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ALZHEIMER EUROPE NEWSLETTER

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WELCOME



This month, in a decision closely watched by the European dementia community, the European Medicines Agency decided not to authorise aducanumab for the treatment of mild cognitive impairment due to Alzheimer's disease and mild Alzheimer's dementia, deeming that there was not enough scientific evidence on clinical efficacy. This is of course disappointing news, but we welcome the announcement from Biogen confirming the launch of a post-approval trial in May 2022, aiming to provide more definitive evidence.

Staying within the area of research, three papers have recently been published to which Alzheimer Europe has contributed, including a paper on the use of computer tools in memory clinics, another about developing a mobile health platform for dementia prevention, and a report on Alzheimer's disease in the EU during and after the pandemic. We are also delighted to announce that the EU-Fingers project website is now live, and that our 2019 yearbook on "Estimating the prevalence of dementia in Europe" has been included in the WHO Global Dementia Observatory Knowledge Exchange Platform.

Adding to this flurry of new publications and resources, videos of the 31st Alzheimer Europe Conference sessions are now available on the conference platform. If you did not attend the event, you can still gain access, for a small fee. All recordings will be available until 31 March.

On the policy front, the European Group of Governmental Experts on Dementia held its final meeting of 2021, which was attended by representatives of 19 countries, the European Commission, and the WHO. Also at the European level, French President Emmanuel Macron announced his country's priorities for its 6-month term of the Presidency of the Council of the European Union. These include a section on health, with major research plans and Alzheimer's disease as a possible focus.

My team has every reason to be proud of its achievements over the past 12 months and I would like to thank everyone who supported us in our efforts to ensure dementia remains a European priority, not least the EU and its health and research programmes. This newsletter is the last edition of 2021 and the last funded under an operating grant from the European Union's Health Programme 2014-2020. I am relieved and delighted to inform you that our application for a new grant under the EU's Disability programme has been accepted and we are currently negotiating the details of this. I hope to be able to provide further details in our first newsletter of 2022.

I would also like to thank the European Working Group of People with Dementia, our members, partners, sponsors, the European Alzheimer's Alliance, and the Alzheimer Europe Foundation and Board for their hard work and support.

Despite another strange and difficult year with the ongoing global pandemic, I hope that 2021 nonetheless has had some silver linings for you all and that 2022 has started well!

Jean Georges
Executive Director

Sponsors of the month

Alzheimer Europe would like to express its gratitude to a new sponsor for its 2021 activities and a new sponsor for its 2022 activities

Read more about sponsorship opportunities here:

<https://www.alzheimer-europe.org/about-us/governance/finances/2021-sponsorship-opportunities>

2021



An Roinn Talmhaíochta,
Bia agus Mara
Department of Agriculture,
Food and the Marine

2022



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ALZHEIMER EUROPE

3 December: Alzheimer Europe co-authors paper on "Assessing the Views of Professionals, Patients, and Care Partners Concerning the Use of Computer Tools in Memory Clinics"



Alzheimer Europe is delighted to have co-authored a new paper, published in JMIR Publications and entitled "Assessing the Views of Professionals, Patients, and Care Partners Concerning the Use of

Computer Tools in Memory Clinics: International Survey Study".

The study found that the majority of all end-users (i.e. professionals, patients, care partners) gave positive feedback regarding using computer tools in memory clinics, and this held true for diagnostic tools, prognostic tools, communication tools, and tools directed at patients such as online cognitive testing.

The authors of the study who include Jean Georges, Executive Director, Alzheimer Europe, identified several important hindering and stimulation factors regarding the use of such computer tools.

Stimulating factors (facilitators) were found to be:

- Tools should be user-friendly and increase diagnostic accuracy.
- Furthermore, tools should cost little time and contain information on reliability and validity.

Hindering factors (barriers) were:

- A tool not being connected to electronic patient files.
- Fear of losing important information.

Patients and care partners thought favourably of tools as long as they were used in a complementary fashion with the current way of working and not as a replacement.

These results provide an important step in the iterative process of developing computer tools for memory clinics and pave the way for further implementation.

During the recent Alzheimer Europe Conference, lead author Aniek M. van Gils had the opportunity to share these results in a parallel session, on "New ways of diagnosing dementia and of recruiting and assessing research participants".

You can read the paper, here:

[JMIR Formative Research - Assessing the Views of Professionals, Patients, and Care Partners Concerning the Use of Computer Tools in Memory Clinics: International Survey Study](#)

10 December: Alzheimer Europe contributes to EURACTIV report on Alzheimer's disease in the EU during and after pandemic

Ana Diaz, Project Officer at Alzheimer Europe and Chris Roberts, Chairperson of the European Working Group of People with Dementia (EWGPWD) have contributed to a special report by EURACTIV, about Alzheimer's disease in the EU during and after pandemic. The report includes five articles: The first article, published on 29 November 2021, features Dr Natasha Azzopardi Muscat, Director of Country Health Policies and Systems at WHO Regional Office for Europe: [WHO official: COVID-19 seriously worsened dementia's state-of-play in Europe](#).



The second article, published on 7 December, features Chris Roberts and his wife and carer Jayne Goodrick, who highlight some of the challenges both patients and carers face daily: [Dementia: everyone has heard the word, but no one understands](#).

The third article, published on 8 December, discusses the benefits of patient involvement in dementia research and includes a comment from Ana Diaz: ['Increasingly popular' patient engagement in Alzheimer research is bearing fruit](#).

The fourth article, published on 10 December, is written by EFPIA and looks at concrete steps Europe can take to be prepared for Alzheimer's disease: [European health systems must prepare for Alzheimer's](#).

The fifth article, published on 10 December, examines transposing research outcomes into digital products and services: [Alzheimer's researchers do not want to get lost in digital translation](#).

The report received support from the European Federation of Pharmaceutical Industries and Associations (EFPIA). It can be downloaded [here](#).

16 December: Alzheimer Europe continues to comply with EMA's strict eligibility criteria

On 16 December 2021, the European Medicines Agency (EMA) confirmed that Alzheimer Europe continues to comply with its strict eligibility criteria, as defined by its Management Board, and can continue to be involved in its activities. The list of all the patients' and consumers' organisations that are involved in EMA activities can be viewed here:

<https://www.ema.europa.eu/en/partners-networks/patients-consumers/eligible-patients-consumers-organisations>

17 December: Videos of 31st Alzheimer Europe Conference #31AEC are now available on-demand

We are pleased to announce that videos of the 31st Alzheimer Europe Conference sessions (plenary, parallel and symposia) are now available on-demand.

If you missed a session or if you want to re-watch a presentation, you can now go to the agenda, find the session and watch the recordings of the truly inspiring speakers who

participated. You can also watch any of the posters and quick oral presentations.

If you were not previously registered for the event, but would like to gain access to these videos, you can still register for a reduced fee of EUR 25.

All recordings will be available on the conference platform until 31 March 2022.

Register here:

[Online conference registration](#) | Alzheimer Europe (alzheimer-europe.org)



Alzheimer Europe networking (online)

On 29 November, Iva and Jean attended the INTERDEM General Assembly.

From 29 November to 1 December, Alzheimer Europe organised its 31st Annual Conference "Resilience in dementia: Moving beyond the COVID-19 pandemic".

On 3 December, Ange attended the kick-off meeting of the IMI EPND project.

On 6 December, Ange, Cindy and Jean attended the summit of the World Dementia Council.

On 7 December, Alzheimer Europe organised a meeting of the European Group of Governmental Experts on Dementia.

On 8 December, Dianne and Ana attended the meeting of the EWGPWD on brain donation.

On 9 December, Jean attended a meeting of the Biogen Brain Trust.

On 13 December, the Alzheimer Europe Board met.

On 13 December, Dianne and Chris attended the EPF AI in Healthcare: Ethics and Implications Webinar.

On 13 December, Ange participated in a meeting of the NeuroCohort taskforce.

On 14 December, Ana, Ange, Dianne and Jean attended the pre-project start meeting of the Pattern-cog project.

On 15 December, Ana and Cindy participated in the EU FINGERS Advisory Board Social Get Together.

On 15 December, Owen attended an online webinar on the European Commission's Healthier Together initiative on Non-Communicable Diseases.

On 16 December, Jean attended the GSK Health Advisory Board.

On 17 December, Jean attended the OneNeurology European Summit.

On 17 December, Jean met with the European Association of Service Providers for Persons with Disabilities.

On 17 December, Jean attended a WHO Europe meeting on the COVID-19 situation in the European region.

On 22 December, Ana and Dianne attended the social meeting of the EWGPWD.

EU PROJECTS

26 November: The work of the LETHE Advisory Board kicks off



The LETHE Advisory Board (AB) was set up in October 2021 and is composed of people at a higher risk of dementia and members of the public with an interest in brain health. The LETHE AB has 7 members (2 from Austria, 2 from Italy, 2 from Sweden and 1 from

Finland) and will be supporting LETHE until the end of the project. This will provide an opportunity for the LETHE team to obtain relevant feedback from people who could be potential users of the LETHE app and intervention.

To achieve this, the AB will meet regularly and will address different topics of interest for the project. The first of these interactions took place during the last week of November. The topic of the meetings was the use of technology in everyday life and the most relevant requirements for the LETHE app from the perspective of users.

The meetings lasted around 2 hours and the discussions were very lively and fruitful. The discussions were co-moderated by Alzheimer Europe and THL; many other LETHE colleagues from the clinical sites and technological partners contributed to the meeting. The feedback was much appreciated by the LETHE leadership and team and will be used during the development of the app and intervention.

LETHE is a four-year project aiming to provide a data-driven risk factor prediction model for older individuals at risk of cognitive decline building upon big data analysis of cross-sectional observational and longitudinal intervention datasets from 4 clinical centres in Europe including the 11-years analysis of the FINGER study.

