in the US. Participants would receive aducanumab and be followed up to five years. The study was designed to enrol 6,000 participants with AD in the US, but only 29 had joined over a seven-month period.

This follows the April announcement from the Centers for Medicare and Medicaid Services (CMS) on aducanumab and future monoclonal antibodies directed against amyloid that might be approved by the FDA for the treatment of AD. The decision is ultimately that Medicare will be able to cover the cost of aducanumab only for participants enrolled in qualifying clinical trials. The FDA approved aducanumab last year in US under an accelerated approval pathway, based on clinical trial data showing that aducanumab could reduce amyloid plaques in the brains of people treated with the drug.

Biogen is still running the Phase IV ENVISION post-marketing study, conducted as a part of aducanumab’s accelerated FDA approval. The primary objective of this study is to verify the clinical benefit of monthly doses of aducanumab in slowing cognitive and functional impairment as measured by changes in the Clinical Dementia Rating Scale Sum of Boxes (CDR-SB) score as compared with placebo. The study plans to enrol about 1,500 participants with early AD and confirmation of beta-amyloid pathology.

Blood flow in the brain is often compromised in people with Alzheimer’s dementia, and is thought to contribute to the functional and cognitive decline associated with the disease. Laboratory research published in the PNAS journal (Proceedings of the National Academy of Sciences) has provided new clues about the biological causes of brain blood vessel dysfunction in Alzheimer’s disease (AD), identifying pathways that could potentially be targeted for future drug development.

The brain microcirculation consists of tiny blood vessels and arteries, which help perfuse the brain with blood. In people with AD, the brain microcirculation can be compromised, with reduced blood flow, and dysfunctional responses to stimuli. This dysfunction is at least partly driven by the presence of amyloid proteins in and around blood vessels, which is thought to lead to some of the functional and cognitive changes that people with AD experience during disease progression. In their PNAS article, a team of researchers led by Prof. Adam Greenstein of Manchester University (UK) used an animal model of AD to understand how blood vessels of the brain microcirculation are altered in AD.

By exposing pial arteries from AD mice to different stimuli, they were able to observe that the contraction of these arteries was significantly altered compared to mice without AD. The arteries from AD mice contracted and narrowed much more extensively, and were less able to dilate than arteries from mice without AD. In particular, exposure of arteries to amyloid proteins, the primary component of the prevalent amyloid plaques in the brains of people with AD, caused the arteries to narrow substantially. By using molecular tools, the researchers were able to identify a specific ion channel that was dysfunctional in arteries from AD mice, which may explain why they were more prone to contract and, therefore, restrict blood flow to the brain. Further studies are now required to understand the importance of these findings in the clinical context. To read the article: https://www.pnas.org/doi/10.1073/pnas.2204581119

27 June: Otsuka Pharmaceuticals and Lundbeck announce positive clinical trial results of Brexpiprazole for agitation in Alzheimer’s dementia

Trial 331-14-213 was a Phase 3, multicentre, randomised controlled trial designed to assess the safety, efficacy and tolerability of Brexpiprazole, sponsored by Otsuka Pharmaceuticals and Lundbeck. On 27 June, the two companies published a press release announcing that participants treated with Brexpiprazole had a statistically significant reduction in agitation compared to participants treated with a placebo drug.

Brexipiprazole is a drug already approved for the treatment of schizophrenia in the US, Canada and Europe. It is thought to act through interactions with serotonin, dopamine and noradrenaline receptors in the brain. Trial 331-14-213 recruited 345 participants with probable Alzheimer’s dementia and agitation, administering Brexpiprazole or placebo tablets twice a day for a 12-week period. Participants were based in Bulgaria, Hungary, Serbia, Slovakia, Spain, Ukraine and the USA.

Agitation is a prevalent clinical manifestation in Alzheimer’s dementia, and has a large impact on quality of life of patients and caregivers. Early analysis of the trial results showed that participants receiving Brexpiprazole had a reduction in agitation compared to those receiving placebo, based on the Cohen-Mansfield Agitation Inventory (CMAI) questionnaire that assesses the frequency of behaviours such as pacing, restlessness and yelling. Otsuka and Lundbeck are now planning a regulatory filing to the US Food and Drug Administration (FDA) in late 2022, based on the results of this study and two earlier trials.