<https://www.lethe-project.eu/>

30 November: IDoService project hosts first co-design workshop about developing a skills exchange service



The IDoService project aims to co-develop tools to make it easier for people living with mild to moderate dementia to connect with relevant groups and to have more opportunities for active

participation in meaningful activities. It addresses the need to

feel valued for any skills or expertise people might wish to share.

Interviews and focus groups organised during the first year of the project revealed that people are looking for more opportunities to participate in social and cultural activities, to volunteer, or to benefit from one-to-one support to be able to master personal challenges or activities again. A design concept derived from these suggestions and other collected information would be to develop a skills exchange service in Greater Manchester making it easier for people to share their skills by volunteering for others and being supported in return by other volunteers.

The IDoService project has now moved into its second stage where it conducts co-design workshops to work together on the service concept. A first workshop with people living with mild to moderate dementia and care partners was organised at the end of November with the support of Age UK Salford at one of their dementia cafés. Participants were encouraged to bring personal objects related to activities they cherish or would like to practice in (again). Using these objects, over cakes and cups of coffee, the project team discussed their interests and possibilities for the skill exchange service. Following this, three online workshops were organised with staff from charities and organisations related to dementia, service provision and volunteering to discuss volunteering opportunities in Greater Manchester and how to connect people with them.

Further workshops are planned for February 2022, to discuss a more advanced concept of the skills exchange service and its realisation. The objective is to simulate the service concept later in the spring or summer, with interested people living with dementia in Greater Manchester to assess the feasibility of the service as well as various outcomes such as perceived usefulness and usability.

For more information see www.idoservice.org.

For any questions or suggestions contact Dr Isabelle Tournier by email idoservice@mmu.ac.uk or Twitter [@idoservice4dem1](https://twitter.com/idoservice4dem1)

1 December: PRIME project hosts a masterclass on Alzheimer's disease and vascular risk factors

The Horizon 2020-funded PRIME project ("Prevention and Remediation of Insulin Multimorbidity in Europe") aims to unravel how brain disorders throughout life can be traced to alterations in insulin signalling and how this relates to type 2 diabetes and obesity. Last month, PRIME organised a webinar for its project partners, entitled "Alzheimer's Disease



pathophysiology and vascular contributions". Angela Bradshaw (Project Officer) attended for Alzheimer Europe.

During the webinar, Prof. Pieter Jelle Visser of Maastricht University gave an overview of Alzheimer's disease pathophysiology and diagnostics. He explained how our understanding of AD has progressed since Alois Alzheimer first identified the condition in 1906, and showed how tests that measure different biomarkers can help diagnose Alzheimer's disease more accurately and earlier. Next, Veerle van Gils discussed the vascular contributions to Alzheimer's disease and its related cognitive decline, presenting her latest findings on the association between diabetes and Alzheimer's disease. These findings indicate that older people with diabetes may have an altered risk profile for Alzheimer's disease. She underlined that there are multiple vascular risk factors that may contribute to increased Alzheimer's disease diagnoses, such as cardiovascular disease and hypertension as well as diabetes.

<https://prime-study.eu/>

1 December: bPRIDE and MIRIAD projects co-author paper on blood-based biomarkers for Alzheimer's disease and their clinical implementation



Researchers from the bPRIDE (blood PRotein Identification to Discriminate dEmentias) and MIRIAD (Multi-omics Interdisciplinary Research Integration to Address DEmentia diagnosis) projects have co-authored a new paper, published in The Lancet Neurology, entitled "Blood-based biomarkers for Alzheimer's disease: towards clinical implementation". They also

held a joint parallel session at the recent virtual Alzheimer Europe Conference, to share their findings. Here is a summary of the paper:

For many years, blood-based biomarkers for Alzheimer's disease seemed unattainable, but recent results have shown that they could become a reality. Convincing data, generated with new high-sensitivity assays, have emerged with remarkable consistency across different cohorts, but also independent of the precise analytical method used. Concentrations in blood of amyloid and phosphorylated tau proteins associate with the corresponding concentrations in CSF and with amyloid-PET or tau-PET scans. Moreover, other blood-based biomarkers of neurodegeneration, such as neurofilament light chain and glial fibrillary acidic protein, appear to provide information on disease progression and potential for monitoring treatment effects. Now the question emerges of when and how to bring these biomarkers to clinical practice. This step would pave the way for blood-based biomarkers to support the diagnosis of and development of

treatments for Alzheimer's disease and other dementias. You can read the paper, here:

[Lancet Neurol BBB Towards implementation.pdf](#)

1 December: RADAR-AD represented at 31st Alzheimer Europe Conference "Resilience in dementia: Moving beyond the COVID-19 pandemic"



RADAR-AD researchers Marijn Muurling from Amsterdam UMC, Sajini Kuruppu from King's College London and Thanos Stavropoulos from the Centre for Research and Technology Hellas represented the RADAR-AD project at the 31st Alzheimer Europe Conference (31AEC) which took place online from 29 November to 1 December 2021.

They spoke about the research in RADAR-AD, the set-up of the clinical study and its ambitions, as well as the selection of functional domains and devices for the project.

Among the audience for RADAR-AD's virtual booth were patients and carers, academics and clinicians.

Read the full news story [here](#).

3 December: AI-Mind presents at Alzheimer Europe and ISPOR Europe conferences

At the 31st Alzheimer Europe Conference held online from 29 November to 1 December 2021, Dr Ira Haraldsen from Oslo University Hospital (Norway), representing



and leading the EU-funded AI-Mind project, presented a quick-oral presentation entitled "AI-Mind: artificial intelligence as key for dementia prevention for people affected by Mild Cognitive Impairment". Patients and carers, policy makers, academics and clinicians were among the audience.

The presentation provided an overview of the AI-Mind project including its objectives, key facts, consortium, concept, and expected outcomes. The AI-Mind clinical study is a key part of the project and will help develop and validate artificial intelligence (AI)-based tools to predict who is likely to develop dementia. The study will enrol people with mild cognitive impairment in January 2022 in Italy, Spain, Finland and Norway.

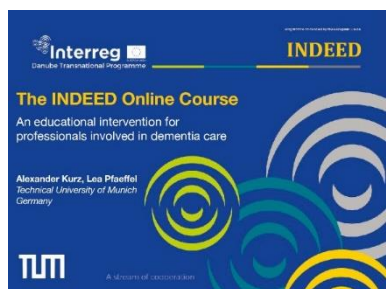
The AI-Mind Consortium also had the opportunity to hold a branded virtual booth during the Alzheimer Europe Conference, where the AI-Mind communication tools were showcased such as the website, infographic, factsheet and explanatory video. All the materials give an overview of why and how the AI-Mind innovations will contribute to dementia risk estimation and impact patients' medical journey.

The AI-Mind project was also represented at the Virtual ISPOR Europe 2021 conference held between 30 November to 3 December under the theme "Emerging Frontiers and Opportunities: Special Populations and Technologies". Dr Signe Daugbjerg from Università Cattolica Del Sacro Cuore (Italy) presented a poster entitled "Assessment Methods of Artificial Intelligence Supported Health Technologies. A Systematic Literature Review and Web-page Search". In this work, a literature review of studies describing methods or frameworks to assess AI-supported health technologies was performed as well as a web-page search of international agencies to identify important aspects to consider when implementing and assessing AI technologies.

For more information about the AI-Mind project, visit:

<https://www.ai-mind.eu/>

6 December: INDEED project launches new online course aimed at multiple professions involved in dementia care



On 6 December 2021, the INDEED project launched a new online course on dementia, which is developed for multiple professions involved in dementia care including (social) entrepreneurs.

It has been created by experts from 11 countries with support from the EU Interreg Danube Transnational Programme.

INDEED has tried to make the course attractive and pleasant by including texts, infographics, videos, quizzes and a comprehensible language style. The content is compatible with European medical guidelines. Please have a look at the course here:

<https://indeed-project.eu/about-us/>

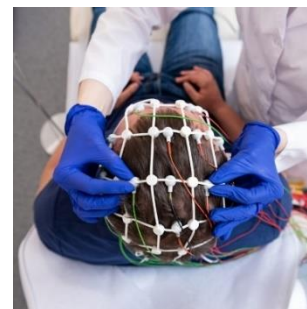
You can also watch a short video about the course, here:

<https://www.youtube.com/watch?v=IY8Z62x4-sI>

10 December: Prof. Hanna Renvall, leader of WP2 in AI-Mind, listed in the top 10 influencers in the health sector

On 10 December, the leading Finnish medical magazine *Mediuutiset* has published the list of the most influential people who impacted the health sector in 2021. "Care and Treatment Developers" is one of 10 different categories considered in the ranking.

For her work within the AI-Mind project, Prof. Hanna Renvall from Helsinki University Hospital (HUS) was recognised by the Finnish medical magazine as one of the top 10 Care and Treatment Developers in the health sector in 2021. AI-Mind aims at developing Artificial Intelligence (AI)-based tools for people with Mild Cognitive Impairment (MCI) who are at risk of developing dementia. In AI-Mind, different methods are used to study brain functionality including electroencephalogram (EEG) and magnetoencephalogram (MEG).



In the Work Package 2 led by Prof. Renvall, which includes research on brain data extraction, teams are bringing together and implementing different analysing methods for data collected through EEG and MEG screening of people with MCI. One of the strengths and opportunities of the AI-Mind project is the amount of neuroimaging data to be analysed, which is often a bottleneck for developing novel and functional neuroimaging tools for clinical use.

<https://www.ai-mind.eu/blog/prof-hanna-renvall-leader-of-work-package-2-wp2-in-ai-mind-listed-in-the-top-100-influencers-in-the-health-sector/>

16 December: Alzheimer Europe co-authors PRODEMOS project paper on "Design and development of a mobile health (mHealth) platform for dementia prevention"

The PRODEMOS project has published a new paper in the journal *Frontiers in Neurology*, entitled "Design and Development of a Mobile Health (mHealth) Platform for Dementia Prevention in the Prevention of Dementia by Mobile Phone Applications (PRODEMOS) Project".