MEMBERS NEWS

2 June: Spominčica-Alzheimer Slovenia organises “In the Rhythm of the Human Brain” conference in Ljubljana

On 2 June 2022, Spominčica-Alzheimer Slovenia held a conference called “In the Rhythm of the Human Brain”, together with co-organisers the Multiple Sclerosis Association of Slovenia, the Let’s Get to Know Multiple Sclerosis Association, Trepetlika - the Association of Patients with Parkinsonism and Other Extrapyramidal Disorders, the Association of Huntington’s Disease Patients and Relatives and the Association of International Dystrophics. They prepared a

21 June: New laboratory research study provides clues to the biological causes of brain blood vessel dysfunction in Alzheimer’s disease

Blood flow in the brain is often compromised in people with Alzheimer’s dementia, and is thought to contribute to the functional and cognitive decline associated with the disease. Laboratory research published in the PNAS journal (Proceedings of the National Academy of Sciences) has provided new clues about the biological causes of brain blood vessel dysfunction in Alzheimer’s disease (AD), identifying pathways that could potentially be targeted for future drug development.

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rich programme and attracted many participants to the event, which took place in the country’s biggest conference centre, Cankarjev dom, in Ljubljana, as well as online.

The conference, which was held under the honorary patronage of the President of the Republic of Slovenia Borut Pahor, was attended by patients and their carers/supporters, as well as many experts who deal with neurological diseases in various ways.

Representatives from Alzheimer Europe and Alzheimer’s Disease International, as well as other distinguished lecturers from abroad honoured the conference with their presence and speeches (Paola Barbarino, Director, Alzheimer’s Disease International; Prof. Iva Holmerová, Chairperson, Alzheimer Europe; Dale Goldhawk, President, Alzheimer’s Disease International; Prof. Dr Ninoslav Mimica, Vrapče Psychiatric Clinic, Zagreb, Croatia; and Prof. Dr Voyko Kavčič, Wayne State University, Rochester, New York, USA), whose collective aim is to put dementia at the top of the health agenda. They emphasised that there are still too many people with dementia who remain without a diagnosis, and that people in Slovenia should receive the same care and treatment as in other parts of Europe.

Numerous local speakers and speakers at a roundtable discussion also participated in the conference:

Bogdan Tušar, Director, Directorate for Health System Development, Ministry of Health; Andrej Grdiša, Director, Directorate for the Elderly and Deinstitutionalisation, Ministry of Labor, Family, Social Affairs and Equal Opportunities; Tomaž Gržinič, European Working Group of People with Dementia, who gave a video presentation; Assistant Professor Polona Rus Prelog, PhD, University Psychiatric Clinic, Ljubljana; Assistant Professor Martin Rakuša, PhD, Maribor University Medical Center; Tatjana Cvetko, MSc, Health Center Koper; Dr Zdenka Čebašek Travnik, Expert Council, Spominčica-Alzheimer Slovenia; Štefanija L. Zlobec, President, Spominčica-Alzheimer Slovenia; Dr Rok Berlot, University Clinical Center Ljubljana; Cvetka Pavlina Likar, President, Trepetlika - Association of Patients with Parkinsonism and Other Extrapyramidal Disorders; Rudi Jakovac, President, Association of Patients with Huntington’s Disease and Relatives; Dr Tanja Valenta, Faculty of Theology; Renata Žohar, President, Let’s Get to Know Multiple Sclerosis Society; Dr Sara Ahlin Doljak, Executive Board, Multiple Sclerosis Association of Slovenia; Nada Tomančič, Executive Board, Multiple Sclerosis Association of Slovenia; Dr Milica Gregorič Kramberger, University Medical Center Ljubljana; Dr Božidar Volič, Emonicum Institute; David Krivec, Secretary General, Spominčica-Alzheimer Slovenia; Marija Sajovic, Franc Salamon Trbovlje Retirement Home; Tina Zadravec, Franc Salamon Trbovlje Retirement Home; Urša Mršnik, DEOS - Home for the Elderly of Notranje Gorica; Katarina Davidovič, DEOS - Home for the Elderly of Notranje Gorica, Assoc.; Prof. Dr Anton Zupan, Expert Committee, Slovenian Dystrophic Association; Martina Sardoč, Dom dvatopola; Mateja Toman, President, Slovenian Dystrophic Association; and Prof. Zvezdan Pirtošek, PhD, Head of the Department of Neurology, Faculty of Medicine Ljubljana, who moderated the roundtable session.