Mobile health (mHealth) has the potential to bring preventive healthcare within reach of populations with limited access to preventive services, by delivering personalised support at low cost. Although numerous mHealth interventions are available, very few have been developed following an evidence-based rationale or have been tested for efficacy. This article describes the systematic development of a coach-supported mHealth application to improve healthy lifestyles for the prevention of dementia and cardiovascular disease in the United Kingdom (UK) and China.

Early involvement of end-users in the development process and during evaluation phases improved acceptability of the mHealth intervention. The actual use and usability of the PRODEMOS intervention will be assessed during the ongoing PRODEMOS randomised controlled trial, taking a dual focus on effectiveness and implementation outcomes.

Jean Georges, Executive Director, Alzheimer Europe, is one of the co-authors of this paper. You can read the paper, here:

[Frontiers | Design and Development of a Mobile Health \(mHealth\) Platform for Dementia Prevention in the Prevention of Dementia by Mobile Phone Applications \(PRODEMOS\) Project | Neurology \(frontiersin.org\)](#)

22 December: EU-FINGERS project launches its website



The EU-FINGERS consortium is proud to announce the official launch of its website <https://eufingers.com/>

EU-FINGERS is, by means of a precision medicine approach, working on the topic of the prevention of Alzheimer's disease (AD) and builds on the work of similar existing European studies. The mission is to develop, test and validate methods and tools supporting precision prevention of Alzheimer's disease and dementia through multidomain interventions, including both non-pharmacological and pharmacological interventions. Alzheimer Europe is involved in the Patient and Public Involvement (PPI) activities of the project and also co-leads the communications activities of the project.

22 December: Neuronet convenes annual event on European research collaboration in Alzheimer's disease & beyond



Neuronet, a coordination and support action funded by the Innovative Medicines Initiative (IMI), brings together 21 IMI consortium projects working on neurodegenerative disease (such as Alzheimer's), encompassing

over EUR 386 million in research funding.

The Neuronet programme held four parallel sessions as part of the Alzheimer Europe conference on 29 November to 1 December 2021. This involved showcasing public and patient involvement, common challenges & lessons learned, how preclinical research can have a potential impact on people's lives and have a look into the future as well as the portfolio's impact.

The first parallel session was chaired by Dianne Gove from Alzheimer Europe. It was entitled "Elevating the patient voice: public involvement in Innovative Medicines Initiative neurodegeneration projects". The four presentations in this session introduced the work of involving the public, patients as well as people affected by neurodegenerative conditions in IMI projects. First, Ana Diaz (Alzheimer Europe) spoke about Alzheimer Europe's work to promote Public Involvement in dementia research. Next, Stina Saunders & a member of the participant panel (The University of Edinburgh) introduced the

lessons from the European Prevention of Alzheimer's Dementia Research Participant Panel. After that, Johanna Graeber (University Medical Center Schleswig-Holstein) reflected on the patient involvement & engagement in IDEA-FAST. The session closed with a presentation by Alison Keogh (University College Dublin) on a roadmap of activity to develop patient and public involvement and engagement structures in Mobilise-D.

The second parallel session was chaired by Carlos Diaz from SYNAPSE, who is Neuronet coordinator. The session revolved around "Collaboration and best practice: common challenges & lessons learned from the Innovative Medicines Initiative neurodegeneration portfolio".

After an introduction to the Neuronet approach on supporting collaboration and showcasing achievements, by Carlos Diaz. Four consortium members introduced the work that has been done as part of Neuronet's Working Groups, followed by a general discussion between panel members. The speakers included:

- Lennert Steukers (Janssen) – Data sharing & Re-use
- Dalia Dawoud (NICE) – Health Technology Assessment/Regulatory
- Angela Bradshaw (Alzheimer Europe) – Ethics & Patient Privacy
- Lewis Killin (SYNAPSE) – Sustainability

The third session was chaired by Craig Ritchie, Director of the Centre for Dementia Prevention at Edinburgh University, and was entitled "From bench to bedside: preclinical research in Innovative Medicines Initiative neurodegeneration projects". In this session, Shruti Desai (Radboud UMC) started with a presentation about the quantification of mitochondrial morphofunction in neuronal cells that is being investigated within the PD-MitoQUANT project. Next, Tania Fowke (MIMETAS) reported on the progress building on the neurovascular model they developed during the ADAPTED project, as they are working on blood-brain barrier and neurovascular unit models, including a model of stroke which frequently co-occurs with Alzheimer's disease as part of the IM2PACT project where (in collaboration with Horizon 2020 projects ENTRAIN and CoSTREAM). Showcasing how developments from closed projects can be repurposed and developed further. After that, Yang Shi (MRC Laboratory of Molecular Biology) introduced the most recent findings from the IMPriND project about the structure-based classification of tauopathies and identification of PET ligand binding sites, a significant contribution to the field which was acknowledged as a front cover feature of Nature. The session closed with a presentation by Jannis Wißfeld (University Hospital Bonn) who presented about Alzheimer's disease and PHAGO's findings that a protective variant of CD33 increases microglial activation.

The fourth session was chaired by Lennert Steukers (Janssen), entitled "Looking to the future: Impact of the Innovative

Medicines Initiative's neurodegeneration portfolio". It started with two presentations:

Fatima Salih (NICE) – Outcomes from the consultation on the IMI neurodegenerative disease research agenda

Carlos Diaz (SYNAPSE) – Neuronet's NEURO Cohort, Knowledge Base & Asset Map

This was then followed by a roundtable discussion involving representatives of a HTA/regulatory authority – Fatima Salih (NICE), an SME – Carlos Diaz (SYNAPSE), Industry – Laurent

Pradier (SANOFI), Patient advocacy – Angela Bradshaw (Alzheimer Europe) as well as academia – Martin Hofmann-Apitius (Fraunhofer SCAI), bringing together the perspectives from a wide range of stakeholders to the table.



EU project acknowledgements



innovative
medicines
initiative



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

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NEURONET – grant agreement 821513

PRIME – grant agreement 847879

PRODEMOS – grant agreement 779238

RADAR-AD – grant agreement 806999



Luxembourg National
Research Fund



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Members of the European Alzheimer's Alliance



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

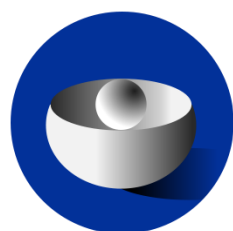
Austria: Claudia Gamon (Renew Europe); Monika Vana (Greens/EFA). **Belgium:** Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D). **Czech Republic:** Tomáš Zdechovský (EPP). **Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe); **Finland:** Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (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); Chrysoula Zacharaopoulou (Renew). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). **Greece:** Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE-NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraiki (EPP); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (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 Blinkeviciute (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:** Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP). **Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D). **Romania:** Cristian-Silviu Busoi (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Tanja Fajon (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtsaus (Greens/EFA). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (ECR).



EU DEVELOPMENTS

1 December: EMA convenes a virtual meeting of its Patients and Consumers' and Healthcare Professionals Working Parties



Last month, the European Medicines Agency (EMA) hosted an online meeting of its Patient and Consumer's (PCWP) and Healthcare Professionals Working Parties (HCPWP). The meeting was attended by all eligible patient organisations and professional bodies, and was chaired by Juan Garcia Burgos

(EMA), Kaisa Immonen (EPF; PCWP) and Ulrich Jaeger (HCPWP). Angela Bradshaw (Project Officer) represented AE at the meeting.

The first half of the meeting was focused on updates from the EMA on new regulations, guidelines and directives, specifically the recently-proposed HTA (Health Technology Assessment) regulation, the Clinical Trials Regulation (which will come into force in January 2022) and the ICH E8 Guideline on general considerations for clinical studies. Michael Bertgen of the EMA explained how the EMA has worked closely with EUNetHTA, the European Network for HTA, since 2010, developing a workplan for activities between 2017 and 2021. Areas with specific needs for collaboration included scientific advice, patient and clinician engagement, and therapeutic innovations.

Peter Vankeerberghen (EMA) then reminded the audience of how the Clinical Trials Regulation will be implemented, with the launch of the new Clinical Trial Information System (CTIS) on 31 January 2022. The CTR aims to streamline clinical trials conduct and increase efficiencies and transparency.

After a brief break, Mavris Mavria (EMA) explained to attendees how patient organisations and advocates participate in EMA scientific committees, describing the decision-making process and showing how civil society representatives are included in committees such as the CHMP (Committee for Medicinal Products for Human Use). She emphasised that they can be

involved either as representatives of the PCWP, representatives of their own organisations or as individual experts by experience. At the end of the meeting, the co-Chairs moderated an interactive discussion with feedback from the audience via sli.do polling, asking the attendees to identify the key challenges preventing active engagement with the EMA (e.g. lack of funding or resources) and what their priorities are going forwards.

Among the priorities identified by attendees were: understanding the impact of COVID-19 on the conduct of clinical trials; digital biomarkers; inclusion and accessibility; and areas of unmet need, particularly non-communicable diseases that have been overlooked due to the pandemic. The next PCWP/HCPWP will be held at the beginning of March 2022.

<https://www.ema.europa.eu/en/committees/working-parties-other-groups/chmp/patients-consumers-working-party>

7 December: European Group of Governmental Experts meets online



The European Group of Governmental Experts on Dementia has met online, holding its final meeting of 2021, exchanging information and knowledge on the latest developments in dementia policy and practice.

The meeting was attended by representatives of 19 countries: Austria, Bulgaria, Czech Republic, Finland, France, Germany, Greece, Iceland, Israel, Latvia, Malta, Netherlands, Norway, Portugal, Slovenia, Sweden, Switzerland, Turkey and United Kingdom (England). Representatives from the European Commission (DG SANTE and DG RTD), the World Health Organization (WHO) and WHO Europe were also present at the meeting.

A guest lecture was given by the Global Coalition on Aging (GCOA), sharing details of their work on the Alzheimer's Innovation Readiness Index, a recent publication scoring countries on their progress in relation to dementia policy across different domains (e.g. care and support, research etc.)

The group also heard from the WHO, about the Global Status Report on Dementia which showed that more work is needed if the objectives of the Global Action Plan on Dementia 2017-2025 are to be met. WHO Europe also provided updates on its work on the establishment of a European Mental Health Coalition, to help deliver its programme of work related to the European Framework for Mental Health.

National experts also presented on developments in their countries across a range of issues including the implementation of national dementia strategies, development of resource websites, new models of care and support, as well as guidance on oral health for people with dementia. The next meeting of the group is expected to take place on 14-15 June 2022.

9 December: France sets out its priorities for EU Presidency



During a conference on 9 December, French President Emmanuel Macron set out France's priorities for its 6-month term of the rotating Presidency of the Council of the European Union in 2022.

The agenda builds on President Macron's Sorbonne speech in 2017, in which he set out the need for a sovereign EU, able to play a strong role internationally, whilst protecting its own values and interests.

As part of the strategic overview, the priorities set out a vision of Europe for 2030, focused around investment, values, youth, culture and health. Of particular interest in this agenda, the health section calls for a joint research agency and major research plans, citing Alzheimer's disease as a potential area of focus. More information on the French Presidency of the EU is available at:

<https://presidence-francaise.consilium.europa.eu/>

13 December: European Commission and OECD publish country health profiles



The European Commission and the Organisation for Economic Cooperation and Development (OECD) have published the third edition of the Country Health Profiles (CHPs), part of the of the

State of Health programme.

The CHPs provide a concise and policy-relevant overview of health and health systems in the EU/European Economic area, emphasising the particular characteristics and challenges in each country.

The 2021 edition has a specific focus on the impact and responses of European health systems to the COVID-19 pandemic. Each CHP provides a short synthesis of:

- health status (including mortality from COVID-19)
- risk factors to health (including behavioural and environmental risks)
- the organisation of the health system and health spending
- the effectiveness, accessibility and resilience of the health system to the pandemic.

An accompanying companion report focuses on three main takeaways:

- understanding the far-reaching health impacts of the COVID-19 pandemic
- maintaining the advantages of digital innovation in healthcare delivery and public health
- rethinking health workforce strategies and planning after the COVID-19 pandemic.

The CHPs are part of the State of Health in the EU cycle and are released once every two years, alternating with the release of the Health at a Glance: Europe report. The CHPs and companion report can be found here:

https://ec.europa.eu/health/state/country_profiles_en

POLICY WATCH

6 December: World Dementia Council hosts its 2021 Summit, "Looking to the future: the dementia landscape"

On 6 December, the World Dementia Council (WDC) held its 2021 Summit, under the banner "Looking to the future: the dementia landscape". Originally conceived as an in-person, hybrid event in

London, the Summit was reorganised as a virtual-only event due to travel restrictions and COVID safety concerns. The Summit was focused on dementia science and research and drew and was attended by over 150 stakeholders from industry, academic institutions, patient associations and international initiatives. Dr Cindy Birk and Dr Angela Bradshaw represented Alzheimer Europe at the Summit. A further event will be held in January 2022, addressing awareness, prevention and care.

Discussions at the Summit were framed around three key topics: data sharing, innovation and incentives, and research policy & funding. Sessions on these topics were interspersed with perspectives and presentations by policymakers, including



Dr Catherine Berens of the European Commission, Ulrik Vestergaard Knudsen of the OECD, and Devora Kestel of the WHO. The Summit was chaired by Prof. Philip Scheltens (Chair of the WDC) and Lenny Shallcross (Executive Director of the WDC), and was sponsored by Johnson & Johnson and Eli Lilly.

The first session addressed the topic of data sharing, and was chaired by Dr Niranjana Bose, Managing Director of Health & Life Sciences at Gates Ventures. First, Dr Pierre Meulien (Executive Director of the Innovative Medicines Initiative/IMI) presented an overview of the IMI neurodegeneration portfolio, underlining the breadth of data being generated, and describing the European Platform for Neurodegenerative Diseases, a new IMI project that is aiming to facilitate data and sample sharing. Then, Prof. John Gallacher (Director of Dementias Platform UK) described the abundance of data being generated through dementia research, explaining that researchers are very keen to share and reuse data, but are impeded by technical and financial challenges. Next, Prof. Miia Kivipelto (Karolinska Institutet) spoke about the FINGER network, and the data that are being generated through different projects and centres. She explained that there is a need for more effective collaboration as a stepping stone towards data sharing, and that there is value in sharing insights and good practice as well as data.

The second session was focused on innovation and incentives, and the role of funders, regulators and industry in developing the dementia research landscape. Chaired by former FDA commissioner Dr Peggy Hamburg, this session included presentations and remarks from Prof. Fiona Wyatt, Chair of the UK Medical Research Council (MRC), Dr Hussein Manji, Global Head of Johnson & Johnson Science for Minds, and Dr Greg Moore, Corporate VP at Microsoft. Prof. Fiona Wyatt showed the substantial financial investment in research, and the extent of clinical data being generated in the UK, outlining the ambition to accelerate the pace of translation and build on existing initiatives. Dr Manji then described how Science for Minds is creating an open research culture to tackle areas of unmet medical need, by addressing societal aspects alongside science and innovation. The final panellist, Dr Greg Moore, focused on technical and cloud-based innovation and its role in enabling data sharing, helping scientists to unlock the full potential of data for the benefit of patients.

The third and final session of the Summit was entitled "Are we on track?" and was co-chaired by Prof. Philip Scheltens and Dr Maria Carrillo (Chief Scientist, Alzheimer's Association). The session addressed some important questions: is the research and policy landscape facilitating the development of new treatments? Is there enough global coordination? Is funding sufficient, and are the right projects being funded, or are new funding models required? Commenting on these questions were Dr Richard Hodes (Director of the National Institute on Aging/NIA), Dr Paul Stoeffels (Chief Scientific Officer, Johnson & Johnson), Prof. Mary Sano (ICAHN, Mt. Sinai, New York) and Prof. Julie Williams, Director of the UK Dementia Research Institute. Panellists discussed key challenges and barriers to effective dementia research and innovation, including

fragmented global funding infrastructures, and spoke about new initiatives being developed to address these challenges. Chris Roberts, Chair of the European Working Group of People with Dementia, made one of the final interventions in the session, highlighting the importance of effectively communicating research, and the value of participating in research, to address misconceptions and to help overcome fears. He also emphasised the value of involving people who are experts by experience in developing communications and conveying messages to the dementia community.

<https://worlddementiacouncil.org/summit2021>

9 December: WHO publishes Brief to raise awareness of impact of disease associated to mental health conditions and how to reduce it

The World Health Organization (WHO) has published a Partners' Brief called "Mental Health: It is Time to Act". The objective of this document is to sensitise the organisation's partners and the general public about the huge impact of disease associated to mental health conditions and the actions needed to reduce it.

One billion people have mental health disorders worldwide and the economic consequences of these conditions amount to around USD 1 trillion (approx. EUR 885 billion) per year in loss of productivity and higher health-care costs. To reverse these numbers, national and international investment in mental health must be stepped up and rationalised, insists the WHO, to ensure increased access to quality and respectful mental health services. Readers will also gain a better understanding of the role of the WHO in supporting organisations and governments to implement a scientific approach to mental health.

The WHO's work in mental health spans a broad range of activities including action on suicide prevention; alcohol, drugs and addictive behaviours; child and adolescent mental health and brain health; research and implementation of innovative psychological interventions and digital tools; human rights-based reforms for policy, law and services; mental health at work; mental health and psychosocial support tools for emergencies (including for COVID-19); and a new area of work on promotion of brain health and prevention and management of neurological conditions, including dementia.

Its proposed actions to transform and scale up mental health programmes worldwide will require social and financial action by individuals, communities and governments everywhere, in order to achieve Sustainable Development Goals (SDGs) targets 3.4 and 3.5. The SDGs were set up in 2015 by the United Nations General Assembly and are intended to be achieved by the year 2030.

[WHO Partners brief_Mental health and Substance Use.pdf](#)



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European priority**

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MEMBERS NEWS

30 November: Ireland's Dementia: Understand Together campaign raises awareness with "Let's Talk about Dementia" on 13 radio stations

In November 2021, the Dementia: Understand Together campaign partnered with the IRS group of local radio stations across Ireland to help create awareness of dementia.

The partnership highlighted:

- personal experiences of people who have been affected by dementia
- the importance and value of hobbies, social connection and community for people who are living with dementia
- the supports that are available for people who are affected by dementia and
- the helpful actions that people in local communities can take to help create a dementia-inclusive community.

The IRS and campaign partnership encompassed 13 local radio stations, who together reach out to over 990,000 weekly listeners and 1.2 social media followers. As a collective, over a period of three weeks, through 60-second content pieces, "stings", interviews and social media messages the campaign raised awareness for dementia and inspired local communities to take actions for dementia.

Interviewees included people with dementia, family carers and former carers as well as local community champions, who focused on one specific theme during the interview "Supporting the person with dementia to keep up hobbies and interests". Together they highlighted the importance of staying socially connected and talked about the things we can all do as friends,

family, neighbours, clubs and colleagues to support a person in doing so.

The practical nature of the conversations, with personal experiences and helpful tips and resources for those who want to ensure people with dementia can stay socially active and included, led to positive feedback from stations, participants and listeners alike.