On 9 June, a symposium on “Early Diagnosis of Alzheimer’s Disease: Where we are and where we are going” was held in Madrid, organised by Fundación Alzheimer España (FAE) to mark its 30th anniversary. More than 500 people attended the event, which could be followed via online streaming, as well as in person at the Colegio Oficial de Médicos de Madrid. Healthcare professionals, civil society representatives, patients and family members participated in the event, which was chaired by Micheline Selmes, FAE President and Carolina García, Coordinator of the Strategy for Neurodegenerative Diseases of the Ministry of Health in Spain. D. A. David Pérez, patron of FAE and head of the Neurology service at Hospital 12 de Octubre de Madrid, moderated the event and introduced the speakers.

During the first part of the day, different themes were covered around early diagnosis in Alzheimer’s disease (AD), highlighting the use of biomarkers that allow a diagnosis of the disease as early as possible. The importance of screening protocols in primary care as a fundamental tool for the detection of suspected cases was also discussed. In addition, the point of view of the patient and the family was also highlighted, concerning early diagnosis of AD.
The second part of the symposium addressed the most recent and innovative advances in early treatment of AD from a pharmacological and non-pharmacological perspective. In this second part of the day, a person diagnosed with AD had the opportunity to talk about his personal experience in relation to diagnosis and to describe his day-to-day life with the disease. In the last part of the symposium, a roundtable discussion was held, around the question “Are we facing a new era in Alzheimer’s Disease diagnosis?” This roundtable was conducted by Dr Pascual Sánchez, Scientific Director of Fundación CIEN in Madrid. The speakers had the opportunity to discuss about different topics regarding the present and the future of early diagnosis in AD. Finally, family members and other healthcare professionals were able to put different questions to the panellists.

10 June: Alzheimer Switzerland’s Assembly of Delegates meets in Bern, elects four new members to Central Committee

On 10 June 2022, representatives of the 21 cantonal sections of Alzheimer Switzerland met at its Assembly of Delegates and elected new members to the Central Committee of Alzheimer Switzerland. For the first time in two years, the Assembly of Delegates was able to take place in person, in Bern. The delegates elected four new members to the Central Committee:

- Kristine Ewert, assistant doctor in the psychogeriatric department at the FELIX PLATTER University Hospital in Basel
- Hans Gut, former President of the Careum Foundation, a leading educational institution and independent think tank in the Swiss health sector
- Stéfanie Monod, professor at the University of Lausanne, senior physician and co-head of the Health Policy sector at Unisanté, Lausanne
- Jürg Schlup, former President of the Swiss Medical Association FHM, family doctor and doctor in charge of an EMS for many years.

The delegates also thanked the outgoing members of the Central Committee, Monika Schümerli, Andreas Studer and Philippe Vuillemin, for their work and dedication over the past years. In addition, Ulrich Gut, former president of Alzheimer Switzerland, was appointed as an honorary member. The Central Committee of Alzheimer Switzerland is the highest body responsible for the National Board and the chapters of Alzheimer Switzerland.

18 June: Alzheimer Bulgaria and Prof. Diaz present their collaboration at conference on social aspects of mental health

In the summer of 2021, Alzheimer Bulgaria, in collaboration with Professor Felix Diaz from the American University in Bulgaria (AUBG), organised seminars on "Improving the quality of life, cognitive functioning, and communication for people with dementia." The workshops introduced various modern intervention systems that would help people with dementia and their families in their daily lives. The seminars were carried out with the financial support of the Open Society University Network.