7 December: Alzheimer Nederland marks National Volunteer Day in the Netherlands

National Volunteer Day took place on 7 December in the Netherlands. This is a day to pause and reflect on the country's fantastic volunteers. Annually, Alzheimer Nederland can count on the help of around 20,000 collectors and 3,600 volunteers spread right across the country. They represent the interests of people with dementia and their carers, provide information and organise for example the Alzheimer Cafés, enabling people to share experiences and come into contact with others. Thanks to their hard work Alzheimer Nederland is never far away for people with dementia and their loved ones. This is something the organisation is extremely grateful for and says that they are worth their weight in gold.

"It wasn't made easy this year for volunteers to offer people with dementia and their families what we would like to offer them," explained Gerjoke Wilmlink, Director of Alzheimer Nederland. "Particularly now, carers and people with dementia need a listening ear and contact with their peers. The Corona rules are changing all the time and the way things are organised have to be adjusted continually. We are so impressed by the creativity and flexibility of the volunteers. The starting point is always: What is possible? Different times, alternative locations and other ways of coming into contact."

Alzheimer Nederland can also count on volunteers for making more scientific research possible. From 7-13 November, collectors went door to door with a collection box - either



physically or digitally. The money raised is still being counted at this very moment, but the counter currently stands at EUR 2,137,000. This means that the record achieved in 2019 (EUR 2,017,000) has already been surpassed. Alzheimer Nederland thanks all the volunteer collectors, coordinators and district heads and notes that they are truly indispensable for a successful collection week!

During November, there was also a campaign to recruit new volunteers. Alzheimer Nederland volunteers are active in all kinds of ways. They provide neighbourhood support for people with dementia and their families, and provide information to increase awareness locally. Those interested can first take a test to see which volunteer functions suit them best.

Gerjoke Wilmink said: "Everyone has their own passions and talents that are of value to volunteer work. It is great to see that so many volunteers commit and an increasing number of volunteers with diverse backgrounds are signing up."

9 December: Germany presents its project "Sport moves people with dementia"



The project "Sport moves people with dementia" has brought together the German Olympic Sports Confederation (DOSB) and the German Alzheimer Association (DALzG). Later than originally planned because of the COVID-19 situation, four member organisations of DOSB have started with practical field work for people with dementia.

The table tennis club VfL Fortuna Marzahn and the Steglitzer Table tennis club (STTK) in Berlin as well as two clubs in Stuttgart are offering new services for people with dementia and their caregivers. The VfL has already tested a table tennis offer in a nursing home in Berlin where the weekly table tennis sessions are highlights of the week. Wheelchair users are also able to participate by using soft balls, for example. It has thus been possible for everybody to enjoy life through movement.

In the federal state of Nordrhein-Westfalen some clubs have started with a cognitive sport model of the German Sport University Cologne. The German Gymnastics Federation will address clubs in Frankfurt to help them be more inclusive of people with dementia and to adapt to their needs, so as to support them staying in clubs and not to leave because dementia sets in. Not all of these ideas are easy to realise. The situation of sport clubs in more rural areas are different from

city clubs. This has been shown in the region around Osnabrück which is a rural area in the federal state of Niedersachsen.

DOSB and DALzG have used the COVID "break" in a good way. Four online courses for trainers were designed to inform them about dementia and how to communicate with people with dementia in a proper way. They have got practical instructions on how to organise sporting activities for them. Many people have participated.

The German centre for neurodegenerative diseases (DZNE) Greifswald has joined the project for scientific evaluation. They will analyse the use of materials given to training persons, to examine sports for people with dementia.

The project was supported by the Federal Ministry of Family Affairs.

This has so far been a wonderful project where volunteers of the sport and the dementia movement have come together to improve participation, quality of life and prevention through movement and enjoyable activities for people with dementia and their carers.

More information:

<https://richtigfitab50.dosb.de/demenz>

15 December: Alzheimer Larissa hosts four events during December, to get into the Christmas spirit



During the first half of December, Alzheimer Larissa (Greece) got into the Christmas spirit with a number of activities organised for people with dementia and older people.

On 1 December, the festive atmosphere began with a session decorating with poinsettias (a.k.a. Christmas roses), as well as Christmas carols and the lighting of the tree by the President of Alzheimer Larissa, Eleni Nifli. Decorating with poinsettias captured the imagination of the participants, who asked to learn more about the flower. Eleni Nifli told them the myth and legend of the flower, explaining that it symbolises appreciation and gratitude and that it is offered as a Christmas present by many people. The content of the legend, the living sensory contact with the asteroid and colourful leaves of poinsettias fascinated and motivated the members of the group to share some of their own Christmas memories. Subsequently, the women's group asked for pots of poinsettias from the volunteers to prepare a Christmas present for the elderly in a

closed structure. The volunteers gave pots as well as the necessary materials, and they decorated the poinsettias.

On 3 December, Nafsika Kyritsi and Alexandra Mano led a large group of older people in creating cards with themes like Christmas trees, angels, and bells, in order to send them to their loved ones.

Finally, on 15 December, Konstantina Bethava presented a construction in the form of an angel, with a motion sensor, which transported the people with dementia and older people in attendance, to the manger of Bethlehem with the song "Holy Night".

17 December: Alzheimer Croatia achieves record attendance at its 7th Educational Conference on Alzheimer's Disease, EdukAI 2021



This year's EdukAI, held online on 17 December 2021, attracted a record number of participants (515) from Croatia, Sweden, Slovenia, Bosnia and Herzegovina and

Montenegro, so this gathering that deals with practical issues of care and nursing for people with dementia has become the most prominent place for regional exchange of knowledge, skills and experiences in this mostly neglected public health area in its particular region.

The City of Zagreb, as a dementia-friendly community, has been supporting the work of the Alzheimer Croatia for many years and successfully cooperates with it, among other things, in various European projects - said Mirela Šentija Knežević, PhD, delegate of the Mayor of the City of Zagreb, Tomislav Tomašević and Head of the City Health Office.

As many eminent Croatian scientists, neurologists and psychiatrists pointed out at the 7th EdukAI, COVID-19 infection can significantly affect cognitive abilities. This is especially dangerous for people with Alzheimer's and related diseases because it worsens the symptoms of dementia. The conference also noted that, in Croatia, the statistics showed a relatively low level of COVID-19 infection among people with dementia in nursing homes, but that epidemiological measures of "locking down" have had a negative impact on people with dementia, especially those who already found it difficult to understand and remember. They should be further protected during this pandemic, it was noted.

Participants of EdukAI 2021 welcomed the information that a modern ward for people with dementia will soon open in another home for the elderly in Zagreb, and that the users of the Home for the Elderly in Glina will return to it until the upcoming holidays.

Among other things, the conference discussed the real possibilities of a new drug against Alzheimer's disease, aducanumab, whose use is conditionally approved in the US, but for which Europeans will have to wait, because the

European Medicines Agency has decided to wait for results of the final clinical trials for this new and very expensive drug.

Particularly touching was the speech of a member of the Alzheimer Croatia, in which he pointed out that his bigger problem was fighting the administration rather than dementia itself. He is the youngest person diagnosed with Alzheimer's disease in Croatia, having contracted it at the age of 40. He is no longer able to work, so he lost his job, and the competent services do not recognise his disability. Therefore, with the help of Alzheimer Croatia, he is fighting to correct this injustice and to have his right to such income recognised.

- Among the conclusions of the conference are the need to:
- develop a comprehensive education programme for formal and informal caregivers
- establish a program for early diagnosis and destigmatisation of dementia
- ensure respect for the rights of people with dementia
- update the process of adopting the National Alzheimer's Plan in accordance with World Health Organization recommendations.

<https://www.edukal.alzheimer.hr/edukal-2021>

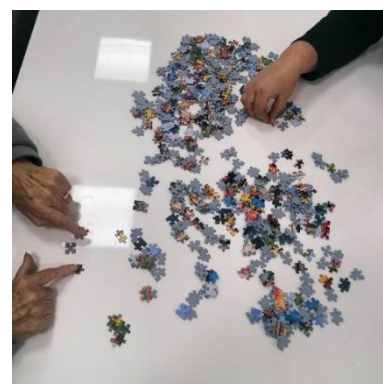
18 December: NGO Futura Montenegro's day care centre is holding a series of workshops for people with dementia

The NGO Futura Montenegro day care centre is a citizen support service to provide people with dementia and their families with day care and counselling, as well as support and assistance for the person with dementia in daily activities during their stay at the centre.

The project is being implemented by the Public Institution Center for Social Work for the municipalities of Nikšić, Plužine and Šavnik in partnership with NGO Futura from Podgorica, which has been dealing with dementia for years and developing counselling centres for dementia and Alzheimer's. The project is funded by the European Union through the IPA II program - the Program of the European Union and Montenegro for employment, education and social protection 2015-2017.

The goal of this project is defined as raising awareness at the local community level about the need to develop non-institutional social protection for people with dementia and their families through daily services in the community.

The project started on 1 March 2020 and lasts for 27 months, the service itself will be provided for 12 months as a pilot project, keeping in mind that there is currently no centre for people with dementia in Montenegro.



The capacity of the day centre is 15 people with dementia cared for by professional staff (psychologist, nurse and caregiver) who have passed the accredited "Training program for early detection, recognition of the first symptoms of dementia, prevention and education for proper treatment and care of the elderly and people with dementia and Alzheimer's disease" and received certificates.

NGO Futura, as a partner in the project, provides counselling services for centre users and members of their families as well as for all interested citizens who do not use the services of the centre but need to consult with experts.

People with dementia are to be given "mental exercises" that can help slow down memory loss. These exercises include a whole range of activities aimed at encouraging general thinking and memory. NGO Futura did some of these exercises in workshops with centre users. So far, 6 workshops out of a planned 25 have taken place.

20 December: Fundación Alzheimer España presents new platform for older people and pensioners in Spain



Alzheimer España

Last 8 October, the presentation of the "Platform for the Elderly and Pensioners" (Plataforma de Mayores y Pensionistas - PMP) was held in the Spanish Senate, where Fundación Alzheimer

España (the Alzheimer Foundation of Spain) was convened as a national entity that represents the interests of people with Alzheimer's disease and their families.

This platform was born as a process of confluence of the most important organisations, Federations and Confederations of elderly people and pensioners in Spain. This initiative was launched by the "Democratic Union of Pensioners" (Unión Democrática de Pensionistas - UDP), the "Spanish Confederation of Organizations for the Elderly" (Confederación Española de organizaciones de Mayores - CEOMA) and the "National Organization for the Blind" (Organización Nacional de Ciegos Españoles - ONCE).

The objective of this new platform is to establish, in the framework of government action, a permanent channel of contact about key decisions and public policies that could affect the interests of elderly people and pensioners, in such a way that policies and actions are not carried out without the participation (direct or indirect) of this group. Ultimately, this platform is an interlocutor between civil society and political parties.

The main agenda of this platform is focused on:

- pensions
- health and social services
- care and dependency
- legal protection of elderly people.



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20 December: Alzheimer Hellas hosts four events during December

On 2 December 2021, Alzheimer Hellas held on an online event entitled "New Clinical Study for a new drug for patients with mild dementia and mild cognitive impairment!" Magda Tsolaki, Professor of Neurology at Aristotle University of Thessaloniki (AUTH), neurologist-psychiatrist, theologian and President of the Panhellenic Federation of Alzheimer's Disease and Related Disorders.



On 9 December, Alzheimer Hellas in collaboration with the Panhellenic Federation of Alzheimer's Disease and Related Disorders presented an online event on "Speaking to Families on Heredity: Genetic Counselling in Dementia" by Marina Makri, mental health counsellor. At the same time, a short film about dementia was shown by Eleni Antoniadou, lawyer. The event was coordinated by Anastasia Pantazaki, Professor of Biochemistry, AUTH.

Moreover, the University Publications of Crete in collaboration with the Panhellenic Federation of Alzheimer's Disease and Related Disorders co-organised an online event on: "When reason chases memory - The multidimensional management of Alzheimer's Disease in the 21st century" on 16 December. The speakers at this event were: Nikos Koumbias, Scientific Curator of University Publications of Crete and Head of Publishing Series "Medicine & Society"; Ioannis Sotiropoulos, neuroscientist; Antonios Politis, psychiatrist; and Magda Tsolaki.

Finally, on 20 December Alzheimer Hellas held a Christmas Concert in cooperation with "Vocal Ensemble".

21 December: Alzheimer Nederland and Resto VanHarte organise "Unforgettable Cooking Clubs"

In October 2021, the first five Unforgettable Cooking Clubs were launched in the Netherlands. At these clubs, people with dementia and their loved ones can prepare a delicious three-course meal and then sit down and enjoy eating it together. The Cooking Clubs are organised monthly by Resto VanHarte and Alzheimer Nederland. Pleasure, a fun evening out and meeting others with similar experiences are at the heart of the clubs. And mistakes are allowed!

Of the 290,000 people with dementia in the Netherlands, 70% live at home. Gerjoke Wilmink, director of Alzheimer Nederland said: "One in five people get dementia. The diagnosis is incredibly sad, but it doesn't mean that life immediately has to come to a halt. Many people become isolated, because of shame or a feeling of having to tiptoe around. Participating for as long as possible and feeling valuable is so very important for



every individual, together with a loved one or carer, enjoying such simple pleasures while still able. At the Unforgettable Cooking Club, this is possible. Each doing what they are capable of, and in a safe and welcoming environment.”

Thanks to the fantastic contribution of EUR 418,000 by the participants of the Dutch National Postcode Lottery, Alzheimer Nederland and Resto VanHarte are able to organise Unforgettable Cooking Clubs in thirty locations over the next three years.

“The Unforgettable Cooking Clubs are in line with the mission of Resto VanHarte. We bring people together at the dinner table to tackle loneliness. At the cooking clubs, people with dementia and their loved ones get to know other people living with dementia and get to be active in the kitchen. A wonderful and effective way to tackle loneliness,” explained Polle Janssens, director of Resto VanHarte.

Gerjoke Wilmink also noted: “The Unforgettable Cooking Club is inspired by the TV programme Restaurant Misverstand (in the UK: The Restaurant That Makes Mistakes). There, we saw that dementia is far-reaching, but also how fellow people with dementia can really support each other. It is valuable to roll up your sleeves together, to achieve something and experience pleasure. We are incredibly proud that we can offer this nationally, starting with five locations.”

Pictured: Participants of the first Unforgettable Cooking Club in Veghel preparing dinner.

31 December: Sabine Jansen steps down as Executive Director of Deutsche Alzheimer Gesellschaft



Sabine Jansen has stepped down as Executive Director of Deutsche Alzheimer Gesellschaft (DALzG), effective 31 December 2021. She will stay on as Chairperson of the DALzG Foundation and as a Board member of Alzheimer Europe.

Sabine Jansen joined DALzG in 1997 and became its Executive

Director in 2000. She is succeeded in the role by Saskia Weiss.

Alzheimer Europe extends a warm welcome to Saskia Weiss and looks forward to continuing its close working relationship with DALzG.

SCIENCE WATCH

10 November: Athira Pharma provides updates on its clinical trials for Alzheimer’s disease

On 10 November, Athira Pharma, a clinical-stage biopharmaceutical company aiming to restore neuronal health in neurodegenerative diseases reported financial results and updates on its two clinical trials evaluating the safety and efficacy of ATH-1017 in people with mild to moderate Alzheimer’s disease (AD). ATH-1017 is a once-daily investigational drug designed to enhance the activity of hepatocyte growth factor (HGF) and its receptor, MET, to impact neurodegeneration and regenerate brain tissue.

In both trials — the larger LIFT-AD and ACT-AD — participants are randomly assigned to receive either ATH-1017 at low-dose (40 mg/day), ATH-1017 at high-dose (70 mg/day), or to a placebo for 26 weeks. The ACT-AD Phase II trial has enrolled 77 participants across 14 sites in the US and Australia. Enrolment has been completed with top-line data expected in the first half of 2022. Its primary aim is to access event-related potential (ERP), a functional measure of working memory processing speed and executive function. Secondary goals include improvements in cognition, function and behaviour. The recruitment of the LIFT-AD Phase II/III study is ongoing in US with top-line data expected by the end of 2022. Participants who complete either the ACT-AD or LIFT-AD trials are eligible to enrol in an open-label extension trial and receive ATH-1017 at the high dose for an additional 26 weeks.

In addition, the company expects to initiate a Phase II trial SHAPE for people with Parkinson’s disease dementia or dementia with Lewy bodies by the end of 2021.

<https://www.athira.com/athira-pharma-reports-third-quarter-2021-financial-results-and-business-update/>

1 December: Higher coffee consumption linked to slower cognitive decline in a cohort of older adults

According to a new study, drinking two or more cups of coffee a day could be linked to slower cognitive decline and reduced risk of developing mild cognitive impairment or Alzheimer’s dementia.

Coffee contains a number of bioactive compounds, the most well-known of which is the stimulant caffeine. It is one of the most popular hot drinks for adults across the world, and when



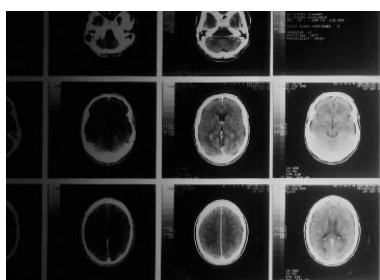
consumed in moderation, can have beneficial effects on conditions such as diabetes, Parkinson's disease and cancer.

Studying data from the Australian Imaging, Biomarkers and Lifestyle (AIBL) cohort, a longitudinal study of 227 cognitively normal adults aged over 60, a team of researchers led by Prof. Ralph Martins at Edith Cowan University in Western Australia looked at whether coffee consumption was linked to cognitive decline and measures of Alzheimer's disease detected on brain scans.

Higher self-reported coffee consumption was associated with slower cognitive decline in executive function and attention, as well as a lower likelihood of converting from cognitively normal to mild cognitive impairment or dementia over a period of 126 months. Analyses of brain scans from a subset of participants revealed an association between higher coffee consumption and slower accumulation of amyloid plaques over the 126-month time period, but no differences in terms of other measures such as white matter hyperintensities or hippocampal volume.

<https://www.frontiersin.org/articles/10.3389/fnagi.2021.744872/full>

1 December: Researchers publish safety data from Phase 3 aducanumab trials, showing incidence of ARIA



Amyloid-related imaging abnormalities occurred relatively often in participants enrolled in the Phase 3 clinical trials of aducanumab, according to a recent study published in the JAMA Neurology journal.

Aducanumab is a monoclonal antibody treatment that targets amyloid beta proteins in the brain, leading to clearance of these damaging proteins by the immune system. The Phase 3 ENGAGE and EMERGE clinical trials investigated the efficacy and safety of aducanumab in participants with mild cognitive impairment and mild dementia due to Alzheimer's disease, delivering aducanumab or a placebo to participants over a period of 76 weeks.

Focusing on data from trial participants receiving the highest monthly dose of aducanumab (10mg/kg, delivered via intravenous infusion), the researchers evaluated the incidence of amyloid-related imaging abnormalities, also known as ARIA. ARIA are detected using brain MRI scans, and can either manifest as accumulation of fluid deposits in the brain (known as ARIA-E) or as small brain bleeds (ARIA-H). Drugs such as aducanumab, which target and clear amyloid plaques, are known to cause side-effects that include ARIA.

Overall, 41% of people receiving the highest dose of aducanumab developed ARIA (425 of 1029 participants),

compared to 10% of people receiving a placebo treatment. The majority of these ARIA cases were linked to fluid deposits in the brain (ARIA-E), and approximately 25% experienced mild symptoms linked to ARIA-E, including headache, dizziness or nausea. 1.4% of participants experienced more serious symptoms, requiring hospitalisation and/or causing long-term impairment. However, most cases of ARIA-E resolved within 16 weeks.