Thanks to the partnership, Alzheimer Bulgaria gave two AUBG students the opportunity to do an internship in the association in order to gain knowledge and experience in working with people with dementia as well as with administrative tasks related to the organisation. In addition, Prof. Diaz and Alzheimer Bulgaria will write a book based on the topics of the seminars and research based on the covered topics.

On 18 June 2022, representatives of the association and Prof. Diaz presented their work in the conference hall of Sofia University "St. Kliment Ohridski" at the conference "Public Aspects of Mental Health and Mental Disorders" under the project “Mental Health and Social Inequalities,” funded by NSF. It was attended by experts and scientists in the health and social field, and various studies and scientific papers were presented. Prof. Diaz and Kalina Ekova, Project Coordinator at Alzheimer Bulgaria, spoke about the problems of people with dementia in Bulgaria, such as: the difficulty of receiving a diagnosis of the disease; the lack of legal framework for people with dementia and their relatives; the lack of statistics, etc. They also shared more about the seminars held, their structure, and results.

Alzheimer Bulgaria will continue to work with Prof. Diaz in the future, as this will contribute to the development of quality teaching materials and programmes and the inclusion of more young people in the association’s cause.

23 June: Serbian Society for Alzheimer’s Disease celebrates anniversary of piloting of its day care centre for people with dementia in Belgrade

Serbia belongs to the “older” countries with 21.3% of its population being 65 years old or more. It is estimated that more than 120,000 people in Serbia are living with Alzheimer’s disease (AD) and other types of dementia. While there is institutional support for families caring for people with dementia, through financial compensation for the help and care of another person, only a small number of the affected people benefit from it because the conditions for receiving that compensation are very strict. The capacity for the accommodation of older people in welfare institutions can only support 0.8% of the older population and there are no
specialised community services for people with AD and other types of dementia except for two day care centres at two gerontology centres, in Subotica and in Kragujevac. That’s why, in June 2021, in Belgrade, the Serbian Association for Alzheimer’s Disease ran the pilot programme of the day care centre for patients and counselling centre for their carers/supporters. The Centre is open every Thursday from 3 pm to 7 pm. Staff carry out occupational therapy and entertainment activities to help engage the patients. They also provide information and advice to the carers/supporters.

This June, the Serbian Society for Alzheimer’s Disease celebrated the first anniversary of the Centre, together with health and welfare system officials, service users and their carers, and volunteers. They presented the results of the pilot programme and discussed its effects on patients and carers.

The weekly functioning of the Centre is insufficient, so the Society cannot state that the service has contributed to the improvement of patients’ general health, however, according to the statements of relatives and to their own observations, they were able to conclude that the activities being carried out contribute to an increase in self-confidence for patients, as well as to mood improvement.

With advice and support, the staff empower patients’ family members to grow in their complex caregiving/supportive role. It was noted that the opportunity to meet other carers is extremely important to them.

With the financial support of the Swiss government, within the project "For an Active Civil Society Together", the Serbian Society for Alzheimer’s Disease is now launching a community awareness campaign on recognising dementia, on the needs of patients and their relatives, as well as on the positive effects of the programme. They are also advocating for the city of Belgrade to continue to develop and finance the service of the day care centre.

In 2021, OZANA, a non-governmental organisation offering programmes for young people and adults with intellectual disabilities, started an initiative to make "twiddle muffs" for people living with Alzheimer’s disease or other dementias. Until then, twiddle muffs were virtually unknown in Croatia. Since that time, the association has managed to donate more than 200 twiddle muffs for patients, and is working on making them available for all who might benefit from using one.

A "Twiddle muff" is a sensory therapy tool designed to help alleviate certain symptoms of dementia. It is a knitted, crocheted, felted, or weaved muff (kind of sleeve or glove in which hands can be placed from both sides) used to keep patients’ hands warm and occupied. It has a lot of knitted, crocheted, or felted details attached on the outside and on the inside of the muff which patients can explore and twiddle with their fingers. Twiddle muffs are vivid in colour and texture and as such they provide visual, tactile and sensory stimulation while ensuring that hands of the patients are tucked in and warm. In addition to comforting and calming patients down, they stimulate their motor skills and cognition.

This non-pharmacological intervention has been recognised in clinical practice to be an effective complement to medication, without the risk of additional side effects. They are a useful aid when caring for people with neurodegenerative disorders, both at home and in institutions.

A short video of OZANA’s initiative is available here: https://youtu.be/9YSTFOVgY4

Building on this initiative, the European Wool Exchange Foundation (EWE Foundation) has launched the European Twiddle Muff Awards 2022, to promote the benefits of twiddle muffs and encourage their use at a European level. The aim is also to encourage creativity in the creation of twiddle muffs and to provide ideas for people who are interested in making them, as well as to encourage an abundance of twiddle muffs so they can be distributed to as many institutions caring for people with dementia as possible. All the information about the Awards can be found, here: https://www.ewe.network/european-twiddle-muff-award-2022
THE PANHellenic Federation of Alzheimer’s Disease and Related Disorders (Alzheimer Hellas) is participating in a new and exciting Erasmus+ funded project. InfoCARE has a two-year duration and aims to support informal carers by providing them with non-formal education on dementia, innovative devices to improve social interaction and by creating a network between informal carers through support groups. The InfoCARE consortium consists of five partners coming from five different countries across Europe. Specifically, the countries/organisations involved are Spain (Foundation Sorapan de Rieros) which is the leading organisation, Austria (Austrian Association of Inclusive Society), Greece (Greek Association of Alzheimer’s Disease and Related Disorders), Turkey (EURASIA Innovative Society Association) and Denmark (Danish Committee for Health Education).

Families, adults and legal guardians, the informal carers, are largely the main care providers for people with dementia. Informal carers are often associated with higher levels of stress, more depressive and anxiety symptoms and lower levels of subjective wellbeing when compared to non-carers. The lockdown and the restrictive measures imposed due to the COVID-19 pandemic have amplified the physical, emotional and economic burden of informal carers of people with dementia.

Partner countries will develop a set of four modules on cognitive activities for people with dementia, to provide informal carers with training on coping with the cognitive deterioration of the people they are supporting. The activities will be adapted to allow the implementation in a remote format using innovative devices, when being physically present is not possible, i.e. distance caring. The hope is that, by creating a network of informal carers, this will provide a support group which can serve as a collective coping tool for both psychological support and for sharing experiences and best practices. Each partner country will recruit at least 15 participants, for a total of 75 participants to pilot each project result in order to test and optimise the outcome of the project.

NEW PUBLICATIONS AND RESOURCES

2 June: Gina Awad’s new book "United" explores aspects of life as a family carer/supporter for a person with dementia

"United" is Gina Awad’s new book, published on 2 June 2022, which explores themes around caring for a loved one with dementia. The author hopes it will make a difference to many families and professionals. It is a short read, offering a selection of resources, together with a variety of stories bringing to life a range of situations encountered by carers/supporters. Each gives the reader a look at different challenges posed by dementia, as well as sharing some creative and inspiring responses to these challenges.

The book, illustrated by British Cartoonist Tony Husband, has met with high praise in the dementia field, with glowing reviews from patient advocates, carers, and dementia professionals, including Kate Lee, Chief Executive Officer, Alzheimer’s Society, who commented: "What a compelling read, so skilfully written and with a deep understanding of the condition. The insight and ‘tips’ were invaluable and many chimed with me as challenges (and opportunities!) I faced with my own mum. An excellent piece of work."

English actor, author, broadcaster, comedian, presenter and political activist Sir Tony Robinson, called it “a beautiful and moving book that vividly brings home the challenges faced by those with dementia and their carers.”

EDUCATION

28 June: Registrations are open for free University of Tasmania online course “Understanding Dementia” taking place from July 2022

The Wicking Dementia Research and Education Centre of the University of Tasmania (UTAS) welcomes registrations for its next Massive Open Online Course (MOOC) on “Understanding Dementia”. This is an easily accessible online course that builds upon the latest in international research on dementia. The course is run on an annual basis, is completely free and anyone can enrol. There are no entry requirements.