About 40% of participants with ARIA-E also had small brain bleeds (called ARIA-H). Participants who already had evidence of ARIA-H prior to commencing the trial were at double the risk of ARIA. In addition, participants with one or more ApoE4 alleles had a heightened risk of ARIA; 66% of participants with two ApoE4 alleles experienced ARIA, compared to 20% of participants with no ApoE4 alleles.

<https://jamanetwork.com/journals/jamaneurology/fullarticle/2786606>

6 December: Viagra identified as a potential treatment to reduce Alzheimer's disease risk

Viagra could potentially help prevent Alzheimer's disease (AD), according to a new study published in the Nature Aging journal.

Sildenafil, better known as Viagra, was originally developed to treat hypertension and angina pectoralis (high blood pressure and chest pain). During early clinical trials, however, it soon became clear that sildenafil was an effective treatment for erectile dysfunction. Since 1998, it has been widely prescribed for this indication.



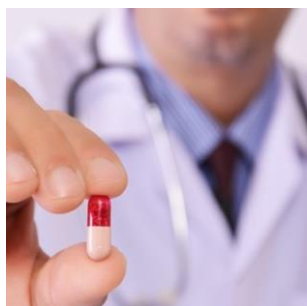
In their Nature Aging study, a team of researchers led by Dr Feixiong Cheng at the Cleveland Clinic used a computer-based approach to identify genes associated with both amyloid and tau, two proteins that are linked to the development of AD. They then cross-referenced this molecular map with the targets of over 1,600 drugs currently approved by the US Food and Drug Administration (FDA), identifying 66 drugs that targeted the AD-associated genes. Of these, sildenafil – or Viagra - was one of the top candidate drugs, thanks to its mode of action which targets an enzyme called phosphodiesterase 5 (PDE5).

Next, the researchers analysed the medical records of 7.23 million men who had taken sildenafil, looking at whether they were diagnosed with AD over a 6-year follow-up period. Comparing this group with peers who had not taken sildenafil, they found that men who had taken sildenafil were 69% less likely to develop AD, even when factors such as age, sex, race and cardiovascular comorbidities were taken into account.

To understand how the drug might be acting on the brain, the researchers performed laboratory experiments using brain cells derived from stem cells donated by people with AD. These studies indicated that sildenafil could improve brain cell function and reduce the expression of tau. Further research, including a randomised, controlled trial involving women as well as men, are required to check whether there is a direct, causal link between sildenafil use and AD prevention.

<https://www.nature.com/articles/s43587-021-00138-z>

10 December: Researchers are launching a new trial to test diabetes drug in reducing risk of Alzheimer's dementia



On 10 December, the Diabetes Trials Unit and the Department of Psychiatry at the University of Oxford announced the start of a new clinical trial with the global healthcare company, Novo Nordisk. The Impact of Semaglutide in Amyloid Positivity (ISAP) trial will examine semaglutide, a tablet prescribed

for diabetes, for reducing the risk of Alzheimer's dementia.

The trial will recruit 88 people without dementia in five UK clinical sites. Participants will have a brain scan (PET, Positron emission tomography) to check levels of amyloid protein in their brains. People with high amyloid protein levels in their brains will have further PET scans to determine levels of the amyloid protein but also check tau protein and the level of inflammation in the brain. They will then be asked to take either semaglutide or a placebo tablet, every day for one year. Researchers will repeat the brain scans to see if those taking semaglutide have lower levels of tau protein and inflammation in their brains compared to people taking placebo.

<https://www.psych.ox.ac.uk/news/new-clinical-trial-to-test-drug-for-diabetes-in-reducing-risk-of-alzheimer2019s-dementia>

16 December: Biogen and Eisai to launch post-approval trial of aducanumab in May 2022



In their decision to approve aducanumab for the treatment of patients with Alzheimer's disease, the US Food and Drug Administration (FDA) mandated a post-approval study to confirm the

anticipated clinical benefit for the drug. On 16 December, Biogen and Eisai announced plans to launch its Phase 4 confirmatory study of aducanumab in May 2022.

The new study will be a global, placebo-controlled trial, aiming to enrol over 1,300 participants with mild cognitive impairment or mild Alzheimer's dementia. Participants will receive monthly

intravenous infusions of aducanumab (100mg/mL), a monoclonal antibody that is directed against amyloid beta, which accumulates in plaques within the brain during the development of Alzheimer's disease. The Phase 4 trial will have a primary clinical endpoint at 18 months, but will also collect longer-term data for up to 48 months.

Biogen and Eisai hope to complete the trial within 4 years, with final results expected in 2026.

<https://investors.biogen.com/news-releases/news-release-details/update-phase-4-confirmatory-study-aduhelmr>

17 December: European Medicines Agency rejects marketing authorisation application for aducanumab



On 17 December 2021, the European Medicines Agency (EMA), in a decision closely watched by the European dementia community, decided not to authorise aducanumab for the treatment of mild cognitive impairment due to Alzheimer's disease and mild Alzheimer's dementia.

Alzheimer Europe understands that people living with Alzheimer's disease and their families had high hopes and expectations about the introduction of new treatment options and that they will be disappointed that there was not enough scientific evidence for the EMA to support the authorisation of aducanumab.

The decision about this new medicine was also highly debated in the US, where the Food and Drug Administration (FDA) chose to grant conditional approval for aducanumab following an "accelerated approval pathway". This pathway can be used to approve a drug for a serious or life-threatening illness based on surrogate end points. The FDA approval was based on aducanumab's proven effect on lowering amyloid, a surrogate end point that the FDA deemed "reasonably likely" to predict a clinical benefit to patients. In addition, the FDA required a post-approval trial to verify that the drug provides the expected clinical benefit. As a result of these diverging decisions, Europeans with Alzheimer's disease will not have access to treatment options available to American patients.

Alzheimer Europe appreciates the fact that the EMA had to base its decision on the more ambiguous results on cognition and executive function derived from the two phase III clinical trials conducted to date, rather than the significant effect of the

medicine on amyloid reduction. Whilst this will delay access to aducanumab for European patients, Alzheimer Europe hopes that the post-approval trial mandated by the FDA or a new confirmatory phase III trial will provide the necessary scientific evidence for the EMA to reconsider its position.

Alzheimer Europe welcomes the [recent announcement](#) from Biogen confirming the launch of its post-approval trial in May 2022, aiming to provide more definitive evidence on the clinical efficacy of aducanumab. Alzheimer Europe also remains encouraged by the number of companies and organisations continuing to invest in research and the new treatment options currently being developed. The organisation therefore reiterates its call for continued research into other treatment options, including symptomatic treatment for people in more advanced stages. In addition, Alzheimer Europe remains committed to a holistic approach to Alzheimer's disease and other types of dementia where new and exciting treatment options are included alongside counselling, support and adequate care of people with dementia and their carers throughout the disease process.

<https://www.ema.europa.eu/en/medicines/human/summaries-opinion/aduhelm>

20 December: New clinical trial of gantenerumab for people with rare genetic mutations linked to early-onset Alzheimer's disease



On 20 December, the Washington University School of Medicine in St. Louis announced that it will launch an international primary prevention trial for people who have inherited rare genetic mutations that predispose them to early-

onset Alzheimer's disease.

The new trial will investigate whether gantenerumab (an antibody that binds and clears amyloid beta proteins) can prevent familial Alzheimer's disease, in young participants who have no or very few amyloid deposits in the brain. Led by Prof. Eric McDade, and supported by Roche, Genentech and grants from the National Institutes of Health, the Alzheimer's Association and philanthropic funders, the trial will last 4 years and aims to recruit 230 participants from families with genetic mutations leading to early-onset Alzheimer's disease.

<https://medicine.wustl.edu/news/new-alzheimers-prevention-trial-in-young-people/>

DEMENTIA IN SOCIETY

15 December: Bob & Diane Fund awards Visual Storytelling Grant to American photographer Cheryle St. Onge



On 15 December 2021, The Bob & Diane Fund announced it was awarding USD 5,000 (EUR 4,440) to Massachusetts-born photographer Cheryle St. Onge for her project, "Calling the Birds Home". Calling the Birds Home is a photographic exchange of the energy of life - the give and take of the familial between mother and daughter who lived side by side on the same New Hampshire farm for decades.

The Bob & Diane Fund, launched in June 2016, is an American grant-making organisation dedicated to promoting awareness of Alzheimer's and dementia-related diseases. It is the passion project of Gina Martin, whose mother, Diane, died from Alzheimer's dementia. Diane's husband of 50 years, Bob, who was her primary carer, died three months later.

The "Visual Storytelling Grant", now in its sixth year, aims to bring awareness, interest, and support for funding research efforts, by awarding a photographer whose work tells the stories of people living with dementia, with dignity and respect.

"Cheryle St. Onge's project, "Calling the Birds Home" is a beautiful tribute to her mother who recently passed away from vascular dementia. The mother and daughter collaboration is a poetic and touching portrayal of one living with dementia. Cheryle's ability to show us beauty, humour and love during a time that can be dark, sad and painful is why the Bob and Diane Fund is honoured to have Cheryle St. Onge as our 2021 Grantee", said Gina Martin.

You can view Cheryle St. Onge's work, "Calling the Birds Home" here: <http://www.bobanddianefund.org/2021-grantee>



16 December: Forget Me Nots choir presents its new song "Snowflakes"



Órla Horn, Chairman, A Choir to Remember
The Forget-me-Nots Organisation | Charity No. 20144661 | Baldoyle Community Hall, Main Street, Dublin 13 |
info@forgetmenots.ie | 086 383 2257 | www.forgetmenots.ie

Proudly sponsored by:


The Forget Me Nots choir is proud to present its latest song "Snowflakes", to ring in the festive season.

The Forget Me Nots Dementia-Inclusive Community Choir Baldoyle, North Dublin is a seniors choir and counts many people with memory loss conditions and their carers within its ranks. Inspired by Kathleen Tierney in 2014, the choir has gone from strength to strength – featuring in performances from local nursing homes to The Olympia and even an RTE Brendan Grace documentary – "Thanks for the Memories". The choir also featured at the closing ceremony of the 31st Alzheimer Europe Conference (31AEC) on 1 December 2021.

One of the choir members, Gerry O'Halloran, wrote the song Snowflakes for his children to sing at Christmastime when they were young. He gifted it to the choir, and to celebrate his 90th birthday, Forget Me Nots Musical Director Norah Constance Walsh, also a renowned composer, created a musical arrangement with harmonies and piano.

<https://www.youtube.com/watch?v=u4vvx9a6nS4>

17 December: Fondation Médéric Alzheimer completes survey on psychosocial and recreational interventions for people with dementia and their carers and their evolution from 2011 to 2019 in French facilities



Since 2011, the Fondation Médéric Alzheimer has been conducting surveys among all French facilities for people with dementia and carers. These surveys aim to monitor the implementation of the successive national Alzheimer's plans and to provide an overview of the involvement in psychosocial and recreational interventions. For the 2019 survey, 6,070 facilities responded (nursing homes, long-term care units, memory centres, respite care platforms, national carers' support associations) and 82% reported organising at least one intervention.

Interventions for people with dementia were divided into six categories: therapeutic and relational (reminiscence, psychological support...); functional (manual work, cooking...); care and well-being (gentle gymnastics, aromatherapy...); recreational, cultural and sporting (museum visits, games...); rehabilitative (cognitive stimulation, cognitive rehabilitation...); environmental (space management, therapeutic garden). For carers, interventions included public information meetings, discussion groups and dementia cafés, among others. For

people with dementia and their carers, interventions included social events, discussion groups, walks, etc.

Interventions tend to develop over time compared to the 2011 and 2017 surveys. Some are more frequently provided: art therapy, music therapy, sensory stimulation, animal mediation, crafts and gardening. Leisure activities and social events are poorly represented. Some interventions are not sufficiently developed and this could be due to lack of knowledge among professionals, a lack of professional training, transport difficulties to access interventions and budgetary choices between interventions, without always assessing the needs of people with dementia and carers.

Several suggestions emerged: strengthening training for staff; raising awareness of interventions among people with dementia and carers; pooling of staff resources across facilities within a defined geographical area to facilitate access to these interventions; and considering dedicated funding for these interventions.

One of the limitations of this survey is that the facilities do not necessarily have the same definition of interventions listed in the questionnaire. However, this survey showed a growing awareness among facilities of the benefits of these interventions.

The results of this survey will be published in French in a letter from the Fondation Médéric Alzheimer in 2022. Recognised as a public utility, the Fondation Médéric Alzheimer works with professionals, prescribers and public authorities to improve the quality of life of people with dementia and carers.

20 December: Gerontological Society of America hosts symposia series on "Friendship and Loneliness among People Living with Dementia"

The Gerontological Society of America (GSA) recently held a symposia series on "Friendship and Loneliness among People Living with Dementia" which brought together more than 30 practitioners and experts, including people with lived experiences. Subtitled



"Social Practices and Identity" and "Toward Community and Shared Humanity," the symposia discussed state of the art approaches to dementia care and prevention in community settings since Tom Kitwood's *Dementia Reconsidered* (1997), and future directions. Dementia self-advocate Dr Jim Mann and mental health theologian Dr John Swinton (University of Aberdeen) provided critical insights into the limits of current approaches. The agency of people living with dementia must be carefully acknowledged across all interaction settings, and experts and policymakers should be sensitised to how our words or discourse construct worlds unto themselves that potentially harm or impede the inclusion of people living with dementia in their own communities.

The practical implications of these discussions are further elaborated in a brief report, published in December 2021:

<https://www.geron.org/publications/gerontology-news>

Taken together, scholars and experts called for radical inclusion to provide “ways of being in the world that are more accepting and embracing” (Hillman & Latimer, 2017) and kind, to the varied socio-cognitive struggles of people living with dementia, including the dismantling of residual industry complex. Genuine friendships are required to intercept the development of chronic loneliness upon dementia diagnosis in their communities.

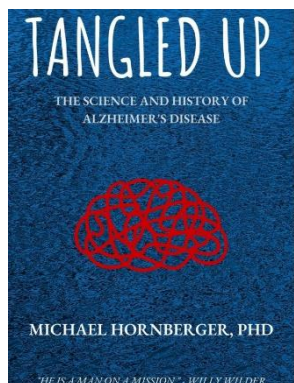
For the wellbeing of people with dementia in assisted living, the working conditions of care aides must also be improved. For the wellbeing of people living with dementia in their neighbourhoods, stigma and malignant social practices must be addressed before they place unhelpful constraints on the social identity of the person living with dementia.

The value of a community depends on the quality of its friendships, and has been found to be crucial during crises such as the COVID-19 pandemic (Gan & Trivic, 2021). A toolkit to “flip stigma on its ears” is available here:

<https://www.flippingstigma.com/>

NEW PUBLICATIONS & RESOURCES

1 December: Professor Michael Hornberger publishes new book looking at science and history of Alzheimer’s disease

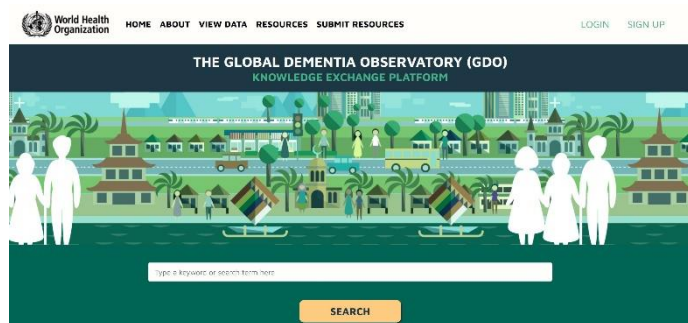


Michael Hornberger, Professor of Applied Dementia Research at the Norwich Medical School, University of East Anglia, United Kingdom, has published a new book called “Tangled Up – The science and history of Alzheimer’s disease”. The book aims to provide readers with a detailed insight into the science of Alzheimer’s disease (AD), what actually causes it, and how the science explains the

symptoms and risk of AD.

“Tangled Up” is specifically written about AD and not dementia in general. The reason Professor Hornberger gives for focusing the book only on AD is that it would be an almost impossible task to write a book explaining the science of all types of dementia, since there are many and they each have different causes. Instead, the author chose to be more specific and to provide in-depth insights into the science of this particular type of dementia, allowing for a better understanding of the underlying causes but also the risks of developing AD dementia. You can find out more about the book in the author's own words, and where to purchase it, via his website “Dementia Science”: [Tangled Up – The science and history of Alzheimer’s disease \(dementiascience.org\)](https://dementiascience.org)

22 December: Alzheimer Europe yearbook on “Estimating the prevalence of dementia in Europe” included in WHO Global Dementia Observatory Knowledge Exchange Platform



Alzheimer Europe’s 2019 yearbook on “Estimating the prevalence of dementia in Europe” has been included in the World Health Organization (WHO) Global Dementia Observatory Knowledge Exchange (GDO KE) Platform. The process for inclusion of this resource included a review by the WHO secretariat together with the GDO KE peer review panel and Focus Group of people with lived experience.

Alzheimer Europe is delighted to have its yearbook shared via this important platform.

It can be accessed here:

<https://globaldementia.org/en/resource/estimating-the-prevalence-of-dementia-in-europe>

GDO KE Platform homepage: <https://globaldementia.org/en>



AE CALENDAR 2022

Date	Meeting	AE representative
7 January	Meeting with Rotary Foundation	Jean
11 January	Office New Year's get-together	AE team
12 January	EMA raw data pilot project meeting	Ange
12 January	Meeting with Brain Health Scotland	Ange and Jean
12 January	AI-Mind WP1 meeting	Dianne, Ana and Ange
12 January	Meeting with Alzheimer's Disease International	Jean
13 January	AD/ADRD Research Funders Meeting	Jean
13 January	ADAIR project meeting	Jean
13 January	RADAR-AD Steering Committee	Ana and Dianne
14 January	Meeting with European Public Health Alliance	Jean
17 January	INTERDEM Prevention Task Force	Jean
20 January	EU4Health Civil Society Alliance	Jean and Owen
25 January	Meeting of the European Working Group of People with Dementia	Ana and Dianne
26 January	Innovative Health Initiative webinar "Introducing IHI: Europe's new partnership for health"	Jean, Chris and Owen
27 January	Management Board of the Dementia Panel of the European Academy of Neurology	Jean
27 January	Webinar of European Association of Service Providers for Persons with Disabilities	Jean and Dianne
27 January	MinD network meeting	Dianne
27 January	TVB_Cloud period 2 review meeting	Ange
27 January	EPND Management Board meeting	Ange and Jean
28 January	OECD/Human Brain Project Round Table (Paris, France)	Jean

CONFERENCES 2022

Date	Meeting	Format/ Place
15-20 March	International Conference on Alzheimer's and Parkinson's Diseases and related neurological disorders (AD/PD 2022), https://adpd.kenes.com/	Barcelona, Spain
7-9 June	7 th World Conference on Adult Capacity, https://wcac2022.org/	Edinburgh, Scotland
8-10 June	35 th Global Conference of Alzheimer's Disease International (ADI 2022), https://adiconference.org/	London and online
21-24 October	2022 IPA International Congress, https://www.ipa-online.org/events/events-calendar/2022-lisbon	Lisbon, Portugal
29 November-2 December	Clinical Trials on Alzheimer's Disease (CTAD 2022), www.ctad-alzheimer.com	San Francisco, USA
5-7 December	32 nd Alzheimer Europe Conference, https://www.alzheimer-europe.org/Conferences	Bucharest, Romania



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