The release of course content will occur at 9:00am AEST (1:00am CET) on the following dates: Module 1: Orientation - 5 July 2022; Module 2: The Brain - 7 July 2022; Module 3: The Diseases - 21 July 2022; Module 4: The Person - 4 August 2022; Module 5: Completion - 25 August 2022.

Once the course commences, you will be able to log in to engage with the course content and activities, and share perspectives with other participants. The course is scheduled to close on 16 September, 2022 at 5:00pm AEST (9:00am CET). When you have completed the course, you will be eligible to download a free, personalised certificate of completion. For more information about this course and to enrol, visit: https://mooc.utas.edu.au/landing/ucedmpro11
Gina Awad is the founder and lead of the Exeter Dementia Action Alliance and is also a Dementia Friends Champion. She was awarded a British Empire Medal in 2018 for her voluntary services to people with Dementia in Devon. "United" can be purchased at many book stores and online, for example via Amazon:

https://www.amazon.co.uk/dp/1472146514/ref=redir_mobile_desktop?encoding=UTF8&qid=&ref_=tmm_pap_swatch_0&sr

**22 June: Short film made in collaboration between Alzheimer’s Society and Museum of London showing experience of a person with dementia visiting Museum of London Docklands**

A short film has been made a collaboration between the Alzheimer’s Society (UK) and the Museum of London. It shows the experience of someone living with dementia visiting the Museum of London Docklands, which is an accredited dementia-friendly museum. Watch the video, here:

https://www.youtube.com/watch?app=desktop&v=z_Vp_egzERk

**JOB OPPORTUNITIES**

**28 June: Association for Dementia Studies at University of Worcester seeks Senior Research Fellow in Dementia Studies**

The Association for Dementia Studies at the University of Worcester is seeking an experienced and inspiring Senior Research Fellow in Dementia Studies to be a key player in the Association of Dementia Studies and contribute to research across the wider School of Allied Health and Community. The post is offered full-time but part-time applicants will be considered. They are particularly interested in hearing from candidates who have a track record in research in later stages of dementia, complex diagnoses, family care, distress behaviours, frailty, care homes and hospital care. Please contact Dr Shirley Evans by email on shirley.evans@worc.ac.uk for an informal discussion. For further information please see:

https://jobs.worcester.ac.uk/Vacancy.aspx?ref=SADC2201-R
### AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
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<tr>
<td>1 July</td>
<td>Neuronet Meeting (Barcelona, Spain)</td>
<td>Ange, Chris and Jean</td>
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<tr>
<td>7 July</td>
<td>Novo Nordisk Neuroinflammation Summit</td>
<td>Jean</td>
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<tr>
<td>11 July</td>
<td>GSK Health Advisory Board</td>
<td>Jean</td>
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<td>11 July</td>
<td>eBRAIN-Health kick-off meeting</td>
<td>Dianne, Daphné and Ange</td>
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<td>14 July</td>
<td>PRIME dissemination team</td>
<td>Ange</td>
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<tr>
<td>14-15 July</td>
<td>ADIS Kick-off meeting (Sankt-Augustin, Germany)</td>
<td>Ana, Soraya and Chris</td>
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<td>15 July</td>
<td>Joint PCWP - Patient Engagement Collaborative (FDA) meeting</td>
<td>Ange</td>
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<tr>
<td>23-25 August</td>
<td>Kuopio Alzheimer Symposium 2022</td>
<td>Ana</td>
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### CONFERENCES 2022

<table>
<thead>
<tr>
<th>Date</th>
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<tbody>
<tr>
<td>8-9 September</td>
<td>International Dementia Conference 2022: Brave New World, <a href="https://www.dementiaconference.com/">https://www.dementiaconference.com/</a></td>
<td>Sydney, Australia</td>
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<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>29 September-1 October</td>
<td>11th Congress of the German Alzheimer Association (Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz), “Dementia: Daring new ways”, <a href="http://www.demenz-kongress.de">www.demenz-kongress.de</a></td>
<td>Mülheim an der Ruhr, Germany</td>
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<td>29 November-2 December</td>
<td>Clinical Trials on Alzheimer’s Disease (CTAD 2022), <a href="http://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